University of Southampton

Faculty of Environmental and Life Sciences

Psychology

Creatively Supporting the Transition from Primary to Secondary School For and With Autistic Girls

by

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Abstract

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Autistic children are currently being let down by the school system. They are more likely to be excluded and to suffer from poor mental health, and less likely to achieve their academic potential than their non-autistic peers. Evidence shows that the transition from primary to secondary school is particularly challenging for autistic children, but their own perspectives and particularly those of autistic girls, are underrepresented in the literature. This research aimed to promote the voices of autistic girls by working creatively within a participatory framework to support the embodied exploration of their experiences.

The following research questions were addressed: What do autistic girls feel are the barriers to successful transition from primary to secondary school? How can creative data collection and analysis methods promote the voices of autistic girls? What are the challenges and benefits of including autistic girls in participatory research?

There were four phases to the research: (1) pilot studies; (2) establishing a participatory group to creatively explore school experiences; (3) co-creating and evaluating school resources; (4) reflecting on the experience of participatory research.

First, a pilot study was conducted with five children with special educational needs (including autism) to investigate the value of using a novel Body Mapping method for exploring embodied experiences. This is a creative method of data collection, which has not been used with autistic children before.

Having established the advantages of the method and adjusted it for online use, a participatory research group was created – Fizzacc - which included six autistic girls aged 13 – 18 who met weekly online over the course of one academic year. The meetings involved exploring transition experiences and creating resources to support future cohorts based on group members' lived experiences. Data was analysed collectively using a novel method that Fizzacc devised to address the Double Empathy problem in autism research, and to prioritise the voices of the group. This analysis showed that educating staff and pupils about autism in girls was a priority and that autistic strengths as well as challenges were important to include in materials that could be shared with schools.

The data was then used to help create resources for schools, including a presentation and lesson activities aimed at raising awareness of autistic girls' strengths and challenges. Resources were trialled in three schools which provided feedback from 263 pupils and seven staff members gathered using feedback forms, interviews, and focus groups. Pupil and teacher feedback showed that the resources were favourably received, well-designed, and informative.

Finally, reflexive thematic analysis was used to identify the challenges and benefits for the group members of working on a participatory research project together. Fizzacc members were empowered by their involvement in the research. Working creatively in a group to share common experiences for a common purpose was a positive experience.

Together, the findings support the value of working creatively with autistic girls to address the issues that are important to them, and Body Mapping is a method which empowers the exploration of embodied experiences. There is potency in including the voices of autistic girls in resources to raise awareness for school staff and peers about their experiences. Improving education to allow autistic girls to flourish demands that their voices be central within the dialogue, and school staff need to be more aware of how to best support neurodivergent children in their classroom, whether or not they have a formal diagnosis.

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Research Thesis: Declaration of Authorship

Print name: Chloe East

Title of thesis: Creatively Supporting the Transition from Primary to Secondary School For and With Autistic Girls

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:

Date: March 2024

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Definitions and Abbreviations

AAC	Augmentative and Alternative Communication
ABA	Applied Behavioural Analysis
ACoRNS	Autism Community Research Network @Southampton
ADHD	Attention-deficit/hyperactivity disorder
ANI	Autism Network International
APA	American Psychiatric Association
APPGA	All Party Parliamentary Group on Autism
CAMHS	Child and Adolescent Mental Health Service
DHSC	Department of Health and Social Care
DfE	Department for Education
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5th edition
EHCP	Education, Health and Care Plan
FE	Further Education
GCSE	General Certificate of Secondary Education
IQ	Intelligence Quotient
ISC-11	International Classification of Diseases 11th Revision
JAACAP	Journal of the Academy of Child and Adolescent Psychiatry
JADD	Journal of Autism and Developmental Disorders
KS3	Key Stage Three
LA	Local Authority
MS	Microsoft
NAS	National Autistic Society
NCRM	National Council for Research Methods
NICE	National Institute for Health and Care Excellence
PAR	Participatory action research
PGCE	Post graduate certificate in education
PSHE	Personal, social, health and economic education
SDQ	Strengths and Difficulties Questionnaire
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
STEP-ASD	Systemic Transition in Education Programme for Autism Spectrum Disorder
WISC	Weschler Intelligence Scale for Children

Creatively Supporting the Transition from Primary to Secondary School for and with Autistic Young People

1.1 Philosophical Standpoint and the Importance of Language and Terminology

The work described in this thesis focuses on the experiences of autistic children in education. More specifically, it is based on autistic girls sharing their experiences of education and co-creating resources to support successful transitions for future cohorts.

I have conducted this research fully aware of my positionality regarding the issues I am covering. I am neither autistic myself nor the family member or advocate of an autistic person. The professional expertise I bring to the project is as a Doctoral researcher, and a teacher with experience of educating children in a creative subject (drama). It is important to me, and to this project, that I take every opportunity to include and promote the voices of the autistic children and young people (‘children’ will be used to refer to all children and young people for brevity from this point) whom I am seeking to include, represent, and support with this research. Before introducing the work included in this thesis, it is also important to consider how I will be conceptualising autism throughout the research, and how language and terminology frame and shape these conceptualisations. To help to inform my stance, I have considered the views of autistic people and their advocates as defined in the literature and turn first to how autism is defined and described.

1.1.1 Standpoints in Autism Research

Autism is defined by the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5; American Psychiatric Association (APA), 2013) as a disorder characterised by deficits in social communication and restrictive and repetitive behaviours and is given the formal label of autism spectrum disorder (ASD). Both the DSM-5 (APA, 2013) and the International Classification of Diseases 11th Revision (ISC-11; World Health Organisation, 2018) define autism using a deficit view i.e. as a ‘disorder’ which engenders ‘symptoms’ that need to be treated or fixed. Through describing autism according to its psychiatric diagnostic characteristics, there is a tendency in the field of autism research to take a medical model approach to understanding autistic people and responding to their needs (Bagatell, 2010; Pellicano & den Houting, 2022; Rioux & Bach, 1994). The medical model views disability as a direct result of an individual’s differences or ‘deficits’ (APA, 2013; WHO, 2018) and regards these differences as undesirable (Kapp, 2019). By framing autism as a functional deficit, this has led to limits on what is researched and how this research is conducted (Pellicano & den Houting, 2022). The historical focus on the medical model has led to a proliferation of studies looking into causes and cures (Pellicano & Stears, 2011). For autistic children this has led to the development of a multitude of interventions, many of which are designed to make the child behave in a way that is perceived as being more ‘normal’ (Pellicano et al., 2013 p. 761).

By contrast, the social model of disability views disability as a socially constructed phenomenon (Bagatell, 2010; Oliver, 1992). Whereas the medical model puts the emphasis on the so-called deficits of the disabled person, the social model of disability views society as deficient in its ability to meet the needs of its citizens (Shakespeare, 1996). Although the development of the social model was spearheaded by individuals with physical disabilities (Shakespeare, 1996), it has, more recently, been espoused by the autism community and informs many of the contemporary debates about the framing of autism in research (Jurgens, 2020: Kapp et al., 2013). The application of the principles of the social model of disability have led to the introduction of autism as a neurodivergence rather than a disorder. ‘Neurodiversity’ thus refers to a movement that sees those diagnosed with neurological or neurodevelopmental conditions as neurodivergent and as having differences in the way their brains work as a part of natural human variation (Fenton & Krahn; Kapp et al., 2013). Crucially, neurodiversity recognises that there are strengths inherent in autism such as abilities in identifying patterns (Armstrong, 2015), as well as societal benefits to having variation. For example, in an early article about neurodiversity, published in The Atlantic, Blume (1998) wrote ‘Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment?’ However, neurodiversity also recognises the disabling nature of autism (Den Houting, 2019). Milton (2020) argues that neurodiversity as a concept counters the idea that there is only one ideal way of being i.e. neurotypical, and points to the importance of the neurodiversity movement in supporting neurodivergent researchers. Moreover, as den Houting, (2019) argues, this way of conceptualising autism also requires a ‘paradigm shift’ in autism research. One of the implications of this paradigm shift of direct relevance to my thesis is that research should focus on finding ways to make elements of society, such as schools and workplaces, more inclusive for people of all neurotypes (Jurgens, 2020; Robertson, 2010) and on the strengths associated with autism rather than the ‘deficits’. This contrasts with the priorities for research that have aligned with the medical model which attempt to change behaviour through use of interventions designed to extinguish or disguise neurodivergent behaviour (Kapp, 2019). A more in-depth exploration of the literature surrounding the medical and social models of disability and neurodivergence can be found in Chapter 2.

1.1.2 Use of Language and Terminology

In line with the neurodiversity reframing of autism, autistic self-advocates and their allies have challenged the way in which the language around autism disables autistic individuals, highlighting issues with using person-first (person with autism) versus identify-first (autistic person) language (Bradshaw et al., 2021; Sinclair, 2013). Accordingly, the language used to describe and define autism is inherent to the positionality of the person using it. Disability rights advocates argue that the language used not only impacts self-perception, but also how the general public views disability (Dunn & Andrews, 2015; Haller et al., 2006). For example, Haller et al. (2006) discussed how the language chosen to represent disabled people in the media perpetuates medical model stereotypes of disability. Use of the phrases 'wheelchair-bound' or 'confined to a wheelchair' have negative connotations suggesting the person is limited by their wheelchair use. In contrast, 'wheelchair user' describes the same person without the damaging implications. Autistic academic Jac den Houting (2019) described in their TED talk the dichotomy between feeling their autism diagnosis was the best thing that had happened to them, and hearing from others that autism was a 'tragedy'. Brown (2011), an autistic disability rights advocate, lawyer, and educator, argued that language has 'the power to transform ideas and attitudes' (para. 20) and reflected on the impact of using person-first language to their self-worth. Person-first language aims to put the person before the label of disability. This was a position argued for by the disabled rights movement as being more humanising as it emphasizes the person over the autism (Brown, 2011). However, identity-first language proponents argue that it is impossible to separate the person from (in this case) the autism and that the 'with' also suggests the possibility of a 'without' (Bradshaw et al., 2021; Sinclair, 2013). In an essay titled 'Why I Dislike "Person First" Language' Sinclair (2013) described how the phrase 'person with…' usually ends with something transitory such as an item of clothing – woman with a grey jumper, or something negative – boy with chicken pox. Sinclair does not consider his autism to be either transitory or a problem to be solved.

To address the ongoing debate in this area, Kenny et al. (2016) elicited the views of 3,470 autistic people, family, friends, and professionals who work with autistic people on their language preferences via an online survey. The results were mixed, with 61% of autistic people preferring identity-first language in comparison to only 38% of professionals who tended to prefer person first (49%). These findings reinforced the lack of consensus from different stakeholders but, nevertheless, showed a majority preference for identity-first language amongst autistic people. In more recent research, Bottema-Beutel et al., (2021) considered how arguing to maintain the status quo of person-first language due to lack of consensus minimises the importance of the views of many autistic people and denies them agency. Bottema-Beutel et al., (2021) suggested that researchers consider the views of participants and use the language chosen by them to describe themselves.

