University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

Amplifying the Voices of Autistic Young People: Insights into Puberty, School Experiences, and Participatory Research

by

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Thesis for the degree of Doctorate in Educational Psychology

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Abstract

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Many autistic girls face the challenges of misdiagnosis, late diagnosis, or no formal diagnosis at all, and report feeling overlooked, misunderstood, unsupported, and exhausted by trying to ‘fit in’ to an unaccommodating neurotypical world. When autistic girls reach early adolescence, they experience the additional challenges of the transition to secondary school, increased school demands, the complexities of social relationships, and the onset of puberty, which can all have a considerable impact on mental health. The need to promote the voices and involvement of autistic young people in research is paramount to ensure that current literature reflects the matters which are most important to the autistic individuals themselves, and to bring about effective, meaningful, support.

This thesis is divided into two separate but related research papers: a systematic literature review and an empirical research project. The systematic literature review aimed to summarise existing research addressing autistic girls’ and women’s experiences of puberty and menstruation, as well as the views of those who care for them. This review also aimed to uncover what effective support looks like for autistic girls and women in relation to puberty and menstruation, whether this aligns with current intervention literature, and whether autistic voice is included in intervention design and evaluation. Using a narrative synthesis approach, the systematic review synthesised the findings from 14 studies to tell a story regarding autistic females’ preparation for and journey through puberty, as well as the support that they desire (the ‘what’ and the ‘how’). Lack of education prior to puberty, the detrimental impact on wellbeing, difficulties with menstrual self-care, and the reciprocal relationship between autism and puberty were highlighted as areas of challenge by autistic girls, their caregivers, and educators. While there was some alignment regarding the support desired and the focus of support within the seven identified intervention studies, particularly with regards to self-care, the majority did not include autistic voice and maintained a within-child focus. This review highlights several recommendations for pubertal support, including early education emphasising the ‘normalcy’ of puberty and menstruation, a focus on promoting self-care skills, dignity and advocacy, and the importance of individualisation. Furthermore, the need for autistic voice within research literature, as well as the need for an interactionist perspective on pubertal support is asserted.

The empirical paper aimed to uncover some of the successes, challenges, and future directions of implementing co-created resources within school settings, with the voices of autistic young people at the centre. These resources were previously created by East (2024) and a group of autistic girls and were designed to raise awareness of autistic girls' school experiences. In the present study, a team of five autistic students were recruited to join a participatory research team, and were involved in the planning, delivery, and evaluation phases of resource implementation. Their views of being involved in this process were explored using semi-structured interviews and were analysed using reflexive thematic analysis. Using an oak tree metaphor, representing the positioning of the findings within the wider forest (or 'societal' context), six themes and 11 sub-themes were generated. The six overarching themes included 'conceptualising autism', 'empowering, influencing, and advocating', 'cultivating contentment', 'sense of togetherness', 'conditions for growth', and 'evolution over time'. These themes bring to light the many emotional and social benefits of participatory research processes for autistic young people, including a strong sense of belonging, while also highlighting the challenges of facilitating change within a secondary school setting, with particular regard to motivation and investment. Recommendations to promote the success of participatory research teams and resource implementation are proposed.

In terms of autism awareness, it is hoped that this research will promote the knowledge and understanding of school staff and educational psychologists, with regard to autistic young people's experiences, highlighting the importance and value of actively seeking and listening to their voices. It is also hoped that this thesis may path the way for future participatory research with autistic individuals, on topics that are meaningful and relevant to the autistic community. In terms of intentional behaviour change and impact, it is hoped that this work will continue and that the voices of participants within the empirical study will influence implementation practices within schools.

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Research Thesis: Declaration of Authorship

Print name: Laura Salmon

Title of thesis: Amplifying the Voices of Autistic Young People: Insights into Puberty, School Experiences and Participatory Research.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: [redacted] Date: 02.06.2025.......................

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Definitions and Abbreviations

CYP	Children and young people
EP	Educational Psychologist
RTA	Reflexive Thematic Analysis

Chapter 1 Thesis Introduction

1.1 Language and Terminology

Throughout these research papers, I will use identity-first language (i.e., autistic person) to refer to autistic individuals and have endeavoured to avoid terms that may be perceived as othering, dehumanising, or pathologising. The use of identity-first language aligns with the stance that autism is an inherent part of one's identity, rather than an element that can be separated (Monk et al., 2022). While I acknowledge that there are differing viewpoints and factors that may influence language use, including cross-linguistic and research topic differences (De Laet et al., 2023; Bottini et al., 2023), my use of identity-first language was informed by the preferences of the research participants within my empirical study, and the wider autistic community (Bottema-Beutel et al., 2021), within an English-speaking context. This identity-first preference is compatible with efforts to linguistically reclaim the term autism from stigmatising connotations (Jorba et al., 2024).

1.1.1 Conceptualisation of autism

Since its conception (Kanner, 1943), a medicalised view of autism as a deficit has dominated the narrative. With reference to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2022), autism is classified as a neurodevelopmental disorder, with terms such as "deficits", "impairment", "symptoms", and "disturbances" used to describe autistic features. Such terminology, in line with the medical model of disability, implies that there is something inherently wrong with the autistic individual's biological make-up (Llewellyn & Hogan, 2000). Consequently, within the medical paradigm, interventions or treatments target these perceived deficits to reduce symptomology and promote behaviour in line with normative functioning (Llewellyn & Hogan, 2000; Pellicano & Den Houting, 2022).

Following the disability rights movement, which gained traction in the late 1970s, autistic advocates have challenged this medicalised view and have instead endorsed a shift towards a neurodiversity paradigm (Pellicano & Den Houting, 2022). Coined in the late 1990s, the term 'neurodiversity' refers to the natural diversity in human brains and development (Botha et al., 2024). Viewing diversity along a spectrum, there is a range that can be regarded as ‘typical’ or experienced by the majority (neurotypical), as well as ranges that appear to ‘diverge’ from this typical experience (neurodivergence) (Pellicano & Den Houting, 2022). In contrast to the medical model, neurotypical and neurodivergent development are not viewed in terms of superiority and inferiority, but rather equally valid states, both worthy of respect and acceptance. The unique strengths that neurodivergent individuals bring to society are acknowledged and appreciated within this model (Pellicano & Den Houting, 2022).

It is important to note that, despite advocates’ intentions towards inclusivity, the term ‘neurodivergence’ has itself ignited controversy, with critics highlighting its ‘othering’ and ‘stigmatising’ connotations. As Legault et al. (2021) asserted, the use of a term which represents a departure from the norm (a norm which has arguably been formed and maintained by those with power and privilege) only perpetuates exclusion and marginalisation. Notwithstanding such concerns, McClennan and colleagues (2025), in their recent review of neurodiversity conceptualisations in empirical research, highlighted that the term is largely associated with positive connotations, relating to identity, difference, and change, aligning with the intentions of those who founded the term. While promising, it is important to note that such research represents westernised literature, with researchers currently highlighting the need for a culturally sensitive, contextualised approach to neurodiversity movements across the globe (Hirota et al., 2024).

The neurodiversity paradigm is rooted within the social model of disability (Pellicano & Den Houting, 2022). Rather than viewing disability as a ‘within’ individual problem, the social model asserts that society does not aptly accommodate the needs of neurodivergent individuals (Oliver, 1996; Pellicano & Den Houting, 2022). This model does not intend to minimise or undermine the challenges that neurodivergent individuals may experience but rather places the responsibility of change on society rather than the individual (Pellicano & Den Houting, 2022). The social model of disability and the neurodiversity paradigm have both informed my assumptions and approaches throughout this research process.

1.1.2 Sex and gender

In both papers, I use the term ‘girls’ (or ‘women’) and ‘females’ interchangeably. While I acknowledge that sex and gender are distinct constructs, informed by biological characteristics and social norms (Bamberger & Farrow, 2021), much of the existing literature does not clearly distinguish between sex and gender (Lai & Szatmari, 2020), preventing such constructs from being disentangled. With regards to the systematic literature review, ‘girls’ and ‘females’ are used to describe those assigned female at birth, to capture the unique pubertal experiences of these individuals (particularly menstruation). With regards to the empirical paper, ‘girls’ and ‘females’ are used more broadly to describe those who would identify with these terms. My predominant focus on autism in girls is not to endorse sex or gender as binary constructs but is rather attributable to the gender-based stereotypes, norms, and expectations that uniquely shape autistic girls’ lived experiences (Hamdani et al., 2023).

1.2 Research Context

Conducting research that benefits and creates authentic change for autistic individuals has been my core motivation. Fundamentally, my research has aimed to address the research and practice priorities of the autistic community, with a focus on what matters to autistic individuals and how their needs can be best met in a societal context.

The formulation of this thesis began in an initial discussion with one of my research supervisors, Prof Hanna Kovshoff, co-director of the Autism Community Research Network at Southampton (ACoRNS – co-directed by Prof Sarah Parsons). Through a research-practice partnership, ACoRNS endeavours to address the underrepresentation of autistic voices and focuses on topics that are important and meaningful to the autistic community. Academics, students, and professionals from a wide range of disciplines belong to this network (including autistic individuals and autistic allies) and all pursue a common objective: to promote autistic CYP’s quality of life. With my own desire to meaningfully contribute to the autism research base and make a difference to the lives of autistic CYP, which was inspired by my previous work experiences, I discussed with Hanna the research priorities of ACoRNS. One such priority was to address the underrepresentation of autistic girls and women in research, and another was to promote the voices of autistic individuals through creative, co-produced methods.

During this initial discussion, and within the context of ACoRNS, I learnt about the research of East (2024) and a group of autistic girls who formed the 'FIZZACC' research team. After exploring the girls' experiences of transitioning from primary to secondary school, East and the team co-produced a selection of school training resources aimed at raising awareness of autism in girls. This aligned with the strong consensus within research literature (Morewood et al., 2011; Moyse, 2020) and the publications of autism advocacy charities (The Autistic Girls Network, 2025) on the need for neuro-affirming understanding and practices within schools. Across several supervision sessions, my supervisors and I discussed how my empirical project could extend upon the research of East (2024) and the FIZZACC team, with a specific focus on implementation.

With regard to my systematic literature view, I considered other priorities of the autistic community and their advocates, with a particular focus on topics relevant and meaningful to autistic girls. Through initial reading around autistic girls and adolescence, my attention was drawn to the topic of puberty. Within the 'Keeping it all Inside' publication, produced by the Autistic Girls Network (Wassell & Burke, 2022), the need for co-produced research on topics such as menstruation and wellbeing were explicitly emphasised. Intrigued about what such research could entail, I began to explore existing literature on puberty and menstruation amongst autistic girls. In particular, I wished to identify literature exploring autistic girls' experiences of puberty, their views on what effective support may look like (as well as the views of caregivers and educators), and whether such views aligned with/were incorporated into intervention literature.

1.3 Author Positionality and Epistemology

As stated, by Secules and colleagues (2021, p.21), "positionality has been operationalised as reflexivity, an activity in which a researcher identifies, examines, and owns their backgrounds, perspectives, experiences, and biases in an effort to strengthen research quality." In light of this, it is important for me to share the context that I believe has shaped my decision-making and interpretations throughout this research process, as well as the factors that may have influenced participants' interactions and discourse with me.

Primarily, my desire to conduct research in this area has been driven from my professional background as a special educational needs teacher. Having worked with many autistic CYP and their families, who have been subjected to inequalities and marginalisation, I have intended to use my privilege as a doctoral student to give voice to those who are not always heard. I have observed in practice the under recognition and under representation of autistic girls, which has struck a particular emotional chord with me, likely in part due to my own identification as female. Alongside this primary drive, I must also be transparent in the benefits this research will bring to my professional development, and simultaneously how the pressures and time constraints associated with a professional doctorate will have influenced my decision-making.

I recognise that much of what I know about autism is from my interactions with members of the autistic community and their allies, and the meaning-making we have shared together. As a researcher who identifies as neurotypical, I have acknowledged throughout this process the additional efforts required to build rapport, gain trust, and promote the comfort of participants to share their thoughts, feelings, and experiences with me. Engaging in reflexive processes personally, through supervision, and in shared spaces provided by the ACoRNS community, has been vital in enabling me to critically evaluate the inherent power dynamics within this research context.

I chose to take a social constructionist epistemological position within this research, as such a position aligned with my research questions and focus on lived experiences. Unlike positivist frameworks, which strive for objectivity and universality, social constructionism recognises how concepts have been shaped by language, culture, historical norms and power relations (Burr & Dick, 2017). A social constructionist epistemology aligns with my affinity to the social model of disability (Lester & O'Reilly, 2021), and my personal values of equality, connection, and perspective. Throughout this research, I have endeavoured to thoughtfully represent the voices of members of the autistic community, and to challenge deficit-focussed narratives. Underpinned by the assumption that our reality is inseparable from the discourses we engage in (Burr & Dick, 2017), the interpretations within my empirical paper represent the meanings that were negotiated and constructed with the participants through our interactions.

1.4 Ethical Considerations

Following the University of Southampton's ethics guidelines, ethical approval was sought and granted by the Faculty Ethics Committee and Research Integrity and Governance Team for the empirical project (ERGO number: 92436). Informed consent/assent was gained from parents, student participants, and staff participants through tailored forms, and participants' right to withdraw was clearly communicated throughout the research process. The importance of confidentiality was discussed from the outset and was a fundamental component of the team's ground rules. Furthermore, pseudonyms were chosen by the students and were used in place of their names within interview transcripts to protect their identities.

The Health and Care Professions Council (HCPC) standards (2024) and the British Psychological Society (BPS) Code of Ethics and Conduct (2021) underpinned my personal conduct and behaviour throughout, with the principles of respect, competence, integrity, and responsibility informing all decision-making. Advice and guidance from my supervisors was also sought through regular supervision, which provided a safe space for reflective practice. Of particular influence prior to, during, and upon commencement of the research project, were the person-oriented research ethics guideposts (Cascio et al., 2020), including individualisation, acknowledgement of lived world, empowerment in decision-making, respect for holistic personhood, and researcher-participant relationships, as outlined in further detail below.

1.4.1 Individualisation

With careful consideration of the strengths and needs of the research participants, I individualised several components of this research. This involved creating young person-friendly consent forms, actively gathering information about participant preferences, adapting language, offering fidget resources, providing choice with regard to data collection procedures, and gathering views about their involvement in the research process.

1.4.2 Acknowledgement of lived world

While actively individualising elements of the research process, I also considered the relational, societal, cultural, linguistic and historical factors that may have influenced participants' experiences and interpretations. Throughout the process, I held in mind the stigma and exclusion that participants may have experienced/may be experiencing, and how this might influence their involvement (i.e., low confidence or hesitation to share their authentic views). Acknowledgement of this lived experience shaped my research approach, and the actions I took to promote an inclusive research context.

1.4.3 Empowerment in decision making

Taking a participatory research approach, joint decision making was integral to the empirical research project. From the start of the process, accessible adverts, assent forms, and participant information sheets were provided, promoting informed decision making prior to participation. Participants were also provided with the opportunity to meet with me individually to ask any questions they may have had. During the process, different communication methods were explored and employed including spoken, visual, and written forms, in recognition of different communication styles and preferences. A formal consensus method was also utilized to foster collaborative decision-making. Towards the end of the project, participants were given the opportunity to read transcripts, and plans have been made to share the final research paper and consider dissemination processes within their school context.

1.4.4 Respect for holistic personhood

With respect to the views and research priorities of the autistic community, this thesis aimed to explore meaningful topics that would shine a light upon individual experiences. In recognition of the increasing number of individuals self-identifying as autistic (Overton et al., 2023), participation in the empirical project was not limited to those with a formal diagnosis. The language and communication preferences of participants were actively sought, as well as accommodations that would make the research process more comfortable (e.g., breaks within sessions). Additionally, to reduce the burden of having to catch up on missed school learning in order to take part in the project, meetings were scheduled at different times of the week, thus minimising the impact on any one school subject.

Throughout the project, the contributions of each member of the implementation team were encouraged and valued. The strengths of each individual and the collective strengths as a team were actively explored using a strengths card activity and were explicitly referred to and drawn upon across sessions.

1.4.5 Researcher–participant relationships

To promote trusting researcher-participant relationships, rapport building, open-communication, and authenticity were central to the research process. I devoted time to checking-in with participants at the start of each session and endeavored to communicate my genuine appreciation for the participants' time and contributions. Throughout, I reflected upon positionality and paid particular attention to power dynamics. Through an initial ground rules activity (informed by the '16 Ground Rules for Group Work' by Facilitator School, 2025), I aimed to create a cohesive team context, in which everybody's views and contributions were equally valued. Furthermore, I was mindful of how to draw the project to a close. I spent time in the final few meetings preparing participants for goodbyes and considering how we would together share the research outcomes.

1.5 Dissemination

Both papers within this thesis have been written according to the submission guidelines of two peer-reviewed journals. The systematic literature review has been written with the intention of submission to *Autism*, an international journal, which features research aimed at promoting positive life outcomes for autistic individuals. The empirical research paper has been written with the intention of submission to *Diversity and Inclusion Research*, an open-access journal, which features research aimed at promoting equality, diversity, and inclusion (EDI) across disciplines.

Prior to the final submission of this thesis, I visited the school to share an overview of the empirical research project findings with the participants and school SENCo. This involved explaining the oak tree metaphor, describing the themes, and checking whether I had interpreted the participants' views in a way that matched their perceptions and experiences. The participants responded positively to the metaphor and the meaning I had generated from their interviews (which they expressed both verbally and through their body language), with one participant in particular describing how the positioning of the themes made sense to her. Following this, I also sent the thesis overview to the participants' parents.

In terms of wider dissemination, I have shared a short overview of my empirical project and findings to school staff during a staff briefing session. I have also presented my empirical paper at the University of Southampton Psychology Postgraduate Conference, the International School Psychology Association (ISPA) conference in Portugal, and to ACoRNS members, both through a remote presentation and at their summer networking meeting. Finally, I also intend to present my research to the Educational Psychology Service within my Local Authority upon commencement of my employment in September 2025.

Chapter 2 Navigating puberty: What are the challenges for autistic girls and how can they be successfully supported?

2.1 Introduction

Many autistic girls continue to face the challenges of misdiagnosis, late diagnosis, or no formal diagnosis at all (Wassell & Burke, 2022). This poses considerable challenges regarding access to appropriate support (Hamdani et al., 2023) and representation in research literature, meaning that autistic girls' experiences remain poorly understood (Cridland et al., 2014; Leedham et al., 2022). Sex differences in autism presentations have been posed as one reason for such under-recognition (Lockwood Estrin et al., 2020); autistic females have been shown to be more likely to exhibit camouflaging behaviours than autistic boys, and display 'repetitive and restricted behaviours and interests[*]' that align more closely with gender norms (Tubío-Fungueiriño et al., 2021; Bourson & Provost, 2024; Edwards et al., 2024). Alongside their more nuanced expressions, socio-cultural influences such as differing expectations regarding 'typical' male and female behaviours, as well as diagnostic biases, have been highlighted as significant barriers to identification (Young et al., 2018; Lockwood Estrin et al., 2020; Hamdani et al., 2023).

What is known about autistic girls' experiences is that they are more likely to experience internalising symptoms than non-autistic individuals and report lower quality of life (Jamison & Schuttler, 2015). In a recent systematic review, O'Connor et al. (2023) proposed that the mental health and wellbeing of autistic girls and women can be described through a social lens. They asserted that elements of the autistic neurotype can contribute to social, emotional, and mental health difficulties for autistic

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[*] 'Repetitive and restricted behaviours and interests' (RBBIs) are often referred to as stimulatory or self-regulatory behaviours by autistic individuals themselves. The National Autistic Society (2025) characterizes these as 'focused and dedicated interests', 'preference for order, predictability and routine', and 'repeated movements and behaviours (stimming)'.

females within the context of a stigmatising and unaccommodating ‘neurotypical world’. For example, autistic sensory profiles may contribute to feelings of discomfort and distress within the context of a neurotypical sensory environment, which may be further exacerbated by concealment of needs to avoid stigma (i.e., camouflaging).

2.1.1 Puberty

Puberty can be described as a core developmental milestone, which involves significant neural, hormonal, and physical changes. The process of puberty begins with activation of the hypothalamic-pituitary-gonadal (HPG) axis, which triggers the release of various hormones, such as oestrogen, progesterone, and testosterone (National Academies of Sciences, Engineering, and Medicine, 2019). This hormonal release (and subsequent hormonal fluctuations) stimulates growth, promotes the development and maturity of secondary sexual characteristics and reproductive organs, influences emotional responses, and stimulates sexual curiosity (Mendle & Koch, 2019).

Both early pubertal timing (the onset of puberty) and more advanced pubertal status (the stage of puberty) have been associated with increased negative affect, rejection sensitivity, and rumination amongst females (Mendle et al., 2020). Several hypotheses have been put forward to explain such findings including *the maturity-disparity hypothesis*, which highlights the gap between psychological readiness and advanced physical development; *the contextual amplification hypothesis*, which emphasises the impact of contextual circumstances on adjustment to puberty (e.g., a stressful environment); and the accentuation hypothesis, which describes how significant transitions accentuate pre-existing vulnerabilities (Ge & Natsuaki et al., 2009). While predominantly focussed on pubertal timing, these hypotheses highlight the interplay between individual, societal and contextual influences and how this interaction shapes meaning making and experiences of puberty amongst adolescents.

2.1.2 Autism, Girls, and Puberty

Holding these individual, societal, and contextual influences in mind, puberty is likely to be a particularly challenging process for autistic girls, as highlighted by the

Autistic Girls Network (Wassell & Burke, 2022). The hormonal fluctuations associated with puberty and the onset of menstruation are likely to intensify emotional dysregulation and sensory sensitivities amongst autistic girls, who are already susceptible to poorer mental health outcomes than their neurotypical peers (Lai et al., 2019; Wassell & Burke, 2022). Managing these challenges within a ‘neurotypical world’ (O’Connor et al., 2023), in which conversations around periods arguably remain a ‘taboo’, may constrain conversations around autistic girls’ pubertal needs, hindering them from receiving the support they require (Wassell & Burke, 2022).

In terms of research on puberty amongst autistic populations, a considerable focus has been on pubertal timing, status, and tempo (the rate of puberty), albeit with some conflicting conclusions. In a longitudinal study of Australian children, May et al. (2017) found no difference in pubertal timing amongst autistic and neurotypical females, based on parent and self-report measures. However, when using physical examination to measure puberty, which is asserted to be a more accurate measure of pubertal development (Corbett et al., 2019), researchers have evidenced that autistic females were more likely to start puberty at an earlier age than autistic males and neurotypical females (Corbett et al., 2020; Corbett et al., 2022; Liu et al., 2024). Researchers have argued that the detrimental impact of early puberty on mental health and wellbeing is likely to be exacerbated for autistic individuals, with such a transition intensifying existing difficulties (Corbett et al., 2022).

With regard to menstruation in particular, researchers have also sought information concerning the type and rate of menstrual-related complaints amongst autistic adolescents, neurotypical adolescents, and adolescents with other developmental diagnoses. Through retrospective reviews of medical records, autistic adolescents were found to frequently report period pain, irregular bleeding, and difficulties maintaining personal hygiene (Burke et al., 2010) and were significantly more likely to be diagnosed with menstrual-related disorders (e.g., dysmenorrhea; Ames et al., 2024). Even prior to the onset of menstruation, autistic females and their families have been found to be more likely than females with other developmental diagnoses to seek anticipatory guidance from gynaecological professionals (Fei et al., 2021), particularly regarding puberty and behaviour, highlighting the anxieties associated with this developmental transition.

2.1.3 Rationale for the current review

This systematic review aims to explore and summarise existing research addressing autistic girls' and women's experiences of puberty and menstruation, as well as the views of those who care for them. Adding to existing knowledge regarding pubertal progression, complaints, and conditions amongst autistic females, understanding how autistic females (and those closest to them) make meaning of their pubertal and menstrual experiences, appears a priority. This systematic review also aims to uncover research exploring how to support autistic girls through puberty and menstruation, for two purposes. Firstly, to ascertain whether the methods, approaches, and interventions within such literature align with the challenges that autistic girls face and the support that they (and those who care for them) are advocating for. Secondly, to ascertain whether the voice of autistic girls and those who care for them have been included in such research.

The Autistic Girls Network are advocating for more research on autistic wellbeing, menstruation, and interaction with healthcare professionals, ideally co-produced with autistic individuals themselves (Wassell & Burke, 2022). Aside from the autistic-led 'Autism: from menstruation to menopause' research project that is currently underway (Grant et al., 2024), to my best knowledge there are currently no co-constructed research papers on this topic. It is hoped that this systematic review will meaningfully contribute to the evolving literature base exploring autistic girls' experiences and may path the way for future participatory research projects surrounding the topic of puberty.

2.1.4 Research Questions

1. How do autistic girls and women describe their experiences of puberty and menstruation?
2. What are caregiver and educator experiences of supporting autistic girls through puberty and menstruation?

3. What support do autistic girls, their caregivers, and educators recommend for supporting autistic girls through puberty and menstruation?
4. What research has been conducted on the topic of support for autistic girls through puberty and menstruation, and has autistic voice been included in such research?

2.2 Methodology

2.2.1 Search Strategy

This review was pre-registered with PROSPERO (ID: CRD42024598530). A search was conducted to identify studies exploring menstruation or puberty in autistic female populations, including their views, experiences, and methods of support (as well as the views of their caregivers and educators). The SPIDER tool (Cooke et al., 2012), as outlined in Table 2-1, was used to define key elements of this review question. This tool was chosen due to its applicability to qualitative research, and its potential to promote sensitive and efficient literature searching (Cooke et al., 2012).

The search strategy was developed through consultation with a specialist librarian at the University of Southampton. This involved development of the search terms as outlined in Table 2-2, and the decision to search subject areas, titles, and abstracts to retrieve relevant papers. Four electronic databases, including APA PsycINFO, Web of Science, ERIC and Dissertations and Theses Global were used to search for peer-reviewed and grey literature (theses and dissertations).

Table 2-1 SPIDER Criteria

Sample	**P**henomenon of Interest	**D**esign	**E**valuation	**R**esearch Type
• Autistic girls/ women (with a diagnosis or who self-identify) who are experiencing/ have experienced	• Menstruation and/or puberty* (*relating to physical, emotional, and hormonal changes*)	• Any research design	• Lived experience • Views or perceptions • Benefit to autistic girls	• Qualitative (to address research questions 1, 2, and 3) • Qualitative, mixed methods or quantitative (to address

puberty and menstruation • Caregivers of autistic girls/ women • Education staff		research question 4)

*Note. *If a study is deemed partially relevant, i.e., there is a definitive section within the findings section focussed on puberty and/or menstruation, this study may be deemed eligible if other criteria is met.*

Table 2-2 Search Terms across Databases

Databases	Search Terms
APA PsycINFO	• DE ("autism spectrum disorders" OR “neurodiversity”) OR TI (autis* OR neurodiver*) • DE (puberty OR menstruation OR menstrual cycle OR premenstrual syndrome OR menarche OR dysmenorrhea) OR TI (pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea) OR AB (pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea)
Web of Science	• TI (autis* OR neurodivers*) • TI (pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea) OR AB (pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea)
ERIC	• MAINSUBJECT(“autism spectrum disorders” OR autism) OR TITLE(autis* OR neurodivers*) • MAINSUBJECT(puberty OR menstruation) OR TITLE(pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea) OR ABSTRACT(pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea)

Dissertations and Theses Global	• MAINSUBJECT("autism spectrum disorders" OR autism) OR TITLE(autis* OR neurodivers*) • MAINSUBJECT(puberty OR menstruation) OR TITLE(pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea) OR ABSTRACT(pubert* OR menstrua* OR premenstrua* OR pre-menstrua* OR menarche OR dysmenorrhea)

2.2.2 Study Selection Process

Rayyan, a web-based tool for systematic reviews, was used to store and organise search results. In total 497 publications were retrieved. Once duplicates were removed (*n* = 167), titles and abstracts were screened. Their eligibility was determined by the inclusion and exclusion criteria outlined in Table 2-3. To promote inter-rater reliability, a voluntary research assistant screened the titles and abstracts of 40 papers (12.1%). Cohen's kappa was calculated to assess the rate of agreement between our decisions (*k* = 0.72), which indicated substantial agreement (Landis & Koch, 1977). This was followed by a discussion to resolve conflicts.

Research papers deemed potentially relevant were then read in full. Of the 86 papers, 7 (8.1%) were screened by the same voluntary research assistant, with agreement on four papers, and queries arising for three (two queries relating to publication types and one relating to study outcomes). Due to the small sample size, Cohen's kappa was not deemed appropriate (Bujang & Baharum, 2022). A discussion was held to discuss these queries and make final decisions, resulting in the inclusion of 17 papers. I then conducted manual citation searching to check for additional papers that were not identified in initial searches. I also explored articles that had since cited relevant papers from database searching, to check for recently published literature that might meet search criteria. Four additional studies were identified. The identification, screening, and inclusion/exclusion process are outlined in the PRISMA chart (Figure 2-1).

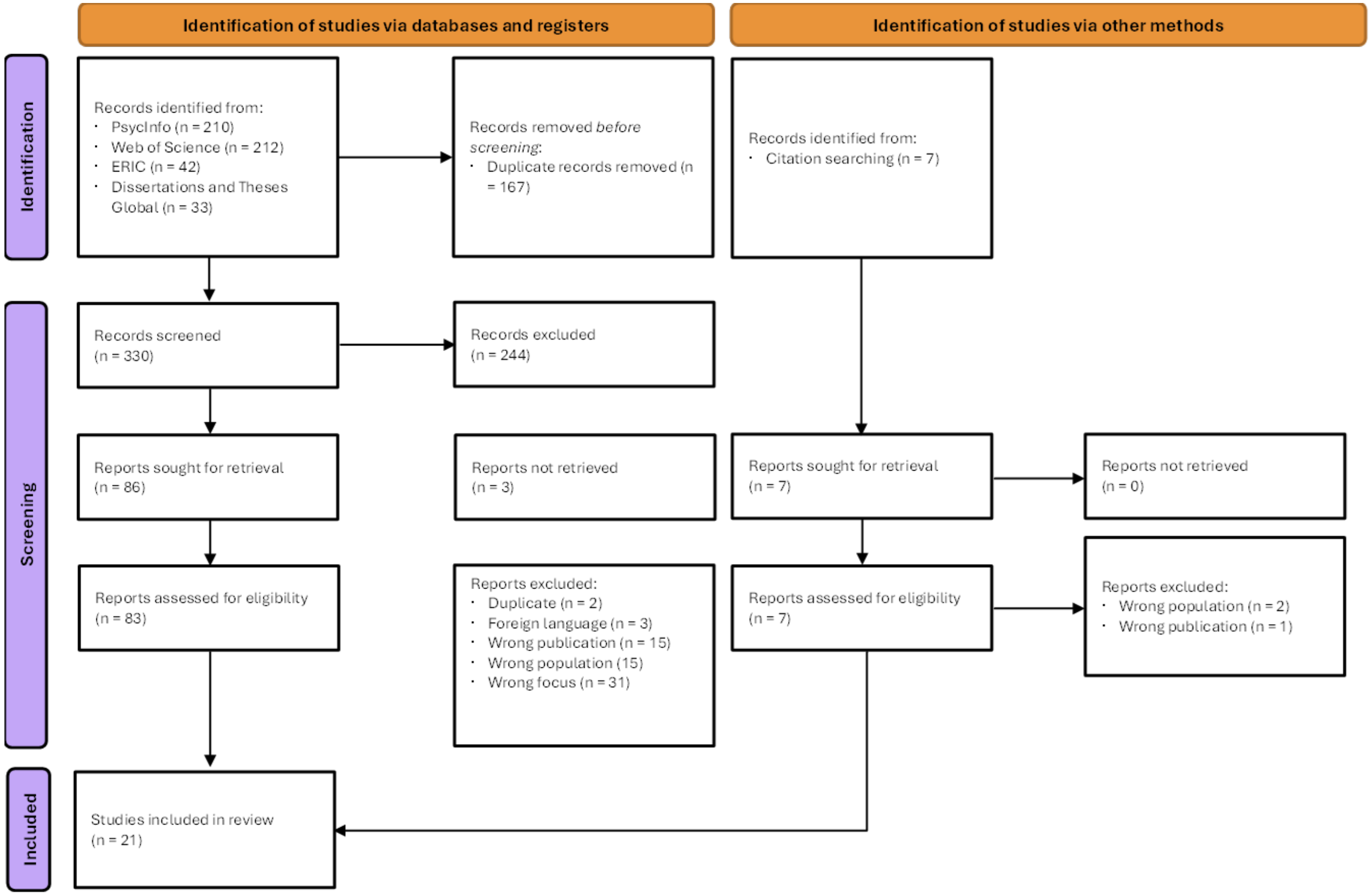
Table 2-3 Inclusion and Exclusion Criteria

Inclusion	Exclusion
• Peer-reviewed articles or grey literature (dissertations and theses)	• Books, book chapters, editorials, reviews
• Qualitative, quantitative and mixed methods studies	
• Studies seeking the views of autistic girls or women (with a formal or self-diagnosis), their caregivers, and/or educators*	• Studies seeking the views of autistic boys/men only or studies seeking to understand only the male experience of puberty
• Studies exploring support for autistic girls/ women through puberty/ menstruation	
• Studies published up to and including February 2025	
• Available in English language**	• Studies not published or translated into English

Note. *Studies including autistic males will be included if data relating specifically to autistic females can be distinguished and is relevant to the research questions. Studies including gender diverse individuals will be included if they have experienced puberty/menstruation.

**Papers published globally will be included, with the requirement that these are written in or have been translated into the English language.

Figure 2-1 PRSIMA Chart (Page et al., 2021)



2.2.3 Analysis

Drawing upon the guidance of Popay and colleagues (2006), the findings from the included studies were analysed using a narrative synthesis approach. Through the iterative process of developing a preliminary synthesis, exploring relationships, and appraising the quality of the synthesis, I endeavoured to “tell a story” about autism and the female pubertal experience (Popay et al., 2006, p. 5), that was both comprehensive and transparent (Lucas et al., 2006). This involved writing textual descriptions of the included studies, systematically arranging data in tables (tabulation), grouping by study design and conceptually similar findings, and critically reflecting upon the synthesis (Popay et al., 2006). As similarly explained by Fisher et al. (2011), development of a theory to inform the systematic review was not deemed appropriate, due to this being a relatively understudied area of research.

The synthesis of the included studies is divided into two parts. Part A represents autistic girls’ and women’s qualitative experiences of puberty (as well as the views of caregivers and educators), encompassing preparations for and the journey through puberty, as well as desired support. Part B supplements Part A by providing an overview of studies investigating puberty interventions, identifying whether autistic voice and views are included.

2.2.4 Critical appraisal

All qualitative studies synthesised within Part A of this review were critically appraised using the Critical Appraisal Skills Programme (CASP; 2018) tool (see Appendix A). This tool was chosen due to its flexibility to be applied to any qualitative research methodology, its focus on meaningfulness as well as ethical and methodological appropriateness, and its endorsement from the Cochrane Qualitative and Implementation Methods Group (Noyes et al., 2018). All studies synthesised within Part B were critically appraised using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2019), enabling the methodological criteria of different study designs to be assessed (see Appendix B).

Overall, the studies included within Part A met the majority of CASP criteria. The studies adequately justified their use of qualitative methodology, provided a clear overview of their findings, and highlighted their unique contribution to the research base. While some studies lacked detail with regard to recruitment, and ethical considerations, the main omission across qualitative papers was the consideration of the researcher-participant relationship (and how this would have influenced data collection and analysis). In terms of Part B, the studies appeared to have relatively more omissions (or partially relevant information). While the studies seemed to use appropriate measures to study their desired outcomes, there was an absence of specific research questions, limited consideration of confounders, and questionable intervention fidelity across several papers. Due to this being a relatively under-researched topic, no studies were excluded based on quality assessment criteria, however the need for more comprehensive research papers is reflected upon in the discussion.

2.3 Findings

2.3.1 Synthesis Part A – Experiences of Puberty

Fourteen studies published between 2014-2024 were deemed eligible for Part A of this review, 11 of which were peer-reviewed journal articles, and three of which were unpublished theses (see Table 2-4 for the data extraction table including numbered citations). Of the 14 studies, three focused specifically on menstruation[1, 2, 3] and five focused on puberty more broadly[4, 5, 6, 8, 9.] In addition, findings from a further six studies were deemed partially relevant (with only relevant data being extracted) with two focussing on the transition from childhood to adulthood[7, 12]; one focusing on the experience of adolescence[10], two focussing on mothers' experiences of raising autistic girls[7, 13]; and one focussing on autistic women's health and wellbeing[14].

The included studies were conducted across several countries, including the UK, Ireland, Turkey, Bangladesh, Pakistan, Saudi Arabia, Ethiopia, USA, and Australia. Of these studies, two included autistic girls, four included autistic women, two included non-autistic women as comparisons, 12 included parents/caregivers, one included siblings, and two included educators. Only two of these studies included participants who self-identify as autistic, with the remaining specifying the need for a formal diagnosis. Participants' developmental needs varied widely across studies.

The number of participants in each study ranged from 5-237. The predominant form of data collection and analysis were semi-structured interviews and thematic analysis, although content analysis, interpretative phenomenological analysis and descriptive analyses were also specified.

Table 2-4 Detailed Summary of Included Studies (Part A)

Author	Type of source	Country of origin	Participant identity	Age range (years)	Number of participants	Data collection	Method of analysis
1 - Gray and Durrand (2023)	Peer-reviewed	UK	Autistic women (D and SD), non-autistic women	19 – 45	37	Semi-structured interviews	Thematic analysis
2 - Arslan et al. (2024)	Peer-reviewed	Turkey	Mothers of autistic girls (D)	11-15 (girls) 30 – 50+ (mothers)	10	Semi-structured interviews	Descriptive analysis and content analysis
3 - Steward et al. (2018)	Peer-reviewed	UK	Autistic women (D), non-autistic women, parents, siblings, professionals	16 – 60+	237	Online survey	Descriptive analysis and thematic analysis
4 - Cummins et al. (2020)	Peer-reviewed	UK and Ireland	Parents and educators of autistic girls (D)	11-19 (girls) (?) (parents and educators)	20	Semi-structured interviews	Thematic analysis
5 - Eriksen (2016)	Thesis	USA	Autistic girls (D), mothers	13 – 16 (girls) 43 – 51 (mothers)	20	Semi-structured interviews	Thematic analysis
6 - Anisa (2019)	Thesis	Bangladesh	Mothers of autistic female girls (D)	12-19 (girls) 29 – 55 (mothers)	12	Semi-structured interviews	Content Analysis

7 - Tadesse et al. (2024)	Peer-reviewed	Ethiopia	Parents and teachers of autistic youth (D)	12 – 17 (youth), 34 – 52 (parents and teachers)	17	Focus groups, semi-structured interviews	Thematic analysis
8 - Ashraf and Toor (2023)	Peer-reviewed	Pakistan	Mothers of autistic girls (D)	10-15 (girls) 30-45 (mothers)	5	Semi-structured interviews	Thematic analysis
9 - Hamdan (2022)	Peer-reviewed	Saudi Arabia	Parents of autistic youth (D)	13-18 (youth) (?) (parents)	12	Semi-structured interviews	(?) (Described but specific method unspecified)
10 - Cridland et al. (2014)	Peer-reviewed	Australia	Autistic girls (D), mothers	12-17 (girls) 47-54 (mothers)	5	Semi-structured interviews	Interpretive phenomenological analysis
11 - Navot et al. (2017)	Peer-reviewed	(?)	Mothers of autistic girls (D)	(10-19) (girls) (?) mothers	11	Semi-structured interviews	An interactive process used in naturalistic inquiry
12 - Balubaid (2017)	Thesis	UK and Saudi Arabia	Autistic adults, mothers of autistic individuals (D)	(13-33) (children of mothers) 18-51 (adults/mothers)	19	Semi-structured interviews	Thematic analysis
13 - Mademtzi et al. (2018)	Peer-reviewed	USA	Mothers and fathers of autistic girls (D)	4 – 29 (girls) (?) (mothers and fathers)	40	Focus groups	Thematic analysis

14 - Grove et al. (2023)	Peer-reviewed	Australia	Autistic women and gender diverse people (D and SD)	21-63	31	Semi-structured interviews	Thematic analysis

Note. D = diagnosed; SD = self-diagnosed; (?) = unspecified.

2.3.1.1 Preparing for puberty

Several parents reported feelings of anxiety in the lead-up to puberty, especially with regard to menstruation. Concerns were shared across studies about their daughters' abilities to manage the self-care demands of menstruation[2, 4, 6, 8, 10, 13], their acceptance of menstrual products[2, 4, 5, 6], and their vulnerability to exploitation[4, 6, 8, 10, 13]. In one study, parents spoke about the anxieties that their daughters had expressed when learning about puberty, including their resistance for their bodies to change[5].

Across studies, participants reflected upon how the topic of puberty and menstruation was taught to autistic girls, with this predominantly being through parents or teachers[3, 5, 6, 8, 12], as opposed to friends or social groups (which was highlighted as a key source of information for non-autistic girls[3]). While some spoke positively about aspects of this anticipatory preparation[4, 5, 12], others spoke about having limited information prior to the onset of puberty for several reasons, including parents and educators feeling ill-equipped to discuss the topic in a developmentally appropriate way[2, 6, 8, 10, 12], and the influence of societal and cultural norms with regard to modesty and discretion[8]. While some educators spoke about the benefits of being female and having had lived experience when teaching girls about puberty, others spoke about the need for schools to learn more, the need for external professional support, the inaccessibility of current resources, and the challenges of whole class teaching in meeting individual needs[4].

2.3.1.2 The journey through puberty

Reflecting the broad spectrum of pubertal experiences across the general population, the girls, women, and parents within the included studies spoke about the plethora of ways that puberty, and particularly menstruation, impacted them both physically and emotionally. While for some, puberty brought about a sense of calmness[4, 6, 12], empowerment[5, 14], and pride[4, 5], for the vast majority, puberty was associated with intense mood swings[2, 3, 4, 5, 6, 7, 8, 9, 12, 14], feelings of anxiety, uncertainty, and overwhelm[1, 3, 5, 9, 12, 14], difficulty adjusting to bodily changes[11, 14], and severe pain[1, 3, 4, [7, 9, 14] which consequently impaired daily functioning, social interactions, and usual activities[4, 5, 9].

Across studies, there were some conflicting views with regard to how being autistic influenced the lived experience of puberty (and vice versa). For some, being autistic was felt to exacerbate difficult menstrual experiences: communication differences were viewed as a barrier to expressing emotions and seeking help for pain[1, 4, 5, 6, 7, 12]; social interaction differences were discussed in the context of limited communication with others about "typical" pubertal experiences[1]; and comprehension differences, with regard to bodily changes, emotions, social norms, and managing sexual urges were highlighted as areas affecting dignity and wellbeing (of both autistic girls/women and their parents)[2, 4, 6, 7, 8, 10, 11, 13]. In addition, some also reflected on how puberty exacerbated challenges associated with their autistic experiences. This included heightened interoception and sensory sensitivities (e.g., smell, touch, and pain sensitivity)[1, 3, 14]; difficulties maintaining a sense of control and self-regulating[3, 6, 7, 8], heightened anxiety[3, 9], and interference with executive functions[3].