Ableism refers to the discrimination of disabled people due to their perceived deficits and assumes that disabled people need to be fixed (Bottema-Beutel et al., 2021). Ableism can have an impact on the health and well-being of autistic people and their families. For example, as described by Bradshaw et al., (2021), the use of medicalised language to describe autism as a disorder by medical professionals can lead to a perception by those newly diagnosed and their families that autism means that a person is broken and requires fixing. This may be detrimental to the way the person or the family view autism and can lead to negative views and stigma. Moreover Bradshaw et al. (2021) point out that the stereotyped view of autism - largely affecting boys - impacts on General Practitioners' ability to identify autism, particularly in girls and women.

Interestingly, calls from the autism community to change the use of language around autism is beginning to filter through to editorial debates in scholarly journals. For example Yerys et al. (2019) submitted a paper to the *Journal of the Academy of Child and Adolescent Psychiatry* (JAACAP) where there was a policy of using person-first language. Yerys et al., (2019) included an explanation of their choice of language in writing about the association between attention-deficit/hyperactivity disorder (ADHD) and adaptive behaviour in autistic children which prompted the journal to include the following note with the published work:

> 'The article by Yerys et al. uses identity-first language ("autistic children") or neutral terms ("children on the autism spectrum" or "children who have an ASD diagnosis") rather than person-first language (children with ASD). In keeping with the AMA Manual of Style, 10th Edition, JAACAP has a standing policy of using person-first language, but the authors have requested and received an exemption to use identity-first language. The authors' request stems from a recent article by Kenny et al., (2016) that interviewed nearly 3,500 stakeholders from various backgrounds (autistic individuals, parents, family/friends, and professionals) asking them to report on preferred terms. Kenny et al. demonstrated that autistic individuals, parents, and family members preferred identity-first language, whereas professionals preferred person-first language. We encourage all stakeholders to read Kenny et al. and the current paper and invite readers to offer their opinions on this important issue by submitting letters to the editor' (JAACAP, n.d.).

As a result, the guidelines on the JAACAP website now read: 'Verify "person-first" language throughout the text, e.g., replace "asthmatic person" with "a person with asthma." Given the preferences of many individuals with autism spectrum disorders, it is acceptable to use 'identity-first' language, i.e., "Autistic person"' (JAACAP, n.d.).

The JAACAP is not the only journal to consider its stance on the use of language. In 2020 the *Journal of Autism and Developmental Disorders* (JADD) published an editorial exploring the 'most appropriate way to talk about individuals with a diagnosis of Autism?' (Vivanti, 2020, p. 691). Vivanti (2020) argued that both identity-first and person-first language should be used in the JADD as Kenny et al., (2016) did not represent the voices of 'minimally verbal' (p. 692) autistic people who may view the issue differently to those who were able to respond. Vivanti (2020) also posited that the importance of emphasising the humanity of those more at risk of being treated as '"less than people"' (p. 692) supports the use of person-first language. In a response to Vivanti (2020), Botha et al. (2020) offered a critique stressing the importance of recognising autism both as a phenomenon in itself and something that is socially constructed. Moreover, Botha et al. (2020) argued that Vivanti's (2020) viewpoint is limited by its lack of engagement with the literature produced by autistic scholars.

Perhaps the strongest example of identity-first language use supported through Editorial guidance comes from the journal *Autism in Adulthood (*Autism in Adulthood, n.d.) which offers detailed guidance on use of language, as well as providing links to further information about the issues involved in writing about disability. The journal's 'Aims and Scope' on the website makes it clear that 'This innovative journal integrates the contributions of autistic adults — as Editorial Board members, authors, peer-reviewers, and readers — into the peer-reviewed literature' (n.d.). Thus, the journal is co-constructed with autistic people and takes a strong position on the importance of language that is non-discriminatory and non-stigmatising.

In line with this stance that recognises the importance of the use of language, and the co-constructed nature of my own research, my approach will be to follow the preferences of the autistic community as described by Kenny et al., (2016), and use identity-first language when describing autistic people unless a participant or co-researcher expresses a different preference. Autism will be written about from a strengths-based perspective and language that promotes ableist views will not be used (Bottema-Beutel et al., 2020).

1.1.3 Functioning Labels

Another contentious issue in the autism field is the use of functioning labels (Alvares, et al., 2020; Kim, 2013; Savarese & Savarese, 2010). 'High-' and 'low-functioning' were labels first ascribed to autistic people in the 1980s to differentiate, respectively, between those with an intelligence quotient (IQ) score of 70 and above and those below that threshold (Alvares et al., 2020). While high- and low-functioning categorisation is not part of the diagnostic process, the terms are still widely used in clinical practice and research (Alvares et al., 2020; Bradshaw et al., 2021) and have become shortcuts to describing how autistic people communicate and their intellectual ability (Williams, 2019). The notion that a person may be classified according to their ability to function at a particular level raises the question of what constitutes functioning. Jaarsma and Welin (2012) see functioning as relating to IQ, with those in 'the normal range (or above)' (p. 21) being considered high functioning. This assumes that an IQ test is an accurate way of measuring intelligence which, as suggested by Dawson et al., (2007) is incorrect: different scores are achieved depending on the test taken. Fenton and Krahn (2007) consider functioning as related to success in the social domain and argue that factors such as independent living or ‘flourishing’ (p. 3) could be used to make the distinction. According to Fenton and Krahn (2007), ‘flourishing’ pertains to factors such as contentment and self-worth. A more recent debate centres on the proposal by a Lancet commission on the future of care and clinical research in autism (Lord et al., 2022) which argues for the use of the term ‘profound’ to categorise non-verbal autistic people with an IQ of 50 or below. This proposal acknowledges dislike of the term ‘low functioning’ and argues that unlike functioning labels, profound autism is defined by intellectual and language disability rather than autistic traits. This distinction seems to lack clarity and has been widely criticised by the autism community (Eucap, 2022), arguing that people with Down’s Syndrome or Cerebral Palsy vary widely in their support needs and abilities and do not require a separate categorisation (ASAN, 2021). Neither does this categorisation address the heterogeneity of autistic people and the way their abilities and needs can change over time.

Concepts of functioning are problematic since they come from an assumption based on ableist views of superiority and, accordingly, are widely criticised by the autistic community (Kim, 2012; Savarese & Savarese, 2010). Autistic self-advocates question whether functioning is a static phenomenon. Kim (2012) describes two different women, one has “has always managed the family finances and investments. She has a diverse set of hobbies and pastimes that include dog training, target shooting, reading mystery novels and fiction writing”. The other “sometimes needs to be reminded to brush her hair, shower or put on appropriate clothing before going out. She’s never negotiated a lease or car purchase by herself and has never lived on her own” (Kim, 2012, para.3). Kim argues that the first woman would be classified as high functioning and the other would be thought to be low functioning. The women she describes are both herself. She contends that functionality is constantly fluctuating depending on factors including time and context. Savarese and Savarese (2010) also criticise the use of functioning labels, giving examples such as Tito Mukhopadhyay, an Indian writer and poet who could be labelled as low-functioning due to his support needs but is able to express his thoughts eloquently through poetry and prose. Mukhopadhyay does not communicate verbally but has published several books.

A particular concern with the use of functioning labels is that an assumption of high functioning may raise expectations of an individual’s ability whereas an assumption of low functioning may prevent people from being offered opportunities that would benefit them (Nicolaidis, 2012). Nicolaidis (2012) argues that the autism spectrum is not a linear concept therefore, individuals should be recognised for their particular strengths and challenges, which may vary. Moreover, functioning labels perpetuate an ableist ideology in which people with disabilities face stereotyping, discrimination, and prejudice due to a belief that there is an ideal way of being that does not include disability (Bogart & Dunn, 2019). Consequently, functioning labels will not be used in my writing, unless when quoting directly from previous published research. In line with the guidance for the avoidance of ableist language provided in Bottema-Beutel et al., (2021), if it is necessary to refer to an individual's abilities within a particular situation it will be from a strengths-based perspective and offer specific acknowledgment of the support needed.

1.2 Positionality and My Background

1.2.1 Teacher/Researcher

My work throughout this thesis has been conducted with the awareness that I have approached it from two different perspectives: as a researcher and as a teacher. While there have been times when the boundaries between these have been blurred and I have struggled with leaving classroom practice behind in favour of the more rigorous nature of social science research, I believe I have achieved a balance. Before moving on to consider my position within the field, I will briefly consider how the skills and experiences garnered as a teacher have shaped my approach.

I qualified as a drama teacher in 1998 and taught for 20 years in mainstream state secondary schools in the south of England before leaving to pursue this research. During that time, I taught many children with special educational needs and disabilities (SEND). At the beginning of my teaching career, it was unusual to teach a child with an autism diagnosis but, by the time I left, the picture had changed, and many more autistic children were identified (cf. Matson & Kozlowski, 2011). Unfortunately, during that period I received very little training on how to best support autistic children and with a busy workload and a department to run, I initially gave it very little consideration. My interest in the educational experiences of autistic children began when I took my GCSE drama class to see the stage production of 'The Curious Incident of the Dog in the Night-time' (Stephens, 2012; Haddon, 2003) and we spent time discussing the characters and the methods used by the director to support the audience's understanding of the world of the protagonist, Christopher Boone. Although autism is not specifically mentioned in either the novel or the play [in fact Christopher describes himself as 'a mathematician with some behavioural difficulties' Haddon, (2004)], the book was publicised as a story about a boy with Asperger's Syndrome (a categorisation of autism no longer included in the DSM-5). However, the book has been widely criticised by the autism community (Bartmess, 2015; Olear, 2012), partly for Haddon's self-confessed lack of research before writing the book (Haddon, 2009) and partly for its unhelpful portrayal of stereotypes such as that of the autistic savant (Barrett, 2016). Nevertheless, it did provoke wider dialogue about autism and provided insights into experiences potentially faced by autistic (or neurodivergent) young people. More recently a new touring production by The National Theatre has announced it is seeking neurodivergent actors to play the role of Christopher Boone (Bonsanquet, 2021), which is a welcome step towards neurodivergent representation.

One scene in the play that was particularly affecting included portrayal of Christopher's experience when travelling on the London Underground. Using projection, lighting and sound, the director showed the audience what it might feel like as a young person with heightened experience of sensory stimulation to be in a busy, unfamiliar, and hostile environment. My limited training on autism during my post-graduate certificate in education (PGCE) and ongoing professional development had never mentioned differences in sensory processing. The insights gained while working on this project with my GCSE class, which included an autistic student, led me to want to discover better ways to support autistic pupils in education more generally.