Of significant concern across many studies (as predominantly expressed by parents), was the increased self-care and hygiene demands associated with puberty and menstruation[2, 4, 5, 6, 7, 8, 9, 10, 11, 13]. While some girls were able to manage independently[4, 5, 6, 10], many were described as requiring considerable support[2, 4, 6, 7, 8, 10, 11], with parents highlighting concerns around discretion and vulnerability. Finding suitable menstrual products that were tolerable and did not intensify sensory sensitivities was posed as a particular challenge[5, 7, 8, 9, 14]. However, for others, experiencing puberty as an autistic individual was viewed in a more positive light with some parents attributing their daughters' logical, "black-and white" thinking style to their better understanding of menstrual routines and experiences[4, 10]. In the research of Cummins et al. (2020), parents suggested that the neurodivergent and neurotypical experience of puberty may be similar, but the way in which individuals cope with these experiences is what diverges, e.g., having the skills to manage their menstrual hygiene. Therefore, considering the support that autistic girls may need across the puberty journey, and how this can be implemented, appears a priority.

2.3.1.3 Desired support – the 'what'

Autistic girls, women and those who care for them highlighted the need for autistic girls to be taught about the process of puberty, including the menstrual cycle, female anatomy, and the reason that periods happen[1, 3]. When doing so, they shared the importance of appropriate (yet specific) language being used, and framing periods as a natural part of female development (not 'dirty' or something to be ashamed of)[3, 4, 5]. Across studies, participants spoke about the 'taboo' nature of menstruation, which is maintained through societal and cultural influences, and the barrier that this creates in terms of autistic girls receiving the information and support they require[1, 3, 8].

In addition, participants raised the importance of teaching girls about the physical symptoms (e.g., cramps, skin changes, weight changes) and emotional symptoms (e.g., mood swings) that they might expect during puberty, as well as methods and strategies to effectively manage them[3, 5]. This includes recognising what is their 'normal' (with understanding that individuals experience symptoms in different ways), and what might be indicative of a medical need[3, 7]. Supporting autistic girls to identify who they might feel comfortable talking to, and empowering girls to develop scripts for when they need help/when something is wrong, was emphasised[3.] Alongside promoting autistic girls' self-advocacy, the importance of autistic girls' needs being taken seriously was stressed (including recognition of differing pain expressions)[1]. This appeared to be a response to autistic women's inadequate healthcare experiences, as well as the societal normalisation of menstrual pain[1].

Across several studies, supporting girls to develop their menstrual hygiene and self-care skills appeared a priority, for their own independence, dignity, and safety, as well as to reduce the strain on parents[4, 5, 6, 7, 8]. This included helping girls to prepare for their periods, teaching them about different menstrual products, and empowering them to choose[3, 4, 5, 6, 10]. Teaching girls about private vs public, how to say 'no', and appropriate touch was also deemed important for girls' personal safety[4, 6, 7, 8, 10, 11].

2.3.1.4 Desired support – the ‘how’

In addition to ‘what’ autistic girls, women and those who care for them would like to see in terms of puberty and menstruation support, participants across several studies also spoke about how they would like such support to look. Several approaches were outlined across studies, including social stories[4, 12], step-by-step guides (with minimal language)[3, 4], books[12], life size dolls[4], calendars or apps to track periods[4, 5], vibrating watches to signal self-care routines[4] and the use of non-animated videos to provide education[4]. However, what was highlighted as particularly important was the individualisation of such strategies, adapting to their needs and level of understanding, and being attuned to their signals (particularly amongst minimally speaking girls)[4, 8]. To do so, the importance of caring relationships, knowing the girls well, being patient, and maintaining open communication was emphasised[4, 5].

Across studies, there was large consensus that education should be provided to autistic girls prior to the onset of puberty/menstruation (and that parents/educators should receive training and support in how to do so). While there was some reflection on the value of teaching girls in the moment (promoting authenticity)[4], the vast majority highlighted the importance of girls knowing what to expect, having the opportunity to practice self-care skills, and to build familiarity with sanitary products/self-care items[3, 4, 5, 6, 12].

2.3.2 Synthesis Part B – Puberty Interventions

Seven studies published between 2012-2024 were deemed eligible for Part B of this review, six of which were peer-reviewed journal articles, and one of which was an unpublished thesis (see Table 2-5 for the data extraction table including numbered citations). Of these studies, six focused on teaching menstrual hygiene skills (through video training[16], visual training methods[17], social stories[20], behavioural skills training[18, 19], task analysis[18, 19, 20], and chaining[21]) and one focused on menstrual product preferences[15]. The majority of studies included pre-post or multiple-baseline designs, and one utilized a cross-sectional design.

All studies included autistic girls (with a formal diagnosis), ranging from 9-18 years. In five studies, the girls had begun menstruation, in one they had not, and in one this was unclear. In four studies, the girls' parents or caregivers also participated. The included studies were predominantly conducted in the USA, as well as one in Turkey and one in India.

Table 2-5 Detailed Summary of Included Studies (Part B)

Author	Type of source	Country of origin	Participant identity	Age range (years)	Number of participants	Design	Data collection	Method of analysis	Autistic voice/ caregivers
15 - Lundy et al. (2024)	Peer-reviewed	USA	Autistic girls (D), caregivers	10-17 (girls), 31-56 (caregivers)	198	Cross-sectional	Surveys	Hierarchical Bayesian estimation and latent class analysis	Yes (caregivers and youth)
16 - Kumar and N (2024)	Peer-reviewed	India	Autistic girls (D)	12-18	50 (25 control, 25 experimental)	Quasi-experimental	Menstrual Practice Needs Scale	Wilcoxon signed-rank test and the Mann-Whitney test	No
17 - Kaydirak et al. (2023)	Peer-reviewed	Turkey	Autistic girls (D)	15-17	15	Pre-test/post-test	Adolescent - Specific Menstrual Hygiene Skill Registration Form	Wilcoxon signed-rank test	No
18 - Lundy et al. (2022)	Peer-reviewed	USA	Autistic girls (D), caregivers	11-12 (girls), (?) (caregivers)	6 (3 youth-caregiver dyads)	Multiple baseline design Reversal design	Technology Acceptability Model-Fast Form, Behaviour Intervention Rating Scale, Children’s Intervention Rating Profile	Visual analysis	Yes (caregivers and youth)

19 - Moreno (2021)	Thesis	USA	Autistic girls (D), caregivers	10-12 (girls), (?) (caregivers)	4 (2 youth-caregiver dyads)	Multiple baseline design across participants	Observation	Descriptive	No
20 - Klett and Turan (2012)	Peer-reviewed	USA	Autistic girls (D), mothers	9-12 (girls), (?) (mothers)	3 girls 3 mothers	Multiple baseline design across participants	Task analysis, Menstruation checklist, Comprehension questions, Parent satisfaction measure, Semi-structured interviews	Descriptive	Yes (parents)
21 - Veazey et al. (2015)	Peer-reviewed	USA	Autistic girls (D)	9-11	2	Multiple baseline design across participants	Observation of task-analysis steps	Descriptive	No

Note. D = diagnosed; SD = undiagnosed; (?) = unspecified.

2.3.2.1 Autistic voice (and the voice of those who care for autistic individuals)

Of the seven identified studies within Part B, only three included the voice of autistic girls and/or their parents/caregivers[15, 18, 20]. In terms of the two menstrual hygiene studies[18, 20], parents/caregivers were said to inform elements of the interventions (i.e., revising social stories or contributing to training development in line with their daughters' needs), and were asked to provide feedback in terms of satisfaction, acceptability, and perceived effectiveness. In just one of these, autistic girls were also asked to complete an acceptability form[18].

In terms of the study on menstrual product preferences, the voice of autistic girls and their parents was central to the research[15]. Through surveys, parents were asked questions about factors that influenced their menstrual product purchasing choices for their daughters, while the autistic girls themselves were asked about their preferences. To inform these preferences, the girls were given the opportunity to try a variety of products, read 'The Autism-Friendly Guide to Periods' (Steward, 2019), and explore menstrual product informational leaflets.

2.3.2.2 Alignment with needs and recommendations

Each of the studies included in Part B were cross-referenced with the studies in Part A, to ascertain how/whether they aligned with the views and recommendations of autistic girls and those who care for them. In terms of *what* topics were covered, the studies predominantly focused upon menstrual hygiene and self-care, demonstrating consistency with the topics discussed in Part A. One study provided additional information about physical and emotional changes, privacy and advocacy[18]; one provided reassurance about periods being a normal, healthy part of development, as well as information about menstrual timings and who to ask for help[20]; and another provided information and guidance on how to choose menstrual products[15.]

In terms of *how*, only one study targeted autistic girls prior to the onset of menstruation[20]. Several studies involved methods in which task steps were broken down into simple steps[15, 16, 21], and in which visual/tangible resources were used (such as social stories[20] and life-size dolls[17]. In just two studies, personalisation of resources was discussed[18, 20].

Some conflicts between Part A recommendations and Part B approaches were also noted, including the inclusion of animated over non-animated videos[16], and the use of the term “dirty” to describe elements of menstrual self-care[17, 20].

2.3.2.3 Study Findings

In terms of study outcomes, the experimental studies demonstrated positive effects of training on autistic girls’ knowledge of pubertal development[20] and menstrual hygiene skills[16, 17, 18, 19, 20, 21], as well mothers’ competence in teaching such skills[19]. Positive reflections on social stories and task analysis were shared by caregivers in one study[20], and acceptability of a menstrual hygiene programme was reported by caregivers and autistic girls’ themselves in another[18]. In the study exploring menstrual product preferences[15], caregivers were found to choose products based on sensory impact, as well as the motor and executive functioning skills of their daughters. While mothers believed that sanitary pads would be their daughters’ most preferred option, in fact period underwear was (with tampons and menstrual cups being the least preferred).

2.4 Discussion

This systematic review aimed to synthesise research into autistic females’ experiences of puberty and menstruation, from their perspectives, as well as the perspectives of their caregivers and educators (Part A). With these experiences in mind, as well as their suggestions regarding effective support, this review also aimed to ascertain whether existing intervention literature aligned with their needs and desires, and whether autistic voice was included in such research (Part B). With research suggesting that autistic females are likely to start puberty earlier than their neurotypical peers (Corbett et al., 2022; Liu et al., 2024), and that they are at increased risk of experiencing menstrual-related disorders (Ames et al., 2024), the need to understand their experiences and recognise what is important to them, is undeniably important. In total, 14 qualitative papers were included in Part A of this review, and 7 papers were included in Part B.

With regard to Part A, the majority of studies included the voice of parents (predominantly mothers). Only two included the voices of autistic girls and five included the voices of autistic women, underscoring the underrepresentation of autistic females within research literature (Cridland et al., 2014; Leedham et al., 2020). Furthermore, of the 14 studies, only three included participants who self-identified as autistic. This is problematic in light of barriers to diagnosis (particularly for females) and the increasing number of autistic individuals self-identifying (Overton et al., 2024).

Part A of this review highlighted several concerns around the pubertal transition for autistic girls and those who care for them. This included anticipatory anxieties (aligning with research on early gynaecological support-seeking; Fei et al., 2021), the impact upon mental wellbeing and functioning, and particular struggles with regard to self-care and menstrual hygiene. A reciprocal relationship between puberty and autism was also alluded to across several studies; some attributed the increased challenges of puberty with elements of their autistic experience (in part supporting the maturity-disparity hypothesis), and others framed puberty as intensifying their support needs (in line with the accentuation hypothesis; Ge & Natsuaki et al., 2009). At the same time, from the perspective of some parents, their daughters' adjustment to puberty and their understanding of menstrual routines was in part attributed to their logical, matter of fact thinking styles, highlighting autistic strengths and challenging negative assumptions about autism as a deficit.

From parents' perspectives, the onus on educating and supporting girls through puberty and menstruation largely fell on them (as well as educators), however, many felt under skilled and underprepared to do so. While neurotypical adolescents often gain pubertal knowledge from conversations with their peers, this was suggested to be less likely amongst autistic adolescents with differing social communication needs and preferences (Arslan et al., 2024). In terms of support, the need for early education and preparation time was recommended by the majority. The need for clear information, using accurate and specific language, highlighting the 'normalcy' of puberty was asserted, while considering individual needs. Furthermore, the need to promote autistic girls' dignity and advocacy also shone through as a priority, as well as for their needs to be taken seriously.

In terms of Part B of this review, the vast majority of studies were experimental or quasi-experimental, with a focus on self-care and menstrual hygiene. While elements of these studies aligned with recommendations from autistic girls and those who care for them (e.g., including step-by-step guidance), few included autistic voice within the studies themselves. The majority of these studies drew upon behaviourist approaches to teach autistic girls basic personal care routines following menarche, taking a within-person approach. While arguably helpful in supporting autistic individuals to develop essential personal care skills, there is concern that such approaches are excessively rigid, promoting conformity and compliance, rather than promoting autonomy (Leaf et al., 2022). One exception to this was the recent study of Lundy et al. (2024), which promoted individual exploration and choice of menstrual products.

When viewing the wellbeing of autistic girls through the social lens as described by O'Connor et al. (2023), the studies included within Part B largely disregard the environmental, relational, societal, and cultural factors that may influence autistic girls' experiences of puberty (in line with the contextual amplification hypothesis; Ge & Natsuaki et al., 2009). As highlighted within the findings of Part A of this study, such factors include the social construction of puberty and periods as something undesirable, 'dirty', and something that should be concealed (Arslan et al., 2024). To promote healthy perceptions of puberty, foster open communication, and promote autistic girls' wellbeing during puberty, focusing research attention beyond the individual is required, yet presently lacking.

2.4.1 Strengths, limitations and implications

This review synthesised studies from an emerging area of research, with a focus on amplifying the voices of autistic females (and those who care for them). While there is currently a small number of peer-reviewed studies within this area, this review incorporated grey literature, expanding the breath of the data and contributing to a balanced synthesis. The included studies represented autistic populations across five continents (Europe, Asia, North America, Africa, and Australia), creating a more comprehensive overview of views and experiences. Furthermore, the quality of such studies were assessed using the CASP (2018) and MMAT (2019) tools, highlighting patterns in study strengths (i.e., appropriateness of research methodology and contribution to the research base), as well as study weaknesses (i.e., limited consideration of the researcher-participant relationship and questionable intervention fidelity), promoting transparency of research validity and bias.

While the diversity of the included studies can be interpreted as a strength of this review, the range of designs and methodologies utilised, as well as the differences in participant groups, creates its own challenges in terms of over-generalised interpretations and transferability. With regard to inclusion and exclusion criteria, the present review focussed on puberty and menstruation, rather than the broader sexual development of adolescents (this was beyond the research scope). During the data screening process, there were some challenges with disentangling puberty from sexuality, particularly in terms of education. It is acknowledged, that while puberty and sexual development are separate processes, there is considerable overlap, and thus studies on sexual education programmes (with sub-sections on puberty education) may have been missed.

By contrast, although this review involved a comprehensive search of research exploring puberty and menstruation experiences amongst autistic females, there were relatively few studies that were solely focussed on this topic. Therefore, studies exploring broader topics, such as adolescence and the transition from childhood to adulthood were included, with puberty often a relevant section of the main findings. This poses its own challenges and potential biases, in terms of topic foci and the questions posed to participants.

As the research base evolves, it would be useful for researchers to increase the specificity of inclusion criteria, to develop more bespoke reviews and understanding. In order for this to be feasible and meaningful, there is a strong need for more studies focussing explicitly on autistic girls' experiences, as well as their views on supportive methods, approaches and programmes (with researcher transparency regarding their influence on the process and outcomes). It will be important that these extend beyond within-child interventions, to programmes aimed at upskilling and empowering parents and educators' (informed by autistic individuals themselves), so that they feel prepared to support autistic girls according to their individual developmental needs. Such studies should discuss adherence to the programmes, providing information regarding acceptability and feasibility. Furthermore, there is a need for further research and action to break the silence and encourage dialogue around puberty and menstruation across wider society.

In terms of practice, this review highlights the need for early, comprehensive and non-ambiguous puberty education for autistic girls. For this to occur, it is important that those providing such education (namely teachers and parents) feel competent and prepared to do so (in line with Bandura's theory of self-efficacy, 1977). The development of accessible information and teaching resources informed by the experiences of autistic individuals (and their caregivers) is needed, with the particular skills, knowledge, and support that autistic girls may require reflected in PSHE curriculums (e.g., input regarding different menstrual products).

Importantly, those working with and supporting autistic girls during this stage of development, need to be aware of how pubertal experiences and challenges may present. Taking a holistic stance, the impact of puberty should be one of various factors considered when exploring what might be influencing autistic girls' wellbeing and development. In particular, EPs, with expertise in complex problem-solving, should bring the potential role of puberty into supporting adults' consciousness, when involved in individual, group, or whole-school work. It is also important that assumptions are not made about autistic girls' ability to adjust to pubertal changes, and that the strengths of autistic individuals (e.g., analytical thinking styles) are recognised and utilised to best support their navigation through puberty.

2.4.2 Conclusion

Through this systematic review, it is hoped that the voice of autistic females (and those who care for them) have been represented in a way that is meaningful for the autistic community. Promoting awareness and empathic understanding of the experiences of autistic females inspired this review, and it is hoped that other researchers will be encouraged to delve further into this important topic, ideally through participatory research projects with autistic voice at the centre.

Chapter 3 "We really can change people's perspectives, and we can, really make a difference”: A participatory study including autistic voice within a mainstream secondary school.

3.1 Introduction

It is widely acknowledged that autism in girls is under-recognised, under-represented, and under-diagnosed (Lockwood Estrin et al., 2021; Hamdani et al., 2023). As supported by NHS data from 2012-2018, boys are more likely to receive an autism referral and be referred at younger ages (Moyse, 2020). In 2017, Loomes and colleagues asserted that the male to female ratio was likely to be closer to 3:1 than the previously estimated 4:1, and highlighted that of those meeting diagnostic criteria, females remained less likely to receive a formal diagnosis. More recently, this has been further challenged, with McCrossin (2022) proposing a ratio of 3:4.

The oversight of autistic females may in part be explained by faulty constructs around autism being a condition amongst males, a processing bias towards male-gendered presentations, and the enduring perception that diagnostic tools are the superior method of identifying autism (Lockwood Estrin et al., 2021; D’Mello et al., 2022). It has been suggested that stereotypical characteristics associated with autism must be exaggerated amongst autistic girls for them to be noticed, including additional language difficulties, emotional dysregulation, and disruptive behaviour (Bargiela et al., 2016; Lockwood Estrin et al., 2021). The social acceptability of many autistic girls’ presentations, such as their quiet and passive natures (Bargiela et al., 2016), and the alignment of their special interests to those of their neurotypical female peers (Bourson & Provost, 2024), likely contributes to them being overlooked.

Additionally, there is a growing body of evidence for sex differences regarding ‘masking’ or ‘social camouflaging’, with autistic females more likely to disguise or suppress parts of themselves to blend in and cope with the predominantly non-autistic social world. This has been demonstrated experimentally (Wood-Downie et al., 2020) and has been described through first-hand accounts of autistic females’ experiences (Bargiela et al., 2016). Not only does this raise concerns regarding autistic females’ vulnerability and wellbeing (Bargiela et al., 2016; Lockwood Estrin et al., 2021) but this may also exacerbate under-recognition and delays to referrals. Nevertheless, even when girls have been referred for diagnostic assessment, they are still less likely to receive a diagnosis than boys (Moyse, 2020) and also frequently report being misdiagnosed with conditions such as anxiety, depression and obsessive-compulsive disorder (Hamdani et al., 2023).

With age, social communication difficulties among autistic females are likely to become more pronounced. This may be explained by autistic traits developing later in females (Lockwood Estrin et al., 2021), or by an increased difficulty in camouflaging as social interactions become increasingly complex (or perhaps, a combination of the two). Such factors inevitably contribute to the late diagnosis of autistic females during adolescence.

Unsurprisingly, together with the under-recognition and the mis/late diagnoses of autistic females, there has been a considerable gender disparity within autism research over time. With males disproportionately overrepresented (D’Mello et al., 2022), terms such as ‘research orphans’ have previously been used to describe autistic girls (Klin, as cited in Volkers, 2018). Accordingly, researchers have recently begun to turn their focus to the perspectives of autistic females in an endeavour to uncover and better understand their lived experiences.

3.1.1 The challenges for autistic girls

Across this relatively contemporary literature, there is much consensus around the challenges that autistic girls face. Many autistic girls have reported internalising symptoms, such as stress and anxiety, exhaustion from masking, difficulties navigating complex social interactions, sex-specific puberty issues, sexual vulnerabilities, negative experiences of school and increased rates of emotionally based school avoidance (Cridland et al., 2014; Bargiela et al., 2016; Tomlinson et al., 2020; O'Hagan et al., 2022). In a recent systematic review, which thematically synthesised the determinants of mental health and wellbeing of autistic females, O'Connor et al. (2024) concluded that while the 'autistic neurotype' formed one of these themes, the neurotype itself did not detrimentally impact emotional outcomes. Rather, when the autistic neurotype was experienced within an unaccommodating neurotypical world, and in the face of societal stigma, it was then that mental health and wellbeing were adversely affected. In line with the social model of disability, which asserts that disability is the product of societal barriers (Oliver, 1986), this review highlighted the widespread disregard and invalidation of the needs, preferences, and experiences of autistic individuals and the need for improved autism understanding and inclusion to promote their mental health and wellbeing.

3.1.2 Autism in the school context

In line with the shift towards inclusive practice within schools, there has been a drive in recent years to make schools more autistic friendly. Morewood et al., (2011) asserted that schools must be "saturated" (p. 64) in autism awareness and understanding in order to create autism friendly environments, which involves actively embedding inclusive values and practices across all elements of school. Staff development and peer awareness are cited as two fundamental requirements. Based on the conclusions drawn from research on autistic females' experiences, there is a clear need for specialist staff and peer education within schools, so that autistic girls can be sensitively supported, meaningfully included, and feel a secure sense of belonging (Goodall and MacKenzie, 2019; Moyse, 2020; Tomlinson et al., 2020).

Despite this need, researchers have demonstrated several limitations to the efficacy of autism awareness programmes and professional development, two of which this paper will further describe. Firstly, there is currently a lack of stakeholder consultation, involvement and feedback on such programmes, raising questions about the meaningfulness and relevance of for autistic individuals (Cremin et al., 2020).

Secondly, although there is emerging evidence for the effectiveness of such programmes in changing attitudes and knowledge amongst school staff and students there is limited evidence for affecting intentional and actual behaviour change (Cremin et al., 2020; Petersson-Bloom & Holmqvist, 2023). This is known as the ‘transfer problem’, which refers to transferring learning into practice (Blume et al., 2010).

3.1.3 Participatory research

In relation to this first problem, one way of addressing the lack of stakeholder involvement in programme development, evaluation, and delivery is through participatory research approaches. Such approaches partner with individuals who belong to or represent the population being studied and include them within the research team (Vaughn & Jacquez, 2020). While researchers have asserted the many benefits of participatory research with autistic young people, including increased empowerment, engagement, and communication of differing perspectives, this is a budding practice with autistic youth, and opportunities for autistic girls to be involved in such research are particularly sparse (Newson et al., 2024).

One recent study which sought to address the absence of autistic girls in participatory research was the Doctoral research of East (2024). Using a participatory framework and creative body mapping methodology (as also described in a creative data analysis chapter by East et al., 2024), a group of six adolescent autistic girls, known as FIZZACC, explored their feelings and experiences of their transition to secondary school. This led to the co-creation of resources aimed at raising schools’ awareness of these experiences, the challenges autistic girls can face, and supportive strategies that can be put in place. After trialling these resources across three schools, East (2024) found that most students reported an intention to change the way they interact with autistic peers. The majority also concurred that the resources were more impactful due to them being developed by a team of autistic girls. This study highlights the benefits of using participatory approaches with autistic young people, not only to respect and advocate their experiences, but to effectively raise autism awareness.

3.1.4 Implementation

In terms of the second limitation, relating to the ‘transfer problem’, researchers have developed and refined an ‘Implementation Framework’ for facilitating change beyond initial training in the context of education (Chidley & Stringer, 2020). This was informed by research on implementation science, including Baldwin and Ford's (1988) model of the transfer process, Graham et al.’s (2006) knowledge to action framework and Fixsen et al.’s (2009) core implementation components.

Through the implementation framework, school staff and stakeholders are encouraged to consider the complexities of behaviour change and what such change entails. Understanding the theory of planned behaviour (Ajzen, 1991) and the influence of attitudes, subjective norms, and perceived behavioural control, is an important goal. Furthermore, the framework requires individuals to consider, plan for, and measure outcomes at different levels, informed by the work of Barr et al. (2000), as acknowledged by Chidley and Stringer (2020). This includes outcomes relating to attitude change, knowledge and skill development, behaviour change, organisational change, and benefits to CYP. While this framework has been introduced and is becoming adopted by educational psychologists (EPs) within the context of school training (Chidley & Stringer, 2020), there is currently no research exploring the involvement of CYP in such processes. Researchers of other models informed by implementation science, such as the ‘school-wide autism competency approach’ (Roberts and Webster, 2022), have recommended the inclusion of students within implementation teams. However, in a multiple-case study of three schools in Australia, in which this model was trialled, student participation was not deemed feasible (Webster and Roberts, 2022).

3.1.5 The present study

The promise of participatory research approaches with CYP and the value of implementation planning and monitoring as posited in existing literature, informed the focus of the present research. Expanding upon the research of East (2024), this study takes a participatory approach, and involves the formation of an implementation team, who engage in a collaborative process to implement the FIZZACC resources within their school setting. In light of a recent systematic review by Freire and colleagues (2022), which highlighted that participatory research with children and adolescents typically only involves the early stages of resource or intervention development (i.e., ideating, creating, and refining), this study encompasses the latter stages (implementation, evaluation, and sharing), adding a unique contribution to the knowledge base. Through this study, the researchers aimed to uncover some of the successes, challenges, and future directions of implementing co-created resources within a school setting, in order to promote the voice and improve outcomes for autistic young people. Accordingly, we aimed to answer the following research questions:

1. How can an implementation team of autistic students and school staff work collaboratively to develop a strategy for dissemination of materials about autism in girls within a mainstream secondary school?
2. What are the experiences of the implementation team in terms of working collaboratively to negotiate, prioritise, and decide upon how information will be disseminated across the school?
3. What factors contribute to a successful participatory research approach in intervention implementation and what are the next steps?

3.2 Methodology

The overarching aim of this research was to work with a mainstream secondary school to consider and co-produce a strategy to implement the FIZZACC resources. In doing so, the researchers hoped to achieve three core outcomes:

1. To raise awareness of autistic girls' experiences of school and promote positive attitude and behaviour change across the school community.
2. To uncover some of the successes, challenges, and future directions of using co-created resources within schools as a method of facilitating change.
3. To include students in implementation processes within a school setting and to explore their experiences of such involvement.

Ethical approval for this research was granted by the School of Psychology's Ethics Committee and Research and Governance Team at the University of Southampton (ERGO number: 92436). The planning and execution of this research was guided by a person-oriented research ethics framework developed by Cascio and colleagues (2020), which involved recognising the needs, strengths and preferences of the individual participants; acknowledging their lived experiences; empowering their involvement in decision-making; respecting and valuing participant contributions; and promoting positive researcher-participant relationships.

3.2.1 Research Design

Underpinned by 'critical consciousness', a construct which encourages researchers to recognise and challenge social inequities (Freire, 1973), the approaches, design, and methods used within this research were selected to promote the voices of autistic young people and promote meaningful change. This study utilised an 'authentic inclusion' participatory research approach, involving stakeholder engagement and power-sharing where possible (Nicolaidis et al., 2019; Newson et al., 2024). Aligning with this approach, I, as the lead researcher, drove the project and developed the research questions. Once recruited, the participants then become actively involved in decision-making (regarding the processes, resource refinement and delivery) and knowledge co-production (Newson et al., 2024). Aligning with my social constructionist epistemological position, which posits that all knowledge is constructed through our interactions and dialogue with others (Willig, 2022), this project employed a qualitative research design, with the aim of gaining in-depth insights into autistic young peoples' narratives and experiences.

3.2.2 Participants and recruitment

A secondary school in the South of England was approached about this study through a shared contact within ACoRNS. After sharing details of the proposed project, members of the school senior leadership team confirmed that they would like the project to be facilitated within their setting. It was agreed that I would attend school assemblies for students in Year 7 to Year 10 to introduce myself, share a video advert about the project, and explain the recruitment process. Following this, autistic young people, including those who identify as autistic were purposively sampled, and adverts and participant information sheets were sent directly to their parents or carers (Appendix C and Appendix D). These documents contained QR codes and weblinks to parental consent and child assent forms on Microsoft Forms (Appendix E).

While the project focussed on autism amongst girls, autistic boys and gender diverse young people were also invited to participate, to encourage inclusion of different gender perspectives. It was hoped that the inclusion of males and gender diverse young people would enable participants to reflect on and consider the similarities and differences between their experiences, which in turn would promote self- and other-awareness, compassion, and allyship. Furthermore, while the FIZZACC resources were designed based on autistic females' experiences, the present study focussed on the implementation of such resources. Thus, providing the opportunity for all autistic young people (regardless of gender) to be involved in implementation processes, felt inclusive and justified.

Consent and assent forms were returned by five parents and students in Years 7 - 10. All students were asked to complete a demographic form (Appendix F), which asked them to identify a pseudonym and provide information regarding their age, gender, ethnicity and diagnoses. All students were aged between 11 and 15; two students identified as male, two students identified as female, and one preferred not to say; four students identified as British, and one as British/Polish; three students had diagnoses of autism and two self-identified as autistic; and three students had other developmental or learning diagnoses, including dyslexia and attention deficit hyperactivity disorder (ADHD).

Participants were sent participant preference forms (Appendix G) with questions about how to promote their sense of comfort while engaging in the project (e.g., communication and location preferences). Participants were also offered the opportunity to meet with the lead researcher prior to the first group meeting. Three students accepted this offer, with two meetings held online and one face-to-face.

During these meetings, we spoke about the students' preferences in greater depth and discussed any questions they had about the process.

During the first group in-person meeting, the student participants discussed which adults they would like to invite to join the team. With three suggestions of staff members provided by the school SENCo (including herself, the Assistant SENCo, and a support staff member), the team decided that they would like to invite the SENCo and assistant SENCo to join. Adverts and participant information sheets with links to consent forms were subsequently send to these staff members. Additionally, the students discussed the possibility of inviting parents to join. However, some discomfort was expressed by members of the team at the thought of including unfamiliar adults, particularly in terms of confidentiality, so this was decided against.

3.2.3 Procedures

Nine team meetings were held between November 2024 and March 2025 (details outlined within Table 3-1). To promote the inclusion of each individual as a research team member, training guidance from the Academic Autism Spectrum Partnership in Research and Education and the Autism Intervention Research Network on Physical Health (AASPIRE & AIR-P, 2022) underpinned decision-making and practice throughout the project, with careful consideration of how such guidance could be applied to meet the needs of child participants. This involved sharing project goals and aims with transparency, prioritising rapport building, identifying accommodations and collaboration practices, and establishing ground rules (see Appendix H for examples of team-building activities). To promote equal power, we also agreed to use the 'five finger method' (developed by Nicolaidis et al., 2011) as our formal consensus method, which involves holding up a number of fingers to indicate level of agreement with an idea or statement (Appendix I). Across meetings, the sensory environment was carefully considered, including meeting in quiet areas of the school, providing access to preferred fidget items, utilising visual communication aids, and incorporating break times. Between meetings, emails were sent to student participants and their parents to outline the timings, location, and areas we would cover in the upcoming session, and to provide an opportunity for questions.

Table 3-1 Team Meeting Attendance, Focus, and Content

Team Meeting	Details
1 – November 2024	Attended by: - Laura Salmon (LS; lead researcher) - 5 student participants Meeting content: - Rapport building - Overview of project aims - Ethical considerations - Accommodations and communication preferences - Identification of group strengths
2 – November 2024	Attended by: - LS - 5 student participants Meeting content: - Icebreaker - Ground rule development - Agreement on consensus method (“five finger communication system”) - Identification of team name (“Team Autism”) - Brief overview of FIZZACC resources
3 – November 2024	Attended by: - LS - 5 student participants, 1 staff member Meeting content: - Emotions check-in activity - Review of previous sessions - Establishing the group vision - Consideration of attitude, skills, and behaviour change
4 – December 2024	Attended by: - LS - 5 student participants, 1 staff member Meeting content: - Review of previous sessions - Sharing and discussing the FIZZACC questionnaire and activity ideas - Considering delivery options

5 – December 2024	Attended by: - LS - 3 students (2 students were absent due to sickness) Meeting content: - Sharing and discussing the story narratives and activity ideas (e.g., Autism Charter) - Considering delivery options
6 – January 2025	Attended by: - LS - 5 student participants, 1 staff member Meeting content: - Review of previous sessions - Finalising delivery plans - Preparation for staff briefing - Considering data collection options
7 – January 2025	Attended by: - LS - 5 student participants Meeting content: - Review of previous sessions - Reflection on staff briefing - Group affirmations - Generation of interview questions - Creation of Bitmojis and discussion regarding presentation slides - Discussion regarding the end of the project meetings and the future of autism awareness implementation within the school
8 – March 2025	Attended by: - LS - 5 student participants - SENCo (for interview only) Meeting content: - Welcome back to Team Autism - Discussion and preparation for upcoming interviews - 4 x students facilitated interview with school SENCo

9 – March 2025	Attended by: - LS - 5 student participants Meeting content: - Judging the masking artwork competition - Collating ideas for the Autism Charter - Discussion and preparation for upcoming interviews

3.2.4 Overview of meetings

3.2.4.1 Implementation and dissemination

As a team, we created a ‘plan’ and ‘do’ vision (Appendix J), using key headings from the implementation framework (Chidley & Stringer, 2020). This outlined the change that students hoped could be achieved within their school setting with regard to autism awareness and acceptance, and which resources might be helpful in facilitating this change. Across subsequent sessions, the individual FIZZACC resources were discussed and appraised by the team, which led to adaptations, and decision-making with regard to how the resources would be shared with the wider school. Together, we conceived the idea of a school Autism Awareness Week, during which the resources could be shared within tutor group sessions. As a team, we designed a timetable (Appendix K) and scheduled sessions in which the FIZZACC video, questionnaire and story narratives would be shared (Appendix L). Through discussions, we also decided to run a ‘masking artwork competition’ across the school, in which students could create a piece to depict the experience of masking. To end Autism Awareness Week, we discussed tutor groups creating a list of statements that could be included in a school Autism Charter, with the aim of promoting a more autistic friendly community and environment.

To promote Autism Awareness Week, and to prepare staff for the delivery, the SENCo invited us to present our timetable and an outline of activities to staff during their weekly staff briefing session. Three student participants and I presented to school staff, one student participant observed the presentation, and one student chose not to attend. Following this, a tutor presentation (Appendix M) and FIZZACC materials were sent to the SENCo and Tutor Lead, which were disseminated to staff and printed within school tutor booklets.

3.2.4.2 Evaluation

In terms of evaluation processes, the students decided that they would like to hold a focus group with students across the school, to explore their views of the tutor group activities. The students also expressed their interest in facilitating an interview to gather the views of the SENCo on the implementation and dissemination process, and to ascertain what the future of autism awareness might look like following this project. Together as a group, we discussed questions that we might like to ask students and the SENCo, and these were printed for each research team member to follow, with acknowledgement that they could deviate from the scripts if they wished to. Both the focus group and SENCo interview were held the Monday following Autism Awareness Week.

Additionally, the masking artwork competition entries were collected, and were shared with the research team during team meeting nine. As a team, we looked at each piece and created a set of our favoured artwork. The team then undertook a ‘blind vote’, in which they individually chose their top two pieces. One piece was voted by all student participants and was subsequently chosen as the winning piece.

Finally, the suggestions for the Autism Charter were also collated, and discussed as a team. It was decided that we would consider these statements, alongside the findings from this thesis in the summer term, to inform the development of the Autism Charter.

3.2.5 Data generation

During session six, we discussed different data collection options for gathering the views of the implementation team about their participatory involvement in the research project. Interviews, focus groups, and written questionnaires were identified as feasible data collection options, and student participants individually ranked their preferred choices. After discussing the benefits and drawbacks of each option, all student participants chose individual interviews as their first-choice method of sharing their views. Participants were asked for their preferred interview times, which were then scheduled accordingly (Cridland et al., 2015).

Semi-structured interviews were conducted with each student participant in March 2025. This method of data collection was chosen due to its clear yet flexible structure, and its potential to promote open communication, allow clarification seeking, and enable the gathering of rich, insightful data (Mashuri et al., 2022). Following discussion with the team, it was agreed that I would formulate the interview questions for this aspect of the project. I developed an interview schedule (Appendix N), which started with a simple open question to prompt a spontaneous response. This could then be followed by relevant questions to gain a richer understanding. These questions were sent to participants and their parents in advance of the interviews, with the aim of promoting predictability and comfort (Schelbe et al., 2015).

The interviews took place in person in a quiet space within the school to ensure confidentiality and promote participants' psychological sense of safety. At the start of the interviews, I reminded participants of the research aims, informed them of the expected length of the interviews, gained their assent, and reminded them of their right to withdraw (Cridland et al., 2015; Quintela Do Carmo et al., 2024). With recognition that participants may be particularly prone to masking, I also highlighted that there were no right or wrong answers to the interview questions, and that I wished to gather their authentic views (Docherty & Sandelowski, 1999**).** Participants were then provided with two cards, one with a 'break time' visual and one with a 'next question' visual and were assured that they could use these at any time during the interview to pause or move on should they wish to (Schelbe et al., 2015).

Throughout the interviews, I sat shoulder-to shoulder with participants and carefully observed non-verbal cues to monitor participants' comfort levels (Kirk, 2007; Griffin et al., 2016). I endeavoured to take an unassuming, flexible approach, actively listening to the participants' responses with openness and following their lead

(Quintela Do Carmo et al., 2024). I also tried to use single-faceted questions and provided visuals to represent key elements of our research process to support information processing (Cridland et al., 2015). At the end, participants were asked about their experience of being interviewed (Quintela Do Carmo et al., 2024), using a 5-point smiley face rating scale (each participant chose the most positive rating). Participants and their parents were also provided with debriefing forms (Appendix O). The interviews lasted between 26 and 41 minutes and were audio-recorded and transcribed using Microsoft Teams. Identifying information was removed from the transcripts and names were substituted with pseudonyms. The transcripts were shared with the participants to read through should they wish to.

3.2.6 Data analysis

The interview transcripts were analysed using reflexive thematic analysis (RTA; Braun & Clarke, 2006; 2019; 2020; 2024). RTA was purposefully chosen as a method that promotes active engagement with the data and necessitates continual reflective processes. Aligning with my personal, social, moral and competency values (Rokeach, 1973), RTA enabled me to delve into the data with curiosity, openness and respect, and to appreciate differing perspectives, acknowledge my assumptions and biases, and build upon my qualitative research experiences.

Using an “artfully interpretative” approach (Finlay, 2021), I engaged in an iterative process of coding and refining themes, recognising that my subjective interpretations would develop as I became increasingly emmeshed in the data. While analysing the data at the more inductive end of the inductive-deductive continuum (Braun & Clarke, 2020), i.e., constructing meaning from within the data itself, I acknowledged and embraced that my own experiences, perspectives, and values would inevitably inform my interpretations. In particular, I held in mind that the “culture gap” between myself as an adult and the participants as CYP would inevitably influence my understanding and thus endeavoured to reflect upon my assumptions throughout (Kirk, 2007). The six phases of RTA included the following processes:

3.2.6.1 Familiarisation

I listened to the audio recordings and checked and edited the transcripts produced by Microsoft Teams. I then checked each transcript again, uploaded these to NVivo, added annotations, and wrote memos, which enabled me to reflect upon the meaning I had made from the dialogue (see Appendix P).

3.2.6.2 Initial coding

I undertook initial coding of the data using NVivo, generating semantic (surface-level) as well as latent (more implicit) level codes (Braun & Clarke, 2020). Through an iterative process of refinement, I produced a codebook, which represents the evolution of my meaning making as I became increasingly immersed in the data (see Appendix Q).

3.2.6.3 Initial themes

Based upon my interpretations regarding the meaningfulness of the data, I created themes, with the aim of ‘telling a story’ about the data (Braun & Clarke, 2006). This involved collating and combining codes based on shared meaning within sub-folders in NVivo, providing me with an initial picture of what the themes and sub-themes may represent (see Appendix R for an example memo).

3.2.6.4 Refining themes

Again, these themes were developed through an iterative process of refinement, which I recorded through memos (see Appendix S). This involved consideration of whether the meaning conveyed by the themes were sufficiently supported by the data, and deliberation regarding the overlap and distinctions between themes. Furthermore, during this stage, I ensured that the themes generated were driven by the meaning with the data, rather than the questions posed or the topics covered within the interviews (Braun & Clarke, 2019; 2024).

3.2.6.5 Defining and naming themes

Through ongoing refinement, I defined and named the themes and sub-themes, using a metaphor to capture their essence (see Appendix T), and created a thematic map. The defining and naming involved moving beyond summarising or paraphrasing, to considering how the themes come together to answer the research questions.

3.2.6.6 Writing up

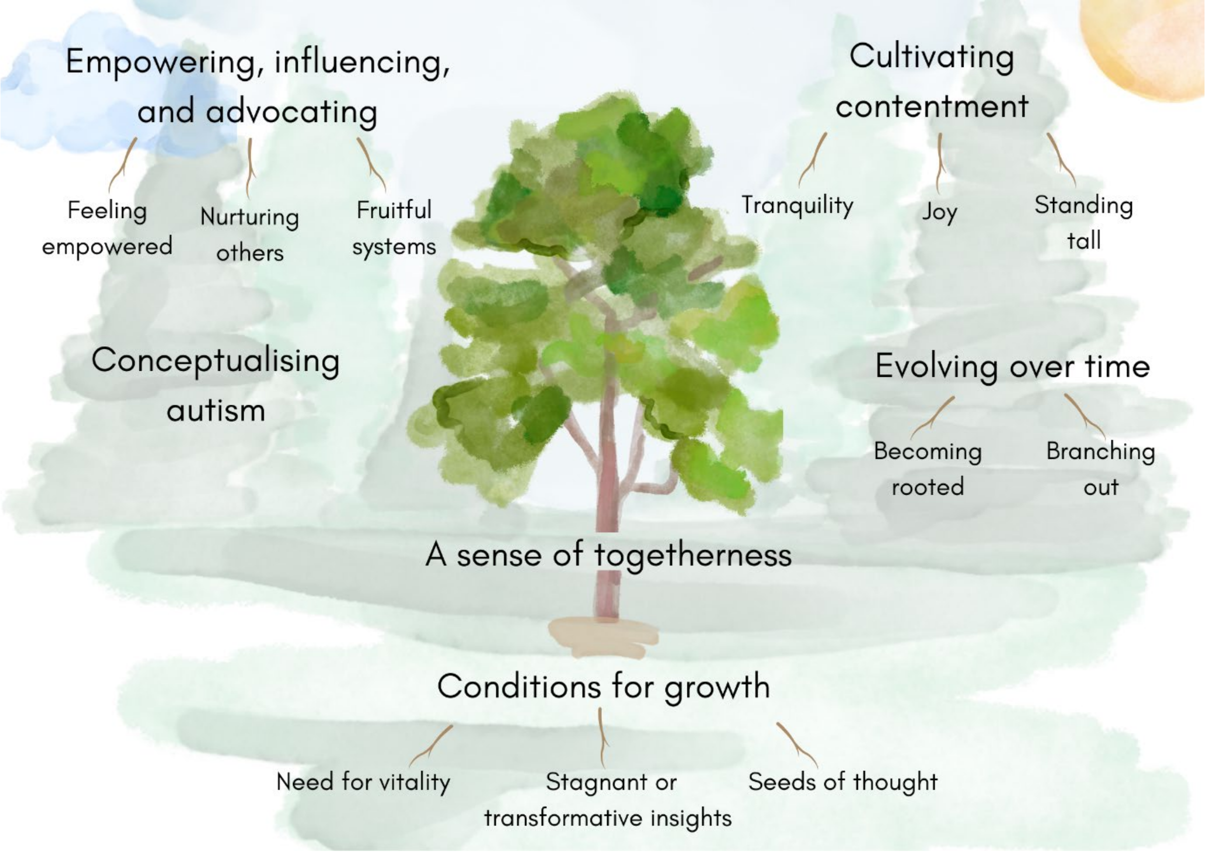
Finally, I produced a written analytic narrative of the themes and sub-themes. This involved careful consideration of data extracts which supported my interpretations and assertions, with regard to the research questions.

3.3 Findings

Through the iterative and reflexive process of analysis, I constructed six themes as illustrated in Figure 3-1. During the refining, defining, and naming stages, I created an oak tree metaphor to hook these themes onto. Not only did this metaphor align deeply with my themes and connect with my membership to ACoRNS, but it also transformed my themes into something tangible. Having used metaphors successfully during our Team Autism sessions, I felt that the oak tree would increase the meaningfulness and accessibility of the themes to the participants, and the wider school community.

As shown in Figure 3-1, the oak tree is positioned within the wider forest context. This represents the influence of society and culture on the participants' construction of their experiences, as well as on my interpretations. The positions of the themes are also purposeful in the following way: 'conceptualising autism' positioned in the background of the forest, representing the influences of history and society on views towards autism; 'empowering, influencing, and advocating' at the crown of the tree, symbolising the projection of voice across the forest; 'cultivating contentment' also at the crown of the tree, conveying a sense of flourishing; 'sense of togetherness' embedded into the tree, portraying interconnectedness; 'conditions for growth' underneath the tree, representing the soil's nutrients, supporting the tree to blossom; and finally' evolution over time', advancing beyond the tree, signifying future hopes and priorities.

Figure 3-1 Thematic Map using the Oak Tree Metaphor



Note. Image created using Canva (Canva Creative Studio and Keith Rivera from Sketchify designs)

3.3.1 Conceptualising Autism

Each of the participants spoke positively about their autistic identity and, through their collective language, portrayed a sense of connection to the wider autistic community. Much of the participants' dialogue aligned with the neurodiversity paradigm, with differences described in terms of uniqueness and individuality, for example: "I mean, I like being different because if you like, have a group or class and they're all the same, it just doesn't think you stand out. But when I have autism, I feel extra special" (Darzel). Assertions were also made about the need for shifts in societal understanding to alleviate the difficulties that autistic individuals may face. Shining a positive light on autism seemed a priority for several participants, "So, I joined the group so that I can make a difference to people's lives and to change the way people think about autism" (Berry). The participants reflected upon the negative societal perceptions of autism, with Berry sharing how she had been subject to mocking and stigmatising language, which often went under the radar:

> Erm, before I joined Team Autism, I would hear a lot of people say things that were like quite mean to me because of my autism, and I would hear words that are not really that appropriate being thrown around like they're nothing.
>
> **(Berry)**

Despite these negative experiences, several participants spoke of wanting to be recognised as autistic. Recognition of their autistic identity not only promoted their own self-awareness but was paramount to the understanding and support from others: “So, people can erm, understand how, well, what I go through” (Darth). For Darzel, this went beyond a lack of awareness to a lack of acceptance from staff about their autistic identity, implying that biases or stereotypes (perhaps around autism in girls) may be influencing identification and recognition.

Despite viewing autism in terms of difference, a couple of participants also spoke about autism as a disability. However, this did not appear to represent a deficit-based view of autism; in fact, participants spoke hesitantly and with concerns around classifying it as so. Rather, the use of the term ‘disability’ appeared to be driven by the desire for needs to be recognised, understood, and validated by wider society, and for individuals (both neurodivergent and neurotypical) to receive the support they require:

> I know it's rude to say, but autism is a disability. Because it may... people say it's offensive, though it actually is, cos disability means you can't do something that other people can’t do. So, technically we’re all disabled and so are normal people because they can't do other things as well.
>
> **(Darzel)**

3.3.2 A sense of togetherness

Across participants, the meaningfulness of connections and relationships appeared fundamental to their Team Autism experience. This encompassed pre-existing friendships for some, as well as the development of new friendships over time, both of which brought a sense of comfort, safety, and enjoyment: “I was really happy the day I saw Scott’s doing this, I was like, *whaaaaat,* I’m doing something with my friend. So yeah, I've always just been like, really happy” (Darth); “I feel like I've been able to talk to them and that or able to be their friend a lot more...” (Berry).

A mutual desire to learn about the experiences of others, as well as the identification of shared experiences seemed to foster these connections and promote a sense of belonging in a group of perceived similar others: “The best bits were meeting new people and learning the perspectives of them because it made me feel like I could branch out more” (Berry); “Just being a part of...a group of people who are like me...” (Darth). These connections were further fostered during ‘down-time’ with Berry reflecting positively on session breaks as an opportunity to get to know each other in a less structured context.

These bonds and this sense of belonging promoted authenticity, openness, and a team ethos: “We all have some sort of thing that is all the same about us. Like it's easier, to communicate with people that are like you” (Oreo). In particular, Darzel reflected positively on working together to make decisions: “So, it's nice to be like we're all working together instead of one person”, with respect for others at the heart of the group: “Er yes, cos, we listen to everybody when they didn't agree”. The strength of these bonds and group affiliation appeared to strongly contribute to participants’ desires for the future of the team, in particular the continued membership of fellow participants in the long term: “I would still like all of like the main people. Like Darzel, Berry, Darth, and Scott” (Oreo).

3.3.3 Empowering, influencing, and advocating

This theme encompasses participants’ reflections on sharing their voice to make a difference to the lives of autistic individuals, and the systems in place that enabled them to do so.

3.3.3.1 Subtheme: Feeling empowered

Across interviews, participants reflected positively and enthusiastically about the opportunity to share their voice: "Yeah, and it's also like I can get my views out because I don't really have anybody to talk to about this" (Darzel). Participants were able to clearly express their views of the FIZZACC resources and spoke about how being involved in the editing and refining processes helped them to feel involved, included and influential.

While some participants spoke about holding leadership positions in other contexts, the opportunity to do so in the context of autism awareness seemed unique, with some reflecting on previous feelings of powerlessness: "I used to think sharing your idea was like pointless, cos they'll like ignore it, but then you started taking actual my points of view, and ideas and that made me think more like I can tell" (Darzel). Feeling heard and having the opportunity to "fight" for a cause (Darth), appeared to foster a sense of empowerment and promote belief in their abilities to make change happen: "Erm... I've learnt that we really can change people's perspectives, and we can really make a difference" (Berry).

3.3.3.2 Subtheme: Nurturing others

Using their voices to advocate for others appeared a significant incentive for participation within Team Autism, with 'helping others' shining through as a core team value: "But you know other kids go through a *lot* of stuff in their lifetime. And I would... I just think it's good to be a hero, not a villain" (Darth). The participants expressed considerable empathy for others: "because I know some people, who are like, autistic can really struggle" (Oreo), thoughtfully reflecting on their needs, and communicating a desire for inclusivity. Being part of Team Autism appeared to fulfil this desire to make a change to the lives of others: "Yeah, I'm helping, I'm not helping just myself, I'm helping... I'm helping other kids *like* me" (Darth), and for Berry, provided an opportunity to act as a role model: "sort of like an older, like *guiding figure* is the best way I can explain it."

3.3.3.3 Subtheme: Fruitful systems

Across interviews, participants reflected on several ‘systems’ and elements of the research process that enabled them to share their voice and actively participate. Such systems appeared to reduce overwhelm, lessen feelings of self-consciousness, and help participants to navigate the social nuances of communication. This included breaking down tasks into manageable steps: “You make them into little tasks that aren’t worrying”... “Breaking down has been helpful, to make me develop” (Scott); establishing ground rules: “because some of them, like confidentiality, and agree to disagree and share the air and that stuff and Elmo... that's all helpful for like all of us and me, it's just easier...” (Oreo); and providing visual systems as alternatives to verbal communication (e.g., the ‘I have an idea’ cards), recognising that these would be beneficial in their classroom settings.

3.3.4 Cultivating contentment

This theme represents the positive impact that the research process had on participants’ emotional wellbeing.

3.3.4.1 Subtheme: Joy

Being a part of Team Autism promoted a sense of fun and enjoyment, with participants using the following descriptors to summarise their research experience: “excellent” (Darth), “helpful” (Scott), “incredible” (Oreo), “really fun” (Darzel), and “fulfilling” (Berry). In particular, participants reflected positively on the joy they got from engaging in creative activities, involving developing the idea for the artwork competition, creating the ‘our vision’ posters, and designing their Bitmojis, as well as appreciating the beauty of the affirmation cards. Participants reflected on the happiness that Team Autism brought them, with Darth playfully requesting extended meeting times: “Can you make it three?”, “Five hours?”, and Scott expressing that he would not alter the activities or experiences in any way:

> Most of the stuff was really positive and some things I know we didn't do, but I feel like if we did do them, I wouldn't have changed them since literally everything that we did here was really positive and made me happy.
>
> **(Scott)**

3.3.4.2 Subtheme: Tranquillity

Being part of Team Autism provided a safe space for participants. Sessions were described as a “relaxing, calm” (Scott) haven, where participants felt comfortable to be themselves. Many participants spoke of the difficulties and struggles that they had experienced at school: “I usually struggle a lot.” (Scott), including upset and anxiety caused by the perceptions and actions of other students, and the disappointment in not receiving the support they required: “I masked a lot more because of the fact that it [autism] was viewed in a negative light.” (Berry)

While Team Autism was not a ‘fix’ for these feelings and experiences, the participants reflected on the positive difference it had made in terms of lowering their stress levels, both during the sessions, and across other times of the school day: “Just think about stuff that would be related to this group what usually makes me relaxed” (Scott); “I just think of you and all the friends, all my friends… and what we were doing. And then I can erm… and it like calms me down” (Darth).

3.3.4.3 Subtheme: Standing tall

Across interviews, participants reflected on how their confidence had grown through the process, facilitated by opportunities to work to their strengths and through stepping out of their comfort zone: “I kind of miss class and then I go to class, and I feel like confident when I walk into everything” (Darzel); “But, doing like that, you know that assembly kind of for the, erm teachers, it after that it kind of boosted my confidence a lot” (Scott).

Participants spoke about how proud they felt of themselves for being part of this research process, doing something admirable, and working hard: “And also, you know, I could just look back at what I did and feel proud” (Scott). For some, this included proudly declaring their Team Autism membership to others and reflecting on the positive response they received from their peers and school staff.

3.3.5 Conditions for growth

This theme encompasses participants' reflections on the impact of Autism Awareness week, as well as their thoughts and ideas about what is required to facilitate long-term change.

3.3.5.1 Subtheme: Stagnant or transformative insights

Participants expressed contrasting views on the difference they believed that Autism Awareness week had made in terms of changing attitudes, promoting understanding, and facilitating change amongst the school community. For some, the insights shared through Autism Awareness week, appeared to have promoted their own understanding of autism, as well as increased the awareness of peers and staff (transformative insights):

> So, ... if like you're not autistic, and have a friend or something and ..., they're overwhelmed..., you'll know because you've done... the week or... you know more about...
>
> **(Oreo)**

In particular, participants reflected on the benefits of others now knowing that they were autistic, staff better understanding what effective support might look like, and peers making fewer judgements around such support: "And a lot more people have begun questioning others less when, for example, they need like headphones or they need like, a computer. Barely anyone's been questioning that kind of stuff recently" (Berry).

Contrastingly, others felt that there had been limited or no difference since the resource roll-out (stagnant insights): "No... nothing's been changed" (Darzel), and that there was still considerable need for sensitive understanding of individuals' needs.

3.3.5.2 Subtheme: Need for vitality

A fundamental determinant of whether insights were stagnant or transformative appeared to be the motivation, attitudes, and receptiveness of members of the school community. In particular, Berry and Oreo reflected on the focus and engagement of their peers:

> In my tutor it was like very good, although I missed some of the exercises. I, I walked in, everyone was like, really working hard and they all had their heads down, like, really focused on it. So, I was kind of happy.
>
> **(Oreo)**

This was particularly so in relation to the artwork competition, which aligned with students' interests: "I think because most people like drawing, when you go to school you can draw. Everyone's really happy" (Oreo).

Contrastingly, for some participants, there appeared to be a lack of 'buy-in', with fellow students showing little interest or having little incentive to engage: "I think, half the kids are not really bothered about that" (Darth). For Darth, personal relevance seemed to influence the extent of buy-in: "And I feel like sort of normal kids were like... just didn't bother, don't care. But all the kids who did have disabilities, like me, like Scott, erm cared, kids like us... we cared." For Scott, the method and style of delivery was a key contributory factor:

> Well, we kinda did the true and false questionnaire on our own and also with that *(pointing at the story narratives)* on our own. So, it's a little surprising since I would have thought that we would have done the true and false questionnaire and that all together, not just on our own.
>
> **(Scott)**

3.3.5.3 Subtheme: Seeds of thought

To promote buy-in and facilitate long-term change, participants shared several suggestions ('seeds of thought'). These suggestions revolved around adequate publicising and student preparation; the need for clear, comprehensive and enthusiastic delivery from staff; extrinsic motivators, including rewards and celebrations; and school events promoting collective energy and excitement: “But if it did involve like an event or something, like the artwork competition, or… if we did something like running and donate the money to an autism charity, people probably would get involved with that.” (Scott)

3.3.6 Evolving over time

This theme represents participants’ optimism and clear-sightedness about the future of Team Autism and autism awareness more broadly.

3.3.6.1 Subtheme: Becoming rooted

Participants shared their desires for Team Autism to become established (or ‘rooted’) within their school, to have a presence, and to continue to have a noticeable effect on their school community: “Yeah, maybe keep us running like a little social group, where we tell people about autism and maybe like a yearly assembly or something…” (Scott). With regard to the other themes, the drive for such recognition appeared to be fuelled by aspirations for personal growth and fulfilment, as well as the ambition to lead, influence and serve others. For some, becoming rooted was also interpreted to bring a sense of stability: “I feel like we're gonna be much more prepared for it… We are not gonna have to, like, wait on and like change suddenly or anything” (Berry).

To promote accountability and to embed an autism-friendly ethos, some participants also spoke about the importance of the ‘autism charter’: “With the charters that people did, have more stuff that we put on the charters like actually happen and stuff. So, then there's more awareness than just like a week” (Oreo). This appeared to be viewed as a tool to promote long-term change, highlighting perceptions around the influence of school policies.

3.3.6.2 Subtheme: Branching out

While participants expressed the desire for the team to maintain its current members, enabling social and emotional connections to be strengthened, they also spoke about ‘branching out’ to other peers and staff across the school. Again, this appeared to serve different purposes, including team growth through the generation of new ideas and the promotion of longevity: “I think, every year we move up and once X leaves, one teacher joins a new teacher and then whilst we leave, new teachers can join and take over the project” (Darzel); as well as benevolence, that is wanting others to experience the gratification that they themselves had experienced: “Maybe each time we have a new person to come in and like, experience it, and then at the end of it they can say if they enjoyed it. If they really enjoyed it, they can come back sometimes.” (Oreo)

Participants also expressed their desire to raise awareness of a wider range of autistic experiences (breadth), while ensuring that topics were explored comprehensively (depth). Raising awareness and understanding of meltdowns and shutdowns appeared to be particularly important to several participants, both in terms of challenging misconceptions and judgement, as well as promoting effective support: “Meltdowns are also should be recognised. It shouldn't be… everything in autism should be recognised, and it should be like a priority” (Scott).

3.3.7 SENCo Interview

While the SENCo’s interview data was not included in the RTA (in part due to her intermittent involvement within team meetings, and in part to maintain a student-focused interpretation on the participatory process), I felt it was important to represent her voice succinctly within this section. During the SENCo’s interview, facilitated by the research team, she reflected upon many positives of the research process and Team Autism’s work. This involved being excited to be involved in research aimed at benefitting and informing the practice of the school (as well as schools more widely); the value of having a group within the school that students can identify with; the positive impact that the staff briefing had on teacher buy-in, and the positive feedback the school had received from several parents of autistic students.

The core challenge that was reflected upon by the SENCo was not having the time and capacity to attend and contribute to each of the team meetings, and thus not having a complete picture of the team's views and priorities. In terms of the future, the SENCo spoke about her desire to further embed autism awareness across the school (with a particular focus on masking), review the impact of the training resources, and establish the school Charter with links to the school's values.

3.4 Discussion

3.4.1 Overview of findings

This study aimed to explore how a team of autistic students and school staff could work together to negotiate, prioritise, and disseminate training resources across their school, which were designed to raise awareness of autistic girls' school experiences (East, 2024). Taking a participatory research approach, this study also aimed to uncover what contributes to successful research collaboration, consider some of the challenges or barriers to such success, and identify future directions. Through RTA of students' interview data, six overarching themes (as well as nine sub-themes) were generated and illustrated through an oak tree metaphor. These included: 'conceptualising autism', 'a sense of togetherness', 'empowering, influencing, and advocating', 'cultivating contentment', 'conditions for growth', and 'evolving over time'. The ways in which these themes answer the research questions are outlined in the following section.

3.4.1.1 Successful Collaboration

Across interviews, participants conceptualised autism in similar ways, reflecting on their autistic identities in a positive light, and largely with alignment to the neurodiversity paradigm (as described by Walker, 2014). While there were references to disability, as well as instances in which the term 'normal' was used to describe their neurotypical peers, this did not appear to imply perceptions that they felt 'disabled' or ‘abnormal’ as autistic individuals. Rather, this seemed driven by their desire to receive appropriate support within a world designed for neurotypical people (Pellicano & Den Houting, 2022), and implied limited exposure or access to more neuro-affirming language (Bottini et al., 2023). Their shared desire to be recognised as autistic as part of their identities, to challenge stigmas, and change the perceptions of others, appeared to bring the team together, fostering a sense of common purpose. This, alongside their shared experiences, seemed to contribute to their strong sense of group affiliation and belonging.

Having the opportunity to share their voice within this research space and make decisions that would not only benefit themselves but others (which appeared to be a shared underlying value), fostered feelings of involvement and empowerment. Participants reflected upon the systems that enabled them to express their views and advocate for themselves, particularly visual support aids and the establishment of ground rules. Training from AASPIRE & AIR-P (2022) and the person-oriented research ethics guideposts (Cascio et al., 2020) guided the adoption of these systems, and the ‘five finger method’ of consensus (Nicolaidis et al., 2011) provided a concrete tool to draw upon.

Being part of this research process also cultivated contentment for the group, with a sense of joy, fun, pride, and safety referred to across participants. Working to their strengths and having opportunities to step out of their comfort zone (within a safe and manageable context) contributed to this sense of satisfaction. While often overlooked in research design and processes, researchers have recently drawn attention to emotions within participatory research with CYP. In particular, the role and value of fun and pride have been described as central to promoting research engagement, research relationships, participation rights, and understanding of what matters most to CYP (Wright et al., 2021).

The above findings coincide with the antecedents of group cohesion as proposed by Forsyth (2021), including social identification (identification as a member of Team Autism); entitativity (unification of team members, influenced by member similarity and frequency of Team Autism interactions); task commitment (dedication to shared goals regarding autism awareness and acceptance); attraction to the group (the formation of bonds amongst Team Autism members, influenced by shared attitudes and values); group structure (the establishment of stable systems, boundaries, and norms within the team); and group affect (the gratification associated with Team Autism experiences). This cohesion was central to participants' reflections on their participatory research experience and appeared fundamental to the success of the team.

3.4.1.2 Barriers and Challenges

While participants did not reflect on difficulties associated with the collaboration or the team context, barriers and challenges were discussed with reference to the implementation and outcomes of 'Autism Awareness Week'. Although there were positive reflections in terms of increased awareness, understanding, and acceptance from some, others spoke about limited change, which aligns with other 'autism awareness' intervention literature (Cremin et al., 2020).

In line with Baldwin and Ford's (1988) model of the Transfer Process and Ajzen's (1991) Theory of Planned Behaviour, there are several explanations as to why the information disseminated during 'Autism Awareness Week' may not have led to effective change. This includes the characteristics or personal attitudes of members of the school community (i.e., limited motivation or low self-efficacy), training design (i.e., lack of perceived relevance), subjective norms (i.e., limited interest and value placed on the training by students' social groups), perceived behavioural control (i.e., limited belief in their ability to bring about change), and workplace environment (i.e., a climate that does not prioritise implementation). From the participants' reflections, student motivation and personal relevance (likely influenced by peer relationships and personal affiliation with autism) appeared to be key determinants of attitude and behaviour change. Suggestions to promote buy-in were posited by some participants, including additional publicising, school events, and further input and support from school staff.

While there were positive reflections from several participants (and the SENCo) about the impact of the staff briefing and staff's enthusiasm, in some instances, participants also reflected upon resources not being delivered by their tutors as expected. While this study did not seek the views of teachers themselves, several barriers to optimum tutor delivery can be hypothesised, based on existing implementation and inclusion literature. This includes time constraints, competing priorities, and limited involvement with external support (i.e., a mentor or coach) during the implementation process (Woodcock & Woolfson, 2019; Chidley & Stringer, 2020; Roberts & Webster, 2022). In the case of the school SENCo, time and capacity were barriers to her full participation in the research project, highlighting workload factors.

3.4.2 Strengths, limitations and implications

This study adds a unique contribution to the literature base regarding autistic students' involvement in the latter stages of participatory research, which was highlighted as a priority by Freire and colleagues (2022). The involvement of autistic girls within this project adds a particularly novel dimension (Newson et al., 2024). Using the Implementation Framework (Chidley & Stringer, 2020), the participants planned 'Autism Awareness Week' at different levels, considering what they would like to see in terms of attitude change, knowledge and skill development, behaviour change, organisational change, and benefits to CYP, as informed by psychological theory and research on implementation processes.

Guided by person-oriented research ethics guideposts (Cascio et al., 2020), as well as AASPIRE and AIR-P (2022) training, the participants' best interests were central to all decisions, fostering a respectful, collaborative, and authentically inclusive research context. In my view, this enabled participants to share their narratives, and in-depth insights into their research experiences to be gained. In this study, I included self-identifying autistic young people, as well as those with a formal diagnosis. While acknowledging the differing opinions regarding self-identification, including scepticism surrounding the validity of self-identification (as highlighted by Overton et al., 2023; Friedman et al., 2024; Ahuvia et al., 2025), I consciously chose to include self-identifying young people for three reasons.

Firstly, with regard to validity, recent research with adult samples has found little difference between those self-identifying and those with a formal diagnosis both psychometrically (i.e., autistic traits, Sturm et al., 2024; Ahuvia et al., 2025) and qualitatively (i.e., autistic experiences, Ardeleanu et al., 2025). While it is not yet known how well these findings translate to adolescents, who are navigating their self-concept and identity development (Tamm et al., 2024), validating their self-identification rather than questioning or dismissing it felt consistent with my ethical stance. Secondly, in light of the aforementioned barriers to diagnosis, particularly for girls and those whose presentations deviate from the traditional view of autism, I felt it was important to represent the voices of those who may feel unrecognised or unheard, which may foster a more nuanced understanding of the broad range of autistic experiences (Overton et al., 2023; Ardeleanu et al., 2025). Finally, aligning with my social constructionist epistemology and the social model of autism, I endeavoured to recognise and respect that self-identification, rather than pursuit of a formal diagnosis, may be a deliberate choice for some, in light of the negative or stigmatising connotations associated with an 'autism spectrum disorder' label (Friedman et al., 2024).

In terms of limitations, without the consistent involvement of staff members (with influence over school policy and processes) within Team Autism meetings, there were some constraints with regard to communication and transforming ideas into actions. To facilitate effective change with schools, researchers have highlighted the need for collaboration amongst school leaders, staff and stakeholders (i.e., autistic CYP and their families) through planning and implementation stages (Fixsen et al., 2013). As aforementioned, the systemic demands placed upon school staff in the current education climate can be reasonably argued to constrain this form of creative, individualised, and in-depth work. Furthermore, due to the scope of this thesis, we were unable to review the outcomes of the implementation framework over time, to ascertain participants' views with regard to long-term change.

This study has important implications for practice and research. In terms of next steps for Team Autism, participants spoke about the future of the team with a strong sense of optimism and purpose. Based on their positive collaborative experiences, participants spoke about wanting current members to remain part of the research team, and for them to become a recognised and established group within the school community. Participants also spoke about expansion of the group, extending invitations to other members of the school community. Aligning with the experiences of late-diagnosed autistic women in the study of Bargiela and colleagues (2016), the participants also spoke about the importance of an increased focus on meaningful topics such as masking. Furthermore, in line with the ‘school-wide autism competency approach’ (Roberts & Webster, 2022), developing school policies (i.e., the Autism Charter) appeared a priority.

Based on the insights gained from participants in the present study and driven by the need to further increase the uptake of participatory research within schools more broadly (Newson et al., 2024), the development of accessible resources, guidelines and a framework to support such processes would, in my view, be desirable. Such tools, informed by CYP voice, and what is currently known about successful participatory research and effective implementation, could assist practitioners in including CYP within school practice and policy development, promoting their sense of empowerment. In particular, EPs with expertise in consultation, problem-solving, and facilitating change (Cameron, 2006) would be well-placed to provide external support and coaching through such processes.

With the creation of such tools, it would be important for researchers to explore stakeholders’ (i.e., CYP, school staff, educational psychologists) perceptions and experiences of using these in practice to determine their usability, acceptability, and priorities for further development. In terms of future research, questions also remain about how to promote the involvement of school staff within participatory implementation teams, in light of the external, systemic constraints they currently face. Research exploring the views of school staff and leaders regarding participatory research and implementation over time, including perceptions on feasibility and support structures, would be beneficial. Furthermore, exploring ways to collaborate with parents regarding such processes, to incorporate their voice and promote positive home-school communication regarding inclusive practice would be beneficial.

3.4.3 Conclusion

This research has demonstrated numerous social and emotional benefits associated with involvement in school decision-making, planning, and implementation for autistic CYP, including, but not limited to belonging, contentment, and empowerment. Furthermore, their in-depth insights illuminate the factors contributing to successful participatory research processes, as well as their views on what is required to embed autism awareness and acceptance within a school context. To conclude, I will end with a quote from one of the participant's parents (shared with permission), encompassing the difference that authentic inclusion can make: "I just wanted to say X has benefited so much from this project. His confidence has grown, and his learning attitude is so much better. I know he will miss his sessions, but he now has tools under his belt to support him and his peers. X was a child who I never thought would join countless after school clubs, yet he has. I look forward to reading your final report. As an educator myself reading about projects which promote inclusion and equality are vital."

Appendix A Quality Appraisal Checklist (CASP, 2018)

	Gray and Durand (2023)	Arslan et al. (2024)	Steward et al. (2018)	Cummins et al. (2020)	Eriksen (2016)	Anisa (2019)	Tadesse et al. (2024)	Ashraf and Toor (2023)	Hamdan (2022)	Cridland et al. (2014)	Navot et al. (2017)	Balubaid (2017)	Mademtzi et al. (2018)	Grove et al. (2023)
Section A. Are the results valid?														
Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the recruitment strategy appropriate to the	Y	?	Y	?	Y	?	Y	?	?	Y	?	Y	Y	Y

aims of the research?														
Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	Y	N	N	N	N	N	N	N	N	N	N	?	N	N
Section B: What are the results?														
Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y	Y	?	N	Y	Y	Y	Y	?
Was the data analysis sufficiently rigorous?	Y	?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Section C: Will the results help locally?														
Is the research valuable?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. (Y) = Yes; (N) = No; (?) = Cannot tell/partially

Appendix B Quality Appraisal Checklist (MMAT, 2019)

Category of study designs	**Methodological quality criteria**	Lundy et al. (2024)	Kumar and N (2024)	Kaydirak et al. (2023)	Lundy et al. (2022)	Moreno (2021)	Klett and Turan (2012)	Veazey et al. (2015)
Screening questions (for all types)	S1. Are there clear research questions?	Y*	N	Y*	Y	N	Y*	N
	S2. Do the collected data allow to address the research questions?	Y	?	Y*	Y	?	Y*	?
(1) Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?						Y	
	1.2 Are the qualitative data collection methods adequate to address the research question?						Y	
	1.3 Are the findings adequately derived from the data?						N	
	1.4 Is the interpretation of results sufficiently substantiated by the data?						Y	
	1.5 Is there coherence between qualitative data sources, collection, analysis, and interpretation?						Y	
(2) Quantitative randomised controlled trials	2.1 Is randomisation appropriately performed?							

	2.2 Are the groups comparable at baseline?							
	2.3 Are there complete outcome data?							
	2.4 Are outcome assessors blinded to the intervention provided?							
	2.5 Did the participants adhere to the assigned intervention?							
(3) Quantitative non-randomised controlled trials	3.1 Are the participants representative of the target population?		Y	Y	Y	?	Y	?
	3.2 Are measurements appropriate regarding both the outcome and intervention (or exposure)?		Y	Y	Y	Y	Y	Y
	3.3 Are there complete outcome data?		?	Y	?	Y	Y	Y
	3.4 Are the confounders accounted for in the design and analysis?		N	?	Y	N	Y	N
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended?		?	?	?	Y	Y	Y
(4) Quantitative descriptive	4.1 Is the sampling strategy relevant to address the research question?	Y						
	4.2 Is the sample representative of the target population?	Y						

	4.3 Are the measurements appropriate?	Y	
	4.4 Is the risk of nonresponse bias low?	?	
	4.5 Is the statistical analysis appropriate to answer the research question?	Y	
(5) Mixed methods	5.1 Is there an adequate rationale for using a mixed methods design to address the research question?		Y
	5.2 Are the different components of the study effectively integrated to answer the research question?		Y
	5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?		Y
	5.4 Are divergences and inconsistencies between quantitative and qualitative components adequately interpreted?		?
	5.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?		Y

Note. (Y) = Yes; (N) = No; (?) = Cannot tell/partially; (*) = hypotheses/aims rather than research questions

Appendix C Adverts

C.1 Advert for Students:

Do you identify as an autistic young person?

Who am I?

Hi, my name is Laura Salmon.
I used to be a teacher. I am now training to be an Educational Psychologist.

I am passionate about listening to the **views** of autistic young people and involving them in **decision making** that affects them.

What is the research about?

Recently, a group of autistic girls and a researcher created some exciting resources to **raise awareness of autism in girls in schools**. Their group was called Fizzacc.*

Now, this current project aims to explore how a group of autistic young people (and adults chosen by them) can **work together** to decide how to **develop and share these resources** in their school.

Who can take part?

Any young person at [redacted] who has a diagnosis of autism/self-identifies as autistic can take part in this project.

What would this involve?

This project will involve several **meetings** at school. These will include:

- Getting to know each other
- Discussing the Fizzacc resources
- Deciding how to develop/share them
- Deciding how to gather the views of pupils
- Deciding how to share the findings

You will also be asked about **your experience** of the project, through a questionnaire or interview.

If you're interested in taking part...

Please read the Participant Information Sheets and follow the links or scan the QR codes for the assent and consent forms.
If you would like any further information please feel free to email me: lja3g14@soton.ac.uk

Child assent form	**Parent/carer consent form**
https://forms.office.com/e/UcaheqwSUF	https://forms.office.com/e/E8W5xq5g6g

Fizzacc

*Visit the Fizzacc page on ACoRNS website to take a look at the resources!
https://acorns-soton.org.uk/2022/03/fizzacc-information/

This project is supervised by Dr Hanna Kovshoff, (h.kovshoff@soton.ac.uk).
The University of Southampton Research Ethics Committee has granted ethical approval for this research study.
ERGO number: 92436 Date: 13.05.2024 Version: 2.0

C.2 Advert for Adults:

Would you like to join a team to raise awareness of autism in girls in school?

Who am I?

Hi, my name is Laura Salmon.
I used to be a teacher. I am now training to be an Educational Psychologist.

I am passionate about listening to the **views** of autistic young people and involving them in **decision making** that affects them.

What is the research about?

Recently, a group of autistic girls and a researcher created some exciting resources to **raise awareness of autism in girls in schools**. Their group was called Fizzacc.*

Now, this current project aims to explore how a group of autistic young people (and adults chosen by them) can **work together** to decide how to **develop and share these resources** in their school.

Why have I received this advert?

This advert has been shared with you as a group of autistic pupils/pupils who identify as autistic would like you to join the team to decide upon how best to disseminate the Fizzacc resources.

What would this involve?

This project will involve several **meetings** at school. These will include:

- Getting to know each other
- Discussing the Fizzacc resources
- Deciding how to develop/share them
- Deciding how to gather the views of pupils
- Deciding how to share the findings

You will also be asked about **your experience** of the project, through a questionnaire or interview.

If you're interested in taking part...

Please read the Participant Information Sheet and follow the link or scan the QR code for the consent forms.
If you would like any further information please feel free to email me: lja3g14@soton.ac.uk

https://forms.office.com/e/8GUW48ZFdL

Fizzacc

*Visit the Fizzacc page on ACoRNS website to take a look at the resources!
https://acorns-soton.org.uk/2022/03/fizzacc-information/

This project is supervised by Dr Hanna Kovshoff, (h.kovshoff@soton.ac.uk).
The University of Southampton Research Ethics Committee has granted ethical approval for this research study.
ERGO number: 92436 Date: 13.05.2024 Version: 2.0

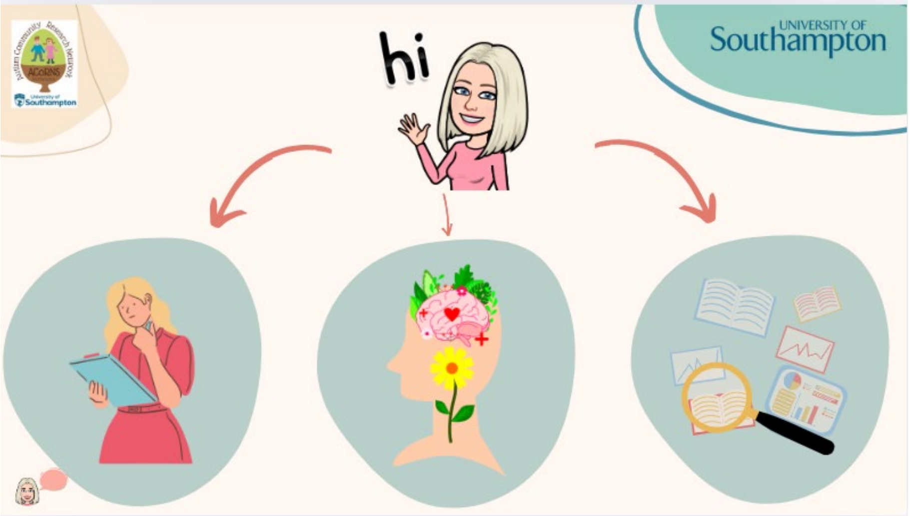
C.3 Video Advert

Slide 1:

UNIVERSITY OF Southampton

HI!

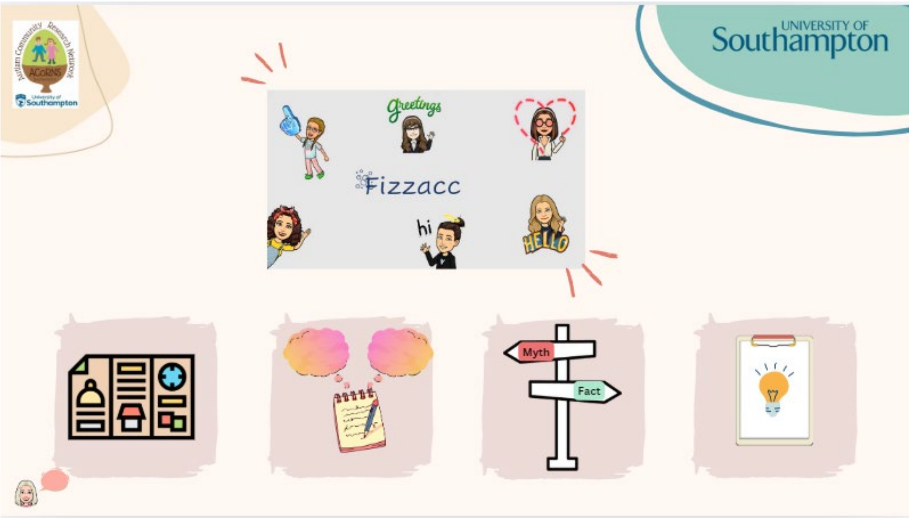
Slide 2:



UNIVERSITY OF Southampton

hi

Slide 3:



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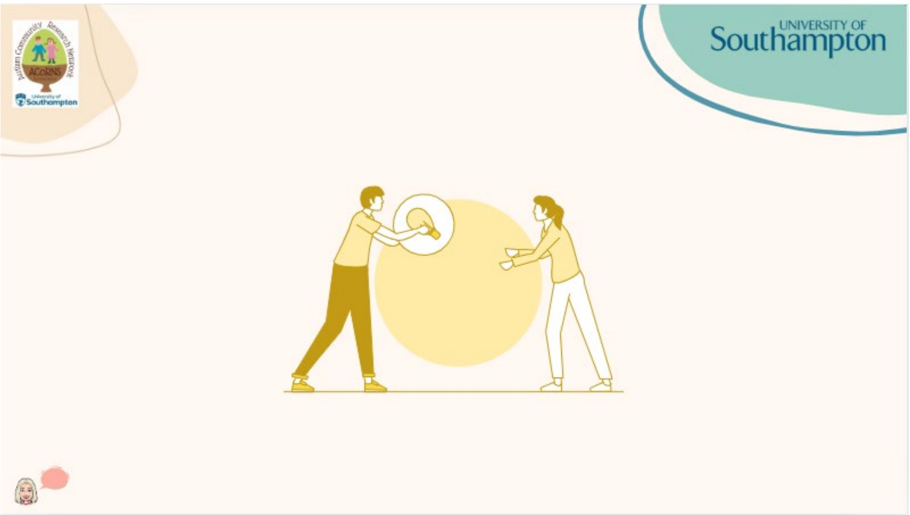

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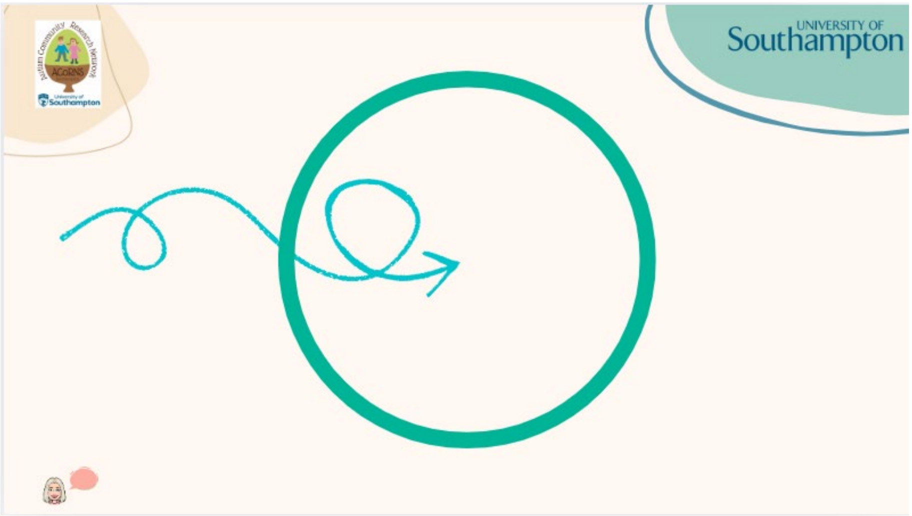
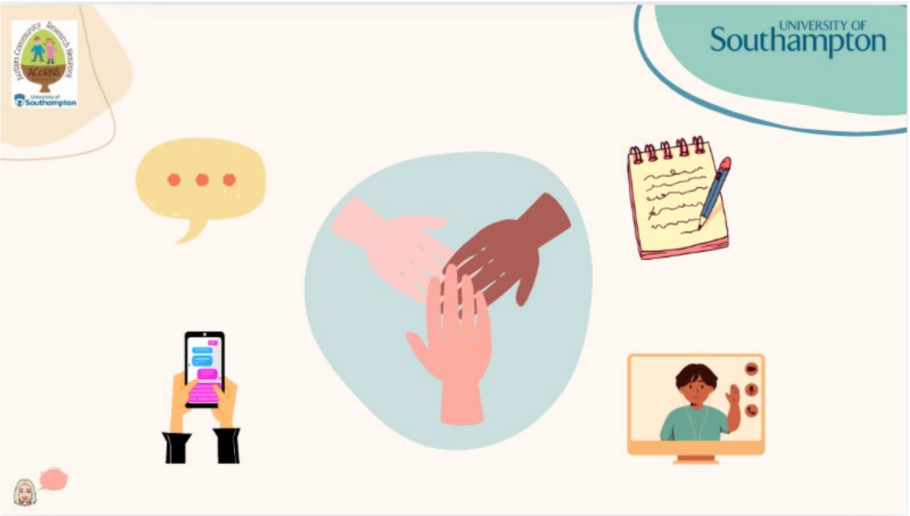
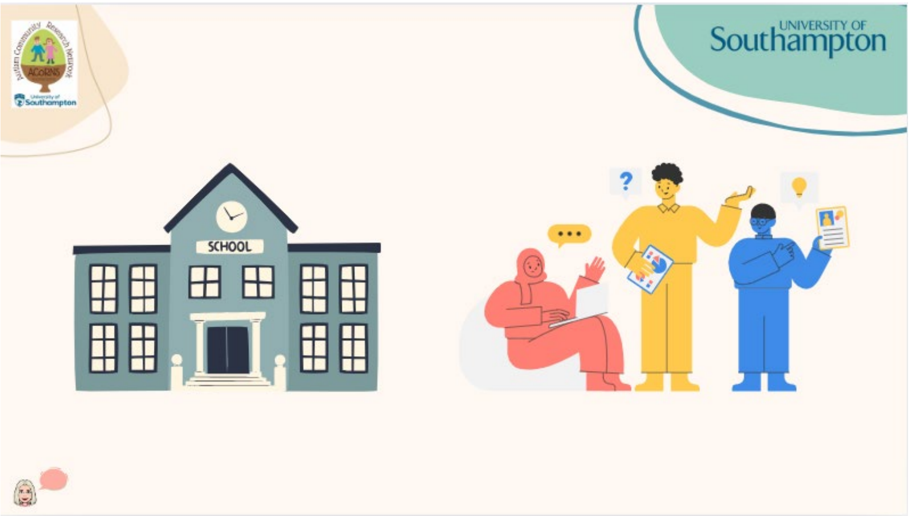


Slide 6:



Slide 7:



Slide 8:

Would you like to share your voice on resources about autism?