1.2.2 Views of the Wider Teaching Profession

My own impression of failing to meet the needs of autistic students has been echoed by teachers more widely. A report published by Ambitious about Autism (2013) found that 60% of the 1,617 teachers surveyed in England felt they had inadequate training to teach autistic children effectively. Many staff felt the training provided about autism was ineffective; that they never, rarely, or only sometimes received the support they needed to teach children with SEND; and that teaching staff were paying for their own training as their schools were not providing it. Hummerstone and Parsons (2020) used semi-structured interviews and photo-elicitation to explore what autistic pupils and their teachers thought constituted a good teacher within two secondary mainstream schools in the south of England. Their findings reflected my own experience in that teachers felt they were not adequately supporting their autistic students and they were lacking the training necessary to change this. Moreover, the pupils in this study identified the importance of supporting their sensory experiences in the classroom, but this was an area of support not recognised by the teachers. With teachers themselves feeling unequipped to adequately support autistic learners in their classrooms, it is unsurprising that pupils feel they are being let down.

1.2.3 Views of Autistic Pupils

The All Party Parliamentary Group on Autism (APPGA) reported that of 176 autistic children surveyed in England, more than half said they were unhappy at school and 40% of the 2,573 parents who responded believed their child's school failed to support their needs (APPGA & NAS, 2017). Of children, 60% said that having a teacher who understands autism was the main thing that would improve school for them. Similarly, Hummerstone and Parsons (2020) found that autistic children wanted their teachers to have a good understanding of their individual strengths and differences to support them effectively at school. Autistic children who are not supported to manage the social environment in school are likely to experience anxiety (Moyse & Porter, 2014), which can present as disruptive behaviour (McDougal et al., 2020). This can be exacerbated by difficulties with processing the complex sensory messages that are inherent in schools (Moyse & Porter, 2014). Childrens' response to anxiety or sensory overload can include meltdowns or the need to escape (Hughes et al., 2020) which, if unrecognised, can look like bad behaviour. 'Meltdowns' are defined by the NAS (2020) as:

> 'An intense response to an overwhelming situation. It happens when someone becomes completely overwhelmed by their current situation and temporarily loses control of their behaviour. This loss of control can be expressed verbally (eg shouting, screaming, crying), physically (eg kicking, lashing out, biting) or in both ways.' (NAS, 2020).

As a result of perceived poor behaviour, autistic children are more likely to be excluded from school (Moyes, 2020) either permanently, by not being supported to access the classroom and learning in alternative spaces within the school, or by being on part-time timetables. There are far reaching consequences for autistic children from this lack of adequate provision, and these are explored next.

1.2.4 The Impacts of Inadequate Provision

Exclusion from school because of challenging behaviour suggests a failure by the school to adequately provide for autistic children (Sproston et al., 2017). Permanent exclusion figures show that 0.32% (3,056 of a population of 956,277) of SEND pupils have been excluded, compared to 0.06% (4,448 of 697,1309) of pupils with no SEN registered (DfE, 2020). Those permanently excluded are also more likely to not be in education, employment, or training (NEET) after leaving school at 16 (DfE, 2018). The figures for autistic children in England are equally concerning with three times the exclusion rate of children with no SEND (DfE, 2020). Moreover, the exclusion rate for autistic children is likely to be higher as the figures do not include the number of undiagnosed or misdiagnosed children (Guldberg et al, 2021). Exclusion from education (Sproston et al., 2017) can have serious consequences for autistic children over the long-term including low self-esteem, negative impacts on family life and unemployment (Munn et al., 2000). A 2016 report by the NAS found that only 16% of autistic adults in the UK are in full-time paid work and only 32% are in paid employment of any kind. This compares to 80% of non-disabled people being in work and 47% of disabled people (NAS, 2016). Of those in work, many are in jobs for which they are over-qualified (Hayward et al., 2018). The problems autistic children are facing in schools have been recognised, however evidence suggests that this recognition is not leading to effective action.

1.2.5 Responses to the Problems of Autistic Children in Schools

The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 (Department of Health and Social Care (DHSC) and Department for Education (DfE), 2021) recognised that 'many autistic children and young people are still having poor experiences within school,' (p. 17).

This is four years on from the APPGA report (NAS, 2017) which stated that three years after reforms to the SEND system in England, 'children on the autism spectrum are still being let down by the education system' (p. 4). It is therefore important to understand and address the barriers to successful education faced by many autistic children and consider how best to support them to increase their chances of a positive future. The social model of disability provides a starting point to address these barriers in that the focus should be on adapting environments to enable the individual to succeed rather than attempting to change the individual. Successfully accommodating people with disabilities in education and the workplace has positive outcomes for all (Blanck, 2020). Of course, a major challenge remains in understanding *how* such adaptations could be made, and in ways that are experienced as valuable and inclusive by autistic children. Trying to address that question brings me to the importance of the creative approaches used within my research, which emphasise the voices and agency of children as partners in the research.

As a former drama teacher, and now a Doctoral researcher, I feel very strongly about the importance of supporting creativity and freedom of expression in pupils. As a teacher, I advocated for creative subjects with a belief that they provided young people with transferable skills and opportunities. These included confidence and self-esteem, the ability to work collaboratively, and the opportunity for students to express themselves in a way that they may not have the agency to do in other areas. A deficit view of autism, which focuses on the challenges and difficulties experienced, may suggest that creativity is limited in autistic people (Roth, 2020). However, this is refuted by the number of successful autistic creatives which would suggest that creativity is a strength of many autistic people and one that many enjoy. A study looking at what autistic children enjoyed and felt they were good at (Clark and Adams, 2020b) reported that of eighty-three 7 to 14-year-old autistic children surveyed in Australia, 14.4% identified a creative pursuit as their response to the question 'what are you absolutely best at?' (p. 5). These research findings are further supported by work produced by autistic artists such as Sonia Boue (https://www.soniaboue.co.uk), autistic writers such as Lizzie Huxley Jones (https://lizziehuxleyjones.com), and autistic make-up artist and recent winner of the BBC TV competition Glow Up - Sophie Baverstock (https://www.sophiebaverstock.co.uk).

With my knowledge and expertise from teaching drama, I felt it was opportune to use my creative experience in the way I chose to conduct my research. This led me to consider the use of creativity within my methodology to elicit the voices of autistic children. By incorporating creative methods in my research, it was hoped that autistic children would be empowered to share their opinions in a thoughtful way that enabled them to use their strengths and interests. A further exploration of creative methods can be found in Chapter 3.

1.3 An Overview of the Research Focus

My interest in improving the educational provision for autistic children led me to pursue my PhD at the University of Southampton, where I am a member of the Autism Community Research Network @Southampton (ACoRNS). ACoRNS is an initiative that aims to link research and practice to support autistic children in education through promoting their voices and supporting creative and participatory approaches to research. ACoRNS brings together academics from the University of Southampton's Schools of Education and Psychology and local education partners from nurseries, schools and colleges, as well as undergraduate and postgraduate students conducting original research with those partners (Parsons & Kovshoff, 2019). Together, ACoRNS members follow a research agenda that is jointly identified with practitioners, and which places the views and experiences of the children at the centre of the research (Parsons et al., 2023). The focus of ACoRNS research is on the transitions and trajectories of autistic children and one of the core principles is that the research conducted will make a difference to practice and therefore be of benefit to autistic children, their families, and teachers (Kovshoff et al, 2018). These principles are very much aligned with the social model of disability and the concept of neurodiversity and are central to my own research.

This research was conducted in line with the principles of ACoRNS and the social model of disability. In keeping with my experience as an educator and researcher, the work focuses on making a difference to practice in addressing the barriers autistic young people identify as preventing equality in education. To better understand these barriers the research will draw on my creative background in its use of research methods. The work prioritises and promotes the voices of autistic young people both in its methods and its outputs.

1.4 Structure of the Thesis

The structure of this thesis is as follows. Having established the key principles and research philosophy in Chapter 1, Chapter 2 provides a review of the literature relevant to the core concepts of this research. The first part of Chapter 2 considers the framing of autism in research, highlighting the contrasts between the medical and social models of disability, and explores the philosophy of the neurodiversity movement. Chapter 2 then argues for the importance of including the voices of autistic young people in research and reflects on the reasons for, and implications of the historical under-representation of the voices of autistic girls in the literature. The third section of Chapter 2 outlines the use of participatory research methods and a rationale for their use in this research. Finally, there is a consideration of the challenges of transition from primary to secondary school and evidence from the literature of strategies to support successful transitions. Having considered the literature pertinent to the key concepts of this research, Chapter 2 concludes by stating the aims and objectives of the research. In Chapter 3 the use of creative methods to support the promotion of the voices of autistic young people is discussed and the use of Body Mapping as a method of data collection is outlined. Body Mapping is a flexible, creative, multi-modal method, which supports the exploration of embodied experiences. The rationale for using Body Mapping as a method that can adapt to the skills and interests of the participant is outlined. Chapter 4 describes the pilot study that was conducted to evaluate the use of Body Mapping to investigate transition experiences with children and conclusions are drawn as to how it can be taken further into the next part of the research.

The next part of this thesis focuses on the substantial research project that was conducted. Chapter 5 introduces the research group that was formed to address the research objectives including details of recruitment and ethical considerations of working within a participatory framework. Chapter 6 describes how the research group worked together to explore transition experiences using Body Mapping during collaborative participatory meetings. Chapter 7 includes details of the 'perspective narratives' that were developed with the group to enable participatory data analysis to be conducted in a meaningful way which prioritised the promotion of autistic voices within the process. Chapter 8 explores how we created educational resources in response to the problems with the primary to secondary transition identified by the group. Chapter 9 includes an evaluation of these resources as well as an evaluation of the benefits and challenges of working on a participatory project with autistic girls. Finally, Chapter 10 includes a discussion which draws together the findings from the different elements of this research and considers how these methods can help develop our understanding and support of autistic children in schools. It concludes with a consideration of the strengths and limitations of the research before offering some suggestions for future development. Finally, the references are followed by supplementary information which can be found in the appendices.

Chapter 2 - Literature Review of Core Concepts

Introduction

This chapter explores existing literature relevant to the concepts that underpin this thesis as depicted in Figure 1. This figure depicts the route I took with my research with an initial focus on the philosophy of autism research and the challenges of educational transitions. Although the conceptual themes are depicted in a linear way in this figure to show how my work developed during the research process, the connections represent how I continually circled back and linked all elements of the research.