Do you identify as an autistic young person?

Would you like to join a team to raise awareness of autism in girls in school?

Slide 9:

THANK YOU FOR WATCHING!

This project is supervised by Dr Hanna Kovshoff, (h.kovshoff@soton.ac.uk).
The University of Southampton Research Ethics Committee has granted ethical approval for this research study.
ERGO number: 92436 Date: 13.05.24 Version: 2.0

Appendix D Participant Information Sheets

D.1 Participant Information Sheet for Students:

Participant information sheet

Who is the researcher?

Hi, my name is Laura Salmon.
I used to be a teacher, and worked with many autistic young people. I am now training to be an educational psychologist.

I am passionate about listening to the views of autistic young people and involving them in decision making that affects them.

What is the research about?

Recently, a group of autistic girls and a researcher created some exciting resources to raise awareness of autism in girls in schools.

Fizzacc

Now, this current research aims to explore how a group of autistic young people (and adults chosen by them) can work together to decide how to develop and share these resources in their school.

Why is the research important?

It is important for schools to learn about some of the challenges that young autistic people face in school, as well as things that support them, from the perspectives of autistic young people.

It is hoped that this research will demonstrate how schools can listen to autistic pupils and work together to share knowledge and raise awareness of neurodiversity.

Why have I been asked to participate?

You have been asked to participate in this project because you have a diagnosis of autism or you self-identify as autistic.

What will happen if I take part?

This project will involve several meetings at school. These will include:

- Getting to know each other
- Discussing the Fizzacc resources
- Deciding how to develop/share them
- Deciding how to gather the views of pupils
- Deciding how to share the findings

You will also be asked about your experience of the project, through a questionnaire or interview.

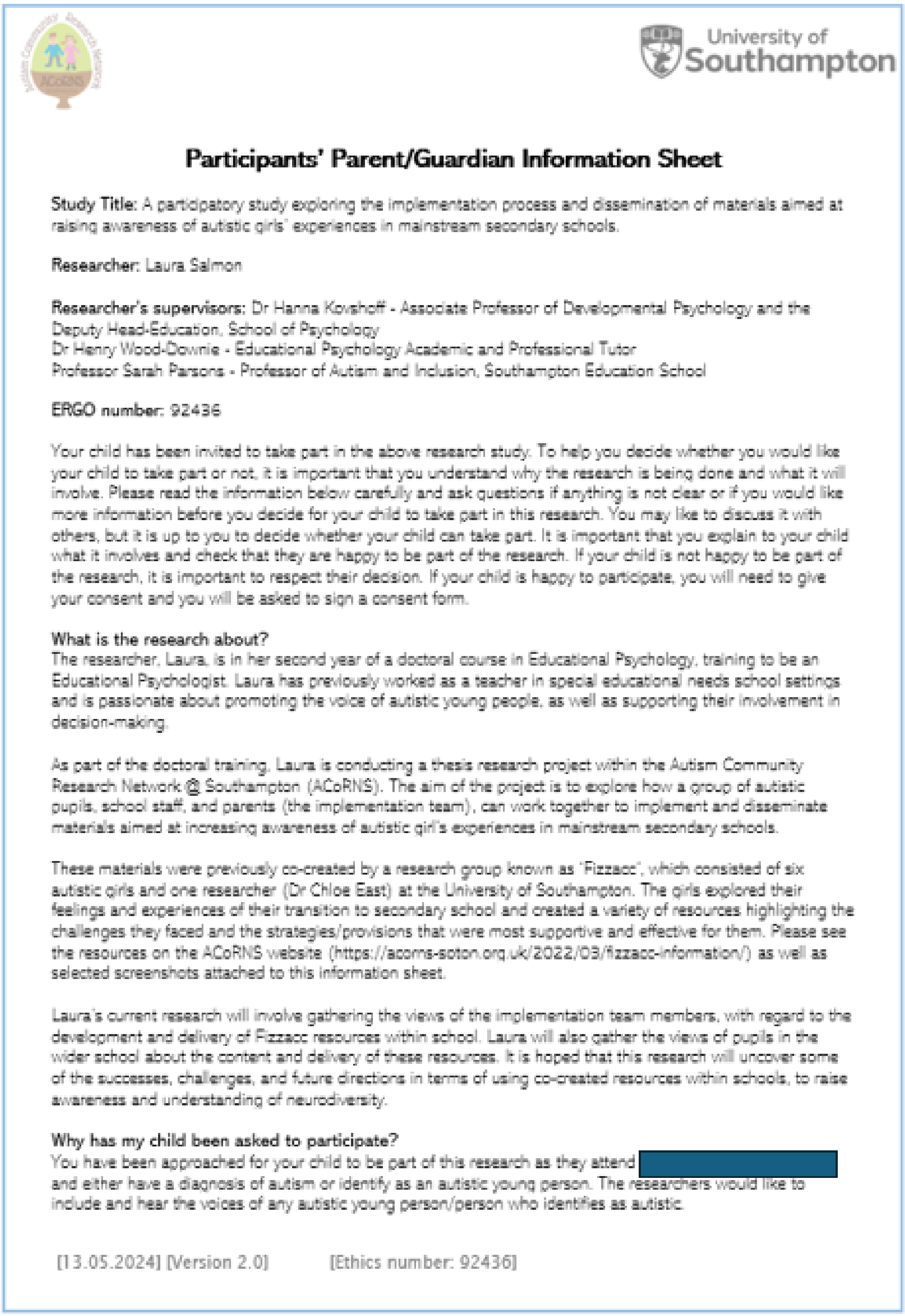
How will you help me to be comfortable?

I will do my best to help you to feel comfortable throughout the project, by offering regular breaks, communicating with you in a way that is best for you, and always listening to your views.
If you change your mind about participating in the project at any time, please just let me know. It is absolutely fine to pause or stop being involved. It is always your choice.

The University of Southampton Research Ethics Committee has granted ethical approval for this research study.

ERGO number: 92436 Date: 25.03.2024 Version: 2.0

D.2 Participant Information Sheet for Parents/Carers:



University of Southampton

Participants' Parent/Guardian Information Sheet

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

Researcher: Laura Salmon

Researcher's supervisors: Dr Hanna Kovshoff - Associate Professor of Developmental Psychology and the Deputy Head-Education, School of Psychology
Dr Henry Wood-Downie - Educational Psychology Academic and Professional Tutor
Professor Sarah Parsons - Professor of Autism and Inclusion, Southampton Education School

ERGO number: 92436

Your child has been invited to take part in the above research study. To help you decide whether you would like your child to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or if you would like more information before you decide for your child to take part in this research. You may like to discuss it with others, but it is up to you to decide whether your child can take part. It is important that you explain to your child what it involves and check that they are happy to be part of the research. If your child is not happy to be part of the research, it is important to respect their decision. If your child is happy to participate, you will need to give your consent and you will be asked to sign a consent form.

What is the research about?
The researcher, Laura, is in her second year of a doctoral course in Educational Psychology, training to be an Educational Psychologist. Laura has previously worked as a teacher in special educational needs school settings and is passionate about promoting the voice of autistic young people, as well as supporting their involvement in decision-making.

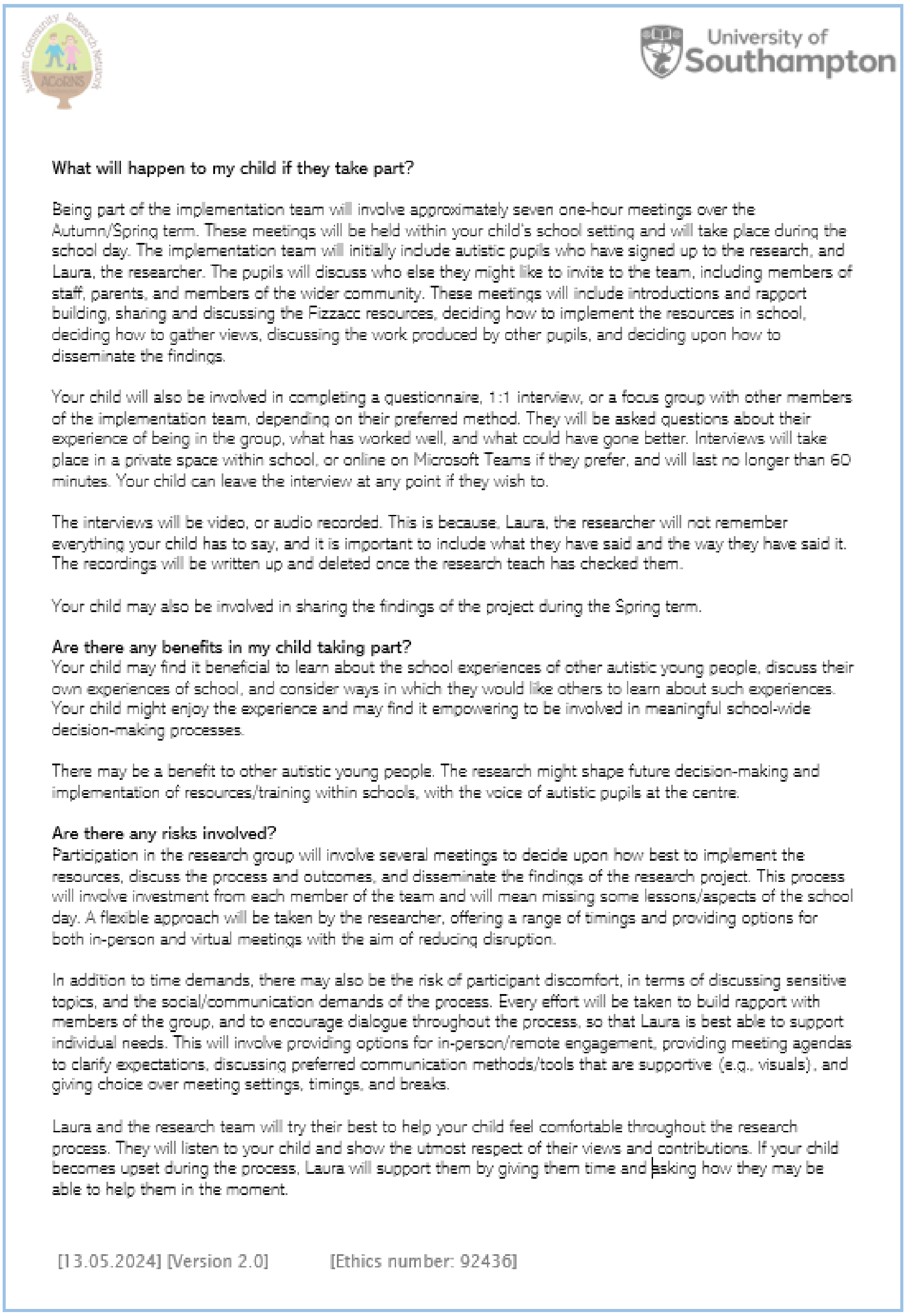
As part of the doctoral training, Laura is conducting a thesis research project within the Autism Community Research Network @ Southampton (ACoRNS). The aim of the project is to explore how a group of autistic pupils, school staff, and parents (the implementation team), can work together to implement and disseminate materials aimed at increasing awareness of autistic girl's experiences in mainstream secondary schools.

These materials were previously co-created by a research group known as 'Fizzacc', which consisted of six autistic girls and one researcher (Dr Chloe East) at the University of Southampton. The girls explored their feelings and experiences of their transition to secondary school and created a variety of resources highlighting the challenges they faced and the strategies/provisions that were most supportive and effective for them. Please see the resources on the ACoRNS website (https://acorns-soton.org.uk/2022/03/fizzacc-information/) as well as selected screenshots attached to this information sheet.

Laura's current research will involve gathering the views of the implementation team members, with regard to the development and delivery of Fizzacc resources within school. Laura will also gather the views of pupils in the wider school about the content and delivery of these resources. It is hoped that this research will uncover some of the successes, challenges, and future directions in terms of using co-created resources within schools, to raise awareness and understanding of neurodiversity.

Why has my child been asked to participate?
You have been approached for your child to be part of this research as they attend [redacted] and either have a diagnosis of autism or identify as an autistic young person. The researchers would like to include and hear the voices of any autistic young person/person who identifies as autistic.

[13.05.2024] [Version 2.0] [Ethics number: 92436]



What will happen to my child if they take part?

Being part of the implementation team will involve approximately seven one-hour meetings over the Autumn/Spring term. These meetings will be held within your child's school setting and will take place during the school day. The implementation team will initially include autistic pupils who have signed up to the research, and Laura, the researcher. The pupils will discuss who else they might like to invite to the team, including members of staff, parents, and members of the wider community. These meetings will include introductions and rapport building, sharing and discussing the Fizzacc resources, deciding how to implement the resources in school, deciding how to gather views, discussing the work produced by other pupils, and deciding upon how to disseminate the findings.

Your child will also be involved in completing a questionnaire, 1:1 interview, or a focus group with other members of the implementation team, depending on their preferred method. They will be asked questions about their experience of being in the group, what has worked well, and what could have gone better. Interviews will take place in a private space within school, or online on Microsoft Teams if they prefer, and will last no longer than 60 minutes. Your child can leave the interview at any point if they wish to.

The interviews will be video, or audio recorded. This is because, Laura, the researcher will not remember everything your child has to say, and it is important to include what they have said and the way they have said it. The recordings will be written up and deleted once the research teach has checked them.

Your child may also be involved in sharing the findings of the project during the Spring term.

Are there any benefits in my child taking part?
Your child may find it beneficial to learn about the school experiences of other autistic young people, discuss their own experiences of school, and consider ways in which they would like others to learn about such experiences. Your child might enjoy the experience and may find it empowering to be involved in meaningful school-wide decision-making processes.

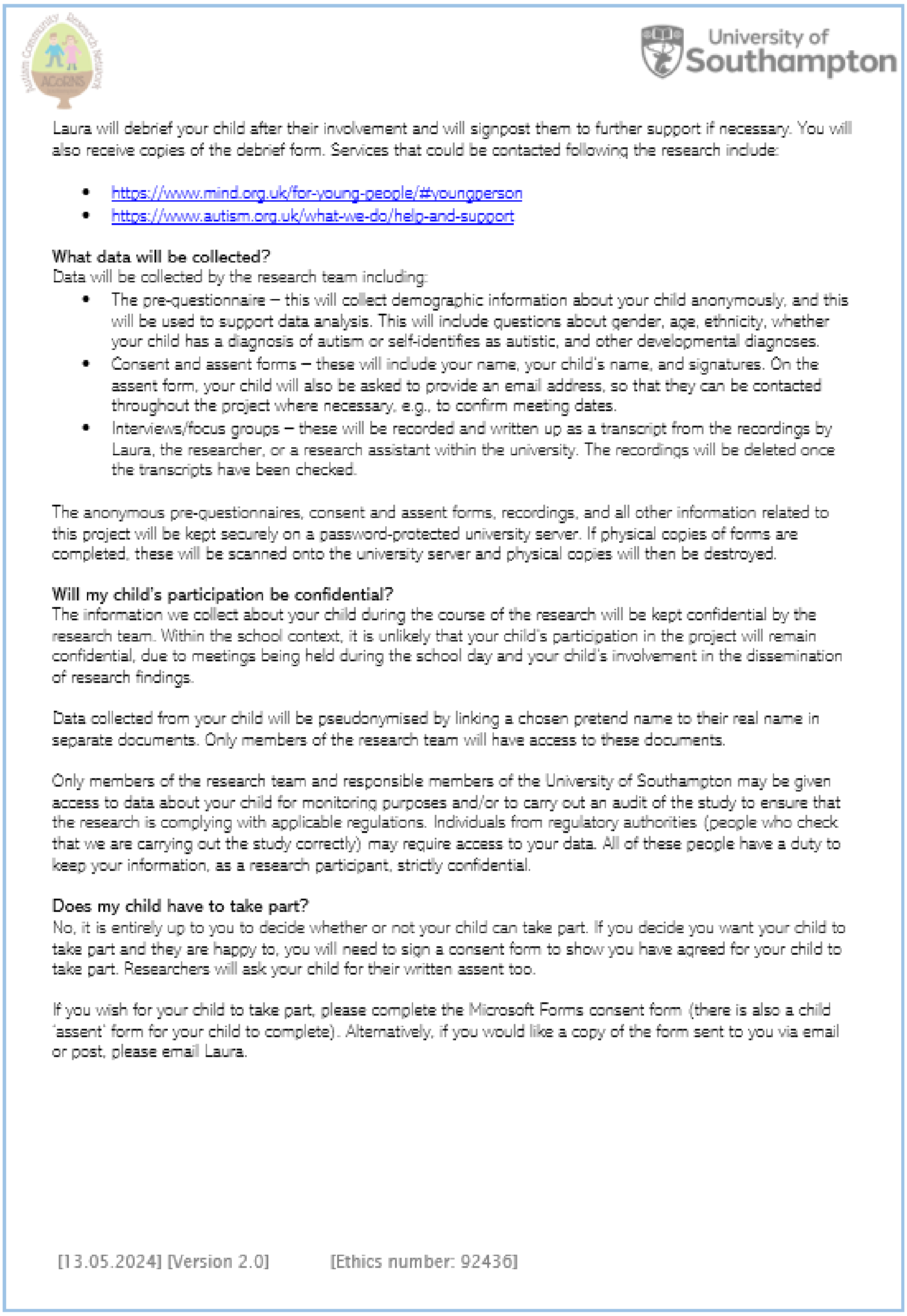
There may be a benefit to other autistic young people. The research might shape future decision-making and implementation of resources/training within schools, with the voice of autistic pupils at the centre.

Are there any risks involved?
Participation in the research group will involve several meetings to decide upon how best to implement the resources, discuss the process and outcomes, and disseminate the findings of the research project. This process will involve investment from each member of the team and will mean missing some lessons/aspects of the school day. A flexible approach will be taken by the researcher, offering a range of timings and providing options for both in-person and virtual meetings with the aim of reducing disruption.

In addition to time demands, there may also be the risk of participant discomfort, in terms of discussing sensitive topics, and the social/communication demands of the process. Every effort will be taken to build rapport with members of the group, and to encourage dialogue throughout the process, so that Laura is best able to support individual needs. This will involve providing options for in-person/remote engagement, providing meeting agendas to clarify expectations, discussing preferred communication methods/tools that are supportive (e.g., visuals), and giving choice over meeting settings, timings, and breaks.

Laura and the research team will try their best to help your child feel comfortable throughout the research process. They will listen to your child and show the utmost respect of their views and contributions. If your child becomes upset during the process, Laura will support them by giving them time and asking how they may be able to help them in the moment.

[13.05.2024] [Version 2.0] [Ethics number: 92436]



Laura will debrief your child after their involvement and will signpost them to further support if necessary. You will also receive copies of the debrief form. Services that could be contacted following the research include:

- https://www.mind.org.uk/for-young-people/#youngperson
- https://www.autism.org.uk/what-we-do/help-and-support

What data will be collected?
Data will be collected by the research team including:

- The pre-questionnaire – this will collect demographic information about your child anonymously, and this will be used to support data analysis. This will include questions about gender, age, ethnicity, whether your child has a diagnosis of autism or self-identifies as autistic, and other developmental diagnoses.
- Consent and assent forms – these will include your name, your child's name, and signatures. On the assent form, your child will also be asked to provide an email address, so that they can be contacted throughout the project where necessary, e.g., to confirm meeting dates.
- Interviews/focus groups – these will be recorded and written up as a transcript from the recordings by Laura, the researcher, or a research assistant within the university. The recordings will be deleted once the transcripts have been checked.

The anonymous pre-questionnaires, consent and assent forms, recordings, and all other information related to this project will be kept securely on a password-protected university server. If physical copies of forms are completed, these will be scanned onto the university server and physical copies will then be destroyed.

Will my child's participation be confidential?
The information we collect about your child during the course of the research will be kept confidential by the research team. Within the school context, it is unlikely that your child's participation in the project will remain confidential, due to meetings being held during the school day and your child's involvement in the dissemination of research findings.

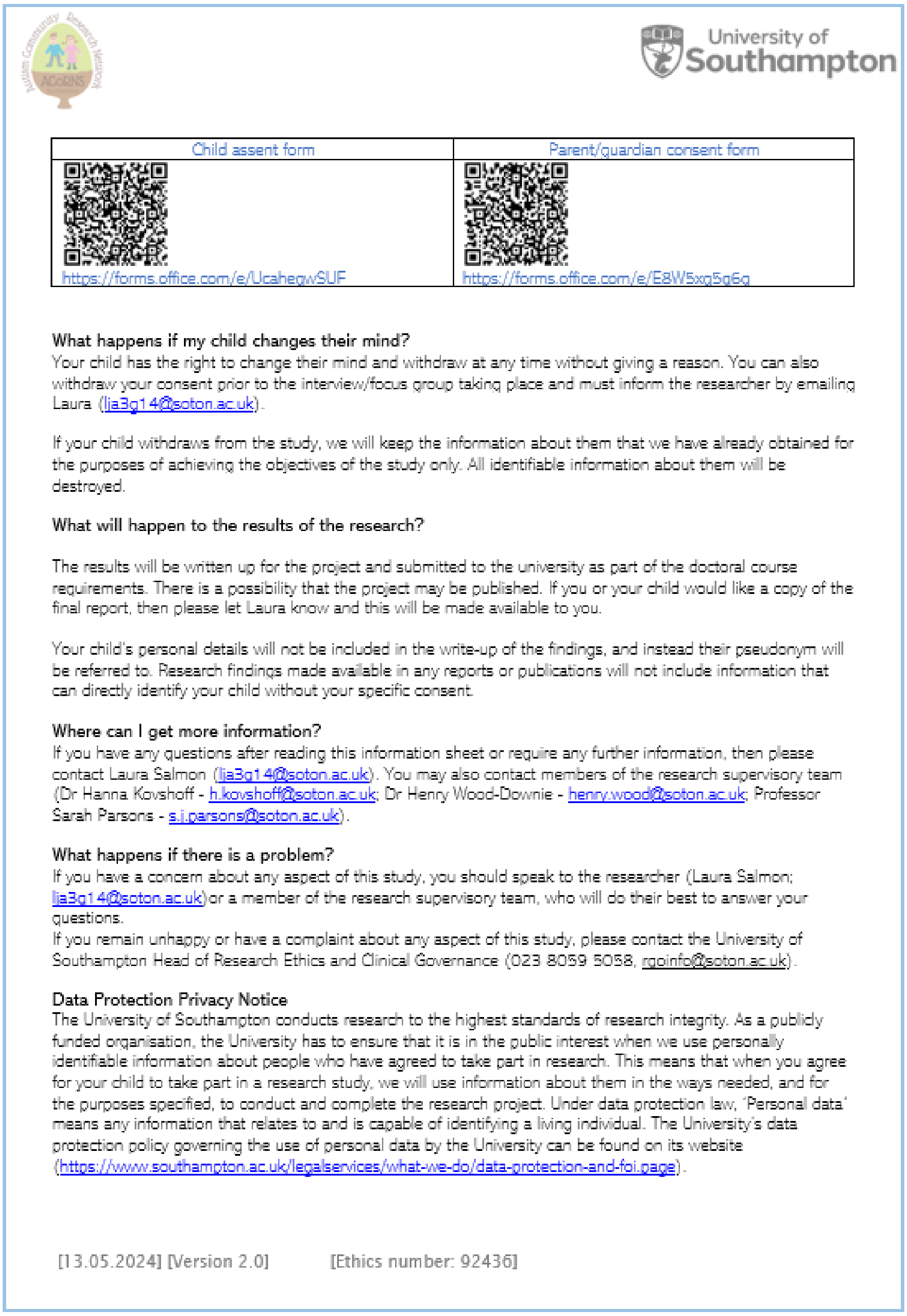
Data collected from your child will be pseudonymised by linking a chosen pretend name to their real name in separate documents. Only members of the research team will have access to these documents.

Only members of the research team and responsible members of the University of Southampton may be given access to data about your child for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Does my child have to take part?
No, it is entirely up to you to decide whether or not your child can take part. If you decide you want your child to take part and they are happy to, you will need to sign a consent form to show you have agreed for your child to take part. Researchers will ask your child for their written assent too.

If you wish for your child to take part, please complete the Microsoft Forms consent form (there is also a child 'assent' form for your child to complete). Alternatively, if you would like a copy of the form sent to you via email or post, please email Laura.

[13.05.2024] [Version 2.0] [Ethics number: 92436]



Child assent form	Parent/guardian consent form
https://forms.office.com/e/UcahegwSUF	https://forms.office.com/e/E8W5xg5g6g

What happens if my child changes their mind?
Your child has the right to change their mind and withdraw at any time without giving a reason. You can also withdraw your consent prior to the interview/focus group taking place and must inform the researcher by emailing Laura (lja3g14@soton.ac.uk).

If your child withdraws from the study, we will keep the information about them that we have already obtained for the purposes of achieving the objectives of the study only. All identifiable information about them will be destroyed.

What will happen to the results of the research?

The results will be written up for the project and submitted to the university as part of the doctoral course requirements. There is a possibility that the project may be published. If you or your child would like a copy of the final report, then please let Laura know and this will be made available to you.

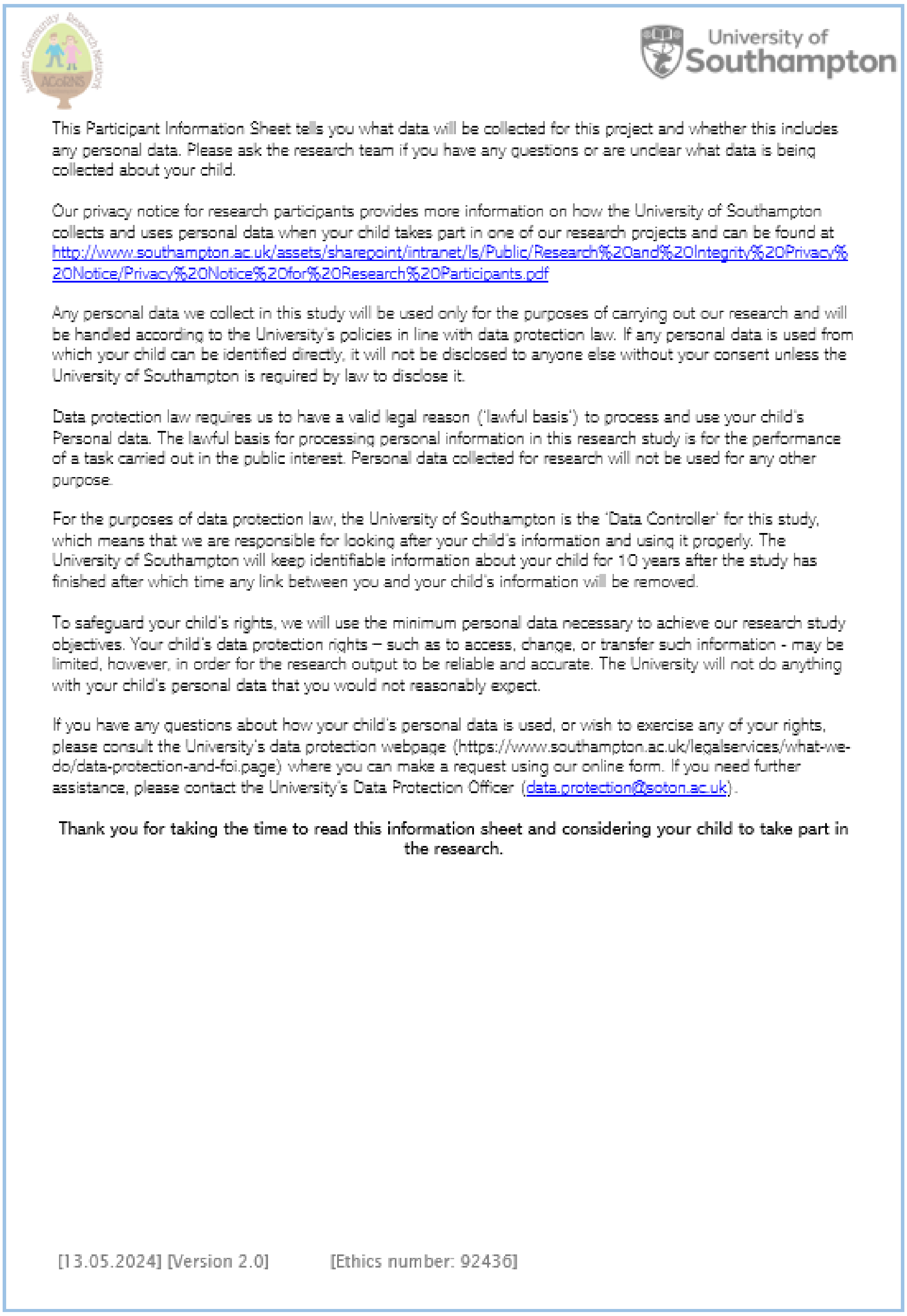
Your child's personal details will not be included in the write-up of the findings, and instead their pseudonym will be referred to. Research findings made available in any reports or publications will not include information that can directly identify your child without your specific consent.

Where can I get more information?
If you have any questions after reading this information sheet or require any further information, then please contact Laura Salmon (lja3g14@soton.ac.uk). You may also contact members of the research supervisory team (Dr Hanna Kovshoff - h.kovshoff@soton.ac.uk; Dr Henry Wood-Downie - henry.wood@soton.ac.uk; Professor Sarah Parsons - s.j.parsons@soton.ac.uk).

What happens if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researcher (Laura Salmon; lja3g14@soton.ac.uk)or a member of the research supervisory team, who will do their best to answer your questions.
If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice
The University of Southampton conducts research to the highest standards of research integrity. As a publicly funded organisation, the University has to ensure that it is in the public interest when we use personally identifiable information about people who have agreed to take part in research. This means that when you agree for your child to take part in a research study, we will use information about them in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

[13.05.2024] [Version 2.0]   [Ethics number: 92436]



This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about your child.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses personal data when your child takes part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which your child can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your child's Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your child's information and using it properly. The University of Southampton will keep identifiable information about your child for 10 years after the study has finished after which time any link between you and your child's information will be removed.

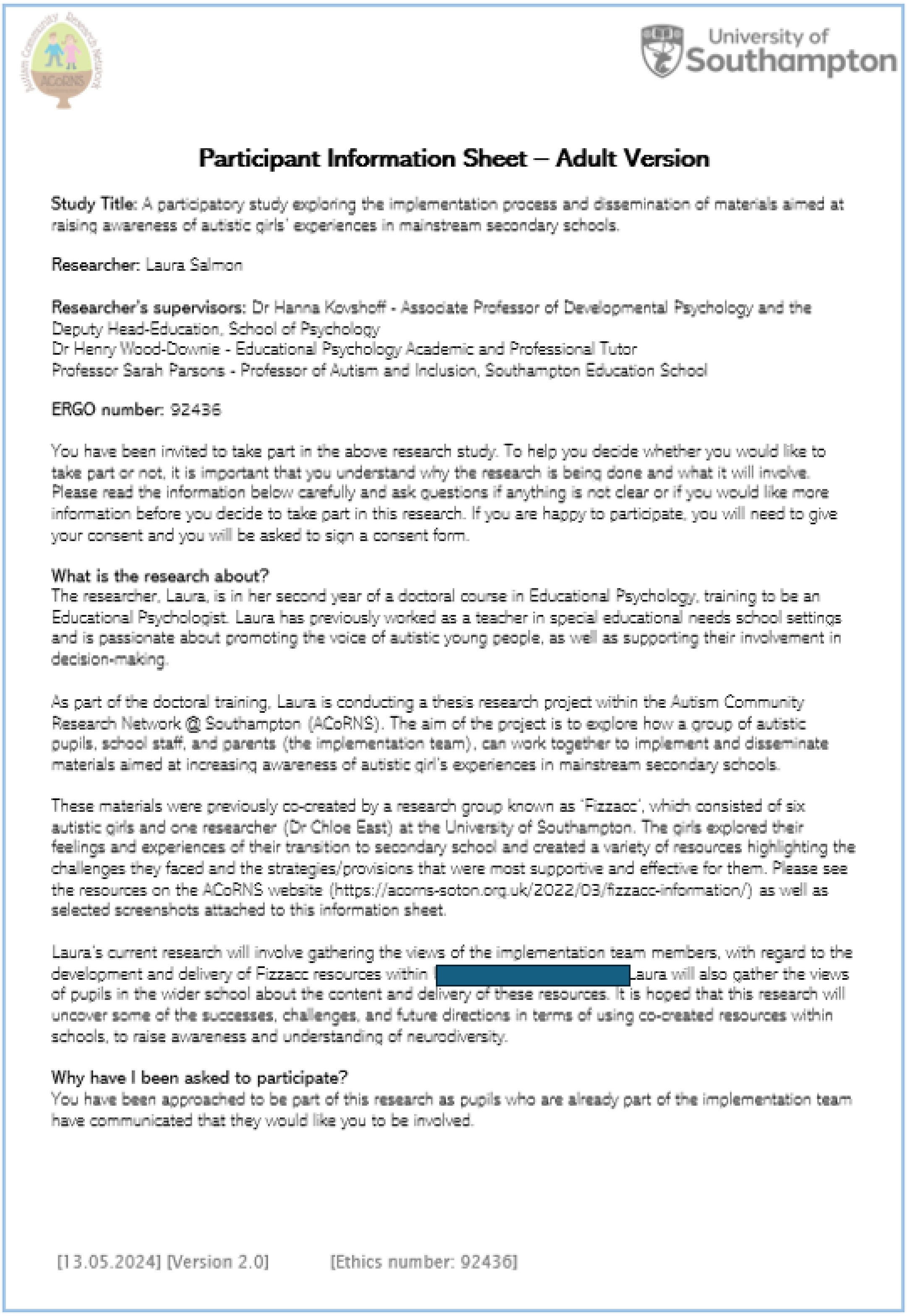
To safeguard your child's rights, we will use the minimum personal data necessary to achieve our research study objectives. Your child's data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your child's personal data that you would not reasonably expect.

If you have any questions about how your child's personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read this information sheet and considering your child to take part in the research.

[13.05.2024] [Version 2.0] [Ethics number: 92436]

D.3 Participant Information Sheet for Adults:



ACoRNS Autism Community Research Network

University of Southampton

Participant Information Sheet – Adult Version

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

Researcher: Laura Salmon

Researcher's supervisors: Dr Hanna Kovshoff - Associate Professor of Developmental Psychology and the Deputy Head-Education, School of Psychology
Dr Henry Wood-Downie - Educational Psychology Academic and Professional Tutor
Professor Sarah Parsons - Professor of Autism and Inclusion, Southampton Education School

ERGO number: 92436

You have been invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or if you would like more information before you decide to take part in this research. If you are happy to participate, you will need to give your consent and you will be asked to sign a consent form.

What is the research about?
The researcher, Laura, is in her second year of a doctoral course in Educational Psychology, training to be an Educational Psychologist. Laura has previously worked as a teacher in special educational needs school settings and is passionate about promoting the voice of autistic young people, as well as supporting their involvement in decision-making.

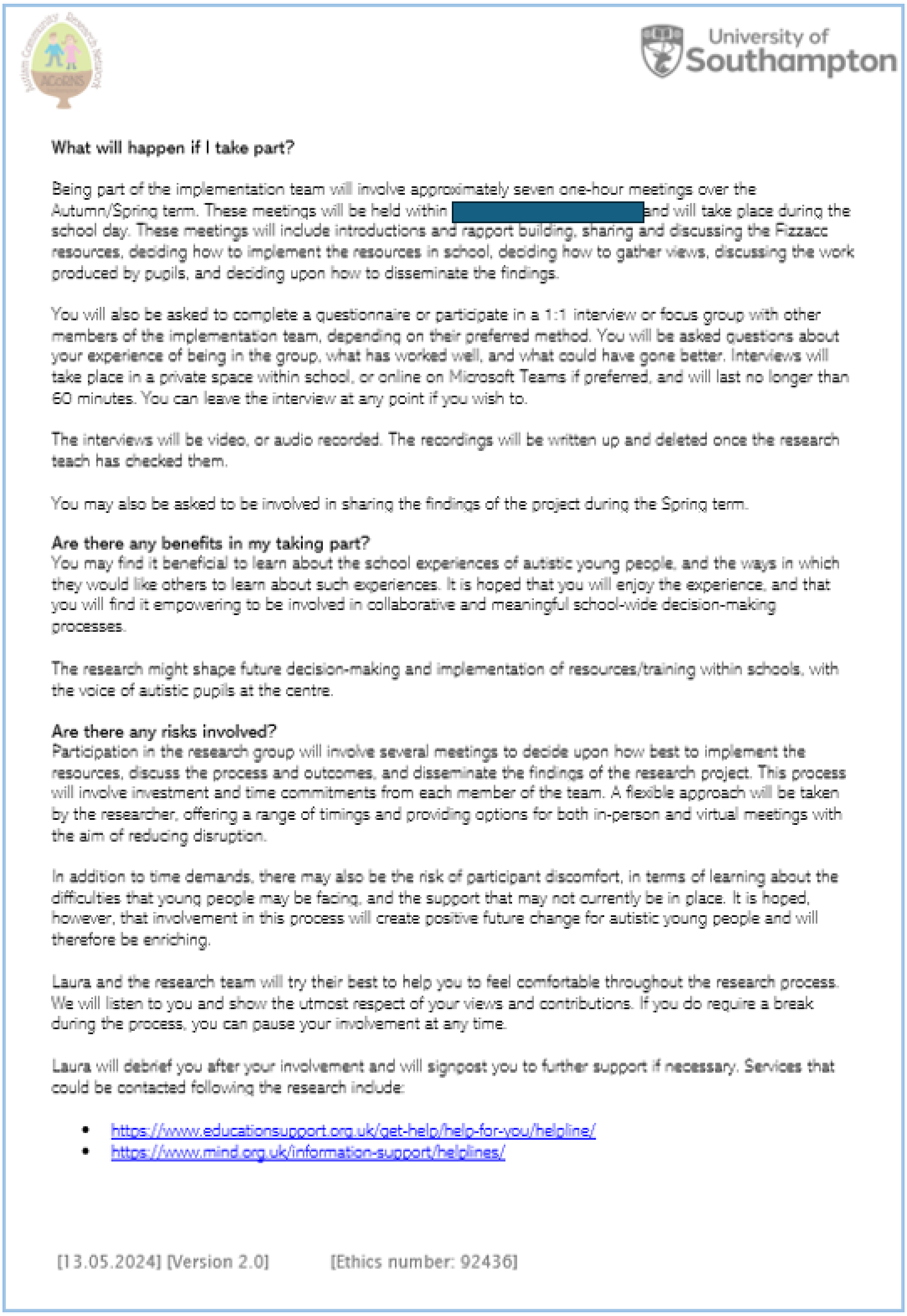
As part of the doctoral training, Laura is conducting a thesis research project within the Autism Community Research Network @ Southampton (ACoRNS). The aim of the project is to explore how a group of autistic pupils, school staff, and parents (the implementation team), can work together to implement and disseminate materials aimed at increasing awareness of autistic girl's experiences in mainstream secondary schools.

These materials were previously co-created by a research group known as 'Fizzacc', which consisted of six autistic girls and one researcher (Dr Chloe East) at the University of Southampton. The girls explored their feelings and experiences of their transition to secondary school and created a variety of resources highlighting the challenges they faced and the strategies/provisions that were most supportive and effective for them. Please see the resources on the ACoRNS website (https://acorns-soton.org.uk/2022/03/fizzacc-information/) as well as selected screenshots attached to this information sheet.

Laura's current research will involve gathering the views of the implementation team members, with regard to the development and delivery of Fizzacc resources within [redacted] Laura will also gather the views of pupils in the wider school about the content and delivery of these resources. It is hoped that this research will uncover some of the successes, challenges, and future directions in terms of using co-created resources within schools, to raise awareness and understanding of neurodiversity.

Why have I been asked to participate?
You have been approached to be part of this research as pupils who are already part of the implementation team have communicated that they would like you to be involved.

[13.05.2024] [Version 2.0] [Ethics number: 92436]



What will happen if I take part?

Being part of the implementation team will involve approximately seven one-hour meetings over the Autumn/Spring term. These meetings will be held within [redacted] and will take place during the school day. These meetings will include introductions and rapport building, sharing and discussing the Fizzacc resources, deciding how to implement the resources in school, deciding how to gather views, discussing the work produced by pupils, and deciding upon how to disseminate the findings.

You will also be asked to complete a questionnaire or participate in a 1:1 interview or focus group with other members of the implementation team, depending on their preferred method. You will be asked questions about your experience of being in the group, what has worked well, and what could have gone better. Interviews will take place in a private space within school, or online on Microsoft Teams if preferred, and will last no longer than 60 minutes. You can leave the interview at any point if you wish to.

The interviews will be video, or audio recorded. The recordings will be written up and deleted once the research teach has checked them.

You may also be asked to be involved in sharing the findings of the project during the Spring term.

Are there any benefits in my taking part?
You may find it beneficial to learn about the school experiences of autistic young people, and the ways in which they would like others to learn about such experiences. It is hoped that you will enjoy the experience, and that you will find it empowering to be involved in collaborative and meaningful school-wide decision-making processes.

The research might shape future decision-making and implementation of resources/training within schools, with the voice of autistic pupils at the centre.

Are there any risks involved?
Participation in the research group will involve several meetings to decide upon how best to implement the resources, discuss the process and outcomes, and disseminate the findings of the research project. This process will involve investment and time commitments from each member of the team. A flexible approach will be taken by the researcher, offering a range of timings and providing options for both in-person and virtual meetings with the aim of reducing disruption.

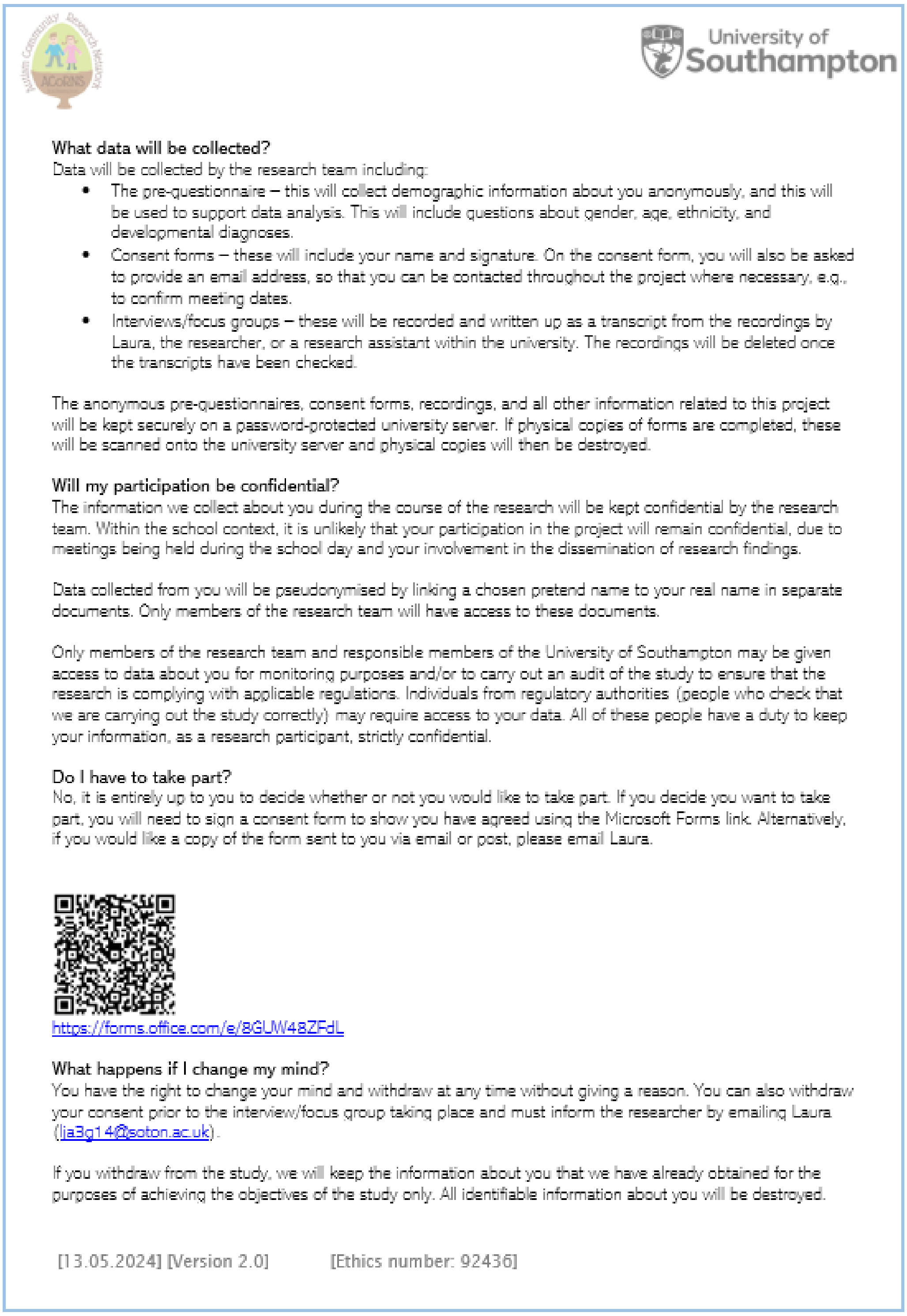
In addition to time demands, there may also be the risk of participant discomfort, in terms of learning about the difficulties that young people may be facing, and the support that may not currently be in place. It is hoped, however, that involvement in this process will create positive future change for autistic young people and will therefore be enriching.

Laura and the research team will try their best to help you to feel comfortable throughout the research process. We will listen to you and show the utmost respect of your views and contributions. If you do require a break during the process, you can pause your involvement at any time.

Laura will debrief you after your involvement and will signpost you to further support if necessary. Services that could be contacted following the research include:

- https://www.educationsupport.org.uk/get-help/help-for-you/helpline/
- https://www.mind.org.uk/information-support/helplines/

[13.05.2024] [Version 2.0] [Ethics number: 92436]



What data will be collected?

Data will be collected by the research team including:

- The pre-questionnaire – this will collect demographic information about you anonymously, and this will be used to support data analysis. This will include questions about gender, age, ethnicity, and developmental diagnoses.
- Consent forms – these will include your name and signature. On the consent form, you will also be asked to provide an email address, so that you can be contacted throughout the project where necessary, e.g., to confirm meeting dates.
- Interviews/focus groups – these will be recorded and written up as a transcript from the recordings by Laura, the researcher, or a research assistant within the university. The recordings will be deleted once the transcripts have been checked.

The anonymous pre-questionnaires, consent forms, recordings, and all other information related to this project will be kept securely on a password-protected university server. If physical copies of forms are completed, these will be scanned onto the university server and physical copies will then be destroyed.

Will my participation be confidential?

The information we collect about you during the course of the research will be kept confidential by the research team. Within the school context, it is unlikely that your participation in the project will remain confidential, due to meetings being held during the school day and your involvement in the dissemination of research findings.

Data collected from you will be pseudonymised by linking a chosen pretend name to your real name in separate documents. Only members of the research team will have access to these documents.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not you would like to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed using the Microsoft Forms link. Alternatively, if you would like a copy of the form sent to you via email or post, please email Laura.

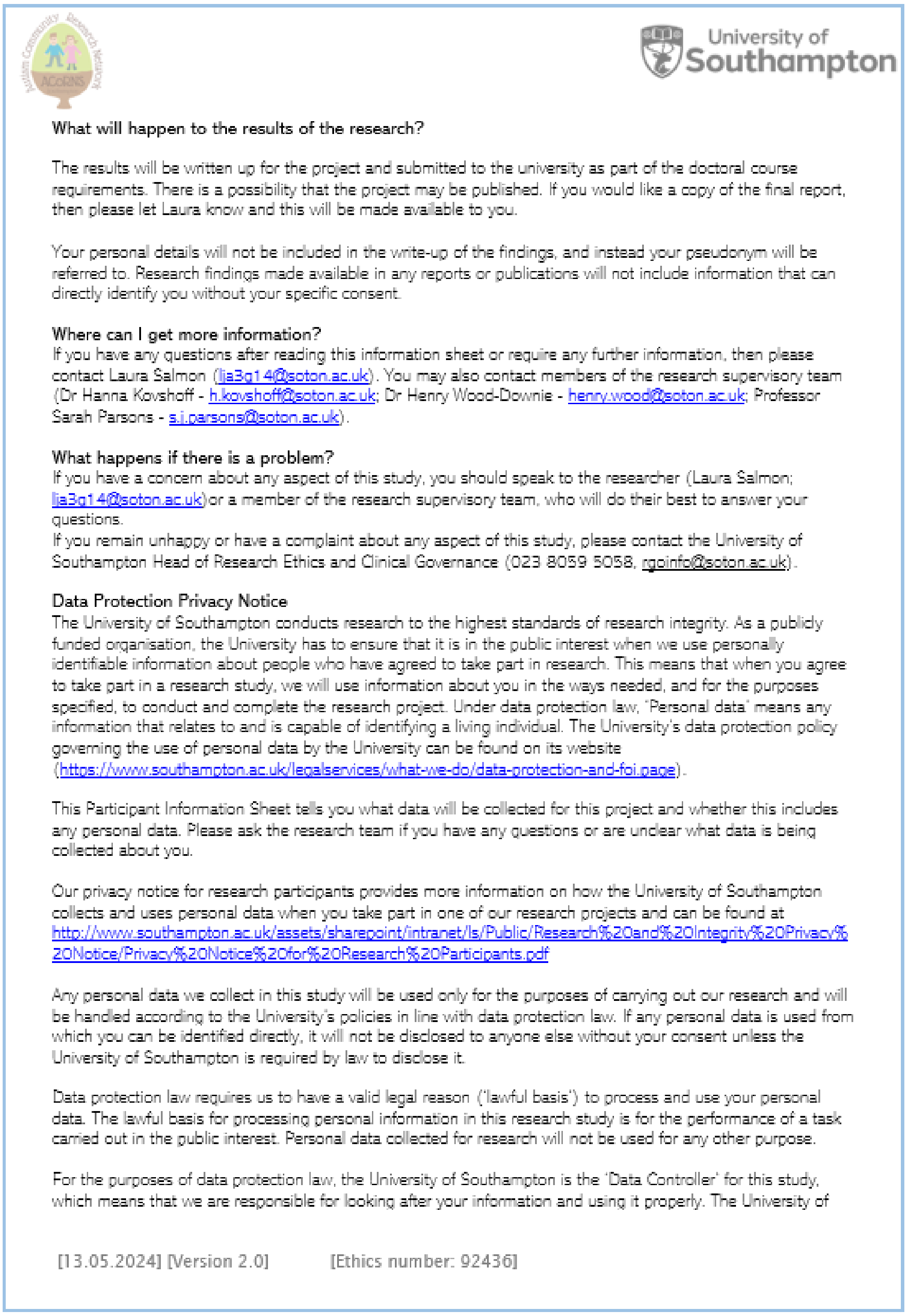
https://forms.office.com/e/8GUW48ZFdL

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason. You can also withdraw your consent prior to the interview/focus group taking place and must inform the researcher by emailing Laura (lja3g14@soton.ac.uk).

If you withdraw from the study, we will keep the information about you that we have already obtained for the purposes of achieving the objectives of the study only. All identifiable information about you will be destroyed.

[13.05.2024] [Version 2.0] [Ethics number: 92436]



What will happen to the results of the research?

The results will be written up for the project and submitted to the university as part of the doctoral course requirements. There is a possibility that the project may be published. If you would like a copy of the final report, then please let Laura know and this will be made available to you.

Your personal details will not be included in the write-up of the findings, and instead your pseudonym will be referred to. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

Where can I get more information?
If you have any questions after reading this information sheet or require any further information, then please contact Laura Salmon (lja3g14@soton.ac.uk). You may also contact members of the research supervisory team (Dr Hanna Kovshoff - h.kovshoff@soton.ac.uk; Dr Henry Wood-Downie - henry.wood@soton.ac.uk; Professor Sarah Parsons - s.j.parsons@soton.ac.uk).

What happens if there is a problem?
If you have a concern about any aspect of this study, you should speak to the researcher (Laura Salmon; lja3g14@soton.ac.uk)or a member of the research supervisory team, who will do their best to answer your questions.
If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice
The University of Southampton conducts research to the highest standards of research integrity. As a publicly funded organisation, the University has to ensure that it is in the public interest when we use personally identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

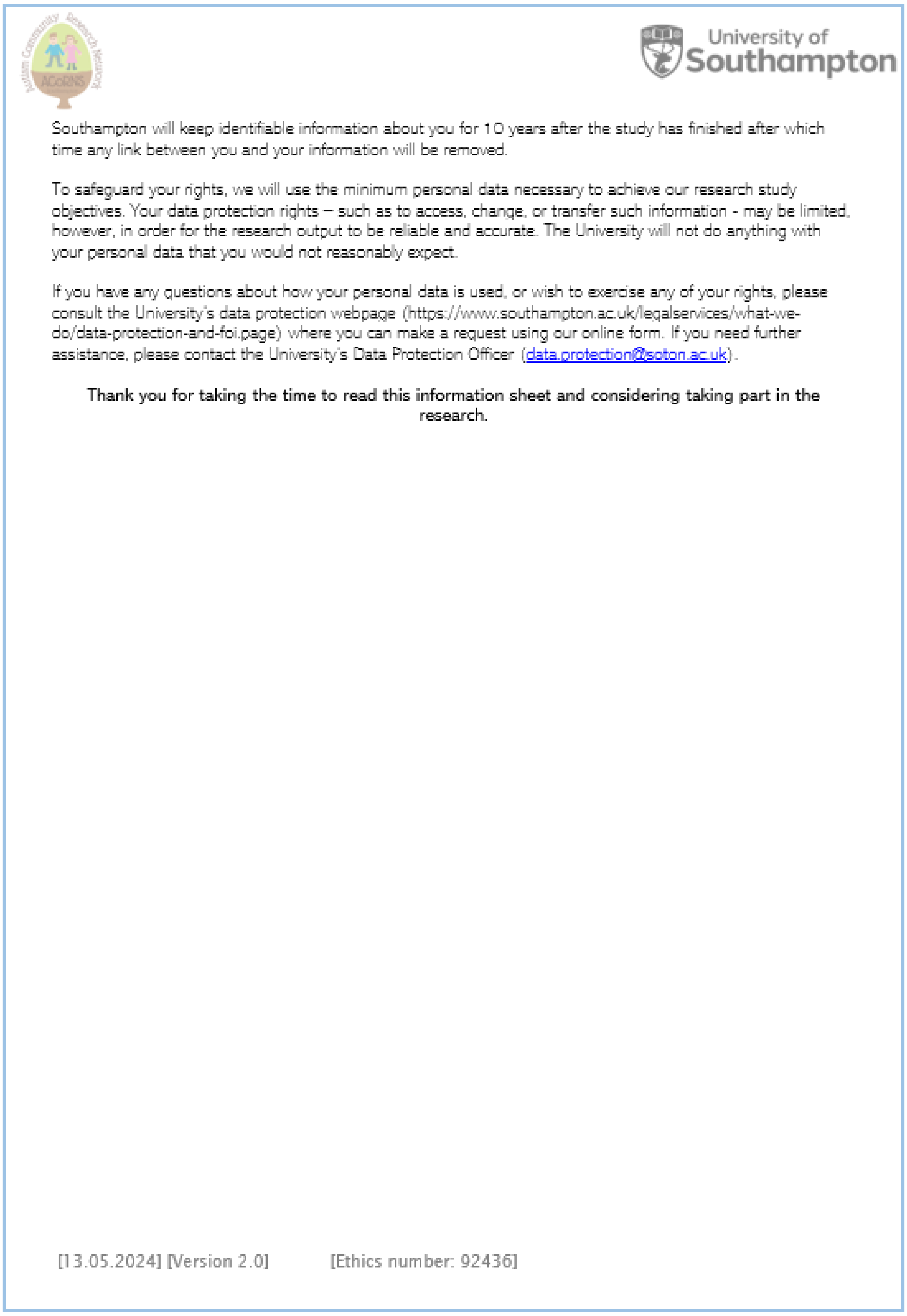
Our privacy notice for research participants provides more information on how the University of Southampton collects and uses personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of

[13.05.2024] [Version 2.0] [Ethics number: 92436]



Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

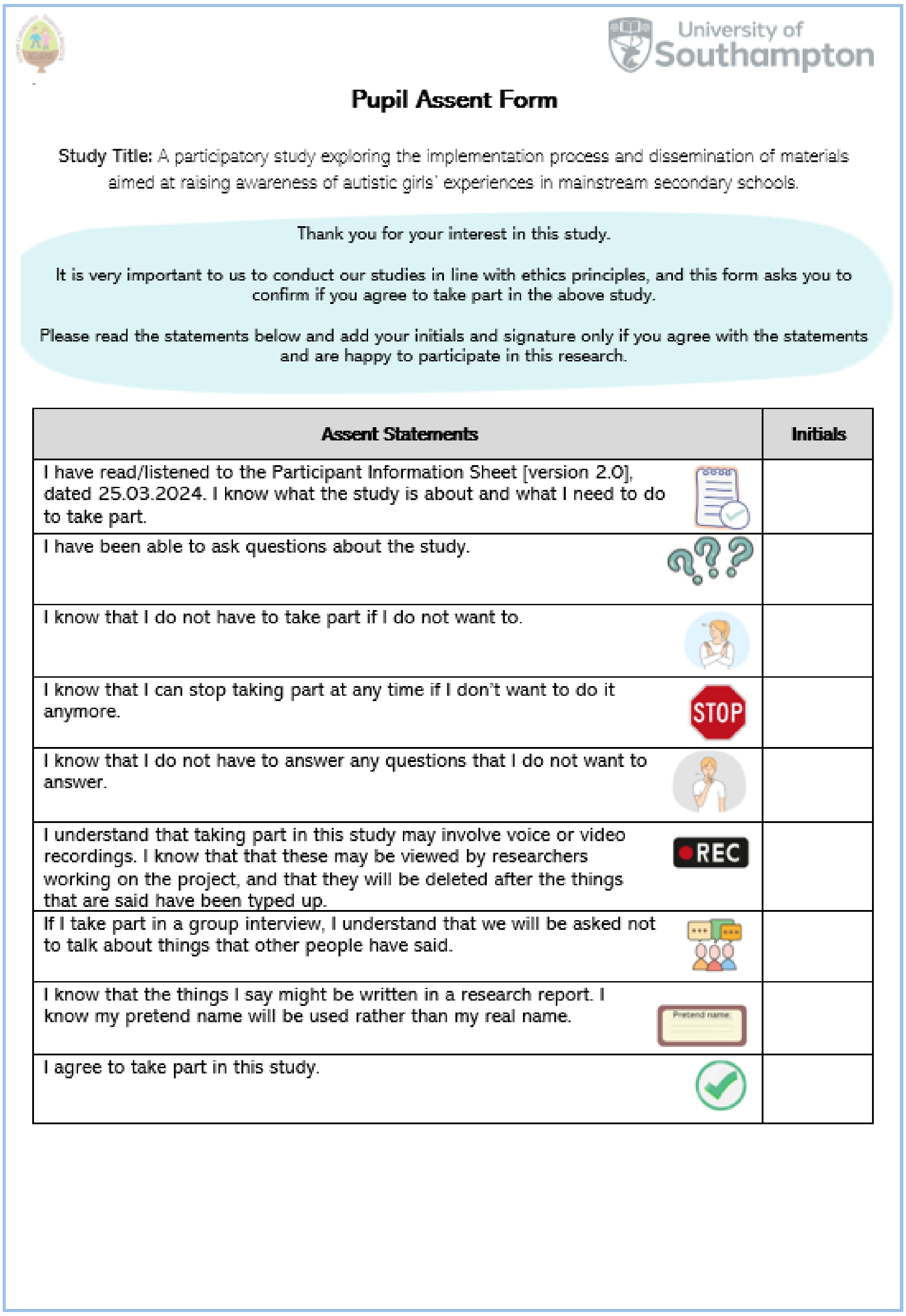
If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking the time to read this information sheet and considering taking part in the research.

[13.05.2024] [Version 2.0] [Ethics number: 92436]

Appendix E Assent and Consent Forms

E.1 Student Assent Form



Pupil Assent Form

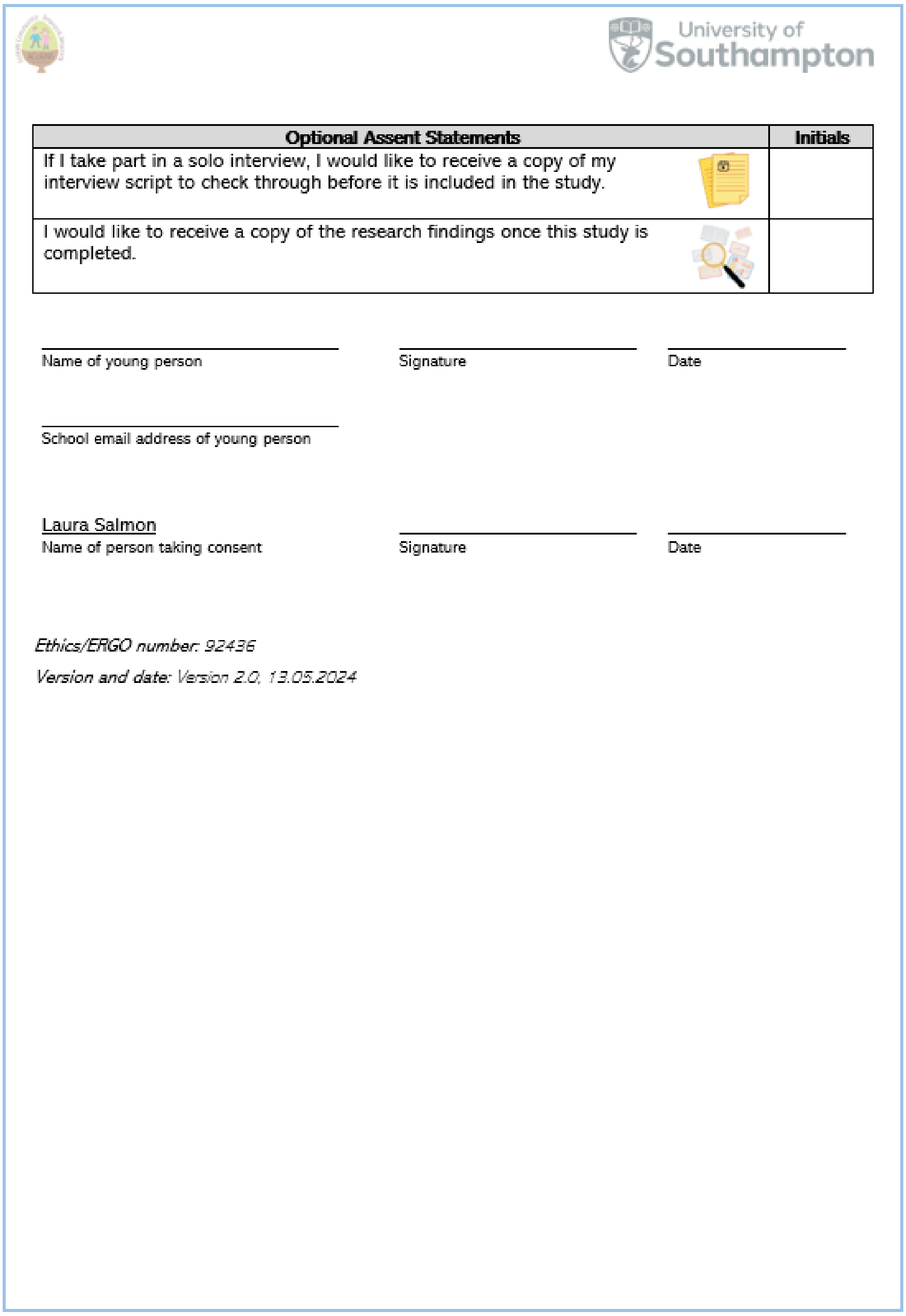
Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

Thank you for your interest in this study.

It is very important to us to conduct our studies in line with ethics principles, and this form asks you to confirm if you agree to take part in the above study.

Please read the statements below and add your initials and signature only if you agree with the statements and are happy to participate in this research.

Assent Statements	Initials
I have read/listened to the Participant Information Sheet [version 2.0], dated 25.03.2024. I know what the study is about and what I need to do to take part.	
I have been able to ask questions about the study.	
I know that I do not have to take part if I do not want to.	
I know that I can stop taking part at any time if I don't want to do it anymore.	
I know that I do not have to answer any questions that I do not want to answer.	
I understand that taking part in this study may involve voice or video recordings. I know that that these may be viewed by researchers working on the project, and that they will be deleted after the things that are said have been typed up.	
If I take part in a group interview, I understand that we will be asked not to talk about things that other people have said.	
I know that the things I say might be written in a research report. I know my pretend name will be used rather than my real name.	
I agree to take part in this study.	



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Optional Assent Statements	Initials
If I take part in a solo interview, I would like to receive a copy of my interview script to check through before it is included in the study.	
I would like to receive a copy of the research findings once this study is completed.	

Name of young person ____________________ Signature ____________________ Date ____________________

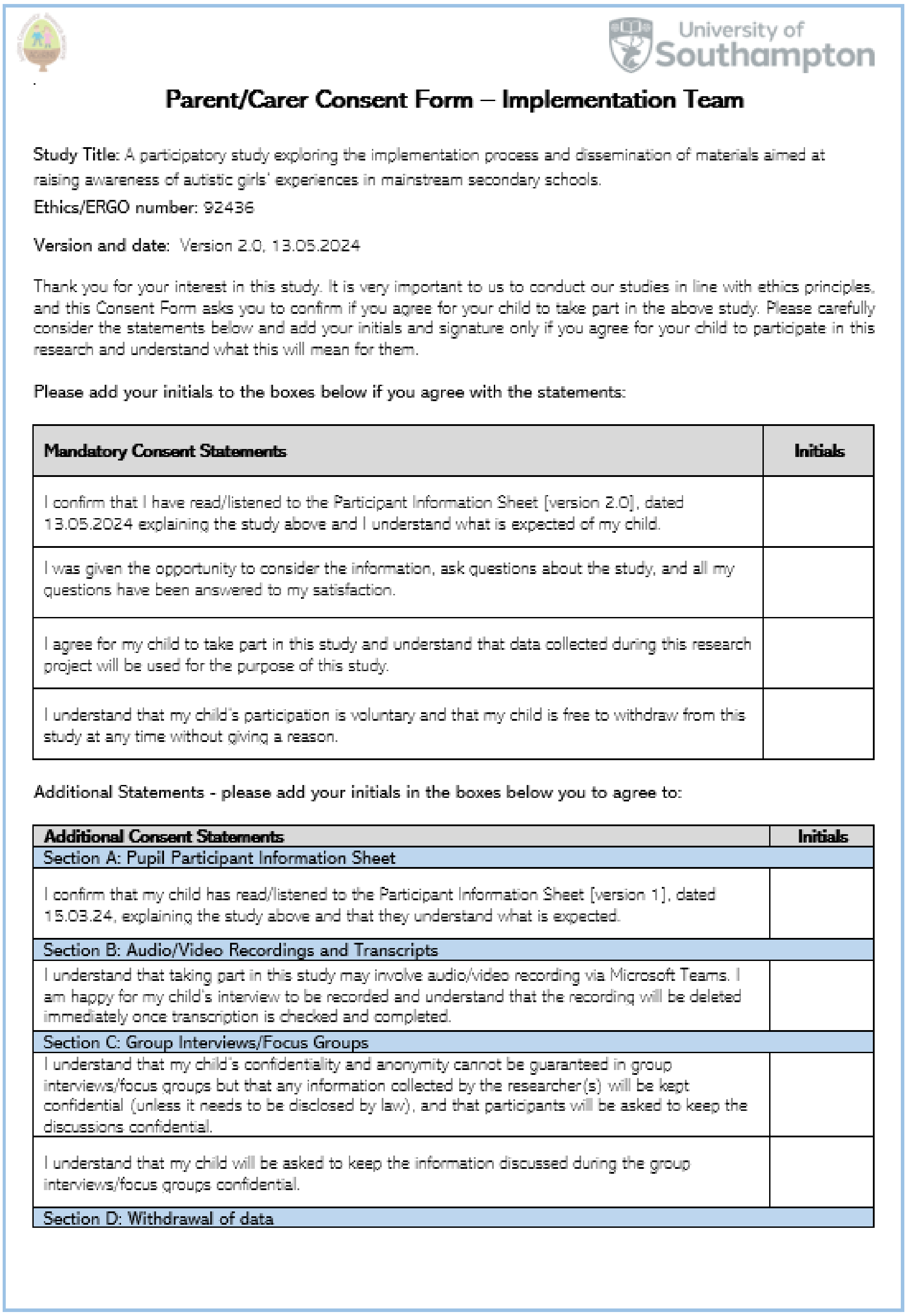
School email address of young person ____________________

Laura Salmon
Name of person taking consent ____________________ Signature ____________________ Date ____________________

Ethics/ERGO number: 92436

Version and date: Version 2.0, 13.05.2024

E.2 Parent/Carer Consent Form



Parent/Carer Consent Form – Implementation Team

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

Ethics/ERGO number: 92436

Version and date: Version 2.0, 13.05.2024

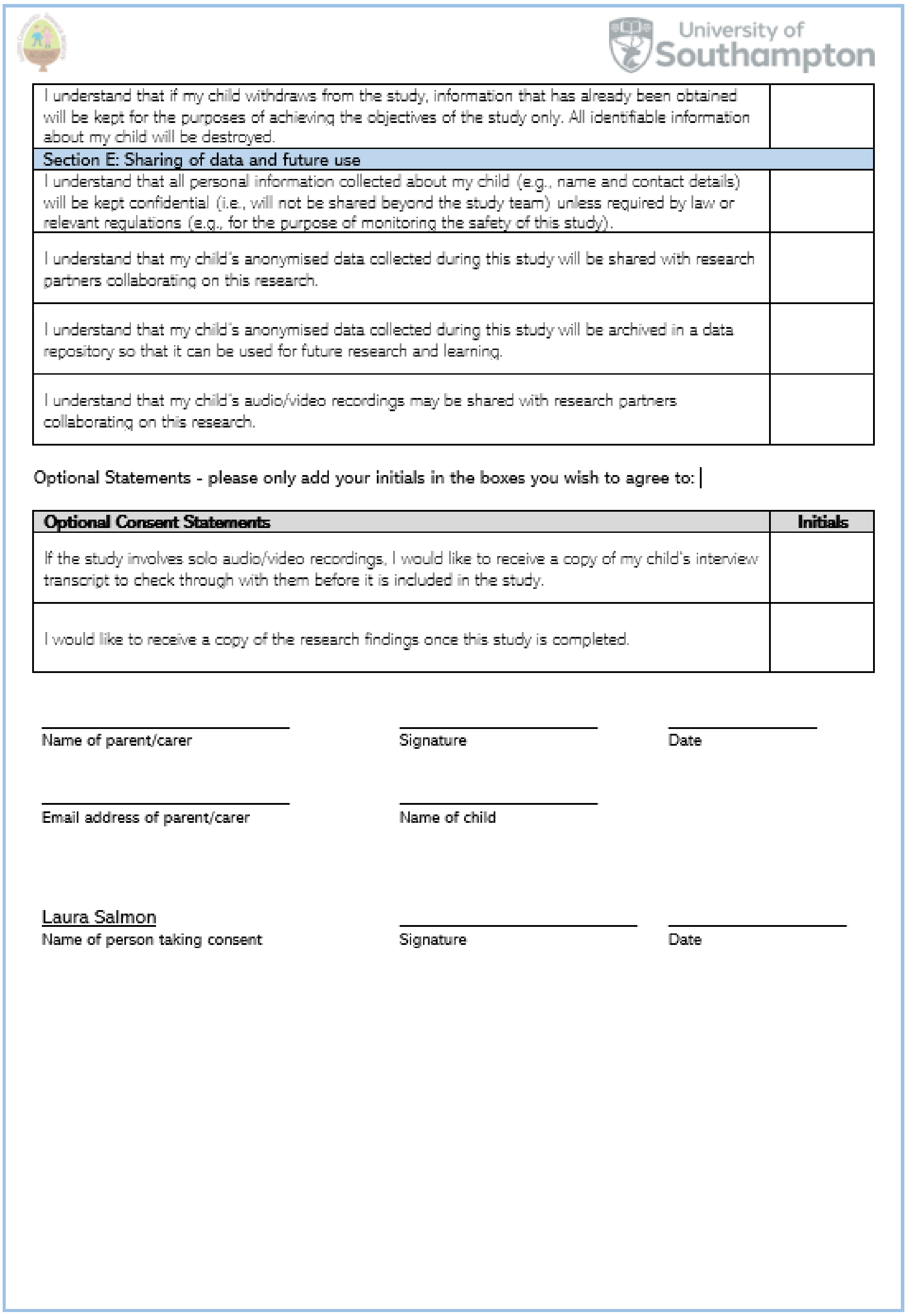
Thank you for your interest in this study. It is very important to us to conduct our studies in line with ethics principles, and this Consent Form asks you to confirm if you agree for your child to take part in the above study. Please carefully consider the statements below and add your initials and signature only if you agree for your child to participate in this research and understand what this will mean for them.

Please add your initials to the boxes below if you agree with the statements:

Mandatory Consent Statements	**Initials**
I confirm that I have read/listened to the Participant Information Sheet [version 2.0], dated 13.05.2024 explaining the study above and I understand what is expected of my child.	
I was given the opportunity to consider the information, ask questions about the study, and all my questions have been answered to my satisfaction.	
I agree for my child to take part in this study and understand that data collected during this research project will be used for the purpose of this study.	
I understand that my child's participation is voluntary and that my child is free to withdraw from this study at any time without giving a reason.	

Additional Statements - please add your initials in the boxes below you to agree to:

Additional Consent Statements	**Initials**
Section A: Pupil Participant Information Sheet	
I confirm that my child has read/listened to the Participant Information Sheet [version 1], dated 15.03.24, explaining the study above and that they understand what is expected.	
Section B: Audio/Video Recordings and Transcripts	
I understand that taking part in this study may involve audio/video recording via Microsoft Teams. I am happy for my child's interview to be recorded and understand that the recording will be deleted immediately once transcription is checked and completed.	
Section C: Group Interviews/Focus Groups	
I understand that my child's confidentiality and anonymity cannot be guaranteed in group interviews/focus groups but that any information collected by the researcher(s) will be kept confidential (unless it needs to be disclosed by law), and that participants will be asked to keep the discussions confidential.	
I understand that my child will be asked to keep the information discussed during the group interviews/focus groups confidential.	
Section D: Withdrawal of data	



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I understand that if my child withdraws from the study, information that has already been obtained will be kept for the purposes of achieving the objectives of the study only. All identifiable information about my child will be destroyed.	
Section E: Sharing of data and future use	
I understand that all personal information collected about my child (e.g., name and contact details) will be kept confidential (i.e., will not be shared beyond the study team) unless required by law or relevant regulations (e.g., for the purpose of monitoring the safety of this study).	
I understand that my child's anonymised data collected during this study will be shared with research partners collaborating on this research.	
I understand that my child's anonymised data collected during this study will be archived in a data repository so that it can be used for future research and learning.	
I understand that my child's audio/video recordings may be shared with research partners collaborating on this research.	

Optional Statements - please only add your initials in the boxes you wish to agree to:

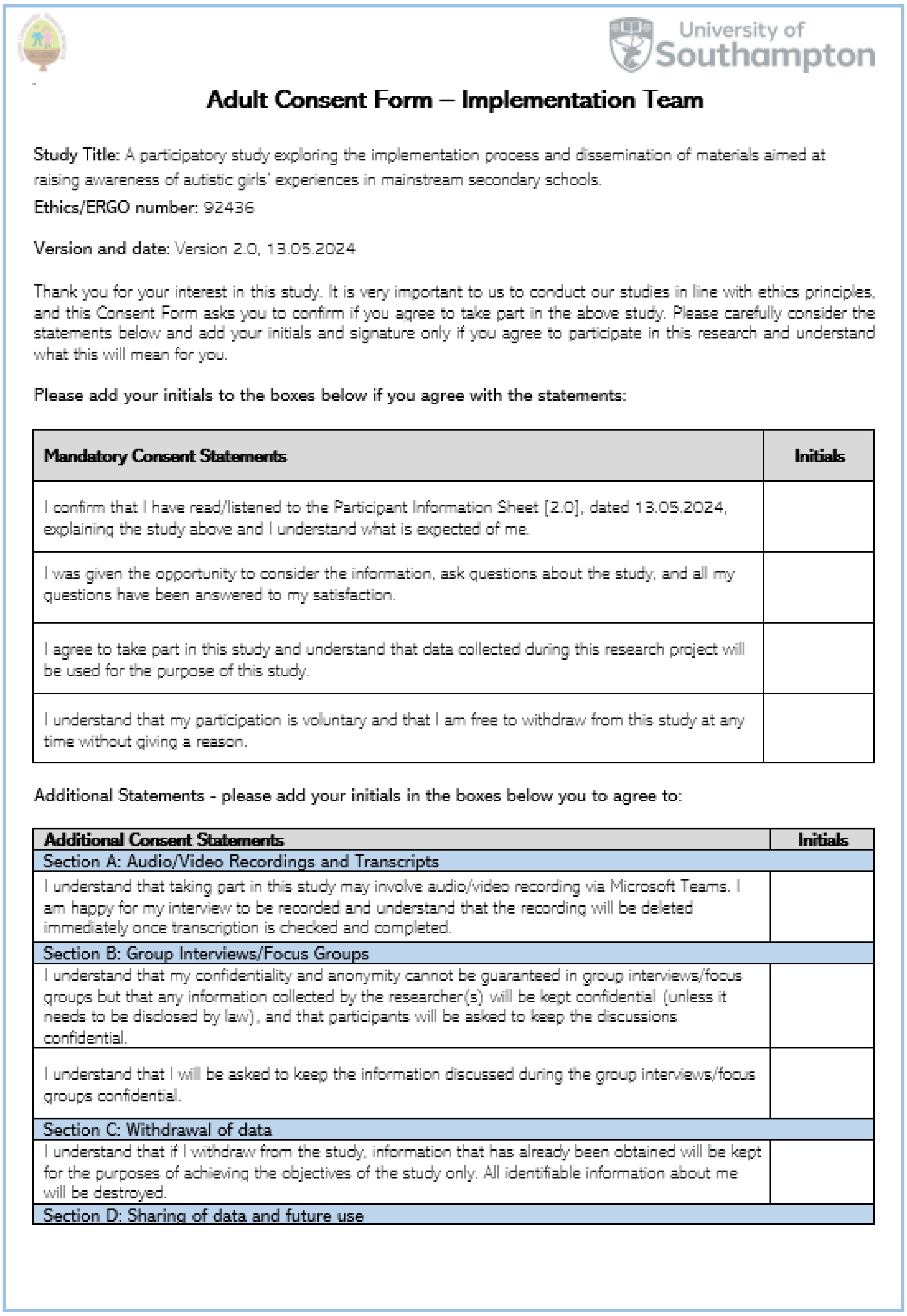
Optional Consent Statements	**Initials**
If the study involves solo audio/video recordings, I would like to receive a copy of my child's interview transcript to check through with them before it is included in the study.	
I would like to receive a copy of the research findings once this study is completed.	

Name of parent/carer ____________ Signature ____________ Date ____________

Email address of parent/carer ____________ Name of child ____________

Laura Salmon
Name of person taking consent ____________ Signature ____________ Date ____________

E.3 Adult Consent Form



University of Southampton

Adult Consent Form – Implementation Team

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

Ethics/ERGO number: 92436

Version and date: Version 2.0, 13.05.2024

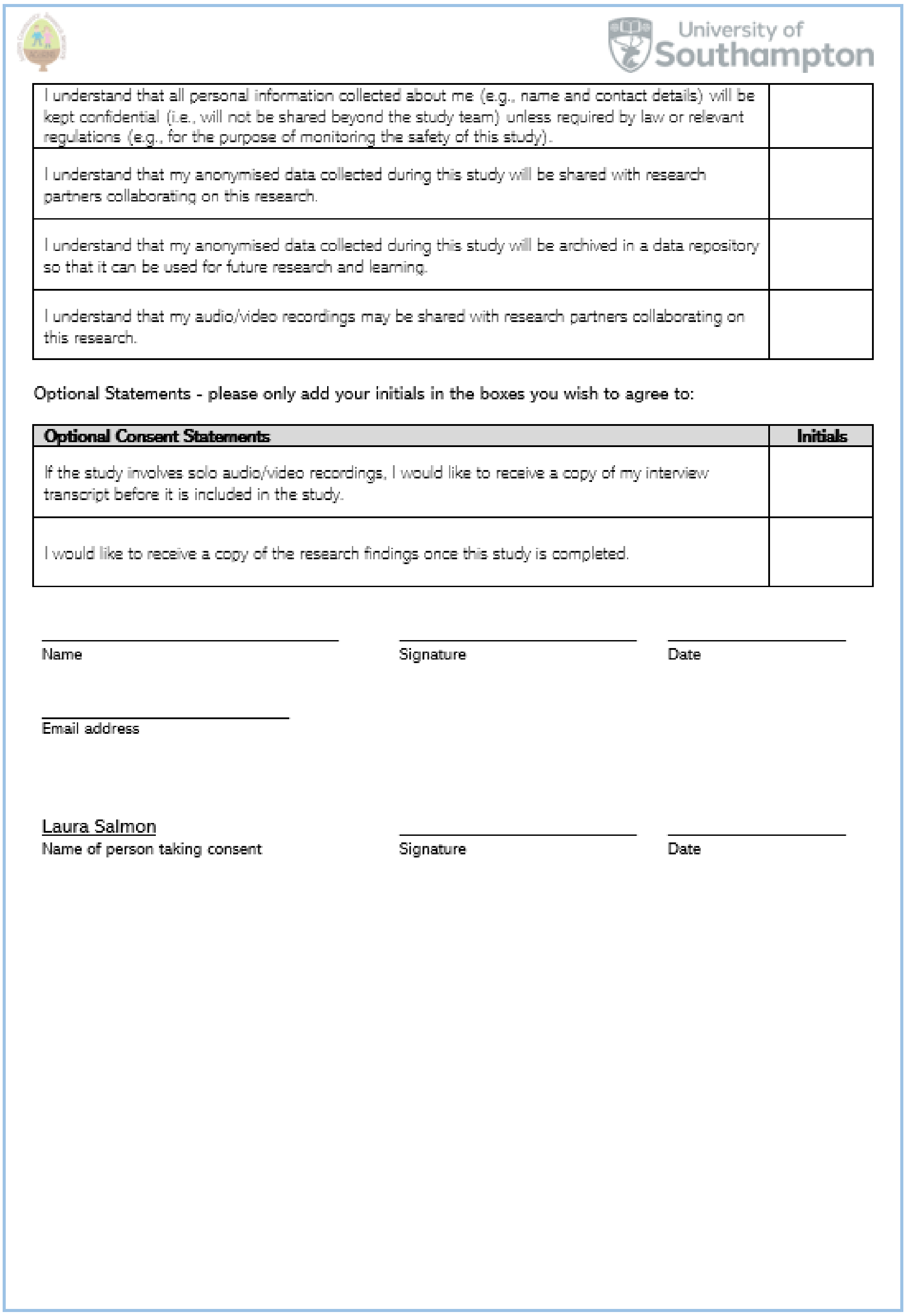
Thank you for your interest in this study. It is very important to us to conduct our studies in line with ethics principles, and this Consent Form asks you to confirm if you agree to take part in the above study. Please carefully consider the statements below and add your initials and signature only if you agree to participate in this research and understand what this will mean for you.

Please add your initials to the boxes below if you agree with the statements:

Mandatory Consent Statements	**Initials**
I confirm that I have read/listened to the Participant Information Sheet [2.0], dated 13.05.2024, explaining the study above and I understand what is expected of me.	
I was given the opportunity to consider the information, ask questions about the study, and all my questions have been answered to my satisfaction.	
I agree to take part in this study and understand that data collected during this research project will be used for the purpose of this study.	
I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving a reason.	

Additional Statements - **please add your initials in the boxes below you to agree to:**

Additional Consent Statements	**Initials**
Section A: Audio/Video Recordings and Transcripts	
I understand that taking part in this study may involve audio/video recording via Microsoft Teams. I am happy for my interview to be recorded and understand that the recording will be deleted immediately once transcription is checked and completed.	
Section B: Group Interviews/Focus Groups	
I understand that my confidentiality and anonymity cannot be guaranteed in group interviews/focus groups but that any information collected by the researcher(s) will be kept confidential (unless it needs to be disclosed by law), and that participants will be asked to keep the discussions confidential.	
I understand that I will be asked to keep the information discussed during the group interviews/focus groups confidential.	
Section C: Withdrawal of data	
I understand that if I withdraw from the study, information that has already been obtained will be kept for the purposes of achieving the objectives of the study only. All identifiable information about me will be destroyed.	
Section D: Sharing of data and future use	



University of Southampton

I understand that all personal information collected about me (e.g., name and contact details) will be kept confidential (i.e., will not be shared beyond the study team) unless required by law or relevant regulations (e.g., for the purpose of monitoring the safety of this study).	
I understand that my anonymised data collected during this study will be shared with research partners collaborating on this research.	
I understand that my anonymised data collected during this study will be archived in a data repository so that it can be used for future research and learning.	
I understand that my audio/video recordings may be shared with research partners collaborating on this research.	