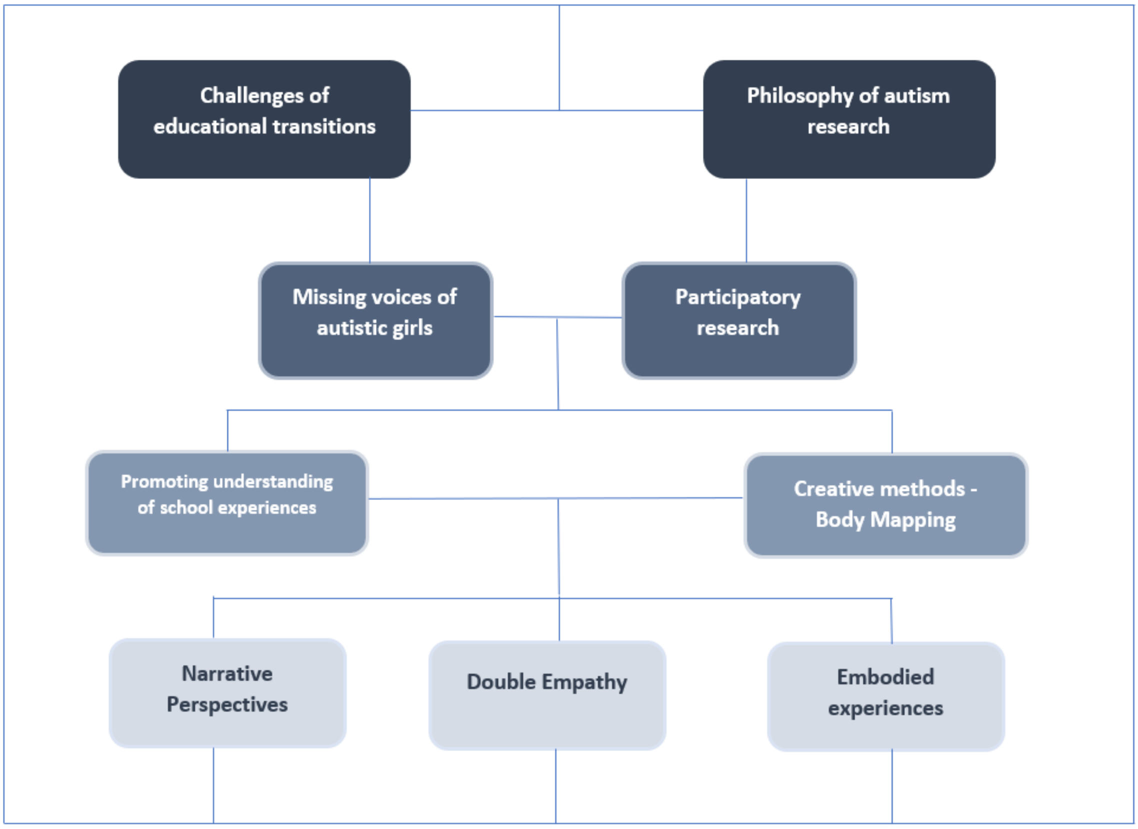


Figure 1 - Conceptual Framework for this Thesis

This chapter will begin with a consideration of how understanding of autism has developed and the influence of the social model of disability and neurodiversity paradigms on my research, it then considers how, within the dialogue around autism, the voices of autistic girls and women are being missed. It then examines the literature defining and evaluating participatory research before introducing challenges posed by educational transitions. It concludes by drawing together the gaps in each body of literature with consideration of how this research will address them.

2.1 The Framing of Autism in Research

This section will outline prevailing views of autism over the past 80 years before considering how the social model of disability and the neurodiversity movements are reframing our understanding of disability and disorder, and so promoting research that aims to do more to include the lived experiences of disabled people.

2.1.1 A History of Autism and the Medical Model of Disability

Views and representations of autism have changed since it was first identified in the 1940s. Early infantile autism was first described by Kanner (1943) who saw similarities between children he was observing in his clinic and children with schizophrenia, such as obsessiveness and echolalia, but noted that the children he observed were affected from birth whereas schizophrenia did not manifest until later. Kanner (1943) blamed a lack of parental warmth for children developing autism, a view that was popularised by Bettelheim in his book The Empty Fortress: Infantile Autism and the Birth of the Self (Bettleheim, 1967), in which he particularly blamed mothers, comparing them to Nazi prison guards. In response to negative discourses of blaming parents, alternative theories were developed by autism advocates such as Lorna Wing - a psychiatrist and the mother of an autistic daughter (Gould, 2014). In the 1970s, Wing introduced the idea of a spectrum of autism which included individuals with varying IQs who were seen to exhibit a triad of impairments (Wing & Gould, 1979), consisting of difficulties with imagination, communication, and social interaction. In the 1980s autism became a topic of public interest with the QED documentary ‘The Foolish Wise Ones’ introducing the story of three autistic men with skills in music, art, and mathematics. This was followed by the film ‘Rain Man’ in 1989 starring Dustin Hoffman as Raymond Babbitt who has an excellent memory and the ability to make instantaneous mathematical calculations. Concurrently, parent-run charity groups, particularly in the United States - such as Cure Autism Now (now renamed The Autism Community in Action) and Autism Speaks - were pushing for research aimed at curing autism (Ortega, 2009). During this period, autism was viewed as a curiosity at best and a tragedy at worst (Jones, 2019; Sinclair, 2022). These organisations contrasted with the NAS in the United Kingdom which was established in 1962 as an organisation to advocate for autistic people, with Lorna Wing amongst its founders (Gould, 2014). By focusing on advocacy rather than cure, the NAS eschewed the medical model of disability that was the primary focus within the field of autism research at this time.

Medical Model of Disability. The medical model of disability focuses on 'disability as the outcome of impairment' (Shakespeare, 1996, p. 95) and considers disabled people according to their medical or physical characteristics (Shakespeare, 1996). Within this model, autism is characterised as a disorder and autistic people as having deficits that need to be "fixed". In positioning autism as a disorder, professionals, researchers, and families respond to the needs of autistic people in terms of what they cannot do or find difficult. For example, in focusing almost exclusively on so-called deficits in autistic cognition, models such as the Theory of Mind (ToM) paradigm have been developed. The ToM paradigm (Baron-Cohen, 1989; Frith & Happe, 1994) describes autistic people as showing widely replicated difficulties in the ability to take the perspective of others - as evidenced in false belief tasks (Baron-Cohen et al., 1985). The theory of Executive Dysfunction is another example, which suggests that autism is associated with deficits in cognitive functions such as planning and mental flexibility (Hill, 2004; Ozonoff et al, 1991). These theories are based on the view that there is an ideal way of functioning and that there should be an aspiration towards autistic people conforming as closely as possible to this norm (Kapp et al., 2013). Critics of these theories point to problems with the empirical evidence provided in their support, such as the failure to pass false belief tasks not being exclusive to autism as well as the tendency of many autistic participants to pass them (Gernsbacher & Yergeau, 2019) and doubt whether false belief tasks are accurately measuring ToM in the first place (Quesque & Rosetti, 2020). Furthermore, by failing to consider the strengths associated with autism, these theories offer a very narrow view of the experiences of autistic people, limiting the success of any strategies designed to offer support that is based on them.

Medical Model and Genetic Research. The medical model of disability has more recently been challenged by autistic voices and their advocates (Chown et al., 2017; Parsons & Kovshoff, 2019; Pellicano & Stears, 2011; Robertson, 2010) as furthering an ableist agenda in which neurotypical, abled-bodied people are considered the norm and those who do not fit the norm are lesser (Bottema-Beutel et al., 2021). As well as focusing almost exclusively on cognitive and behavioural 'deficits' of autism, research based on the medical model also prioritises research into the genetic markers for autism, with an agenda of identification and prevention (Pellicano & Stears, 2011). Concerns around this agenda have been highlighted by the controversy surrounding the Spectrum 10K research project which sought to use genetic material provided by autistic participants to investigate relationships between genetic and environmental factors in co-occurring physical and mental health conditions (University of Cambridge, 2021). While the research team themselves emphasized that their objectives were around the wellbeing of autistic individuals, the implications of a database of the genomes of 10,000 autistic people being available for future research was concerning for many people including the NAS (NAS, 2021). Many protestors drew parallels with Down's Syndrome which is being screened out of the population with around 90% of babies found to have Down's Syndrome in the UK being aborted (Don't Screen Us Out, n.d.). At the time of writing the £3 million Spectrum 10K study has been paused for further consultation.

Interventions. Theories based on the medical model of disability are integral in the development of many educational and psychological interventions for autism. Interventions have been designed and tested that aim to support autistic children to develop skills in a wide range of areas; for example, there are programmes to improve social skills (Gates et al., 2017) and to increase eye contact (Fonger & Malott, 2019). What many interventions have in common is that they are not designed in collaboration with autistic people and often have an ableist agenda in which the research assumes that autistic traits are undesirable and need to be changed (Milton, 2014b). These intervention approaches work on the assumption that it is the autistic person who must adapt to their environment rather than considering how the environment could be better designed with their needs in mind.

The most contentious interventions used with autistic children are based on the principles of Applied Behavioural Analysis (ABA) (Lovaas, 1977). ABA is described as 'the science in which the principles of the analysis of behaviour are applied systematically to improve socially significant behaviour and experimentation is used to identify the variables responsible for behaviour change' Cooper et al. (2013). ABA is an approach widely recommended as the most scientifically proven method for changing behaviour (Dillenburger et al., 2020; Wong et al., 2015). Training programmes based on ABA principles include 'discrete trial training' which breaks down behaviours seen as desirable into simple steps and rewards children for completing each step. An example of this could be for a child to sit still in their chair and complete a colour-matching task such as putting the blue marble in the blue cup. Each time they succeed they are rewarded with a preferred activity, toy, or food. If they fail, they receive a negative response such as an object being taken away. This training can be for up to 40 hours per week for as many as two years (Smith, 2001). As such, ABA is time and money intensive and is considered by many autistic adults who have experienced it as a child, to be cruel and harmful (Cumming et al., 2020; Kirkham, 2017). Although the use of electric shocks (Burkholder, 2014; Cumming et al., 2020) and the withholding of food (Kirkham, 2017) used in the early days of the intervention are no longer part of the programme, the intensity of the therapy can be very distressing to experience (Marie, 2020; Sequenzia, 2015). A further criticism levelled against ABA is the focus it has on reducing what are deemed 'undesirable' behaviours such as vocal or physical stimming (self-stimulatory behaviours including hand flapping) in favour of more supposedly desirable behaviours such as sitting still and maintaining eye contact (Zurcher, 2012). In direct contrast to these assumptions, stimming is a useful adaptive mechanism that can be calming, self-regulating, and a way of expressing emotions for autistic people (Kapp et al., 2019). Moreover, being forced into behaviours such as maintaining eye contact can cause unpleasant physiological reactions for autistic people (Trevisan et al., 2017). The notion of a therapist deciding what constitutes positive behaviour is also problematic as often this will equate to behaviour that masks autistic self-expression (Milton, 2014b).

The views and opinions of autistic people themselves are largely missing from research based on the medical model of disability. As stated in Chapter 1, my focus is to actively challenge the dominant narrative of the medical model through including the voices of autistic people at the centre of this research. Therefore, I do not align myself or my research with the medical model, preferring instead the social model of disability that will be discussed below.

2.1.2 The Social Model of Disability

The social model of disability sees the individual as being disabled by the society in which they live rather than by impairments located within the individual. Oliver (1992) described how disability ‘does not exist outside the social structures in which it is located and independent of the meanings given to it’ (p. 101). An example would be that a wheelchair user would be disabled by living in a house with many different levels, and narrow doorways. This person would be likely to need assistance with day-to-day tasks. If, however, this person was to live in a house designed appropriately for their needs, they would no longer be disabled by their environment and could be more autonomous. For an autistic person, an example of a disabling environment could be office spaces designed with an open plan layout, poor acoustics and harsh lighting as opposed to spaces designed to support those with sensory needs (Gaines et al., 2016).

In the 1960s, disabled people in the United States, inspired by what they saw happening with the civil rights movement, started to connect and campaign for their rights (Ward & Meyer, 1999). A predominant argument was that, for too long, they had been seen through the lens of the medical model of disability and by campaigning for issues such as accessible public spaces, disabled people in both the United States and United Kingdom, began to assert their rights to self-determination (Barnes, 2003). Oliver (1986) outlined a theory of disability which proposed that social policy should no longer assume that disability is a ‘personal tragedy’ (p.12) and instead focus on offering disabled people the support they need to fully integrate in and contribute to society.

Development of autism rights groups came about rather later. For example, Jim Sinclair, an autistic self-advocate, wrote about the creation of the group Autism Network International (ANI) (Sinclair, 2005), which came about through a group of autistic people meeting at a conference aimed at parents and professionals. Although ANI started with a chance meeting, it grew thanks to the possibilities offered by online media. Sinclair (2005) reflected on the important part played by the development of the Internet to allow the group to set their own agenda. The importance of the Internet in supporting autistic people to communicate with one another and self-advocate was also highlighted by Bagatell (2010) who described how, for some autistic people, communicating using a keyboard rather than verbally has been liberating. This, alongside the freedom of communication offered by online platforms, has enabled autistic people to form strong communities and provide their own perspective to autism discourse. This reflects the slogan used by disability rights activists of ‘nothing about us without us’ (Chown, 2017). Autism self-advocacy groups largely support the social model of disability and advocate accordingly. For example, ANI’s mission was to promote civil rights and self-determination from the perspective of autistic people themselves rather than as part of an organisation led by parents (Sinclair, 2005).

In criticising the medical model of disability, autistic advocates and supporters consider the implications of research practices and directions for autistic people. Studies which include autistic people in their design, and which seek to improve the lives of autistic people are prioritised (Ne’eman, 2020; Pellicano et al., 2013). Accordingly, Robertson (2010) argued that the medical model of autism takes autistic strengths such as rational thinking and conceptualises them as deficits by focusing on how this way of thinking can be a barrier to social interaction. Moreover, Savarese and Savarese (2010) highlighted how positivistic research fails autistic people, citing research by Dawson et al. (2007) which showed that autistic children were assumed to have learning difficulties due to low IQ scores based on the Weschler Intelligence Scale for Children (WISC). When the same children were tested using the Ravens Progressive Matrices test (Raven & Raven, 2003), a non-verbal test of abstract reasoning which was more suited to their strengths and abilities, their scores significantly increased, some by as much as 70%. This was not the case for non-autistic children. This research was spearheaded by Michelle Dawson, an autistic researcher who had expressed concerns with the WISC as a measure of intelligence. This study, as Savarese and Savarese (2020) argued, is an excellent example of how ‘nothing about us without us’ works and reinforces the importance of including autistic voices in research. Dawson et al.’s (2007) research supported the assertion that autistic people’s way of thinking is different, not deficient (Lowndes, 2018). In support, Hens et al. (2018) critiqued whether it was possible to study such a heterogenous concept as autism at all, given the inter-individual expression of autism across different people. This forms the basis of the argument made by many advocates of the social model of disability, that autism is a natural variation that should be recognised and respected in the same was as any other human difference (Jaarsma & Welin, 2012). In other words, rather than autism being defined and constructed as a pathological condition it is, instead, a neurodivergence, as discussed next.

2.1.3 The Neurodiversity Paradigm and Movement

The neurodiversity paradigm considers autism and other conditions such as ADHD and dyslexia as a natural neurological variation (Legault et al., 2021). Rather than a set of deficits, autism is instead framed as a neurological difference which recognises both the strengths of autistic people as well as with the challenges they may face. The term 'neurodiversity' was first coined by Judy Singer, an autistic sociologist whose thesis argued that those whose minds worked differently were oppressed and marginalised in the same way as women and gay people (Singer, 1998). Rather than considering autism as a developmental deficit (Rutter, 1972: Van Krevelen, 1971), Singer (1998) argued that autism should be seen as a part of an individual's identity. Neurodivergent activists reject the search for prevention or cure that was the biomedical research focus for most of the latter half of the 20th century (Bagatell, 2010; Hens, 2018; Nicolaidis, 2012; Savarese & Savarese, 2010). Instead, activists and advocates prefer to focus on providing a supportive framework in which adaptive functioning is emphasised while interventions that prevent behaviours such as stimming to meet social norms – are rejected. (Kapp et al., 2013).

Positive implications of the rise of the neurodiversity movement have been seen in studies such as that by Griffin and Pollack (2009) who interviewed neurodivergent higher education students in the UK, finding that those who self-identified as neurodivergent rather than disabled, were more ambitious and had greater self-esteem. Kapp et al. (2013) conducted an online survey of 657 people in the UK and the US and found a link between knowledge of neurodiversity and positive views of autism. This was true of relatives and friends of autistic people, members of the public with no connection to autism, and autistic people themselves. This suggests that awareness of neurodiversity is beneficial in re-framing perceptions and understanding of autism.

While identification of links between recognition of neurodiversity and positive views of autism is positive, there are more complex ethical reasons why viewing autism as a difference rather than a deficit is important. Medical model-inspired theories, which suggest autistic people lack Theory of Mind (Baron Cohen, 1989; Frith & Happe, 1994) or empathy (Lombardo et al., 2007), imply that autistic people are 'lesser than' non-autistic people. Research into the genetic markers that identify autism could allow for the termination of pregnancies or the development of interventions that propose to 'cure' autism (Hens et al, 2018). Barnbaum (2008) argued in her book 'The Ethics of Autism' that, if autistic people do not have a Theory of Mind, they should be considered separately from the neurotypical population in determining the ethical implications for their involvement in biomedical research. Autistic advocates argue that stances such as these are akin to eugenics or conversion therapy purporting to change sexual orientation (Ne'eman, 2010; Savarese & Savarese, 2010) and, therefore, are not supportive of the neurodiversity paradigm which argues that all brains differ and there is no one ideal way of being.

The neurodiversity movement is not without controversy. The question of how successful it is at representing all members of the autistic community is an ongoing debate (Russell, 2020). Jaarsma and Welin (2012) argue that neurodiversity should only apply to 'high functioning' autistic people and that other authors' claims that autistic people are 'not handicapped or pathological' (p. 23) are problematic. Fenton and Krahn (2007) seek to divide people by levels of functioning with pathological status only being ascribed to 'low functioning' autistic people. This to some, would preclude 'low functioning' people from being included in the neurodivergent community (Russell, 2020). These views are countered with the idea that the neurodiversity movement is one which focuses on strengths rather than deficits and that, as a vehicle for self-advocacy and promotion of the social model of disability, it can support all autistic people including those with co-occurring intellectual disabilities (Nicolaidis, 2012).

Neurodiversity is not a paradigm supported by all members of the autistic community. Jonathan Mitchell (2019), who describes himself as being 'affected by the disability autism' (para. 1), argues that members of the neurodiversity movement are threatening scientific research that may offer him a cure for what he sees as an 'affliction' (para. 3) by exerting dominance over the autism discourse and not representing the voices of those who are unable to speak or use a computer to argue for themselves. Savarese and Savarese (2010) recognised the complexity of the argument but contended that by acknowledging the heterogeneity of autism and supporting the sharing of voices of autistic people and their advocates, following a neurodiversity paradigm is more likely to move the debate, and research, on.

What both the neurodiversity movement and the social model of disability share is the perspective that people should be empowered based both on their individual strengths and interests and not limited by their differences, especially the assumptions of other people about those differences. To promote empowerment the autistic community should be central to any research involving them. This is an ethos that underpins this thesis: the inclusion of autistic voices wherever possible.

2.1.4 The Importance of Autistic Voices in Research

Including the voices of autistic people in research is imperative to ensure that research is relevant and acceptable to the target community (den Houting et al., 2021). Many autistic people wish to become more involved in research (den Houting et al., 2021; Pellicano et al., 2014a) and it is important to include autistic voices not only due to the benefits it can offer to the individuals who participate, but also to ensure that research focuses on the issues deemed relevant to the wider autistic community (Pellicano et al., 2014a). For these ideals to be met, reflection on whether voices are being heard in an active and productive way rather than as passive participants is important. A key challenge to ensuring that autistic voices are represented is to recognise the heterogeneity of the voices that should be heard, given the diversity of the autism spectrum. For inclusion to be meaningful, a range of autistic voices must be included (Milton & Bracher, 2013). This challenge is recognised by Cascio et al. (2020) who reflected that people with disabilities are often viewed as representations of their diagnosis rather than as individuals with differing experiences. Cascio et al. (2020) outlined differences that impact how a person experiences the world such as level of support needs, age, and sex and gender and identify that these intersectional characteristics are substantially under-reported in autism research.

Under-representation is also apparent in the dearth of research which promotes the voices of autistic children. Despite funding for research about autistic children being higher for that of adults, it is autistic adults who are most represented in active participatory research and, therefore, the most likely to have the opportunity to have their voices heard (Warner et al., 2016). Article 12 of the United Nations Convention on the Rights of the Child outlines all children’s right to be heard (The United Nations, 1989). Lundy (2011) argued that it is easy for this right to become tokenistic and proposed a model based on four concepts: space – the opportunity to express a view; voice – support for stakeholders to express their views; audience – views must be listened to; and influence – where applicable, views should be acted upon. This framework provides a strong challenge to researchers to ensure that children’s voices are valued and heard in non-tokenistic ways. Moreover, to enable autistic people with differing support needs to engage with the research process, it is necessary to ensure that accommodations are put in place to support their participation (Winstone et al., 2014). These accommodations must be tailored for the individual, be flexible and can benefit from the inclusion of creative methods which encourage the sharing of voices of those with differing communication preferences (Parsons et al., 2020).

Therefore, whilst my research has autistic pupils as its focus, it is important to note that it does so within a particular political, ethical, and practical viewpoint. Through conducting this research I aimed to discover ways to improve the support for autistic children in schools. As such, I sought to be reflexive about the moral and ethical implications of my practice and to consider how my experience as a teacher influenced the way I approached all elements of the project. The notion of autistic differences rather than deficits was central to my thinking, and I strove to promote the voices of autistic people at every opportunity. The next section provides the context and rationale for my own focus on the voices of autistic girls specifically within this space.