Optional Statements - please only add your initials in the boxes you wish to agree to:

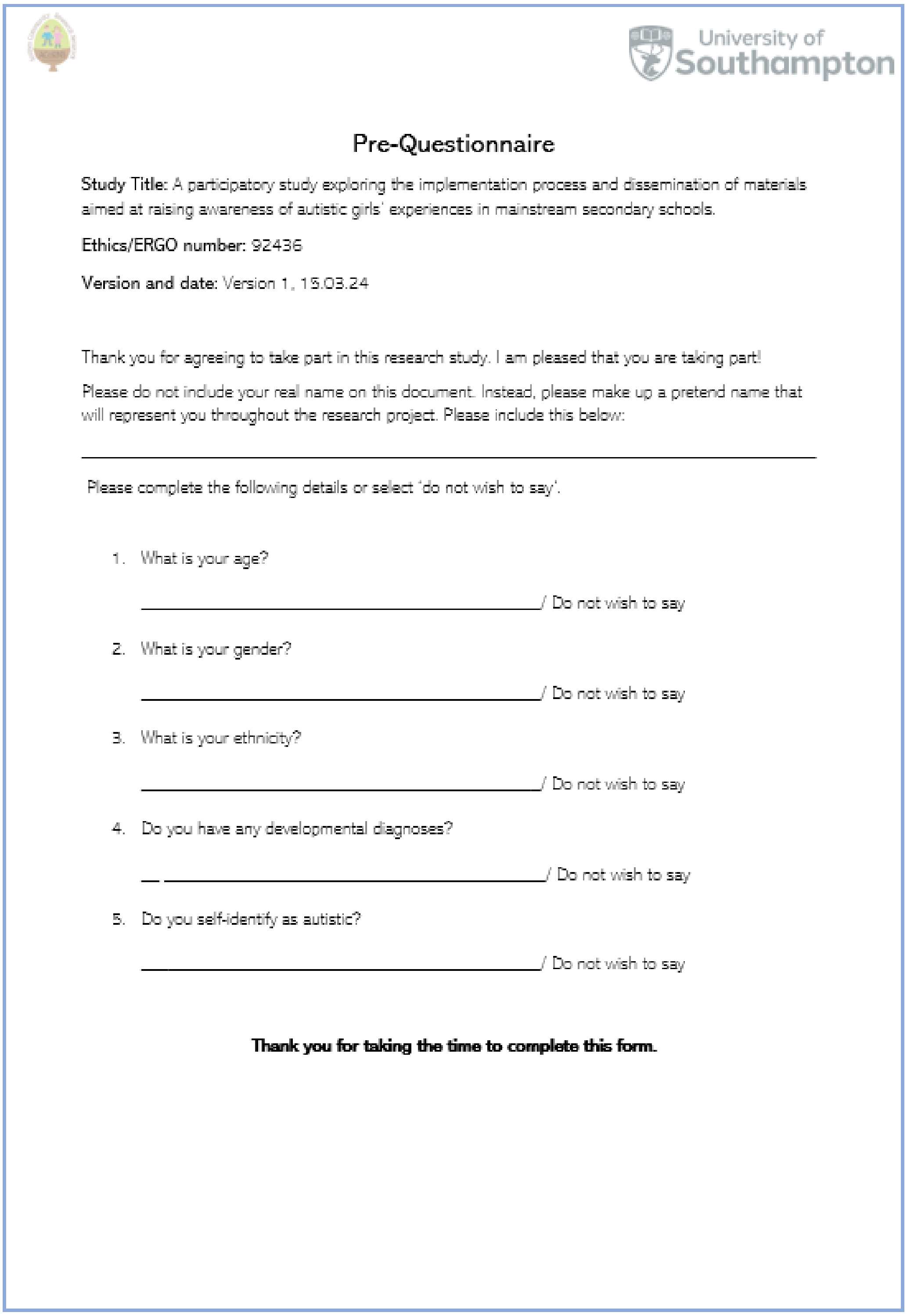
Optional Consent Statements	**Initials**
If the study involves solo audio/video recordings, I would like to receive a copy of my interview transcript before it is included in the study.	
I would like to receive a copy of the research findings once this study is completed.	

Name ______________________ Signature ______________________ Date ______________________

Email address ______________________

Laura Salmon
Name of person taking consent ______________________ Signature ______________________ Date ______________________

Appendix F Demographic Form



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Pre-Questionnaire

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

Ethics/ERGO number: 92436

Version and date: Version 1, 15.03.24

Thank you for agreeing to take part in this research study. I am pleased that you are taking part!

Please do not include your real name on this document. Instead, please make up a pretend name that will represent you throughout the research project. Please include this below:

____

Please complete the following details or select 'do not wish to say'.

1. What is your age?

   ______________________________/ Do not wish to say

2. What is your gender?

   ______________________________/ Do not wish to say

3. What is your ethnicity?

   ______________________________/ Do not wish to say

4. Do you have any developmental diagnoses?

   __ ______________________________/ Do not wish to say

5. Do you self-identify as autistic?

   ______________________________/ Do not wish to say

Thank you for taking the time to complete this form.

Appendix G Participant Preferences Form

Participant Preferences

Thank you very much for agreeing to participate in this research project. Your participation is really valued.

To help you to feel as comfortable as possible throughout the research process, I have put together some questions below to find out more about your preferences.

Once everyone in the team has shared their preferences, we can develop a plan about how our meetings will run so that everyone is listened to.

While it is likely that we will need to do some negotiating (e.g., when deciding on the location of the meetings), I will always do my best to recognise and respect your views.

1. **What is your name?**

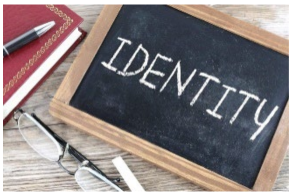
2. **Would you like to meet with me individually online before we start our team meetings?**

   This would be an opportunity for us to introduce ourselves, talk about this form and your preferences, and discuss any questions you have. If you tick yes, I will email you to arrange a time for us to meet.

○ Yes (I would like to meet with you individually before starting the project).
○ No (I am happy to wait until our first team meeting).

3. **Do you have a language preference for the way you identify with autism?**

○ Person-first language ("I am autistic")
○ Identity-first language ("I have autism")
○ No preference (I don't mind either)



4. Would you prefer face-to-face or virtual meetings?

○ Face-to-face
○ Virtual
○ No preference (I don't mind either)

5. How would you feel most comfortable communicating during our meetings? *(You can select as many options as you would like to).*

○ Talking
○ Using visuals (photos or symbols)
○ Writing
○ Typing
○ Drawing
○ It depends on how I am feeling

6. Is there anything that I can do to support your communication during our meetings (e.g., providing symbols or photos, providing options, giving you time to consider your answer)?

7. What would be the ideal length of our meetings?

○ 0-30 minutes
○ 30 minutes-1 hour

8. Would you like us to have a short break during our meetings?

○ Yes
○ No
○ It depends how I am feeling

9. Are there any items or resources that you would like to bring along to our meetings to help you feel more comfortable (e.g., fidget items, noise cancelling headphones)?

10. Are there any items or resources that would be helpful for me to supply during our meetings to help you feel comfortable (e.g., fidget items, noise cancelling headphones)?

11. Where in the school would you like our meetings to take place if they are face-to-face?

12. If a meeting needs to be cancelled at any time, how would you like this to be communicated to you? (Would you like me to email you, or would you like a staff member to tell you? Is there a particular time of day that would be best to communicate this to you?)

13. Are there any cold snacks or refreshments that you would like me to supply (e.g., particular biscuits or soft drinks)?
Do you have any food or drink allergies/intolerances that I should be aware of?

14. Is there anything else that you would like me to know about your needs or preferences before we start our meetings together?

Appendix H Team Building Activities

H.1 Team Strengths

Team Autism's Strengths

Good friend

Kind

Quirky

Perfectionist

Deep thinker

Charming

Organised

Good with animals

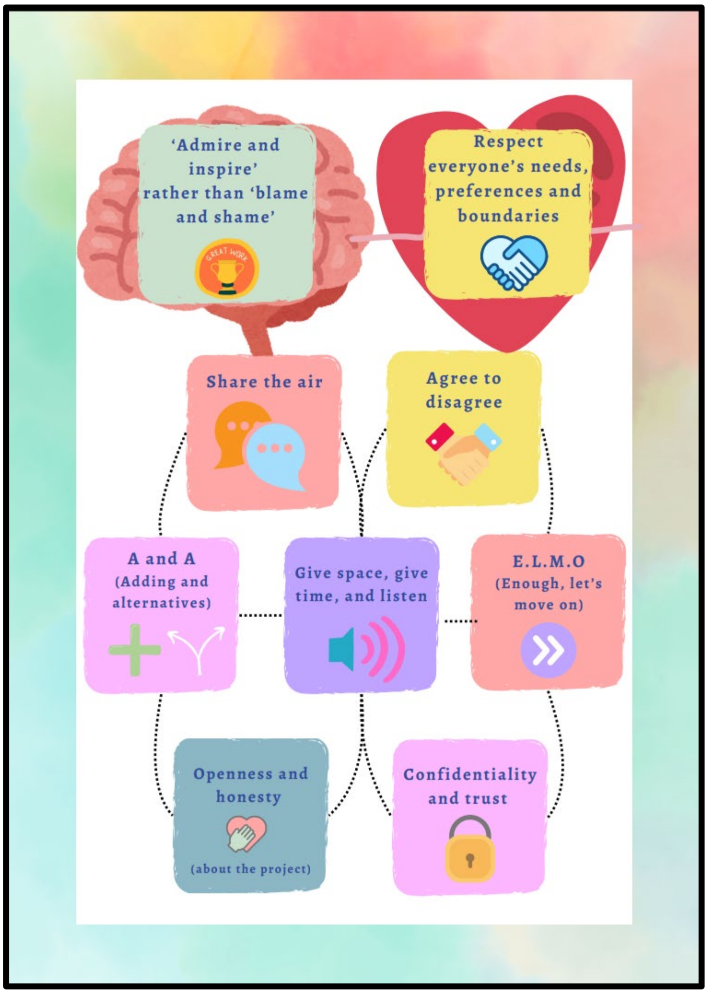
Good at accepting a challenge

Good at seeing patterns

Good actor

Entertaining

H.2 Team Ground Rules



'Admire and inspire' rather than 'blame and shame'

Respect everyone's needs, preferences and boundaries

Share the air

Agree to disagree

A and A (Adding and alternatives)

Give space, give time, and listen

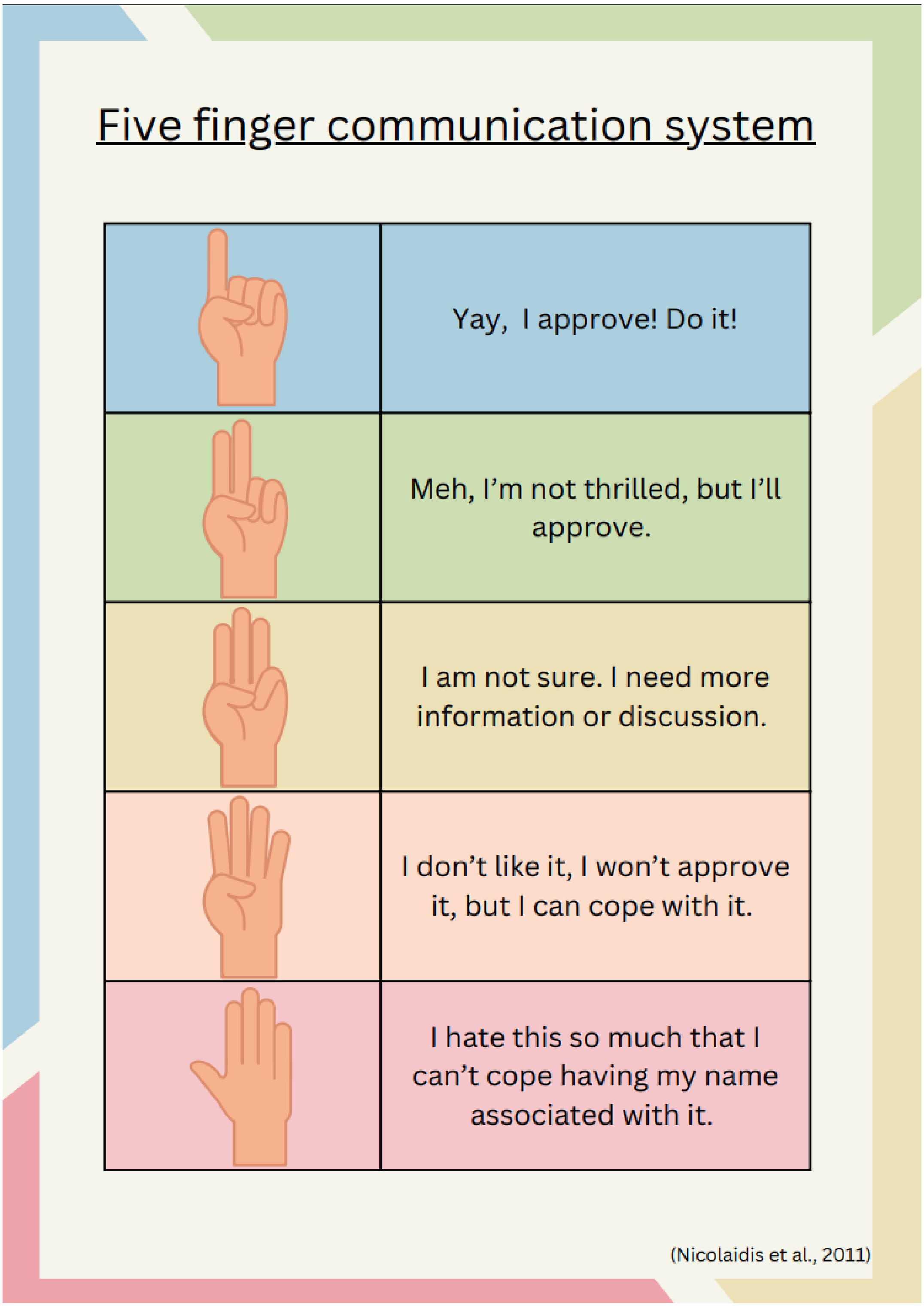
E.L.M.O (Enough, let's move on)

Openness and honesty (about the project)

Confidentiality and trust

Informed by the '16 Ground Rules for Group Work' by Facilitator School (2025)

Appendix I Five Finger Communication System



Five finger communication system

Yay, I approve! Do it!
Meh, I’m not thrilled, but I’ll approve.
I am not sure. I need more information or discussion.
I don’t like it, I won’t approve it, but I can cope with it.
I hate this so much that I can’t cope having my name associated with it.

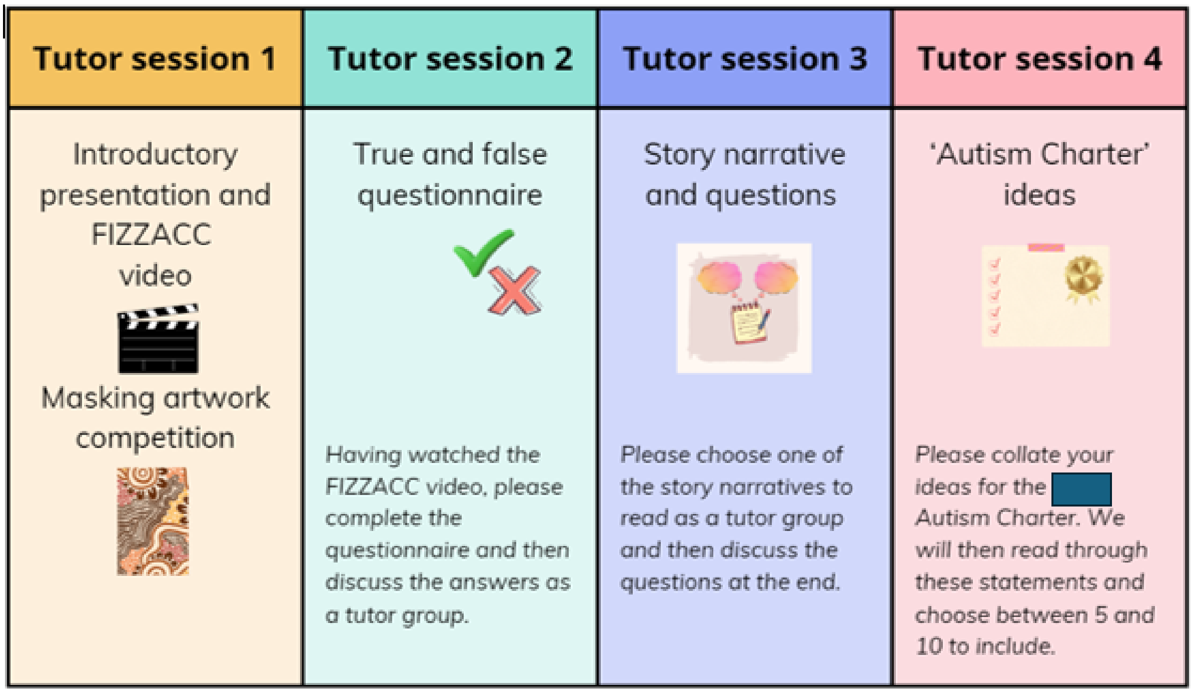
(Nicolaidis et al., 2011)

Appendix J Our Visions

J.1 Plan

J.2 Do

Appendix K ‘Autism Awareness Week’ Timetable



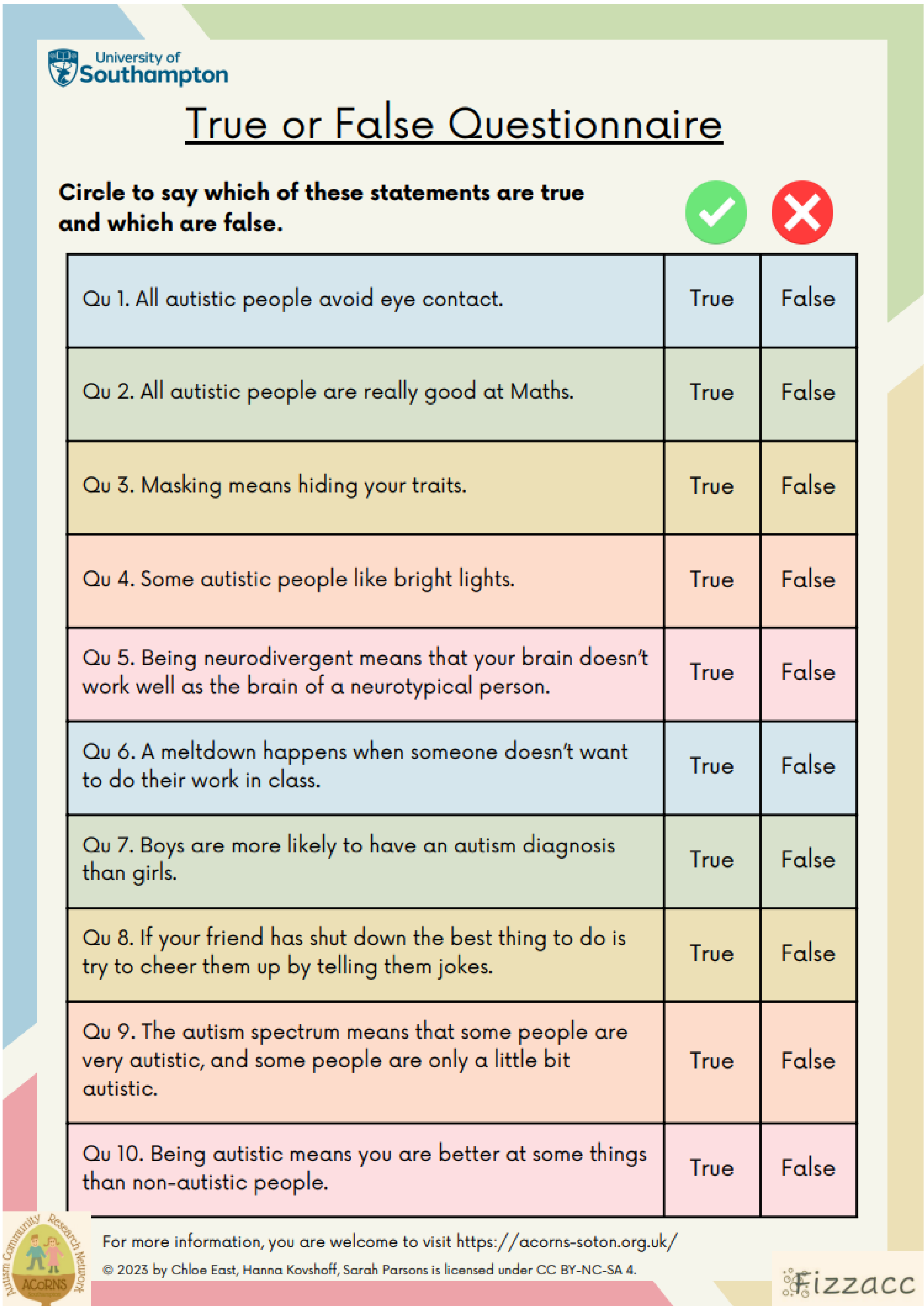
Tutor session 1	Tutor session 2	Tutor session 3	Tutor session 4
Introductory presentation and FIZZACC video Masking artwork competition	True and false questionnaire	Story narrative and questions	‘Autism Charter’ ideas
	Having watched the FIZZACC video, please complete the questionnaire and then discuss the answers as a tutor group.	Please choose one of the story narratives to read as a tutor group and then discuss the questions at the end.	Please collate your ideas for the [redacted] Autism Charter. We will then read through these statements and choose between 5 and 10 to include.

Appendix L FIZZACC Resources

L.1 FIZZACC video link:

https://www.youtube.com/watch?v=F2nvhAttpAU&t=1s

L.2 True and False Questionnaire:



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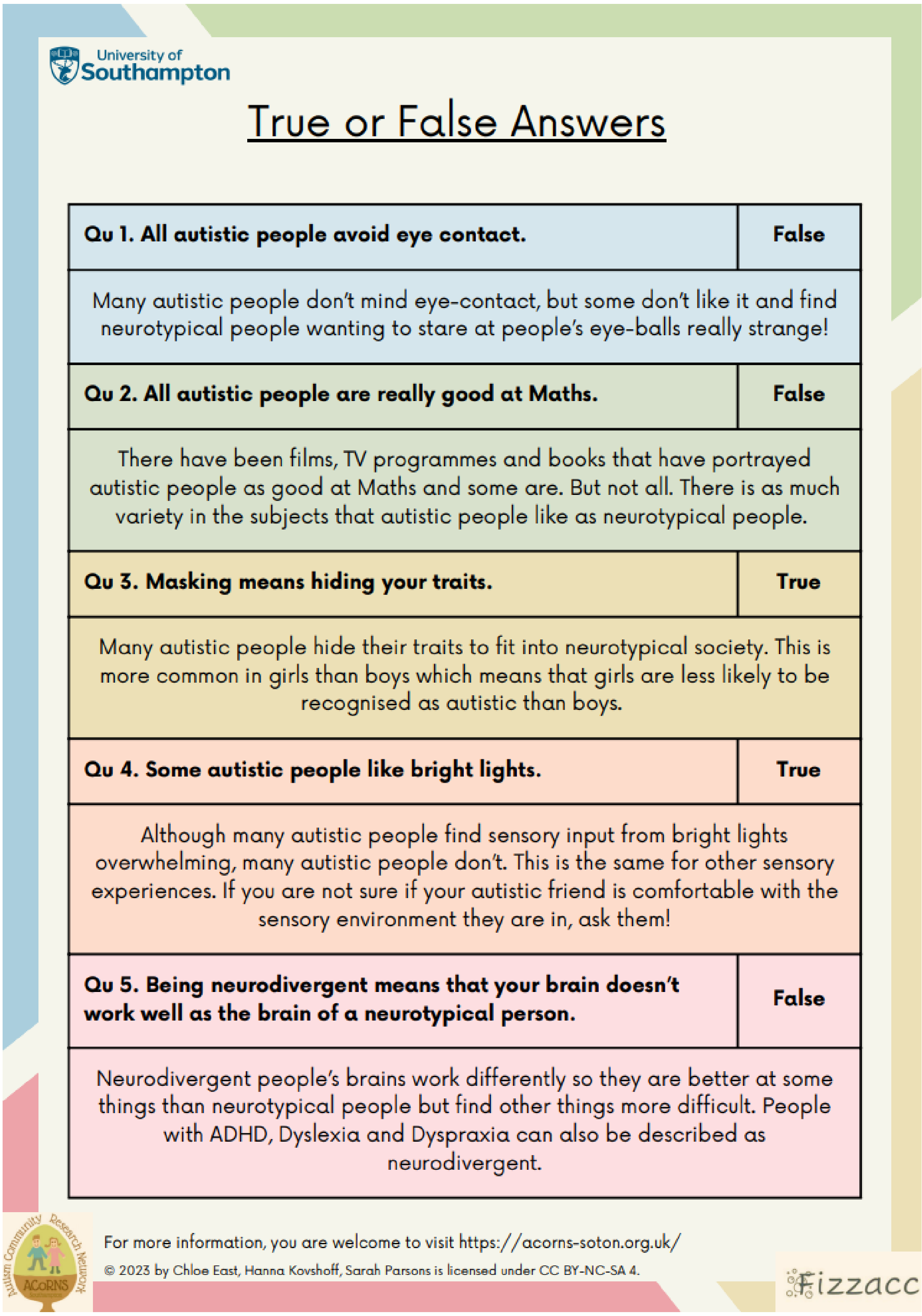
True or False Questionnaire

Circle to say which of these statements are true and which are false.

	✓	✗
Qu 1. All autistic people avoid eye contact.	True	False
Qu 2. All autistic people are really good at Maths.	True	False
Qu 3. Masking means hiding your traits.	True	False
Qu 4. Some autistic people like bright lights.	True	False
Qu 5. Being neurodivergent means that your brain doesn't work well as the brain of a neurotypical person.	True	False
Qu 6. A meltdown happens when someone doesn't want to do their work in class.	True	False
Qu 7. Boys are more likely to have an autism diagnosis than girls.	True	False
Qu 8. If your friend has shut down the best thing to do is try to cheer them up by telling them jokes.	True	False
Qu 9. The autism spectrum means that some people are very autistic, and some people are only a little bit autistic.	True	False
Qu 10. Being autistic means you are better at some things than non-autistic people.	True	False

For more information, you are welcome to visit https://acorns-soton.org.uk/

Fizzacc



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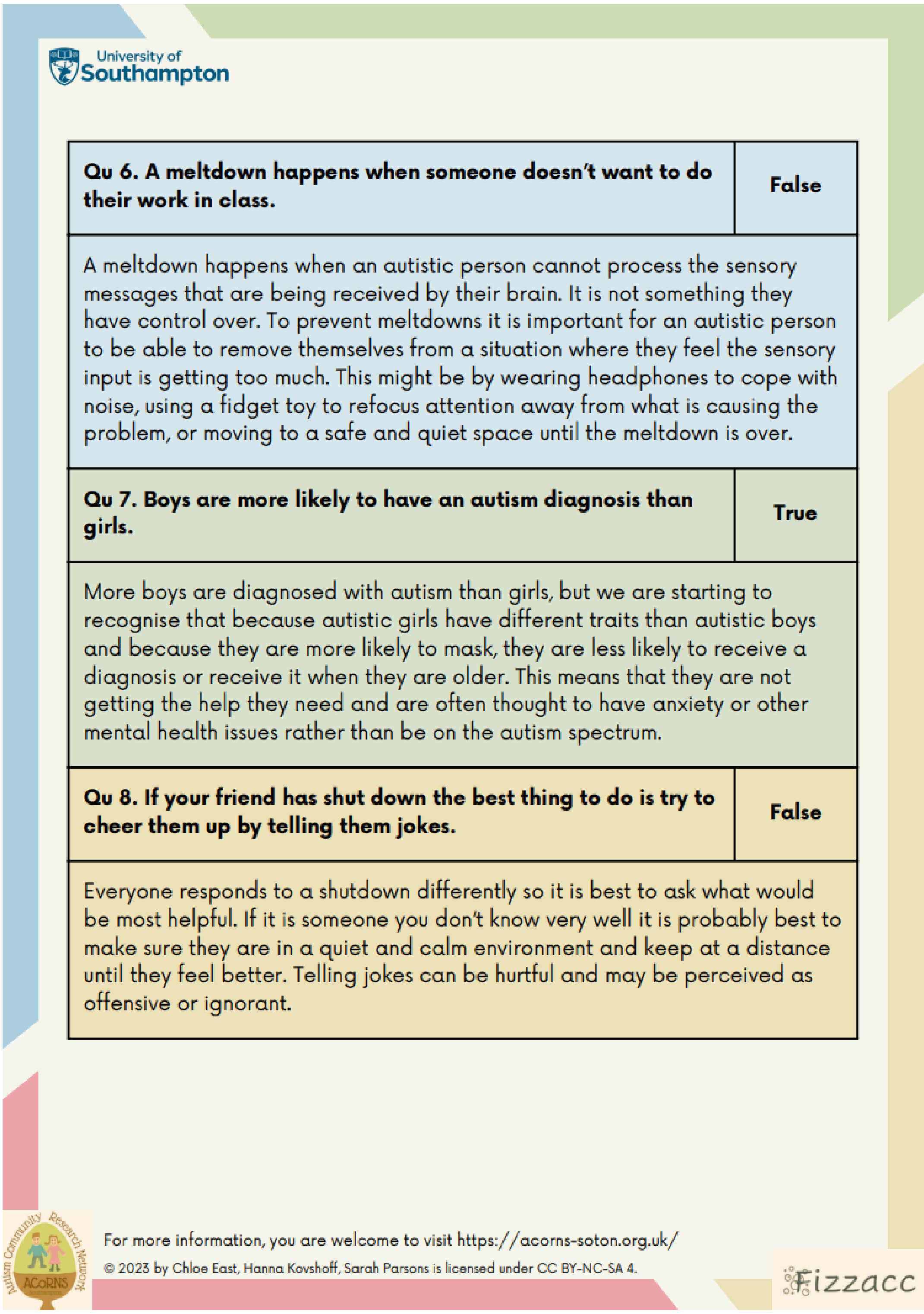
True or False Answers

Qu 1. All autistic people avoid eye contact.	**False**
Many autistic people don't mind eye-contact, but some don't like it and find neurotypical people wanting to stare at people's eye-balls really strange!	
Qu 2. All autistic people are really good at Maths.	**False**
There have been films, TV programmes and books that have portrayed autistic people as good at Maths and some are. But not all. There is as much variety in the subjects that autistic people like as neurotypical people.	
Qu 3. Masking means hiding your traits.	**True**
Many autistic people hide their traits to fit into neurotypical society. This is more common in girls than boys which means that girls are less likely to be recognised as autistic than boys.	
Qu 4. Some autistic people like bright lights.	**True**
Although many autistic people find sensory input from bright lights overwhelming, many autistic people don't. This is the same for other sensory experiences. If you are not sure if your autistic friend is comfortable with the sensory environment they are in, ask them!	
Qu 5. Being neurodivergent means that your brain doesn't work well as the brain of a neurotypical person.	**False**
Neurodivergent people's brains work differently so they are better at some things than neurotypical people but find other things more difficult. People with ADHD, Dyslexia and Dyspraxia can also be described as neurodivergent.	

For more information, you are welcome to visit https://acorns-soton.org.uk/



University of Southampton

Qu 6. A meltdown happens when someone doesn't want to do their work in class.	**False**
A meltdown happens when an autistic person cannot process the sensory messages that are being received by their brain. It is not something they have control over. To prevent meltdowns it is important for an autistic person to be able to remove themselves from a situation where they feel the sensory input is getting too much. This might be by wearing headphones to cope with noise, using a fidget toy to refocus attention away from what is causing the problem, or moving to a safe and quiet space until the meltdown is over.	
Qu 7. Boys are more likely to have an autism diagnosis than girls.	**True**
More boys are diagnosed with autism than girls, but we are starting to recognise that because autistic girls have different traits than autistic boys and because they are more likely to mask, they are less likely to receive a diagnosis or receive it when they are older. This means that they are not getting the help they need and are often thought to have anxiety or other mental health issues rather than be on the autism spectrum.	
Qu 8. If your friend has shut down the best thing to do is try to cheer them up by telling them jokes.	**False**
Everyone responds to a shutdown differently so it is best to ask what would be most helpful. If it is someone you don't know very well it is probably best to make sure they are in a quiet and calm environment and keep at a distance until they feel better. Telling jokes can be hurtful and may be perceived as offensive or ignorant.	

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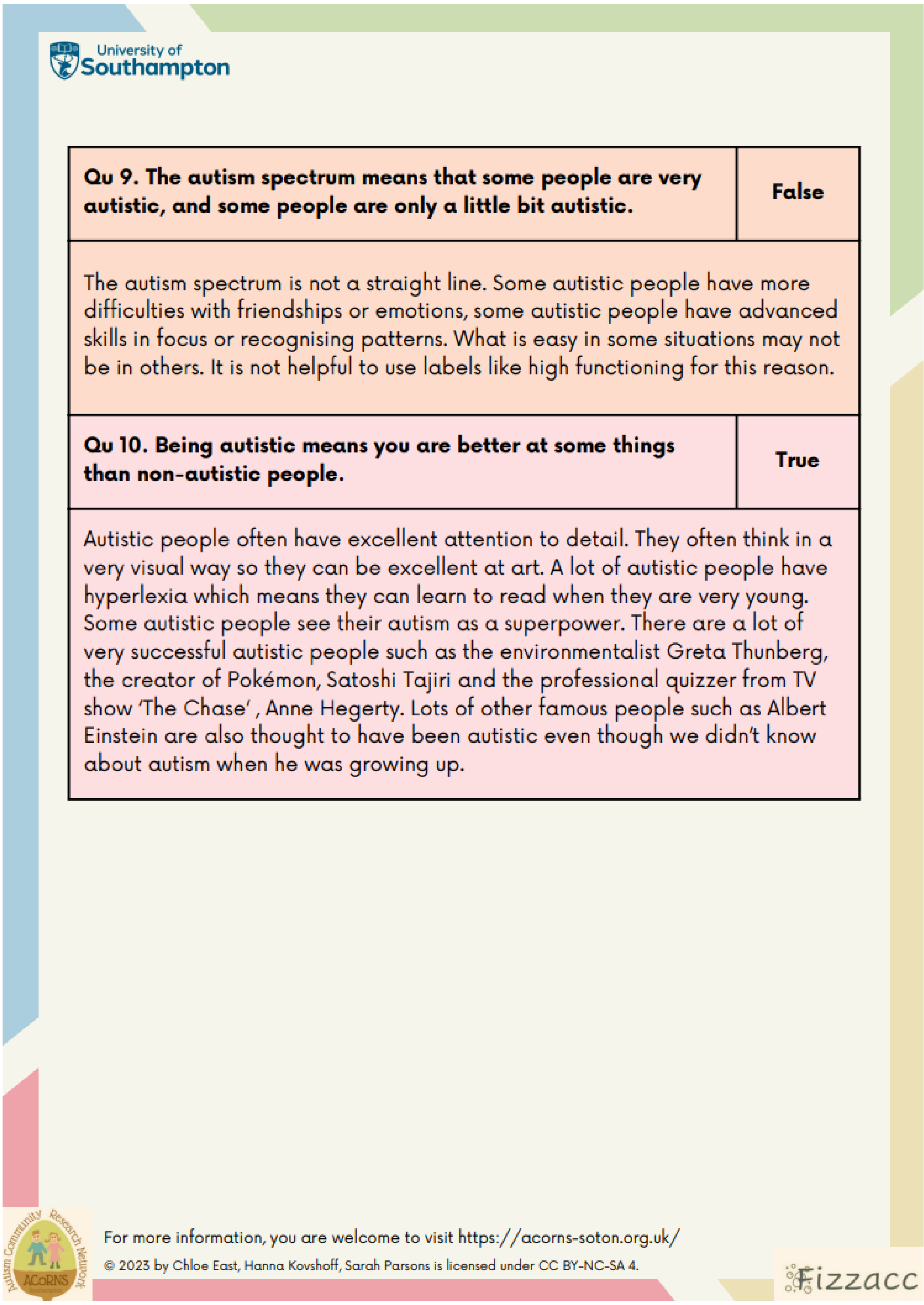

Qu 9. The autism spectrum means that some people are very autistic, and some people are only a little bit autistic.	**False**
The autism spectrum is not a straight line. Some autistic people have more difficulties with friendships or emotions, some autistic people have advanced skills in focus or recognising patterns. What is easy in some situations may not be in others. It is not helpful to use labels like high functioning for this reason.	
Qu 10. Being autistic means you are better at some things than non-autistic people.	**True**
Autistic people often have excellent attention to detail. They often think in a very visual way so they can be excellent at art. A lot of autistic people have hyperlexia which means they can learn to read when they are very young. Some autistic people see their autism as a superpower. There are a lot of very successful autistic people such as the environmentalist Greta Thunberg, the creator of Pokémon, Satoshi Tajiri and the professional quizzer from TV show 'The Chase' , Anne Hegerty. Lots of other famous people such as Albert Einstein are also thought to have been autistic even though we didn't know about autism when he was growing up.	

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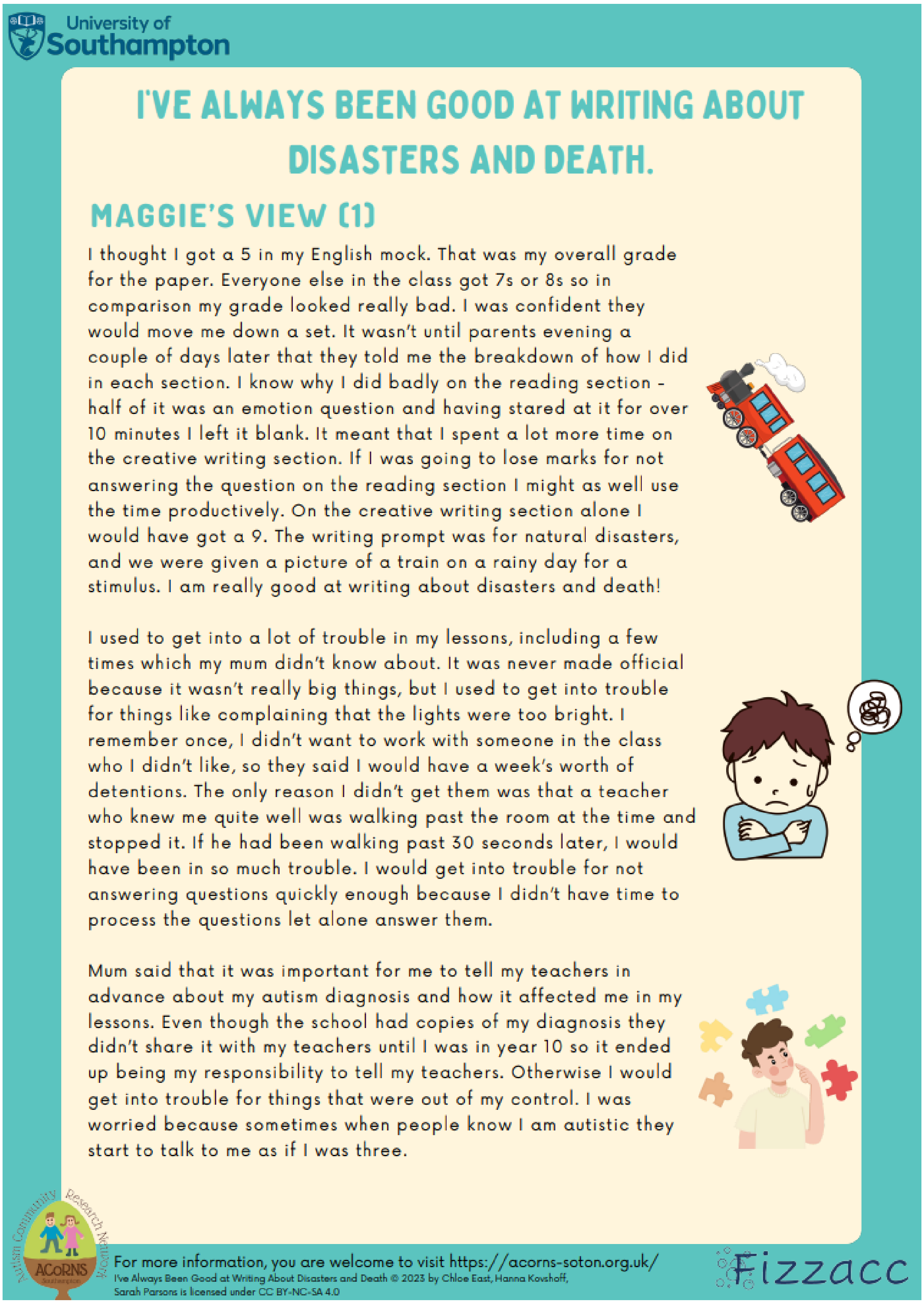
L.3 Story Narrative 1



University of Southampton

I'VE ALWAYS BEEN GOOD AT WRITING ABOUT DISASTERS AND DEATH.

MAGGIE'S VIEW (1)

I thought I got a 5 in my English mock. That was my overall grade for the paper. Everyone else in the class got 7s or 8s so in comparison my grade looked really bad. I was confident they would move me down a set. It wasn't until parents evening a couple of days later that they told me the breakdown of how I did in each section. I know why I did badly on the reading section - half of it was an emotion question and having stared at it for over 10 minutes I left it blank. It meant that I spent a lot more time on the creative writing section. If I was going to lose marks for not answering the question on the reading section I might as well use the time productively. On the creative writing section alone I would have got a 9. The writing prompt was for natural disasters, and we were given a picture of a train on a rainy day for a stimulus. I am really good at writing about disasters and death!

I used to get into a lot of trouble in my lessons, including a few times which my mum didn't know about. It was never made official because it wasn't really big things, but I used to get into trouble for things like complaining that the lights were too bright. I remember once, I didn't want to work with someone in the class who I didn't like, so they said I would have a week's worth of detentions. The only reason I didn't get them was that a teacher who knew me quite well was walking past the room at the time and stopped it. If he had been walking past 30 seconds later, I would have been in so much trouble. I would get into trouble for not answering questions quickly enough because I didn't have time to process the questions let alone answer them.