2.2 The Missing Voices of Autistic Girls in Research

Most representations of autism in the media involve white men with noteworthy skills such as Sheldon in the Big Bang Theory with a career in particle physics or Dr Shaun Murphy in The Good Doctor who can visualise complex medical diagnoses. While it is beneficial to include autistic characters in popular media, the danger is that by predominantly representing white men, people of colour and women are further marginalised (Burkett, 2020; Gambacurta, 2020; Kataja. 2020). While racial representations are beyond the scope of this research, a discussion on the importance of considering the experiences of autistic girls and women will now follow. This will include the implications for diagnosis, the differences in autistic traits regarding friendships, camouflaging and intense interests, and finally how this impacts representation in - and implications of - research.

2.2.1 Identification and Diagnosis of Girls and Women.

The traditional view that autism is a condition that affects mainly males (Baron-Cohen et al., 2011) has been challenged in the last decade (Lai et al., 2015). When comparing those referred for clinical assessment, the ratio is usually at least 4:1 (males to females), whereas in a population sample the numbers are around 2 or 3:1 (Bargiela et al., 2016; Kim et al., 2011) suggesting that the number of females referred for, or receiving, a diagnosis of autism is unrepresentative of the actual numbers living in the community. Therefore, autistic girls and women are being missed both in the provision of support and in research (Lockwood Estrin et al., 2020). Other evidence shows that girls are less likely than boys to meet diagnostic criteria for autism unless they have significantly higher additional needs, which could suggest there are girls with average or above IQ being missed (Dworzynski et al., 2012; Lai et al., 2015, Moyse & Porter, 2014). Begeer et al., (2013) conducted a study in the Netherlands which found that, in a sample of 1,354 children, fewer girls than boys were diagnosed with Asperger's syndrome but not with autism. Asperger's Syndrome was a condition which shared traits with autism in the DSM-IV-TR (APA, 2000) but was associated with higher levels of cognitive ability. Asperger Syndrome has been subsumed as part of the wider classification of 'autism spectrum disorder'. Begeer et al.'s (2013) study supports the assertions that girls with higher IQ are being missed for timely diagnosis. However, one of the limitations of the study was the imbalance between boys and girls who participated with a total of 1,150 boys and 204 girls. Furthermore, females are likely to receive their diagnosis later than males, particularly if there is no co-occurring cognitive impairment (Hiller et al., 2014; Lai et al., 2015). Rutherford et al. (2016) found the ratio between boys and girls changed with age, suggesting that as the ratio was smaller in adolescents than younger children: girls were being diagnosed later. Girls presenting with an intellectual disability are less likely to be considered for an autism diagnosis than males due to the under-recognition of autism in girls (Giarelli et al, 2010; Rutherford et al., 2016). Cridland et al., (2014) looked at the experiences of autistic girls from their own and their mothers' perspectives and found that there was a reported reluctance by health professionals to provide a formal diagnosis. Additionally, mothers said that their experiences were more difficult for their daughters than those of friends with autistic sons. It is important that diagnostic criteria are sensitive to autism in males and females to avoid under or misdiagnosing autistic girls.

A systematic review looking at the barriers to diagnosis for autistic young women and girls (Lockwood Estrin et al. 2020) identified six factors which included girls displaying better social and communication abilities, more exaggerated behavioural difficulties being needed to diagnose girls, and girls showing fewer restrictive and repetitive behaviours. Equally concerning was the perception of autism as a male disorder. Indeed, Lockwood Estrin et al. (2020) argued that:

> 'These current male-centric ideas of autism are detrimental to access to diagnosis and support for autistic females and their families. For any large strides to be made regarding access to services for females, the general public, as well as clinician perceptions of ASD being a male disorder will need to change.' (p. 468)

Diagnosis is important as timely identification enables access to the accommodations or associated services that can support learning and emotional needs (Begeer et al., 2013; Cridland et al., 2014; Rutherford et al., 2016). Moreover, earlier diagnosis can help autistic girls to foster a positive sense of identity and help others around them to respond appropriately to their needs (Bargiela et al., 2016). The implications of a lack of appropriate support include difficulties in engaging with school (Moyse, 2021). Moyse (2021) conducted a qualitative study with autistic teenage girls who were not attending school and found that their lack of attendance was not a rejection of education, but a reaction to the lack of support and understanding they received. Moreover, autistic girls were more likely to be identified as persistent absentees than autistic boys and also more likely than non-autistic girls and boys to be identified as such (Moyse, 2021). This suggests the lack of timely identification and support may disproportionally impact on autistic girls' ability to access education. To provide appropriate support it is important to consider what the differences may be and the implications for identification and provision of resources.

It has been proposed that disparity between the identification of autism in males and females is due to a distinct autism 'phenotype' in women (Bargiela et al., 2016, p. 3281). Evidence to support this includes studies that suggest that autistic girls have a higher level of motivation and skill when it comes to relationships, both with friends and romantically (Lai et al., 2017; Sedgewick et al., 2016; Tierney et al., 2016). A systematic review and meta-analysis conducted by Wood-Downie et al. (2021a) found that autistic girls and women were more successful at both social interaction and social communication skills than autistic boys and men. Furthermore, research suggests that autistic girls and women are found to use camouflaging behaviours to mask their autism at higher rates than autistic boys and men (Lai et al., 2017; Wood Downie et al., 2021b). Furthermore, there is evidence that autistic girls display fewer of the stereotyped repetitive behaviours that are seen in boys (Hartley & Sikora, 2009; Hiller et al., 2014), and their intense interests are more socially focused (McFayden et al., 2019) and therefore not recognised as an autistic trait.

2.2.2 Representation in Research.

Given the imbalance outlined above between girls and boys in identification and diagnosis, it is perhaps not surprising that women and girls are under-represented in research. Watkins et al., (2014) conducted an analysis of research articles involving autistic participants published between 2010 and 2012 and found that, of 607 articles, 82.21% included both male and female autistic participants, 17.3% included male only and 0.49% included female only. When looking at participants in intervention studies, 85.85% were male. This number reflects a ratio of six males to one female, far higher than the estimation of the ratio in the general population (Bargiela et al., 2016; Kim et al., 2011). The lower number of autistic women and girls within studies also influences the statistical power to identify gender differences (Lockwood Estrin et al., 2020). This picture is not reflected in all areas of research, however. Some research into the experiences of autistic individuals with mental health problems shows a different picture, possibly due to the higher levels of internalising problems identified in autistic girls and women (Solomon et al., 2012) or men's reticence to talk about mental health (Stiawa et al., 2020). For example, Cassidy et al.'s (2018) study into risk markers for suicidality in autistic adults included 65 autistic male and 99 autistic female participants. Camm-Crosbie et al. (2019) looked at the mental health support of 77 males and 122 females. Both studies recruited from the Cambridge Autism Research Database in the UK and did not specifically target women.

Considering the differences outlined between autistic males and females, the importance of researching and reporting on the experiences of autistic women and girls is clear. Without this focus girls will continue to be underdiagnosed or receive diagnosis later (Loomes et al., 2017; Moyes, 2021). Moreover, girls are more likely to miss out on receiving appropriate support and services both in education and beyond (Cridland et al., 2014). The implications of this can be very detrimental, from exclusion from school (Moyse, 2021) to becoming victims of abuse (Bargiela et al., 2016). My research, therefore, focused on the experiences of autistic girls in education and used their stories to offer support to other autistic girls. To achieve this, the research was conducted within a participatory framework for which a definition and exploration follows.

2.3 Participatory Framework

The term 'participatory' as regards to research methods covers a variety of approaches, however den Houting et al. (2021) argue it 'means working together with the community that is affected by research to make decisions about that research' (p. 148), while Cornwall & Jewkes (1995) define it as 'primarily differentiated from conventional research in the alignment of power within the research process (p. 1668). Participatory research is important because it aims to construct knowledge with the community in question to provide active solutions to problems in a way that addresses the power imbalance in research. It is therefore, of direct benefit to that community.

Within education research, a participatory framework can help bridge the gap between theory and practice by drawing on the knowledge and expertise of school staff and pupils (Guldberg et al., 2017). The assumption that academic knowledge should be applied *to* educational practice is problematic as it disregards the knowledge and expertise of those working within education (Parsons, 2021). On the contrary, adding the views and experiences of those with lived experiences to research can be transformative, meaning that work that is co-constructed or collaborative can provide a valuable contribution to the generation of knowledge (Parsons, 2021). Moreover, incorporating the voices of the community can provide them with power over the knowledge generated and how that can be translated into practice.

The impact of the power dynamic between researcher and researched is a further consideration in developing a framework for research. In most research designs it is the norm for academics to make the decisions about what should be researched and how, and for the community members to act as providers of data (den Houting et al., 2021). Participatory research can provide a more even balance of power by giving participants ownership and decision-making capabilities in the research process, but it is not guaranteed. Den Houting et al., (2021) considered the differences between perceptions of participatory autism research from the perspectives of academics and autistic participants, finding that while support from both academic and autistic communities for participatory projects was high, the experience of being involved in these projects did not always meet expectations. Co-researchers reported not being invited to planning meetings, and accommodations to support the engagement of the autistic community partners were insufficient.

The challenge is to ensure that autistic voices are included in research in a meaningful way which requires consideration of the balance of power within the research process. This challenge has been addressed by Chown et al., (2017) who included autistic academics as well as a group of lay autistic adults and which developed a draft framework to conduct inclusive research both with, and for, autistic people. The framework addressed the importance of autistic voices being heard in all stages of the research process as well as the consideration of the social model of disability in how challenges for autistic people are addressed. For example, the research focus should be identified by a researcher or research team which includes members with lived experiences of autism, the outcomes of the research should concentrate on improving the lives of autistic people, and the research should be owned in part, by the autistic community. Furthermore, Nicolaidis (2019) reflects not only on the importance of involving autistic participants in research within an inclusive participatory framework, but also of encouraging and supporting autistic young people to enter the world of academia themselves.

While there has been an increase over the past 20 years in the number of studies utilising participatory research with children, there are still methodological challenges to overcome, particularly around how to engage vulnerable children in research and support their contribution (Bradbury-Jones et al., 2018). Fletcher-Watson et al. (2019) wrote about a seminar series organised by autistic and non-autistic people which sought to develop a framework to support meaningful participation in autism research which could help to overcome some of the barriers to participation. Although the outcomes of this work are not specific to children, they are applicable to working with any autistic community. Five topics to consider when developing participatory research were proposed: *respect* in the way lived experiences are presented, *authenticity* in representing the research agenda, *assumptions* about autism which are incorrect should be challenged, *infrastructure* to allow for the inclusion of autistic people and *empathy* for all members of the research team, autistic and non-autistic. This thesis will consider these topics to strive for meaningful participation for the autistic children involved.

While there are many challenges faced by autistic young people in education that warrant exploration, in keeping with the focus of ACoRNS (Parsons & Kovshoff, 2019), this research focuses on the impact of the transition between primary and secondary school. A review of the literature regarding transitions now follows.