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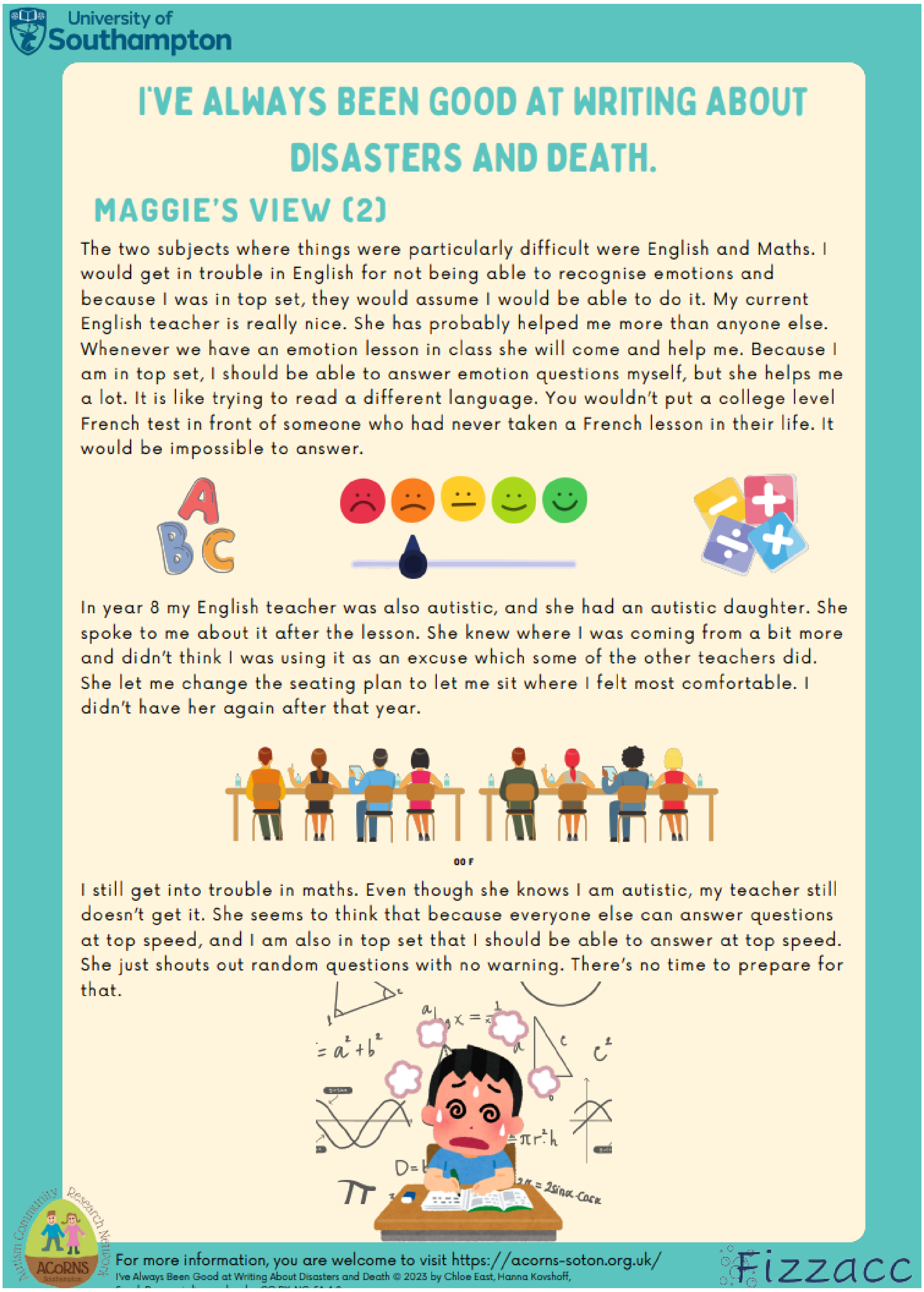

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I'VE ALWAYS BEEN GOOD AT WRITING ABOUT DISASTERS AND DEATH.

MAGGIE'S VIEW (2)

The two subjects where things were particularly difficult were English and Maths. I would get in trouble in English for not being able to recognise emotions and because I was in top set, they would assume I would be able to do it. My current English teacher is really nice. She has probably helped me more than anyone else. Whenever we have an emotion lesson in class she will come and help me. Because I am in top set, I should be able to answer emotion questions myself, but she helps me a lot. It is like trying to read a different language. You wouldn't put a college level French test in front of someone who had never taken a French lesson in their life. It would be impossible to answer.

In year 8 my English teacher was also autistic, and she had an autistic daughter. She spoke to me about it after the lesson. She knew where I was coming from a bit more and didn't think I was using it as an excuse which some of the other teachers did. She let me change the seating plan to let me sit where I felt most comfortable. I didn't have her again after that year.

I still get into trouble in maths. Even though she knows I am autistic, my teacher still doesn't get it. She seems to think that because everyone else can answer questions at top speed, and I am also in top set that I should be able to answer at top speed. She just shouts out random questions with no warning. There's no time to prepare for that.

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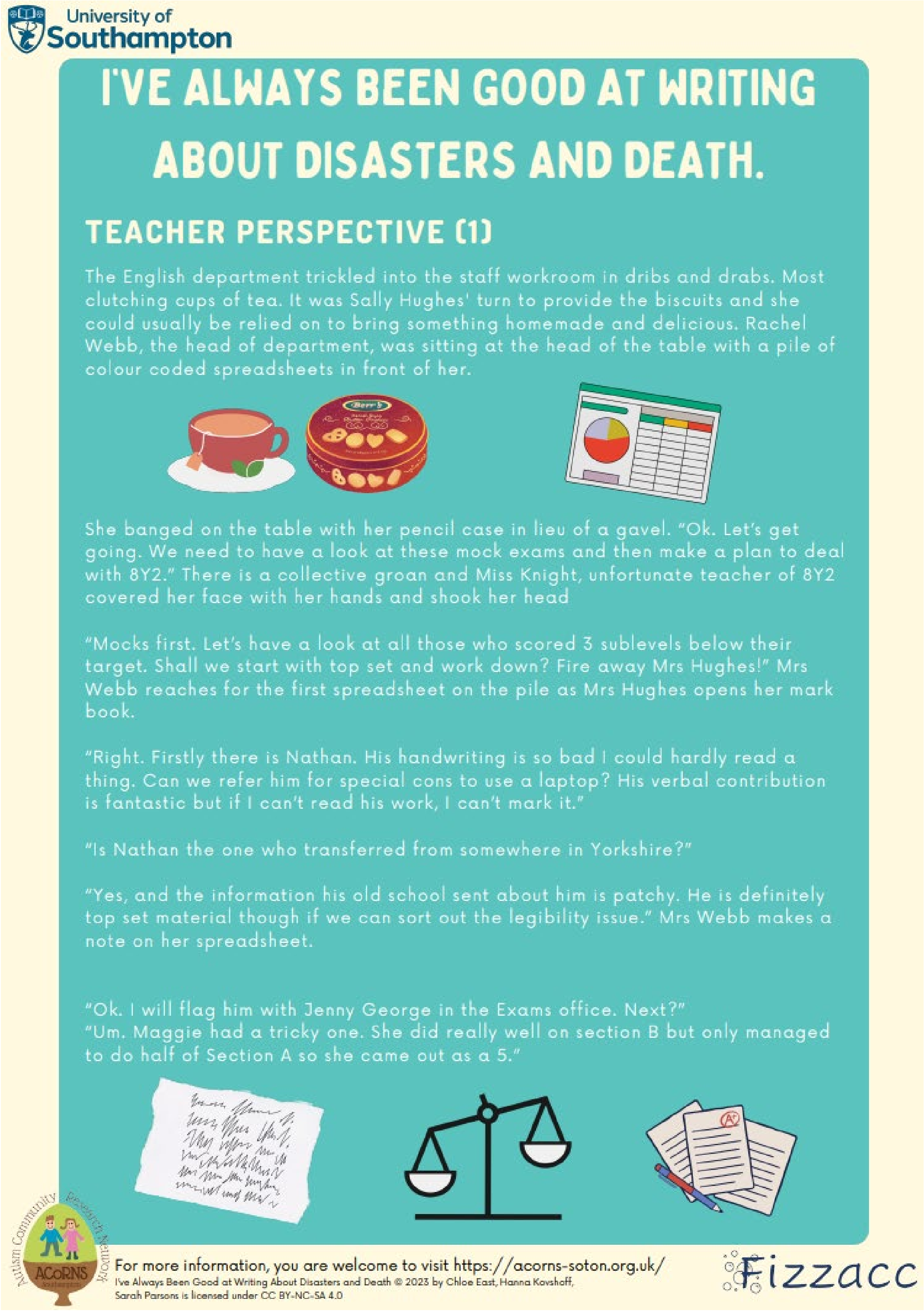

I'VE ALWAYS BEEN GOOD AT WRITING ABOUT DISASTERS AND DEATH.

TEACHER PERSPECTIVE (1)

The English department trickled into the staff workroom in dribs and drabs. Most clutching cups of tea. It was Sally Hughes' turn to provide the biscuits and she could usually be relied on to bring something homemade and delicious. Rachel Webb, the head of department, was sitting at the head of the table with a pile of colour coded spreadsheets in front of her.

She banged on the table with her pencil case in lieu of a gavel. "Ok. Let's get going. We need to have a look at these mock exams and then make a plan to deal with 8Y2." There is a collective groan and Miss Knight, unfortunate teacher of 8Y2 covered her face with her hands and shook her head

"Mocks first. Let's have a look at all those who scored 3 sublevels below their target. Shall we start with top set and work down? Fire away Mrs Hughes!" Mrs Webb reaches for the first spreadsheet on the pile as Mrs Hughes opens her mark book.

"Right. Firstly there is Nathan. His handwriting is so bad I could hardly read a thing. Can we refer him for special cons to use a laptop? His verbal contribution is fantastic but if I can't read his work, I can't mark it."

"Is Nathan the one who transferred from somewhere in Yorkshire?"

"Yes, and the information his old school sent about him is patchy. He is definitely top set material though if we can sort out the legibility issue." Mrs Webb makes a note on her spreadsheet.

"Ok. I will flag him with Jenny George in the Exams office. Next?"
"Um. Maggie had a tricky one. She did really well on section B but only managed to do half of Section A so she came out as a 5."

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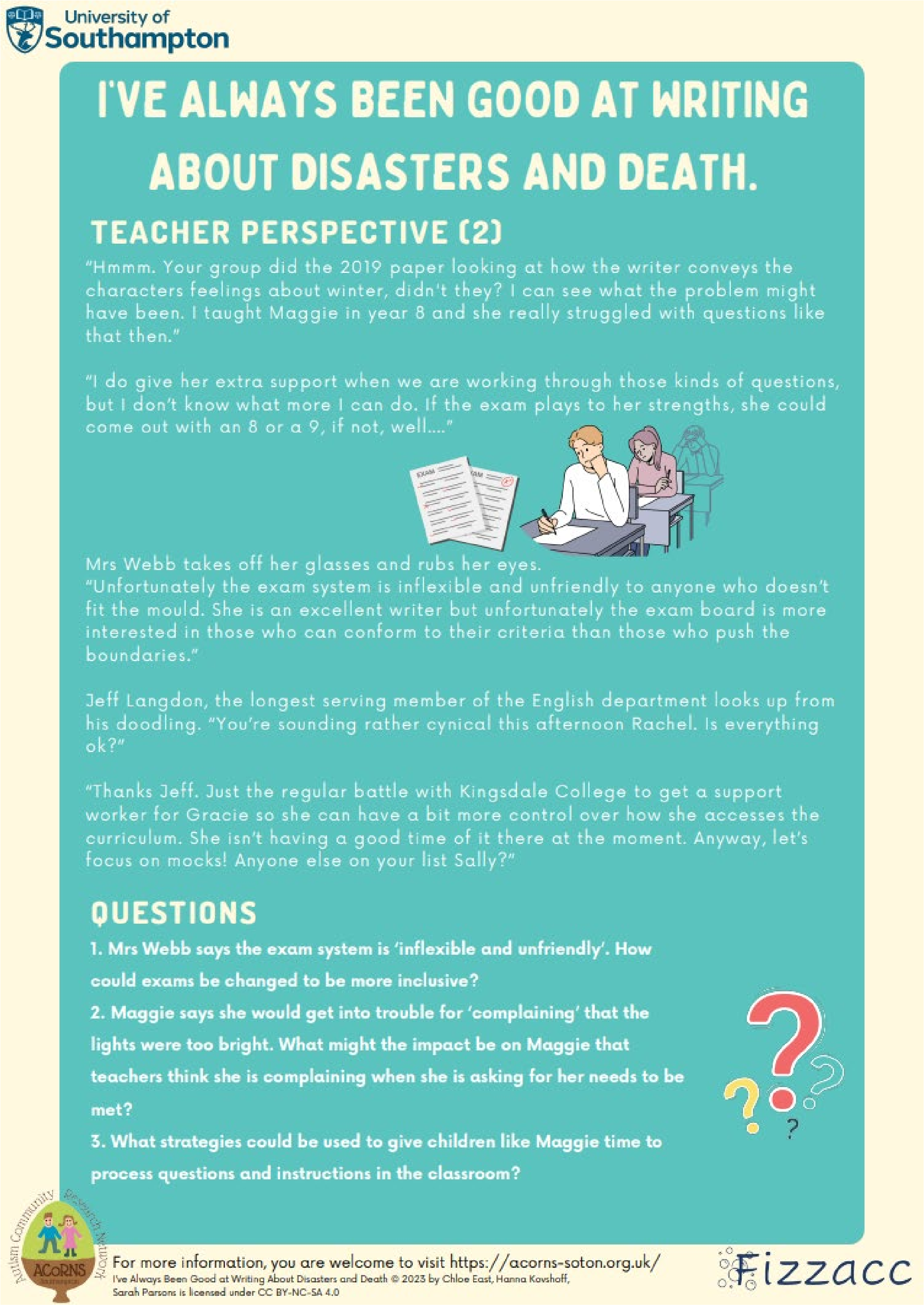

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I'VE ALWAYS BEEN GOOD AT WRITING ABOUT DISASTERS AND DEATH.

TEACHER PERSPECTIVE (2)

"Hmmm. Your group did the 2019 paper looking at how the writer conveys the characters feelings about winter, didn't they? I can see what the problem might have been. I taught Maggie in year 8 and she really struggled with questions like that then."

"I do give her extra support when we are working through those kinds of questions, but I don't know what more I can do. If the exam plays to her strengths, she could come out with an 8 or a 9, if not, well...."

Mrs Webb takes off her glasses and rubs her eyes.
"Unfortunately the exam system is inflexible and unfriendly to anyone who doesn't fit the mould. She is an excellent writer but unfortunately the exam board is more interested in those who can conform to their criteria than those who push the boundaries."

Jeff Langdon, the longest serving member of the English department looks up from his doodling. "You're sounding rather cynical this afternoon Rachel. Is everything ok?"

"Thanks Jeff. Just the regular battle with Kingsdale College to get a support worker for Gracie so she can have a bit more control over how she accesses the curriculum. She isn't having a good time of it there at the moment. Anyway, let's focus on mocks! Anyone else on your list Sally?"

QUESTIONS

1. Mrs Webb says the exam system is 'inflexible and unfriendly'. How could exams be changed to be more inclusive?
2. Maggie says she would get into trouble for 'complaining' that the lights were too bright. What might the impact be on Maggie that teachers think she is complaining when she is asking for her needs to be met?
3. What strategies could be used to give children like Maggie time to process questions and instructions in the classroom?

For more information, you are welcome to visit https://acorns-soton.org.uk/

Fizzacc

L.4 Story Narrative 2:

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UNTHOUGHTFUL THURSDAY

MAGGIE'S VIEW

It was the beginning of the day during tutor time. Once a week we have 'thoughtful Thursday'. It is an extra tutor time where we learn about things like human rights and mental health. This week was World Autism Day so that was the topic for the week.

Our tutor put on a video about the impact of sensory overload. Nobody was paying attention apart from me and my friends. They were interested because they knew I had just been diagnosed as autistic. The rest of the class were shouting, laughing and making a ruckus. The loudest they had ever been. Our teacher, Miss Badger, did nothing.

I realised that I was shaking and that I was crying without making any noise. My best friend noticed me covering my ears and crying so she got Miss Badger who told me to leave the classroom and calm down. As I walked out into the corridor, I could hear that people in my tutor were laughing at me because I was crying at the noise.

I leant my back against the wall and slid down, so I was half sitting and half crouching on the floor. After a little while Mrs Hughes walked past. She took me into a quieter classroom next door to calm down.

That was my first experience of having a meltdown. It was not as bad as the one I had a couple of weeks later.

This time I was in English. It was the end of period 4, before lunch. Again everyone in the class was being as loud as they could, and it was really overwhelming. I started shaking and crying again. Mrs Simms didn't notice until I started hyperventilating. Again I was sent alone, out of the class and into the corridor. Mrs Simms told me to try to calm down, but I was panicking and on my own, so it started to get worse and worse. About 10 minutes later one of the LSA's came. She knelt down with me, but I started to cry even more. She said, "Calm down, tell me what's wrong". I couldn't get any words out and started to sob louder and louder. I was finding it hard to breathe properly.

As I was sobbing and hyperventilating in the corridor the bell to lunch went and the corridor was suddenly packed full of people leaving their lessons. The people from my class started to leave, laughing at me as they passed. The LSA took me to the Hub because I wasn't getting any better in the corridor. It was quieter there and there was a sofa to sit on. I still couldn't stop crying though so she gave me a notebook to write down what had happened because I couldn't speak.

I asked the LSA to walk me down to my grandad who was picking me up so they could explain what had happened. I still couldn't speak without crying. When I got home my parents tried to joke with me to cheer me up and make me feel better. My throat was sore from all the crying and my voice wasn't better until the next day when it had healed.

Autism Community Research Network ACoRNS Southampton

For more information, you are welcome to visit https://acorns-soton.org.uk/

Fizzacc

University of Southampton

UNTHOUGHTFUL THURSDAY

TEACHER VIEW

Helen Simms fills the kettle just enough for one cup of tea. Although it is a bit selfish – there will after all be other people wanting a hot drink at breaktime, she justifies her choice by telling herself she is doing it to save electricity and therefore the planet. As she is mashing her tea bag against the side of the cup, Imogen Badger appears in the staff room. Imogen is a rather plain looking person who has a habit of suddenly materialising in a space without anyone noticing. Helen wonders for a moment whether she might be able to move through walls and then starts to construct a plot in her head for a story about a teacher with mysterious powers. As an English teacher she is prone to getting caught up in imaginative flights of fancy.

"Helen. Just the person I was hoping to see." Imogen's voice is in total contrast to her appearance, being rather harsh and very effective at cutting through a noisy classroom.

"Morning Miss Badger, what can I do for you?"

"I was hoping you might have five minutes to talk about Maggie?"

"Of course. You heard about the incident in my class yesterday morning?"

"I did. A similar thing happened with me in Thoughtful Thursday last week. It seemed rather out of character for Maggie. She is usually fairly quiet and avoids anything that will make her stand out." Imogen reaches into her pocket and brings out a cereal bar which she eats by breaking off tiny pieces to nibble.

"You can't help but wonder if getting an autism diagnosis was actually helpful for her. She was fine until that happened."

"Do you think she is using it to get out of lessons? Or get attention?"

"It's difficult to tell. Maybe you should talk to Mr Jones about getting her a time-out card. Who is the SENDCO at the moment? I can't keep track since Mr Emmanuel retired." Imogen screwed up her cereal bar wrapper and launched it – unsuccessfully – at the bin.

"Dr Braun is filling in, although she has said that she is only prepared to take it on until easter. I will have a chat with her when I have a moment."

As Imogen rescues her wrapper and places it in the bin, the bell for the end of break sounds.

"Once more unto the breach..." Helen takes a deep breath, flings open the staffroom door, and strides out into the corridor.

QUESTIONS

1. What might the impact be of getting a diagnosis for an autistic person?

2. What do the teachers get right in this story and what do they get wrong? What should the teachers have done to better support Maggie?

3. What's the problem with assuming?

4. If you were Maggie in this situation, how would you have felt?

5. What would you have done in that situation?

Autism Community Research Network ACoRNS

For more information, you are welcome to visit https://acorns-soton.org.uk/

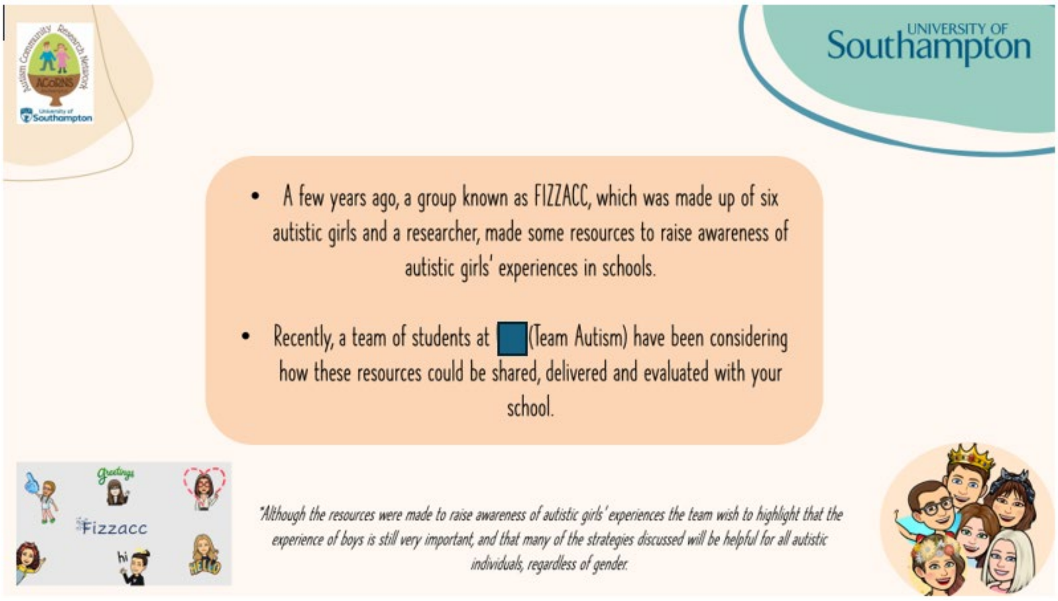
Fizzacc

Appendix M Tutor Presentation

Slide 1:

Autism Awareness Week at [redacted]

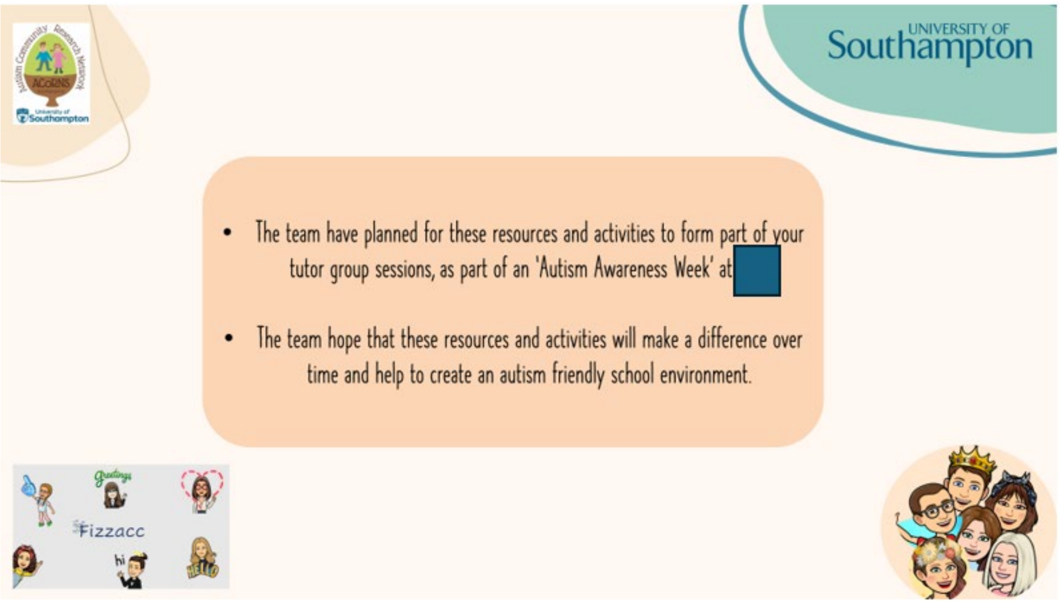
Slide 2:



- A few years ago, a group known as FIZZACC, which was made up of six autistic girls and a researcher, made some resources to raise awareness of autistic girls' experiences in schools.
- Recently, a team of students at [redacted] (Team Autism) have been considering how these resources could be shared, delivered and evaluated with your school.

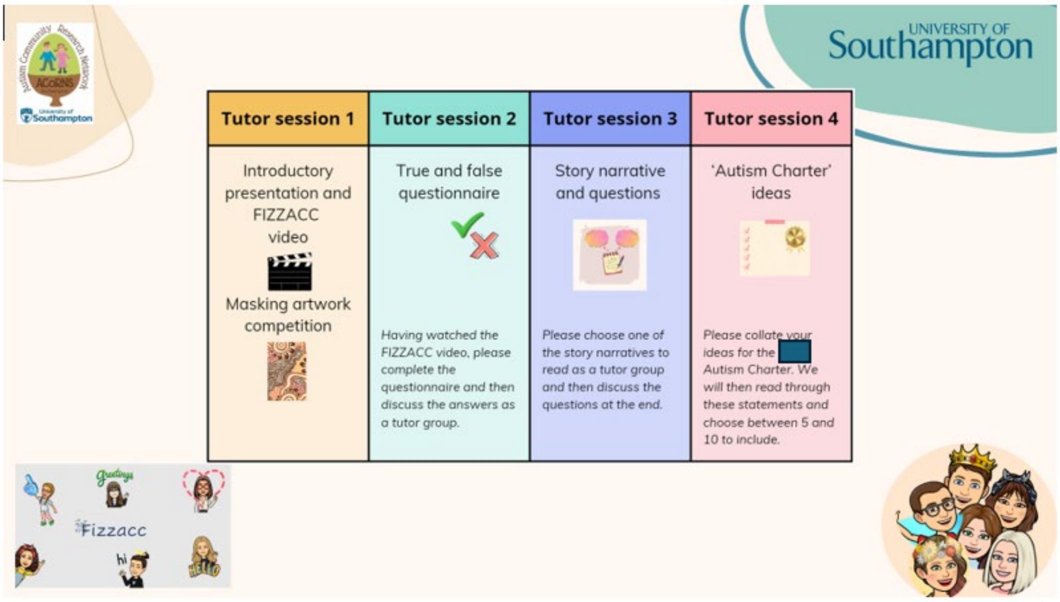
"Although the resources were made to raise awareness of autistic girls' experiences the team wish to highlight that the experience of boys is still very important, and that many of the strategies discussed will be helpful for all autistic individuals, regardless of gender.

Slide 3:



- The team have planned for these resources and activities to form part of your tutor group sessions, as part of an 'Autism Awareness Week' at [redacted]
- The team hope that these resources and activities will make a difference over time and help to create an autism friendly school environment.

Slide 4:



Tutor session 1	Tutor session 2	Tutor session 3	Tutor session 4
Introductory presentation and FIZZACC video Masking artwork competition	True and false questionnaire Having watched the FIZZACC video, please complete the questionnaire and then discuss the answers as a tutor group.	Story narrative and questions Please choose one of the story narratives to read as a tutor group and then discuss the questions at the end.	'Autism Charter' ideas Please collate your ideas for the [redacted] Autism Charter. We will then read through these statements and choose between 5 and 10 to include.

Slide 5:

Tutor Session 1

https://www.youtube.com/watch?v=F2nvhAttpAU&embeds_referring_euri=https%3A%2F%2Facorns-soton.org.uk%2F&source_ve_path=MzY4NDIsMjg2NjY

'MASKING' ARTWORK COMPETITION

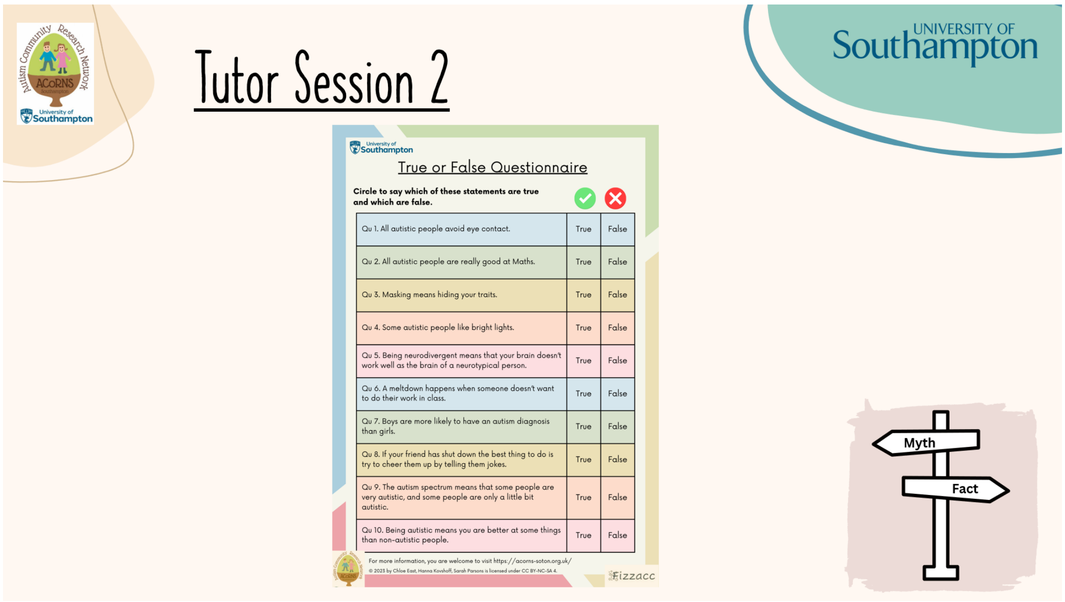
Create a piece of artwork to portray the experience of masking (hiding one's true self).

You can use any techniques/tools/resources you wish to!

Deadline:
Monday 3rd March

The winner will receive 5 achievement points, a certificate, and some sweet treats.

Slide 6:



Tutor Session 2

True or False Questionnaire

Circle to say which of these statements are true and which are false.

	✓	✗
Qu 1. All autistic people avoid eye contact.	True	False
Qu 2. All autistic people are really good at Maths.	True	False
Qu 3. Masking means hiding your traits.	True	False
Qu 4. Some autistic people like bright lights.	True	False
Qu 5. Being neurodivergent means that your brain doesn't work well as the brain of a neurotypical person.	True	False
Qu 6. A meltdown happens when someone doesn't want to do their work in class.	True	False
Qu 7. Boys are more likely to have an autism diagnosis than girls.	True	False
Qu 8. If your friend has shut down the best thing to do is try to cheer them up by telling them jokes.	True	False
Qu 9. The autism spectrum means that some people are very autistic, and some people are only a little bit autistic.	True	False
Qu 10. Being autistic means you are better at some things than non-autistic people.	True	False

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Fizzacc

Slide 7:

Tutor Session 3

I'VE ALWAYS BEEN GOOD AT WRITING ABOUT DISASTERS AND DEATH.

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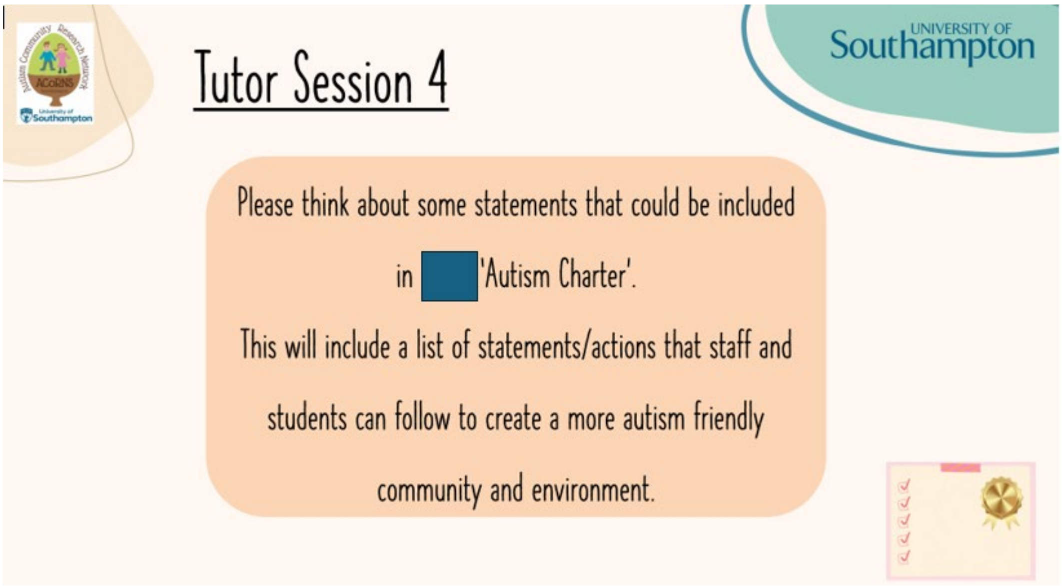
Slide 8:



Tutor Session 4

Please think about some statements that could be included in [redacted] 'Autism Charter'.

This will include a list of statements/actions that staff and students can follow to create a more autism friendly community and environment.

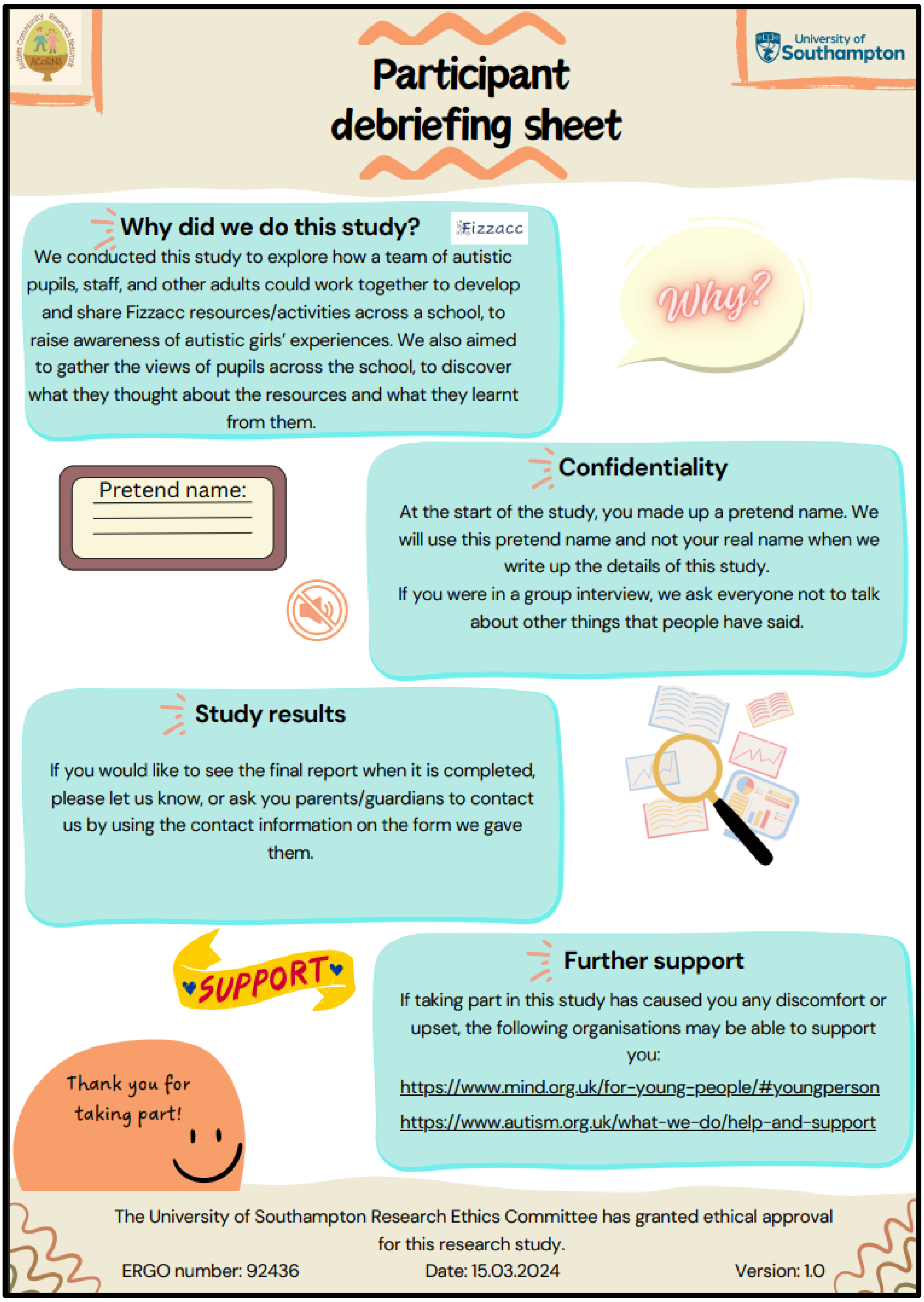
Appendix N Interview Schedule

Interview Schedule

- What was it that made you want to be part of this research team?
- Can you describe what your school experience was like before joining 'team autism'?
- How would you describe your experience of being part of 'team autism'? *(Rating)*
- What were the highlights of being part of 'team autism'? *(Rating)*
- Is there anything that you would change about the 'team autism' experience? *(Rating)*
- Were there any parts of the sessions that made you feel more comfortable or less comfortable?
- How did you find working with the other students in 'team autism'?
- What were your initial thoughts about the FIZZACC resources? *(Ranking)*
- How would you describe your experience of adapting or editing the FIZZACC resources?
- What are your thoughts on the tutor group activities? Did your tutors share them as you expected? Would you change anything about the tutor group activities?
- How would you describe the response to the tutor group activities from your friends and other students across the school?
- How would you describe the response to the tutor group activities from your teachers and staff members?
- Has being part of 'team autism' made a difference to your school experience? Can you tell me about that?
- What were the most/least effective parts of the tutor group activities and resources?
- Is there anything you would change about the tutor group activities and resources?
- What other topics would you like to see covered in the resources? What other topics are important to you?
- What have you learnt from this experience?
- How would you like the future of 'team autism' to look?
- How would you like the work of 'team autism' to continue?

Appendix O Debriefing Forms

O.1 Debriefing Form for Students



Autism Community Research Network ACORNS

University of Southampton

Participant debriefing sheet

Why did we do this study?

Fizzacc

We conducted this study to explore how a team of autistic pupils, staff, and other adults could work together to develop and share Fizzacc resources/activities across a school, to raise awareness of autistic girls' experiences. We also aimed to gather the views of pupils across the school, to discover what they thought about the resources and what they learnt from them.

Why?

Pretend name: ____________

Confidentiality

At the start of the study, you made up a pretend name. We will use this pretend name and not your real name when we write up the details of this study.

If you were in a group interview, we ask everyone not to talk about other things that people have said.

Study results

If you would like to see the final report when it is completed, please let us know, or ask you parents/guardians to contact us by using the contact information on the form we gave them.

SUPPORT

Further support

If taking part in this study has caused you any discomfort or upset, the following organisations may be able to support you:

https://www.mind.org.uk/for-young-people/#youngperson

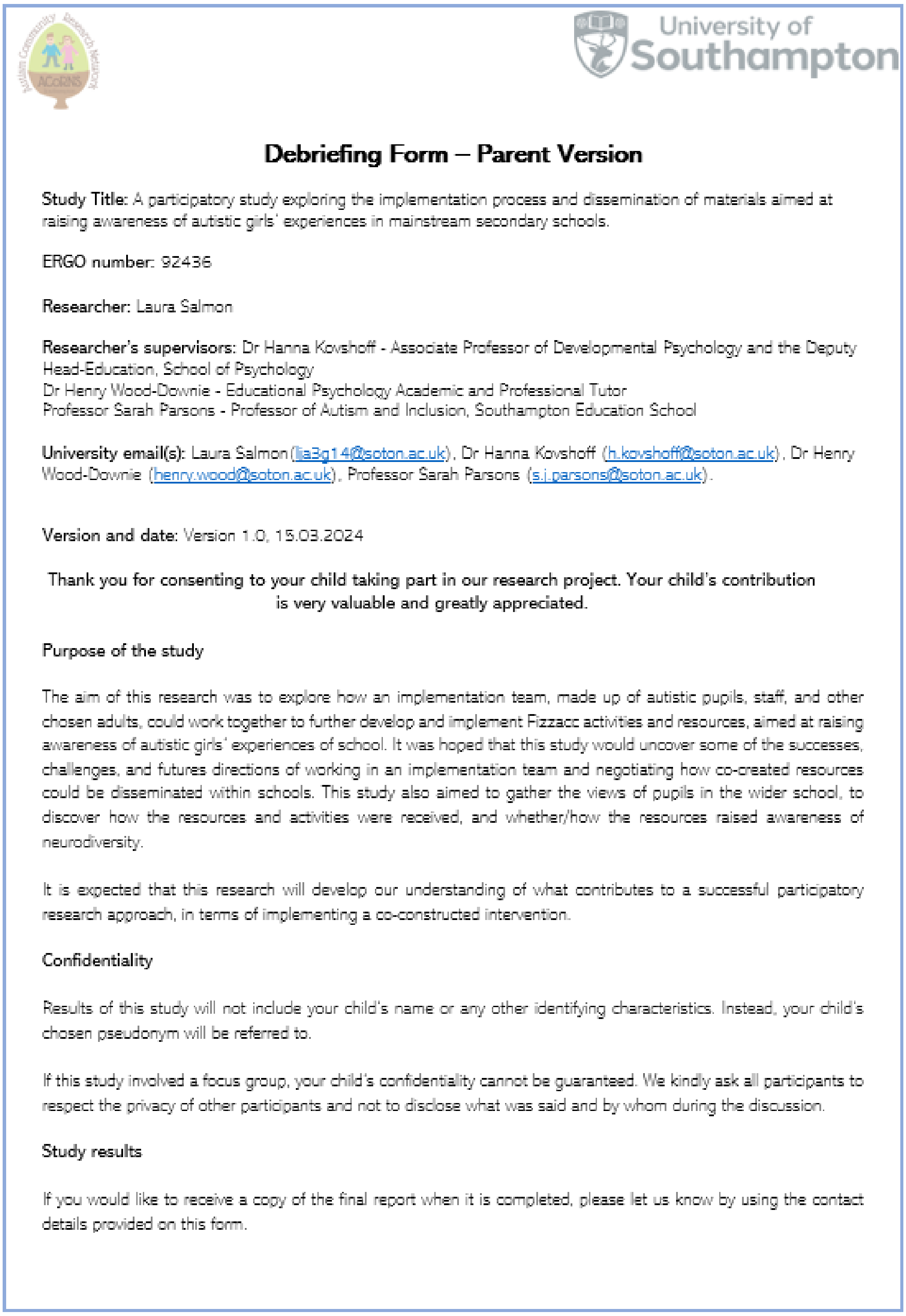
https://www.autism.org.uk/what-we-do/help-and-support

Thank you for taking part!

The University of Southampton Research Ethics Committee has granted ethical approval for this research study.

ERGO number: 92436 Date: 15.03.2024 Version: 1.0

O.2 Debriefing Form for Parents/Carers



Debriefing Form – Parent Version

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

ERGO number: 92436

Researcher: Laura Salmon

Researcher's supervisors: Dr Hanna Kovshoff - Associate Professor of Developmental Psychology and the Deputy Head-Education, School of Psychology
Dr Henry Wood-Downie - Educational Psychology Academic and Professional Tutor
Professor Sarah Parsons - Professor of Autism and Inclusion, Southampton Education School

University email(s): Laura Salmon (lja3g14@soton.ac.uk), Dr Hanna Kovshoff (h.kovshoff@soton.ac.uk), Dr Henry Wood-Downie (henry.wood@soton.ac.uk), Professor Sarah Parsons (s.j.parsons@soton.ac.uk).

Version and date: Version 1.0, 15.03.2024

Thank you for consenting to your child taking part in our research project. Your child's contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore how an implementation team, made up of autistic pupils, staff, and other chosen adults, could work together to further develop and implement Fizzacc activities and resources, aimed at raising awareness of autistic girls' experiences of school. It was hoped that this study would uncover some of the successes, challenges, and futures directions of working in an implementation team and negotiating how co-created resources could be disseminated within schools. This study also aimed to gather the views of pupils in the wider school, to discover how the resources and activities were received, and whether/how the resources raised awareness of neurodiversity.

It is expected that this research will develop our understanding of what contributes to a successful participatory research approach, in terms of implementing a co-constructed intervention.

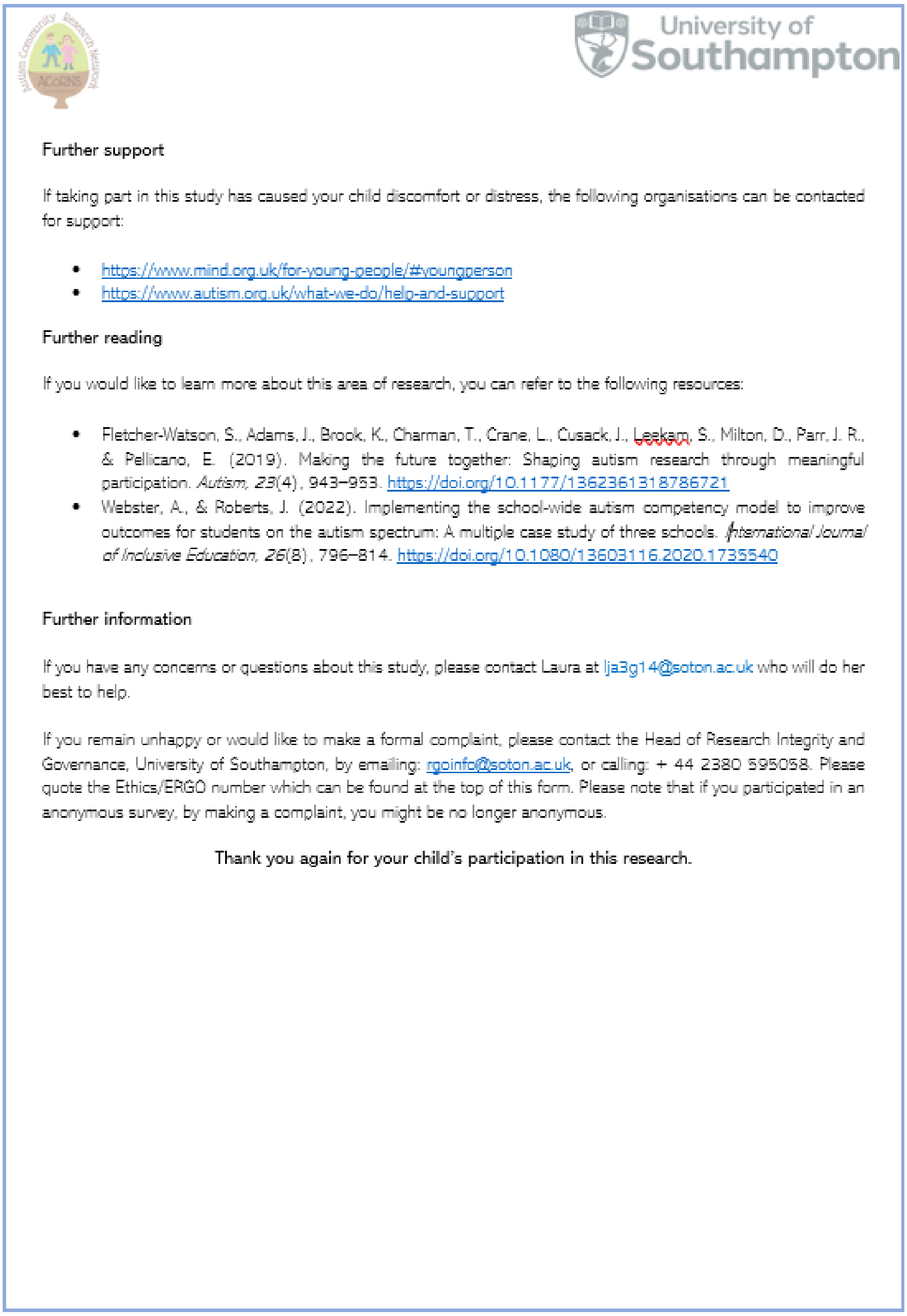
Confidentiality

Results of this study will not include your child's name or any other identifying characteristics. Instead, your child's chosen pseudonym will be referred to.

If this study involved a focus group, your child's confidentiality cannot be guaranteed. We kindly ask all participants to respect the privacy of other participants and not to disclose what was said and by whom during the discussion.

Study results

If you would like to receive a copy of the final report when it is completed, please let us know by using the contact details provided on this form.



Further support

If taking part in this study has caused your child discomfort or distress, the following organisations can be contacted for support:

- https://www.mind.org.uk/for-young-people/#youngperson
- https://www.autism.org.uk/what-we-do/help-and-support

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721
- Webster, A., & Roberts, J. (2022). Implementing the school-wide autism competency model to improve outcomes for students on the autism spectrum: A multiple case study of three schools. *International Journal of Inclusive Education, 26*(8), 796–814. https://doi.org/10.1080/13603116.2020.1735540

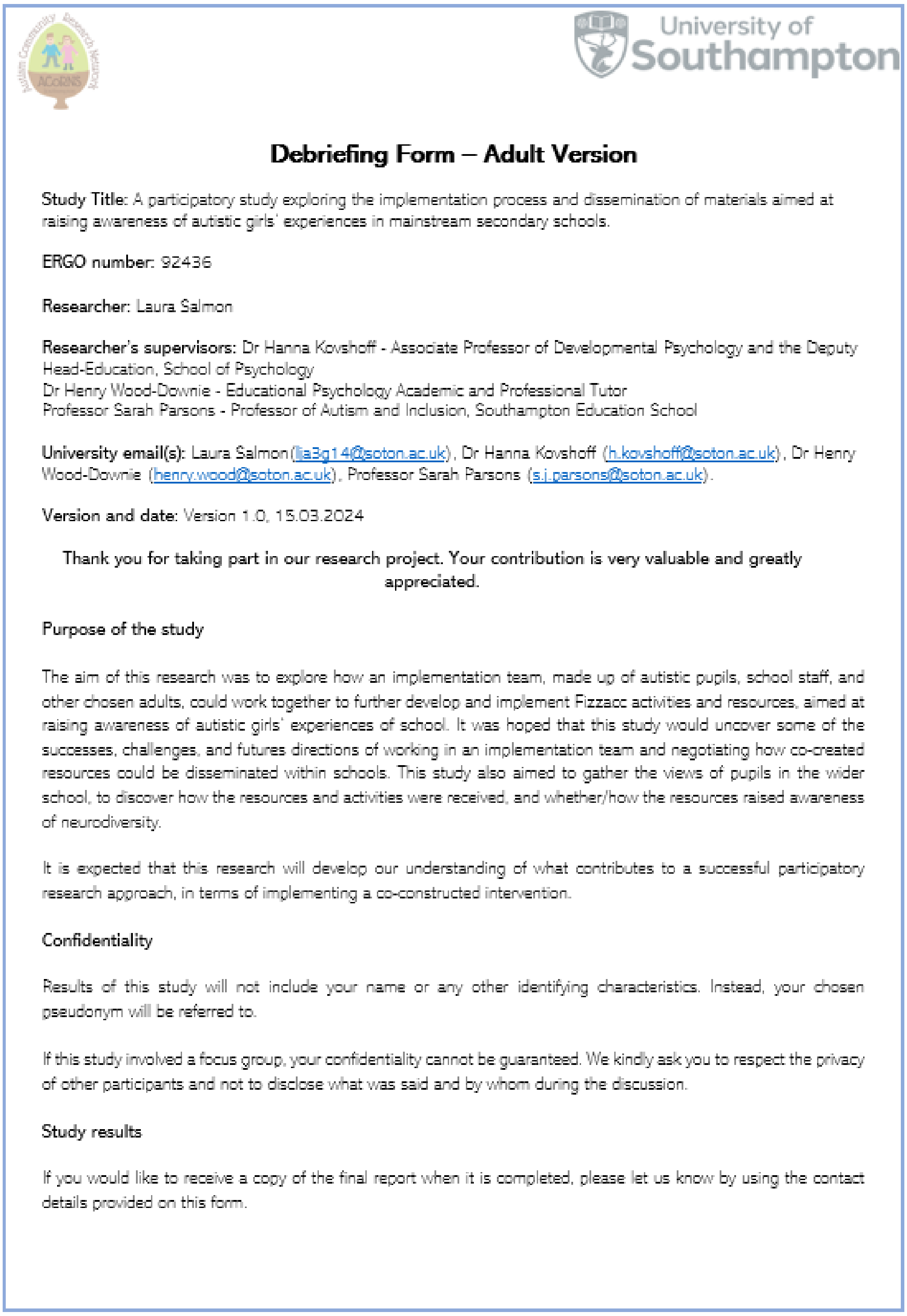
Further information

If you have any concerns or questions about this study, please contact Laura at lja3g14@soton.ac.uk who will do her best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing: rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your child's participation in this research.

O.3 Debriefing Form for Adults



Debriefing Form – Adult Version

Study Title: A participatory study exploring the implementation process and dissemination of materials aimed at raising awareness of autistic girls' experiences in mainstream secondary schools.

ERGO number: 92436

Researcher: Laura Salmon

Researcher's supervisors: Dr Hanna Kovshoff - Associate Professor of Developmental Psychology and the Deputy Head-Education, School of Psychology
Dr Henry Wood-Downie - Educational Psychology Academic and Professional Tutor
Professor Sarah Parsons - Professor of Autism and Inclusion, Southampton Education School

University email(s): Laura Salmon(lja3g14@soton.ac.uk), Dr Hanna Kovshoff (h.kovshoff@soton.ac.uk), Dr Henry Wood-Downie (henry.wood@soton.ac.uk), Professor Sarah Parsons (s.j.parsons@soton.ac.uk).

Version and date: Version 1.0, 15.03.2024

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore how an implementation team, made up of autistic pupils, school staff, and other chosen adults, could work together to further develop and implement Fizzacc activities and resources, aimed at raising awareness of autistic girls' experiences of school. It was hoped that this study would uncover some of the successes, challenges, and futures directions of working in an implementation team and negotiating how co-created resources could be disseminated within schools. This study also aimed to gather the views of pupils in the wider school, to discover how the resources and activities were received, and whether/how the resources raised awareness of neurodiversity.

It is expected that this research will develop our understanding of what contributes to a successful participatory research approach, in terms of implementing a co-constructed intervention.

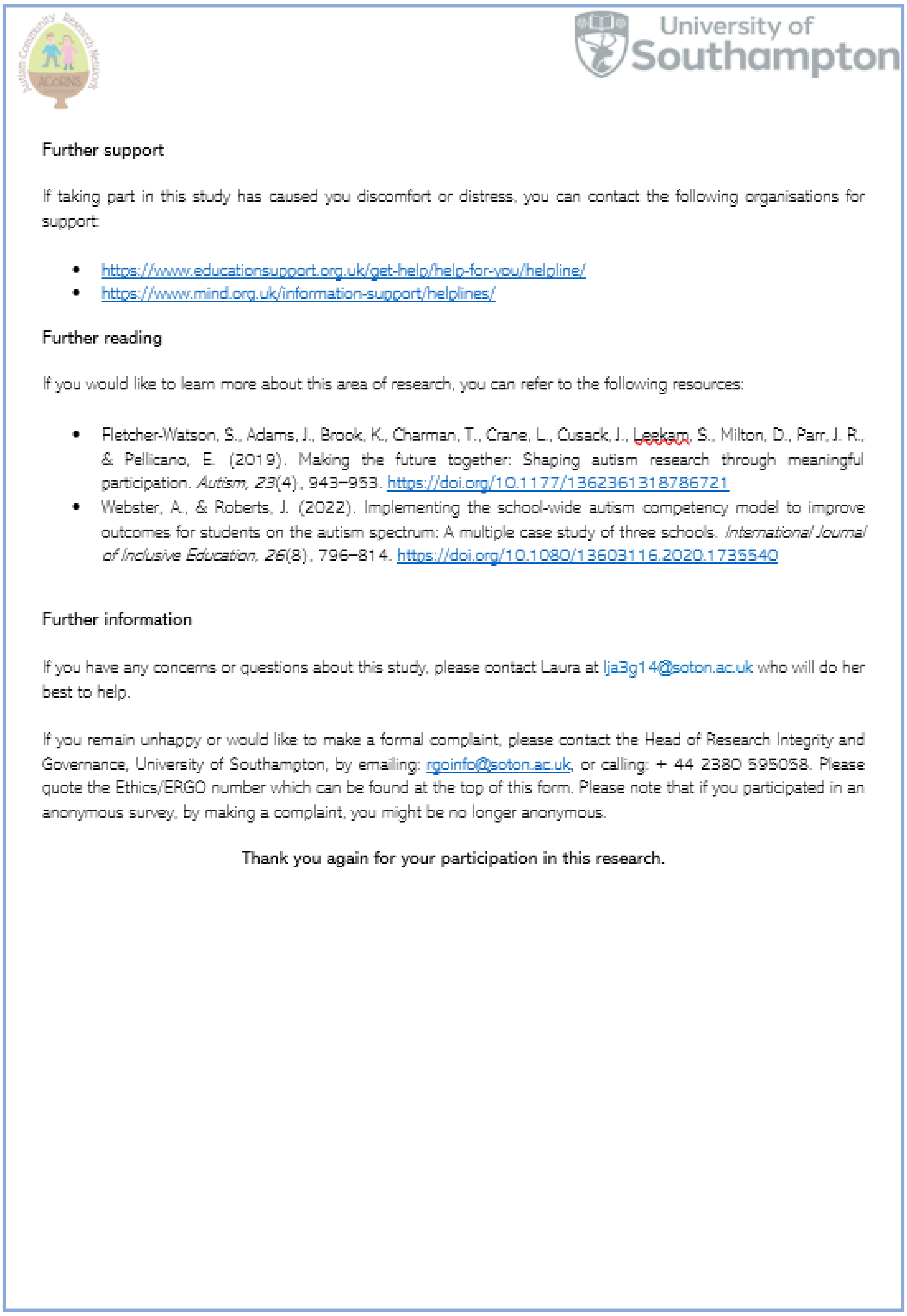
Confidentiality

Results of this study will not include your name or any other identifying characteristics. Instead, your chosen pseudonym will be referred to.

If this study involved a focus group, your confidentiality cannot be guaranteed. We kindly ask you to respect the privacy of other participants and not to disclose what was said and by whom during the discussion.

Study results

If you would like to receive a copy of the final report when it is completed, please let us know by using the contact details provided on this form.



Further support

If taking part in this study has caused you discomfort or distress, you can contact the following organisations for support:

- https://www.educationsupport.org.uk/get-help/help-for-you/helpline/
- https://www.mind.org.uk/information-support/helplines/

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721
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Thank you again for your participation in this research.

Appendix P Phase 1 – Data Familiarisation

P.1 Excerpt of Interview Transcript

Interview Transcript

Redacted to protect the privacy of study participant.

Redacted to protect the privacy of study participant.

Redacted to protect the privacy of study participant.

P.2 Example annotations

Example annotations from transcript
Redacted to protect the privacy of study participant.

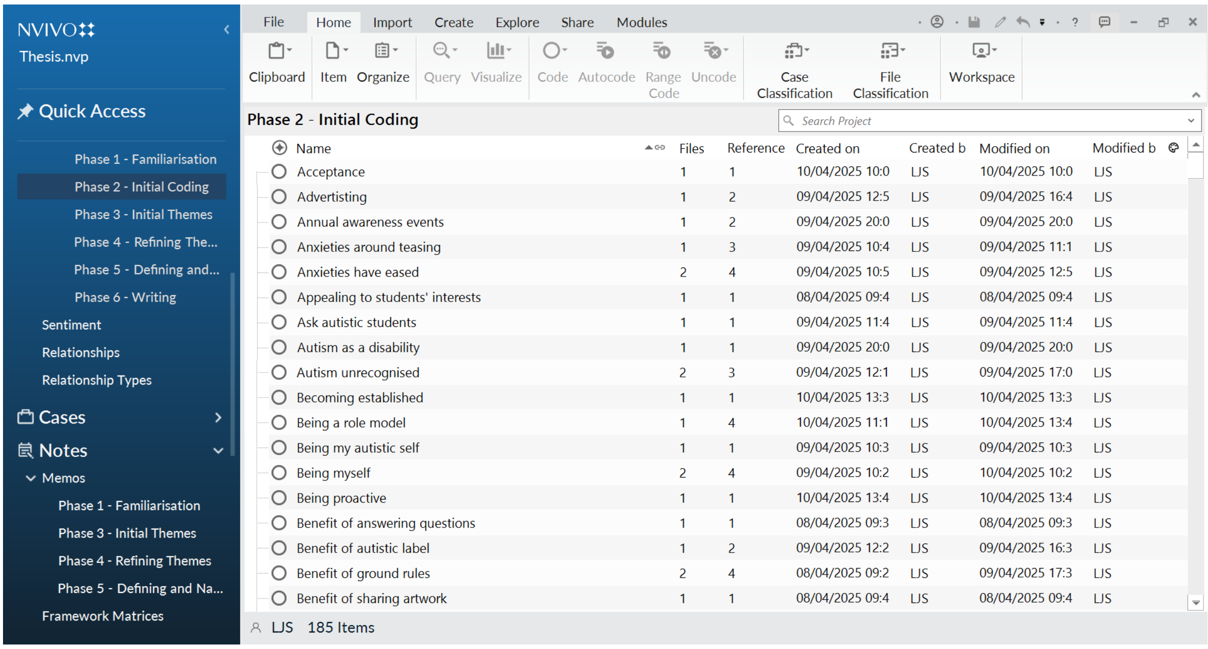
P.3 Example Participant Memo

Redacted to protect the privacy of study participant.

Redacted to protect the privacy of study participant.

Appendix Q Phase 2 – Initial Coding

Q.1 NVIVO Initial Coding Extract



Phase 2 - Initial Coding

Name	Files	Reference	Created on	Created b	Modified on	Modified b
○ Acceptance	1	1	10/04/2025 10:0	LJS	10/04/2025 10:0	LJS
○ Advertisting	1	2	09/04/2025 12:5	LJS	09/04/2025 16:4	LJS
○ Annual awareness events	1	2	09/04/2025 20:0	LJS	09/04/2025 20:0	LJS
○ Anxieties around teasing	1	3	09/04/2025 10:4	LJS	09/04/2025 11:1	LJS
○ Anxieties have eased	2	4	09/04/2025 10:5	LJS	09/04/2025 12:5	LJS
○ Appealing to students' interests	1	1	08/04/2025 09:4	LJS	08/04/2025 09:4	LJS
○ Ask autistic students	1	1	09/04/2025 11:4	LJS	09/04/2025 11:4	LJS
○ Autism as a disability	1	1	09/04/2025 20:0	LJS	09/04/2025 20:0	LJS
○ Autism unrecognised	2	3	09/04/2025 12:1	LJS	09/04/2025 17:0	LJS
○ Becoming established	1	1	10/04/2025 13:3	LJS	10/04/2025 13:3	LJS
○ Being a role model	1	4	10/04/2025 11:1	LJS	10/04/2025 13:4	LJS
○ Being my autistic self	1	1	09/04/2025 10:3	LJS	09/04/2025 10:3	LJS
○ Being myself	2	4	09/04/2025 10:2	LJS	10/04/2025 10:2	LJS
○ Being proactive	1	1	10/04/2025 13:4	LJS	10/04/2025 13:4	LJS
○ Benefit of answering questions	1	1	08/04/2025 09:3	LJS	08/04/2025 09:3	LJS
○ Benefit of autistic label	1	2	09/04/2025 12:2	LJS	09/04/2025 16:3	LJS
○ Benefit of ground rules	2	4	08/04/2025 09:2	LJS	09/04/2025 17:3	LJS
○ Benefit of sharing artwork	1	1	08/04/2025 09:4	LJS	08/04/2025 09:4	LJS

LJS 185 Items

Q.2 Codebook

Name	Description
THEME: CONCEPTUALISATION OF AUTISM	
A 'normal' school experience	Differing views on a 'normal' school experience (1. normal means not receiving out of the ordinary support as opposed to 2. students needing support to have a normal school day).
Autism as a disability	Perception of autism as a disability.
Autism recognised	Others now recognise that they are autistic, which has led to support and behaviour change.
Autism unrecognised	Others did not recognise that they were autistic.
Autistic label and self-awareness	Increased personal understanding since knowing they are autistic/having an autistic label.

Name	Description
Being 'normal'	Describing neurotypical identity/experiences as 'normal'.
Challenging assumptions	Challenging some assumptions/stereotypes around autism.
Desire for others to know about autistic identity	Wanting others within school to know that they are autistic.
Desire for understanding	Wanting other people to understand their experiences/difficulties.
Identification as autistic	The participant identifies as an autistic individual/part of the autistic community.
Mocking	Other students would make unkind comments about autism, but these comments were made discretely so were not picked up by teachers.
Negative perception of autism	Belief that others view autism in a negative light.
Neurodivergence as a difference	Reflecting on autistic strengths and areas of need. Recognising that autism is a difference rather than a disability.
Perception of disability	Defines disability as limiting what an individual can do, suggesting that everyone is disabled.
Positive autistic identity	Describing autistic identity in a positive light.
THEME: A SENSE OF TOGETHERNESS	
Building positive connections	Building connections/friendships with students.
Comfort of a familiar face	Benefit of having a familiar face within the team.
Desire for continuation of team members	Wanting the same team members to continue with the project in the future.
Enjoyment of working with new peers	Enjoyment of collaborating with new peers in Team Autism.
Interacting with students across the school	Positive experience of interacting with students across the school.

Name	**Description**
Not blaming others	Not blaming others for going off on a tangent.
Positive relationship with lead researcher	Positive relationship formed with lead researcher.
Positive relationships with teaching staff	Describing teachers/relationships with teaching staff in a positive light.
Relationships promoting authenticity	Relationships with others (staff, students, group members) has enabled the participant to be their authentic self.
Sense of belonging	Feeling part of a group.
Spending time with friends	Benefit of spending time with friends within Team Autism.
Teamwork	Working collaboratively as a team.
THEME: EMPOWERING, INFLUENCING, AND ADVOCATING	
SUBTHEME: NURTURING OTHERS	
Being a role model	Being a role model or a 'guiding figure' to others.
Desire for others to have a voice	Wanting other participants to have the opportunity to share their ideas/have a voice.
Empathy	Empathy for autistic students who struggle at school.
Helping others	Desire to help others across the school.
Positivity about the treatment of others	Positivity about autistic peers facing less judgement.
Respect	Important to respect other people's preferences.
Thinking of others	Thinking of others wants and needs and wanting them to feel comfortable.
Trying to be inclusive	Trying to be inclusive of students with different needs.
SUBTHEME: FEELING EMPOWERED	

Name	Description
Ask autistic students	Ask autistic people what they need, rather than assuming.
Being proactive	Important to be proactive to make a real difference.
Courage to express opinions	Students expressed their thoughts about the FIZZACC resources while respecting the views and perceptions of others.
Feeling empowered	Feeling as if students really can facilitate change.
Feeling included	Personal feeling of being included in decision-making.
Feeling involved	Feeling involved during the editing process.
Feeling powerless (before)	Sense that sharing ideas was pointless (before Team Autism) as they were not taken seriously.
Feeling seen	Feeling like their experience is recognised and validated.
Fighting for a cause	Wanting to be part of the team to fight for a cause.
Fulfilling long-term wants	Being part of the group has enabled them to feel that they are doing something that they have wanted for a long time.
Importance of feedback	Gathering feedback is a vital part of making effective change/improving practice.
Leadership role	Positive feelings associated with taking a leadership role.
Making change	Feeling of making change by being part of Team Autism.
Opportunity for role reversal	Being involved in the editing provided an opportunity for role-reversal.
Positive experience of being an interviewer	Enjoyment of being an interviewer.
Positive experience of editing	Positive feelings/response to being involved in resource editing.
Previous experience of public speaking	Previous experience of public speaking made elements of Team Autism easier (i.e., speaking in the staff briefing).

Name	**Description**
Research assumptions	Not realising that children/young people could be involved in research too/would want to be.
Sharing voice	The project has provided the opportunity/space to share their voice with others (i.e., ideas, passions, experience of autism).
Unique experience	Taking part in something out of the ordinary.
Worthwhile	Feeling that the efforts made within Team Autism were worthwhile.
SUBTHEME: FRUITFUL SYSTEMS	
Benefit of ground rules	Ground rules increased participant comfort and group productivity.
Benefit of visual systems	Positive reflection on visual systems and the suggestion for these to be embedded into classes.
Breaking down tasks	Benefit of breaking down tasks into small chunks to reduce worries/burden of responsibility.
Desire for interview flexibility	Desire for greater flexibility to expand on views when interviewing the school SENCo.
Going off topic	Difficulties associated with team members going off topic/on a tangent.
Self-consciousness	Feeling self-conscious about raising a hand in class.
THEME: CULTIVATING CONTENTMENT	
SUBTHEME: JOY	
Desire for additional team time	Desire for team sessions to be longer.
Having fun	Having fun during team sessions.
Overall positive experience	Positive sentiment of being part of the group.

Name	Description
Positive experience of activities	Use of positive adjectives to describe resources/activities completed as a group.
SUBTHEME: STANDING TALL	
Desire to be best version of self	Wanting to be the best version of themselves/try their best.
Doing something admirable	Feeling that they are doing something worthy/admirable.
Feeling proud	Sense of pride in self and working with the team who have helped to bring about change/support others.
Increased confidence	Taking part in Team Autism has helped to boost self-confidence.
Positive response from peers	Positive response from peers about being part of the team.
Positive sense of self	Participating in Team Autism has helped them to form a positive view of themselves.
Positive team identification	Positively identifying as a member of Team Autism.
Recognising personal efforts	Recognising the hard work and effort they have put into being part of the group/helping others.
Self-belief	Development of self-belief since being part of Team Autism.
Self-deprecating	Using humour to make light of his perception around his cognitive development.
Stepping out of comfort zone	Confidence grew after stepping out of his comfort zone.
Working to strengths	Team activities worked to members' strengths and allowed them to demonstrate these (i.e., creativity).
SUBTHEME: TRANQUILITY	
Anxieties around teasing	Expressed anxieties around peers teasing or making negative comments relating to autism or their development.
Anxieties have eased	Anxieties have eased since being part of Team Autism.

Name	Description
Being myself	Feeling that they can be their true/authentic selves.
Calming effect of group	Being part of the group helps to create a sense of calm/reduce anxieties.
Difficulty regulating emotions	Difficulty understanding and controlling emotions (before).
Experiencing difficulties or struggles	Broad references to difficulties or struggles.
Feeling stressed (before)	Describing situations/experiences of feeling stressed.
Lack of support	Support from school staff was inadequate (before Team Autism).
Masking experience	Describing personal experience of masking.
Negative experience of school	Describing a negative experience of school (before Team Autism).
Ongoing feelings of anxiety	Continuing to feel a sense of anxiety.
Positive view of school	Positive experience/view of school (after Team Autism).
Sense of shame	Feeling ashamed of being autistic due to the perception of others.
THEME: CONDITIONS FOR GROWTH	
SUBTHEME: STAGNANT OR TRANSFORMATIVE INSIGHTS	
Awareness facilitating support	The FIZZACC resources provide information to others about how to support their autistic peers.
Changing attitudes	Feeling that attitudes have changed since the work of Team Autism.
Changing behaviour	Positive change in peers' language choices since Autism Awareness week.

Name	**Description**
Developing knowledge	Students can gain knowledge from the FIZZACC resources.
Developing own awareness and understanding	Developing own awareness of autistic experiences (e.g., the extent of masking).
Developing understanding	Students had the opportunity to develop an in-depth insight into an experience associated with autism.
Increased acceptance	Other students have been questioning the support of autistic students less.
Increased awareness	Students across the school have increased awareness of autism and the experience of autistic students.
Limited impact	No/limited change since Autism Awareness week.
Long-term impact	Feeling that they had made a long-term impact/facilitated long-term change.
Personal benefit (help)	Participating in this research has been helpful for the participants themselves.
Unhelpful assumptions	Raised awareness of autism has led to some unhelpful assumptions around students being autistic.
SUBTHEME: NEED FOR VITALITY	
Appealing to students' interests	The artwork competition was particularly effective as it appealed to students' interests in drawing.
Facilitation not as expected	The Autism Awareness week activities were not facilitated by tutors as expected.
Feeling disappointed	Feeling disappointed by student response to tutor activities.
Feeling proud of others	Feeling proud of students across the wider school for their engagement in the activities.
Feelings are contagious	When people express their feelings, this can make others feel similarly.
Good delivery of resources	The tutors delivered the resources well, which enabled information to be shared/students to engage with the activities.

Name	Description
Lack of student buy-in	Peers were not particularly invested/motivated/engaged in the tutor sessions and/or interviews.
Limited feedback	Limited feedback from students during student interviews.
Mixed response to the resources and activities	Some students were enthusiastic and engaged, while others were not. This in part depended on the activity.
Need for staff enthusiasm	Need staff enthusiasm to promote student engagement/buy-in.
Need for tutor monitoring	Need for tutor monitoring of activities to promote engagement.
Negative attitudes of student interviewees	Perception that students across the wider school had a negative attitude towards being interviewed.
Personal relevance	Neurotypical students don't appear to care as much about 'the cause' as neurodivergent students.
Positive engagement from wider school	Peers were engaged and focussed on the Team Autism activities within tutor groups.
Positive staff response to resources	Tutors responded positively to the resources/tutor activities.
Wrong audience	Some students were interviewed who did not take part in the tutor activities.
Wrong motive	Perception that students joined the interviews for the wrong reasons (to miss lessons).
SUBTHEME: SEEDS OF THOUGHT	
Need for clear definitions	Clear definitions need to be provided before students participate in activities.
Need for preparation	Need to prepare students for autism awareness week to build anticipation and get people talking.
Need for quality rather than quantity	Better for tutors to facilitate some of the activities properly rather than trying to rush through all of them.

Name	Description
Order of activities	The order of activities needs to be carefully considered so that students have the knowledge to actively engage with them.
Publicising	Suggestion of how to publicise the team autism activities.
Suggestion of extrinsic rewards	Suggesting the use of extrinsic rewards to promote student buy-in.
Suggestion of group activities	It would have been preferable to do particular activities as a group.
Suggestion of purposive sampling	It would have been helpful for students to choose peers to interview (knowing that they had taken part in the activities) to gain more in-depth answers.
Suggestions of school events	Suggestion of events that could be facilitated to increase student buy-in.
Time	Need for and benefit of being given ample time to complete the activities.
THEME: EVOLVING OVER TIME	
SUBTHEME: BRANCHING OUT	
Communication aids	Suggestion to raise awareness of different communication aids in future Team Autism work.
Description of autistic experiences	Describing the experience of a shutdown.
Desire for autism in the curriculum	Desire for autism to be embedded into and across the curriculum, rather than a stand-alone topic.
Desire for resources to grow	Desire for future Team Autism members to develop the resources, so that they can evolve and grow.
Importance of space	Highlighting the importance of providing autistic students with space if they need it.
Meltdowns as a future priority	Raising awareness of meltdowns should be a future priority of the team.
Opening up participation	Suggestion to open up the team to new students from across the school for them to experience what Team Autism is like.

Name	Description
Shutdowns as a future priority	Raising awareness of shutdowns should be a future priority of the team.
Using different stories	Suggestion of using different stories in the future to raise awareness of different autistic experiences.
SUBTHEME: BECOMING ROOTED	
Annual awareness days	Desire for Autism Awareness Week to be an annual event to raise the profile.
Becoming established	The group will become more established/better known across the school.
Charters as a future priority	Suggestion of completing the charters and making these visible as a future priority of the team.
Desire for long-term impact	Important that the impact extends beyond Autism Awareness week and that things are enacted/change continues to be made over time.
Desire for team autism to continue	Expressing a desire for Team Autism members to continue to meet and work together in the future.
Future consistency	The group timings and setting will become more consistent over time.
Hopeful	Feeling hopeful about the future of Team Autism.
OTHER	
Desire for more digital work	Desire to incorporate more digital elements into Team Autism sessions.
Positive mindset	Reflection on happiness.
Positive sense of surprise	Feeling a positive sense of surprise at seeing the FIZZACC resources within tutor sessions.

Appendix R Phase 3 - Initial Themes

R.1 Example Memo

Refining codes:

- Reading through each code and the associated quotes, I noticed some overlap, so began refining code names and descriptions.
- I started to group individual codes together based on shared meaning, creating numerous themes.
- Some of these themes did not feel like themes in their own right, so I explored how some of these might fit together (e.g., safe space)
- Having grouped these, I created the following themes:

Theme 1: The autistic narrative	
1a. Autistic Identity	Encompassed codes referring to their autistic identity, including how they identified themselves, references to autism labels, recognition of autism, and what this recognition/lack of recognition brings.
1b. Deficit, Stigma, and Judgement	Encompassed codes that refer to stigma, negative stereotypes, negative attitudes of others towards autism.
1c. Gaining Insights	Quite a large sub-theme. Included references to the FIZZACC resources and Autism Awareness Week and what this brought in terms of the autism narrative within school/conceptualisations of autism. Not sure whether this fits quite right within this theme (some wonders around what the insights have/have not led to, and what factors might have contributed to this – need to explore further).
1d. Normal	Includes some codes which refer to ‘normality’. This includes referring to neurotypical people as ‘normal’. Interesting

	narratives re ‘normality’. One participant refers to school being ‘normal’ before because they didn’t experience any support out of the ordinary. Another participant talks about autistic students needing support to have a ‘normal day’.

Notes:

- Subthemes a, b, and d involve codes which I have generated with regards to language use/choice and what such language might reflect.
- I experimented with the ‘being myself’ code. Considered whether this was part of autistic identity or whether this linked to feeling safe to be their authentic self.

Theme 2: Belonging, connecting, and feeling safe	
Selection of codes linked to belonging	Accumulation of several codes linked to building connections, friendships, and teamwork.
2a. Safe Space	Encompassed codes relating to difficulties/struggles/anxieties and how the group has provided a safe space to be themselves. Some wonders regarding whether this theme is the best fit/ whether this might fit with sense of self/wellbeing.
2b. Systems	Encompassed codes relating to systems which have promoted participants’ sense of psychological safety. Again, some wonders regarding whether this theme is the best fit/ whether this might fit with sense of self/wellbeing.

Notes: - Considering whether belonging and connecting should be a theme in its own right/whether I am trying to squeeze ‘feeling safe’ into this theme. However, relationships do contribute to feeling safe. Continue to consider…

Theme 3: Empowerment and voice	
Selection of codes linked to empowerment and voice	Accumulation of references relating to sharing their voices, making decisions, being heard, taking leadership roles etc.
3a. Helping others	This seems to be coming through as a core motivator for participants involvement in the group (wanting to provide a voice for others/advocate).

Notes: - Content with this theme. Feel that it encompasses shared meaning regarding empowerment and voice and is sufficiently unique to other themes at the present time.

Theme 4: Motivation and investment	
4a. Staff attitudes and enthusiasm	Includes a selection of codes relating to staff’s facilitation of Autism Awareness week (which appeared to have impacted student buy-in).
4b. Student buy-in	Encompasses mixed responses to Autism Awareness week (some participants reflected on positive engagement, whereas others reflected on disengagement), and the participants’ views/feelings relating to this.

4c. Logistics	Includes a small selection of codes relating to what was needed to make the roll-out successful. Not sure if this completely fits into 'motivation and investment'.
4d. Suggestions	Selection of references to suggestions to promote staff and student engagement/buy-in.

Notes:

- Quite content with 4a, b, and d (not 100% satisfied with the fit of 4c).
- Wondering about how this theme aligns with the 'gaining insights' subtheme currently within 'The autistic narrative' theme. The 'motivation and investment' theme seems to in part explain the success/lack of success of the Autism Awareness week activities.

Theme 5: Sense of self and wellbeing	
Selection of codes linked to sense of self and wellbeing.	Includes references to increased confidence, pride, and positive experiences of being part of the group. Also, some references to anxiety (some wonders about how these fit with stigma within 'The autism narrative' theme.

Notes:

- Consider some sub-themes within this overarching theme.

Theme 6: Starting point leading to growth	
Selection of codes linked to the future of 'Team Autism' and Autism awareness with the school.	It evolved to include a sub-theme on 'depth' highlighting the importance of depth over breadth and the need for sufficient time.

Notes:

- This theme initially included ‘gaining insight’ to explore the change that has happened so far and consider change for the future. This seemed like too large a theme (and actually more like a topic/an answer to an interview question).
- Feel that this theme still needs tweaking/refining.

Other	
1. Positive relationships with teaching staff (before)	2. Code representing a short quote – ‘the teachers are lovely’ (not particularly adding meaning to any of the above themes).

Appendix S Phase 4 - Refining Themes

S.1 Example Memo

Refining themes:

- Read through each code (and quote) within each theme to ascertain whether I felt they belonged in this theme.
- Experimented with moving/re-grouping some sub-themes and developing my meaning making.
- Continued the iterative process of refining codes.
- I refined the themes as outlined below:

Theme 1: ~~The autistic narrative~~ **Conceptualisation of autism**	
1a. Autistic Identity	Kept the majority of codes within this sub-theme. Removed 'being myself' to 'Sense of self' theme. Added participant response to FIZZACC resources (felt that it was helpful to reflect on these responses with regard to their autistic identity).
1b. Deficit, Stigma, and Judgement	Kept this sub-theme as is.
~~1c. Gaining Insights~~	Moved this sub-theme to an alternative theme (felt that it was broader than the conceptualization of autism/contained unique elements that I would like to reflect upon).
~~1d. Normal~~ 1c. Normality	Kept the majority of codes within this sub-theme.

Notes:

- Refined this theme to focus on the 'conceptualisation of autism', including how participants identify, how they view autism (and neurodiversity), and how they perceive others to view autism.

- Preferred the title 'conceptualisation of autism' over 'narrative' – narrative didn't sit comfortably with me (concerned that this implied autism was a story).

Theme 2: ~~Belonging, connecting, and feeling safe~~ Belonging and connecting	
Selection of codes linked to belonging	Kept the majority of codes (some code refinement).
~~2a. Safe Space~~	Incorporated into 'Sense of self and wellbeing' subthemes.
~~2b. Systems~~	Incorporated into 'Sense of self and wellbeing'.

Notes: - Kept this theme solely focussing on belonging and connections to maintain its uniqueness.

Theme 3: Empowerment and voice	
Selection of codes linked to empowerment and voice	Kept the majority of codes (some code refinement).
3a. Helping others	Kept the majority of codes (some code refinement).

Notes: - No significant changes to this theme.

Theme 4: Sense of self and wellbeing	
~~Selection of codes linked to sense of self and wellbeing.~~	Created distinct sub-themes.
4a. Enjoyment	Encompasses references to enjoyment, fun, and a positive experience of being part of the team.
4b. Pride	Encompasses references to pride (relating to self and others).
4c. Self confidence	Encompasses references to sense of self-confidence/self-worth
4d. Wellbeing	Encompasses references to difficulties experienced (and the toll on emotional wellbeing), as well as the influence of being part of the team on wellbeing.
4e. Systems	Encompasses references to systems that have helped (or would help) to promote a sense of self and wellbeing.

Notes:

- Considerable change to this theme (now increased structure).
- Incorporated ‘being myself’ into this theme (related to feelings and wellbeing)
- Incorporated ‘systems’ (these promoted participant comfort)
- Consider combining some of the sub-themes?

~~Theme 4: Motivation and investment~~ Theme 5: Catalysts for change	
~~4a. Staff attitudes and enthusiasm~~ 5a. Stagnant or transformative insights	Incorporated and refined the ‘gaining insights’ sub-theme into this theme. This sub-theme

	represents that sharing insights into autistic experience through the resources and activities led to some transformative change from some (i.e., attitude change, increased understanding), but was stagnant for others (i.e., led to no change). Refined several codes (broader codes relating to awareness, understanding, knowledge etc., rather than the impact of each individual resource).
~~4b. Student buy-in~~ 5b. Attitudes, enthusiasm, and buy-in	Incorporated staff and student responses into one sub-theme (felt these were interlinked).
5c. Logistics	Kept the majority of codes.
5d. Suggestions	Kept the same.

Notes: - Changed the title to ‘catalysts for change’ to incorporate the factors that influenced whether change occurred (i.e., insights, motivation, logistics), alongside suggestions for change.

~~Theme 6: Starting point leading to growth~~ **Evolution**	
~~Selection of codes linked to the future of ‘Team Autism’ and Autism awareness with the school.~~	Created distinct sub-themes.
~~6a. Depth~~	Codes embedded into two sub-themes outlined below.
6a. Future of the resources	Encompasses references to suggestions of how resources could be used/could evolve in the future.

6b. Future of the team	Encompasses references to suggestions of how the team might continue into the future.

Notes:

- Generated two sub-themes to create structure (dividing the two elements of the project: the resource rollout, and the team processes).

Other	
1. Positive relationships with teaching staff (before) 2. Positive mindset 3. Positive sense of surprise	Code representing a short quote – 'the teachers are lovely' (not particularly adding meaning to any of the above themes). Code suggesting that it's better to be happy than sad (not 'fitting in' particularly well with any of the above themes. Code suggesting that the participant was surprised when he saw the resources in the tutor booklets (not 'fitting' in particularly well with any of the above themes).

Appendix T Phase 5 – Defining and Naming

T.1 Example Memo

- Oak tree metaphor to hook the themes onto
- Resonated with me and my themes
- Aligned with my membership to ACoRNS
- Used metaphors within Team Autism sessions (e.g., the human body for ground rules)
- Felt this would be more meaningful, accessible and memorable (particularly when sharing with the students/school community)
- Oak tree in the context of the forest
- Representing the influence of society and culture on the participants construction of their experiences
- Represents the wider influences on my interpretations

THEME: Conceptualisation of autism
This theme encompasses the way in which the participants spoke about autism, and my subsequent interpretations of how they conceptualise autism. This involves language about their autistic identity (both in terms of neurodivergence and as a disability), their desire for others to recognise them as autistic, and their perceptions of others' views of autism.
THEME: A sense of togetherness
This theme represents the meaningfulness of connections and relationships. This encompasses pre-existing friendships, as well as the development of connections and friendships over time, and the comfort and enjoyment this brought to the team. This also encompasses the participants' sense of belonging, and their positive reflections on spending time with others who they perceived to be similar to themselves, and who understood their experiences. These connections fostered a team ethos, with participants working together to make decisions, respecting the views and preferences of others. The participants expressed their desire for continuation of these connections and for members to remain part of the group in the long term.
THEME: Empowering, influencing, and advocating **Subthemes: Feeling empowered, nurturing others, fruitful systems**
This theme encompasses the participants' reflections on sharing their voice, expressing their opinions, and feeling heard. The participants shared their experiences of being involved in decision-making, facilitating change, and taking on leadership roles, fostering their sense of

empowerment. This theme also represents participants' desire and positive feelings towards helping others and advocating for them. The systems in place that enabled the participants to do so throughout the research process are also included within this theme.
THEME: Cultivating contentment **Subthemes: Joy, tranquillity, standing tall**
This theme represents the positive impact that the research process had on participants' emotional wellbeing. This includes their reflections on their enjoyment of being part of the research process, the safe space that Team Autism provided, and he pride and confidence they developed through their participation.
THEME: Conditions for growth **Subthemes: Stagnant or transformative insights, need for vitality, seeds of thought**
This theme encompasses participants' reflections on the difference (or lack of) they felt that Team Autism made in terms of changing attitudes, promoting understanding, and facilitating behaviour change. A fundamental contributor to such growth appeared to be the motivation, attitudes, and receptiveness of members of the school community (including staff and students). Participants' 'seeds of thoughts' are also included in this theme, which represent their ideas and suggestions to promote buy-in and facilitate long-term change.
THEME: Evolving over time **Subthemes: Becoming rooted, branching out**
This theme represents participants' hopes for how Team Autism and autism awareness will evolve over time. This includes Team Autism becoming 'rooted' within the school, developing a presence and becoming established. This also includes raising awareness of a wider range of autistic experiences (breadth) in a comprehensive manner (depth).

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