2.4 Challenges of Transitions in Education

Within education, transitions are often characterised by large systemic changes in setting, for instance between early years settings to primary school, from primary to secondary and from secondary to further educational college. Smaller transitions, including travelling from home to school, classroom to playtime, or between activities in class are also inherent to most education systems. It is important to ensure children and their families do not experience anxiety because of insufficiently targeted support to navigate these transitions (Nuske et al., 2019). Although the larger educational transitions between school systems are likely to result in a certain level of stress and anxiety for most children (Jindal-Snape et al., 2020; van Rens et al., 2018; Schlossberg, 2011), the impact can be more challenging for some children and create more significant disadvantage due to failure to recognise where support is needed (Evangelou et al., 2008;). This may be particularly true of autistic children who are most successful when they are provided with clear structure and routine (Martin et al., 2021; Neal & Frederickson, 2016) and find unpredictability – common during transitions – induces anxiety (Clark & Adams, 2020a). There are, however, strategies that can alleviate the difficulties associated with transition, such as pre-transition visits and good home-school communication (Hoy et al., 2019; Neal & Frederickson, 2016).

A systematic review looking at both the difficulties of transition, and the strategies that can be used to support successful transitions for autistic children was conducted by Nuske et al. (2019). The review took into consideration transitions to both primary and secondary schools and encompassed 27 studies overall with 17 examining the primary to secondary transition. By focusing on the difficulties that autistic children may face during transitions, suggested strategies focus on supporting the child navigate problems and lack focus on how to nurture their strengths. A lack of consideration of strengths-based approaches is unfortunate. A further consideration about the value of this systematic review centres on the balance of participants. The data included comes from 546 teachers, 453 parents and only 443 children; in other words, two-thirds of the data came from adults rather than autistic children. With pupils' voices accounting for less than a third of the data over these studies, there seems to be a disconnect between our understanding of how children experience these transitions and who makes suggestions for supporting them. These are issues that Stack et al. (2021) sought to address in their systematic review.

Stack et al. (2021) reviewed studies focusing on the primary to secondary transition which specifically included the perspectives of autistic children. Examining the results of nine studies, Stack et al. identified common themes and drew up some suggested implications for practice for these themes. Some of these suggestions seem helpful, such as that the children did not appreciate activities like sitting in a circle and talking about their worries, as they preferred to focus on the positive aspects of the transition. Other suggestions seem less constructive such as the assertion that - because the children emphasised the importance of kindness in their teachers – 'even teachers without specialist education in ASD can help support these children at transition' (p. 7). This seems to underestimate the impact of inadequate transitions and to lack ambition for our autistic children. I would argue for kind teachers who also have a good working knowledge of providing quality education for autistic children. This is an approach which is championed in the Good Autism Practice report (Guldberg et al., 2021) and by the All Party Parliamentary Group for Autism (APPGA., 2017), which both emphasize the importance of all teachers receiving training on how to support autistic children in their schools.

What both these systematic reviews tell us is that the transition from primary to secondary school is a particularly challenging one for autistic children (Boulter et al., 2014; Makin et al., 2017; Tobin et al., 2012). This section will include consideration of what is known about the impact of the primary to secondary transitions for autistic children. Firstly, the impact of the school environment and strategies to support autistic children to successfully adapt to it will be considered. Secondly the importance of the social aspect of the transition and the importance of school connectedness will be reviewed and strategies to encourage successful transitions will be outlined. Finally, the potential implications of poor transitions will then be discussed.

2.4.1 Challenges of the Secondary School Environment and the Importance of Communication

Secondary schools differ from primary schools not only in terms of the physical structure of the school, but also the way the school day is organised. The average size of a primary school in England is 281 pupils whereas the average number of pupils at secondary school is 986 (DfE, 2021). Accordingly, secondary school campuses are bigger and busier, and there is stepwise increase in the number of new pupils and school staff that a child will encounter. In contrast, primary school children will often have one teacher (with the same teaching support staff) who will cover most of the curriculum and the majority of time will be spent with the same adults, the same peers, and in the same classroom. By contrast, each teacher a child encounters at secondary school may have different methods and expectations and the differences between the rooms encountered will often mean changing rules to suit the space. The expectations of children will also increase with the necessity to remember specific equipment for different lessons that are scheduled on different days, and to organise homework to be completed and submitted to a deadline. All these changes can be challenging, and this is reflected in the views contributed by autistic children, parents, and staff members to research into this demanding period (Nuske et al., 2019; Stack et al., 2021).

Communication between home and school needs to begin early to ensure children are given time to prepare for the new environment (Nuske et al., 2019). It is important that communication is based on positive and practical information (Neal & Frederickson, 2016). One important practical concern is about what the school looks like and its layout. At secondary school children move between classrooms for lessons. These classrooms are often housed in different buildings, often with very different features as many schools in the UK have grown over time, resulting in a combination of some traditional buildings and some more modern. This may result in changes of light levels and sources, temperature, and acoustics, changes which autistic children with hypersensitivities may find very challenging (Black et al., 2017). Prior visits to the school can prepare children for these changes as can visual cues, such as photographs to prepare children for their changing environment (Dixon & Tanner, 2013). But these will only go some way to preparing children for spending seven hours per day, five days per week engaging with these environments. Moreover, many autistic children report that anxiety at school is exacerbated by unfamiliar routines and unpredictability (Clark & Adams, 2020a).

Preparing for new situations and being given the opportunity to practice in advance has been reported by parents to ease school-based anxiety (Adams et al., 2019). In support, Dixon and Tanner (2013) conducted interviews with two boys aged 14 and 15 with a diagnosis of Asperger's Syndrome, their parents and teachers, and reported the importance of receiving maps and undertaking visits prior to transition. These practices are common and easy to achieve with many studies supporting the importance of visits (Evangelou et al., 2008; Makin et al., 2017) and the benefits of early sharing of information (Coffey, 2013; Dann, 2011; Jindal-Snape & Foggie, 2008). The importance of familiarisation that can be achieved by pre-transition visits was also identified by Hoy et al. (2018) in a study employing photo-voice methods with secondary aged autistic pupils, their parents, and teachers who were all asked to reflect on strategies that supported autistic students' transition to secondary school. One of the children expressed the importance of preparing autistic children for the environment they are moving into which could include school tours and the opportunity to meet teachers in advance. Parents and teachers identified the importance of visits but also of having visual supports such as photographs of the school and key staff members for their child to refer to in the lead up to the transition. This supported earlier research by Neal and Frederickson (2016) who reported that children appreciated being given information on paper as well as visits so they could refer to it again. Both Hoy et al. (2018) and Neal and Frederickson (2016) focused their research on speaking directly to autistic children about the experiences they encountered. This contrasts with research looking at the transition from the perspective of teachers (Deacy et al., 2015) or parents (Peters & Brooks, 2016; Stoner, 2007) which do not represent the views of those experiencing the transitions themselves and therefore provide only partial data about transitions experiences and strategies. The experience of many autistic children in school is one of poorly designed spaces that do not meet their needs (McAllister & Sloan, 2016), and unfortunately the most organised transition visits cannot make up for environments that are poorly designed for the sensory needs of autistic children.

Hoy et al. (2018) reported that communal areas of secondary schools can be challenging for autistic students. Some children expressed dislike for break and lunchtimes due to the noise and busyness of the school but valued having the learning support base as a safe space they could use to avoid crowds and noise. Similarly, Peters and Brooks (2016) conducted questionnaires with parents of 14 male and three female autistic pupils in year 7 or 8 in England and reported that the biggest periods of anxiety during the transition period were during break and lunch times, the changeover between lessons and the commute to school. These concerns can be effectively addressed by easily implementable practical solutions, such as designated quiet areas that the children can use during unstructured times or through allowing children to leave lessons a few minutes early to avoid the crowds (Peters & Brooks, 2016; Hoy et al., 2018). A limitation of Peters and Brooks' (2016) study is that they only questioned parents and so their findings may not represent the views and opinions of the autistic young people themselves.

Research also highlights that communication and familiarisation with the organisational elements of the new school - such as timetabling, layout of the school, and managing homework - are a priority for incoming parents and children (Nuske et al., 2019). However, the often-challenging procedures involved in obtaining a suitable school placement for a child with SEN means that many families do not receive confirmation of their allocated school in time for this communication to take place (Makin et al., 2017). This can be very difficult for all involved and can lead to heightened anxiety for parents and children. Moreover, many parents report feeling overwhelmed by the experience of the process of choosing a school for their child (Nuske et al., 2019). For many parents, the choice of schools available is limited due to geographical area or financial difficulties (Tobin et al., 2012). The APPGA alongside the NAS published a report on how autistic children and young people were served by the education system in England (APPGA & NAS, 2017). 65% of the 2,573 parents who responded to the enquiry said they had not received enough information and support for them to make an informed decision about what was best for their child (APPGA & NAS, 2017). A result which replicated an earlier finding from Parsons et al. (2009) which found that parents of autistic children were likely to be less satisfied about information and choice in choosing schools than parents of children with other special educational needs. For transitions to run smoothly, school placements, and therefore communication between school and home, must be implemented as early and thoroughly as possible. Similarly, the school also needs to consider and plan support for individual children's needs to ensure families and children feel confident to navigate the physical and sensory implications of a larger and busier environment (Nuske et al., 2019). It is not sufficient, however, to merely prepare children for dealing with difficult environments: every effort also needs to be made to ensure schools are designed in a way that support children with different sensory needs (McAllister & Sloan, 2016). Crucially, the impact of a school environment is not just created from the bricks and mortar, the people within the school also have an important role to play in supporting autistic children through and beyond the primary to secondary transition and these people are considered next.

2.4.2 Challenges in Friendships and School Connectedness.

Social connection and friendships are important to children and the integral part relationships play in the primary to secondary transition are important for designing successful transitions for autistic children (Deacy et al., 2015; Evangelou et al., 2008; Makin et al., 2017). The significance of friendships in the transition process was highlighted in a study that interviewed 15 autistic children, their parents, and their teachers, asking them to reflect on their transition experiences (Makin et al., 2017). The children identified friendship as a priority in supporting them to feel confident with the transition process, and the process of making new friends after the move was the cause of their biggest concern as well as something they were excited about. In other research, children reported on the importance of remaining with friends from primary school in their new secondary school, but also on the importance of making new friends (Neal & Frederickson, 2016). Neal and Frederickson's (2016) research focused on the positive aspects of transition and reported that the larger number of pupils in secondary schools made it easier for autistic children to find friends. Parents also recognise the importance of friendships. For example, Dann's (2011) study involved interviews with six autistic pupils including five boys and 1 girl, their parents and school staff, and described a family who decided not to place their daughter within her secondary school's specialist autism provision as she would have been the only girl. Instead, they requested her needs be met within the general school SEN provision where she made her first friendship and was very happy at school.

Relatedly, Hebron (2018) conducted a study looking at how school connectedness or belonging can be a positive factor in determining how successful a primary to secondary transition will be for autistic children. School connectedness is described as 'the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment' (Goodenow, 1993. p. 80). As well as friendships with peers, school connectedness therefore incorporates the relationships formed with staff members and how accepted and included children feel in the wider school community and environment. Using the Psychological Sense of School Membership questionnaire (Goodenow, 1993), which was administered at the end of year 6, the end of the first term of year 7, the final term of year 7, and the end of the first term of year 8, Hebron (2018) found that both autistic children (n=23) and a non-autistic (n= 21) comparison group showed positive levels of school connectedness throughout the transition period, but the autistic group's levels were lower throughout. Of particular interest was the finding that, while the non-autistic group's school belonging levels fell gradually over the transition, for the autistic children there was a marked increase in belonging from the first term to the end of Year 7. Although the reasons for this are unclear, Hebron (2018) hypothesised that that the secondary school routine, once established, may have provided a more structured environment which may have suited the children more than the fluidity of primary school. Nevertheless, the study did not include any qualitative measures which may have helped to explain the findings.

An increase in school connectedness at secondary school may also be linked with a reduction in bullying behaviours towards autistic students as evidence suggests there is a decrease in bullying of autistic children after the first term of secondary school (Mandy et al., 2016b). According to parents using the Schwartz Peer Victimisation Scale (Schwartz et al, 2002,) which was adapted for parent use, Mandy et al. (2016b) reported an overall reduction in overt bullying including name-calling, teasing, and being excluded from conversations and activities. Whether autistic children concurred with their parents' view in this study is unclear therefore this result only offers a partial view of the situation with regards to changes in peer victimisation. It is possible that with the onset of teenage years, information about peer victimisation may be not shared so readily with parents.

With both the physical school environment, communication between home and school and peers and teachers all playing an important part in the success of transitions, it is important to consider how these can be used as part of specific, inclusive interventions to support autistic children at this time.

2.4.3 Inclusive Strategies to Promote Successful Transitions

Effective strategies to support transitions can be found in everyday classroom practice, for example visual timetables (Hoy et al., 2018; Stoner et al., 2007). These are widely used in primary schools and allow children to see visual representations of the activities they will be undertaking each day in chronological order. These are often placed in a prominent place in the classroom and accessed by all children in the class, therefore becoming part of the general routine rather than being a specific intervention for a specific child. By supporting the child to access a visual representation of their day, some of their anxiety can be alleviated (Martin et al., 2021). A similar strategy for transitions between schools is to use pictures, videos, or virtual walk-throughs of the new school and the transition process to increase familiarity with the new school setting and staff. For example, schools who were unable to offer in-person transition visits during the Covid-19 pandemic created virtual tours of their school site and these have been integrated as part of their regular transition package (see https://www.whatsitlike.co.uk/user/75 and https://www.northgate.norfolk.sch.uk/year-6-transition/ for different approaches to this). While these can be useful to introduce a child to their new environment, they do not solve potential problems with that environment, such as excess noise or changing expectations from different teachers. Use of virtual tours alone responds to the child's difficulty at accessing new environments, rather than the potential unsuitability of that environment: thus addressing the medical rather than social model of disability. As part of a wider package of measures it is possible for virtual tours to address both.

Another visual tool that can be created with young people are Social Stories (Gray & Garand, 1993). Social Stories can be written with young people to guide them through the stages of a novel situation they are facing. They may help the child to feel secure as they offer structure and predictability and an opportunity to talk through and visually represent an unexperienced situation before it occurs (Briody & McGarry, 2005). Social Stories can also be helpful as part of a transition support strategy as they can guide a child through some of the expectations of their new school environment and offer them personalised approaches to deal with new situations they may face

(Martin, 2021). But again, used in isolation, they can reinforce the medical model by placing the burden of change with the child, rather than the school.

It is important to include children in transition planning. Neal and Frederickson (2016) reported that the children they interviewed about their positive transition experiences valued being involved in the process of gathering information about their new school. Strategies work best when tailored to the children's individual needs and combined into a package of transition support (Nuske et al., 2019), however, it is also important to consider that the success of transition should not be determined by a child's ability to adapt to the new environment, rather than adapting the environment to the child. Information and training should also be provided to the teachers and other school staff to ensure that they are offering support and understanding (Richter et al., 2019; Tobin et al, 2012). It is also imperative that staff training, and supports put in place, are individual to the needs of that particular child (Dann, 2011; Hughes et al., 2013; Stoner et al., 2007), with heterogeneity of needs being one of the themes identified in Stack et al's (2021) systematic review of studies incorporating pupil views.

Despite there being a solid evidence base for the challenges of transitions for autistic children (Nuske et al., 2019; Stack et al., 2021), there is very little evidence in the literature of studies which evaluate strategies used to support the transition. One study that evaluates a specific strategy was conducted by Mandy et al. (2016a). This involved development of a transition pack referred to as the Systemic Transition in Education Programme for Autism Spectrum Disorder (STEP-ASD). This allowed for an individualised programme to be created by schools for each child which involved specific needs and strategies being identified in an initial meeting between staff, parents, and the child. The identified needs were then linked with specific chapters in a pack of printed transition materials that focused on available support strategies such as how to set targets to support children who have executive functioning difficulties. These strategies were designed for school staff to use to provide individual support to the child as well as to inform the staff about how they can adapt their own practice to be more inclusive. Mandy et al's (2016a) study aimed to investigate the feasibility of STEP-ASD and to discover whether it was effective in reducing problems with behaviour and emotions in autistic children. Although the intention to provide individualised support for autistic children and training for staff was a good one, there were some problems with the study which made it difficult to draw a conclusion as to its effectiveness.

To evaluate STEP-ASD, Mandy et al. (2016a) used the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001). The SDQ measured strengths and difficulties for 15 autistic children in the last year of primary school and in the second term of secondary school to allow for pre and post transition comparison. SDQ scores showed a decrease in teacher-reported total problems with the STEP-ASD group relative to a control group of 20 autistic children who had transitioned two years previously without the intervention and had been part of a previous study (Mandy et al, 2016a). These results should be read with caution, however, as the member of staff completing the measure pre-transition would have a very different relationship with the child as they are likely to have known the child for several years as they progressed through primary school, potentially from the age of four. In contrast, the post-transition measures would likely be completed by a member of staff with far less of a relationship with the child as they would have only known the child for a short time. This suggests that there may be a lack of reliability in the comparison between the measure at the two time points. A further issue with reliability was due to the data from school staff being provided by teachers who knew whether the child had been part of the STEP-ASD trial, which may have resulted in bias in their reporting depending on their own feelings toward the trial.

Mandy et al (2016a) references Bronfenbrenner (1979) in saying 'maladaptation is not an inherent property of the individual but arises from an interaction between the individual and their environment' (p. 581). This seems to align with the social model of disability and yet the intervention focuses on children's difficulties such as those associated with social interaction and executive function. The transition pack offers strategies for the teacher to use with the individual child to overcome these difficulties rather than suggestions of how the whole school environment could be adapted to support the child. Additionally, and much like other studies looking at primary to secondary transition experiences, Mandy et al., (2016a) did not include qualitative methods and were therefore unable to gain participant views and experiences of the intervention, which may play a role in detecting the individual ingredients that were key to successful transitions.

Although studies point to strategies that can support with the transition (Nuske et al, 2019 Stack et al., 2021) there is a paucity of research overall looking at the efficacy of a specific programme of support for children transitioning from primary to secondary school. Nevertheless, there are lessons that can be learned from studies looking at different educational experiences and transitions at different stages of schooling. For example, the transition from nursery to primary school for autistic children was the focus of a study by Wood-Downie et al. (2021). Digital Stories were made to support the transition for nine autistic 3-4-year-old children. These Stories involved video footage of the children taken by nursery staff, but also footage captured by using Wearcams. These are small cameras which were worn by the children on their chests, and which enabled researchers to view the children's interactions with the environment and with other children and staff from the children's own perspective. Consequently, Digital Stories allowed the sharing of the children’s embodied experiences of their nursery environment. In this way the children’s perspectives of their experiences at nursery were able to be shared as part of the process of person-centred transition meetings. This enabled the educational psychologists who were supporting the child with the transition to better prepare the receiving school to cater for their needs. This study has similarities with the Mandy et al. (2016a) research in that it is centred around the communication that is shared between stakeholders involved in the child’s transition. Where it differs is in the way this communication is supported. Due to the young age of the children involved it was not possible for them to take a direct role in the planning and development of their Digital Stories. For the primary to secondary transition and beyond, many children would be able to be more involved in the creation and content of their Digital Story. The strength of including the perspectives of the children are clear in the results of Woods-Downie et al.’s (2021) study. An educational psychologist remarked ‘It helped thinking about provisions and about next steps’ (p. 13) and a parent commented ‘It captured just how he is which words cannot describe’ (p. 17). These insights could help schools to provide the optimal learning conditions for the children transitioning to them, putting the onus back onto the schools to provide a suitable learning environment rather than requiring the child to adapt to an unsatisfactory and non-inclusive situation. With the lack of evidence in the literature about which strategies are most effective in supporting transitions from the direct experiences and perspectives of autistic children there is a need to proactively address this gap. The following section discusses why it is so important to address this gap based on what is known about the implications for children when transitions are badly managed.

2.4.4 Implications of Challenging Transitions for Autistic Children

When transition from primary to secondary school is not well planned at a systemic, school-wide level it can have significant negative consequences for autistic children (Nuske et al., 2019). In general, levels of anxiety and depression in autistic children and teenagers has been found to be higher than that of their non-autistic peers (Kim et al., 2000; White et al., 2009) and autistic girls are found to be particularly susceptible to internalising problems (Solomon et al., 2012) There is little research looking at how young autistic people’ mental health is affected specifically during the transition period, however two studies have found levels of anxiety to be higher in autistic children both during and just after the transition than community samples (Hannah & Topping, 2012; Fortuna, 2014). Hannah and Topping’s study (2012) included eight male participants who completed the Spence Children’s Anxiety Scale (SCAS) (Spence et al., 2003) - both one to two months prior to transition to secondary school and six to eight months afterwards - to compare their anxiety levels on either side of the transition. Their findings were largely inconclusive with scores in some categories decreasing while others increased, although the authors suggested that anxiety levels were higher overall in autistic children. The inconclusive results were due in part to their small sample. Hannah and Topping (2012) also recognised the limitation of using self-report measures that had not been validated for use with autistic children.

Fortuna (2014) explored the transition experiences of autistic children and other key stakeholders, including three boys, two girls, their parents and school staff. Using mixed methods, Fortuna's (2014) study incorporated the SDQ (Goodman, 2001), Likert-scale questionnaires, qualitative data gathered through a diary completed by the children and semi-structured interviews with them. The data collection window spanned the period both pre and post transition, and SDQ and questionnaire data were collected three times from all participants. Lower levels of anxiety were reported in the two children who were placed in the same class in their new school compared to those who were separated from their friends, potentially reflecting the beneficial effects of peer relationships as discussed above (Evangelou et al., 2008; Makin et al., 2007). The combination of methods and timeframe for collection meant that Fortuna's (2014) data was detailed and expansive although limited by a small sample taken from schools who had received transition training from the local authority's autism educational outreach team and therefore are not generalisable to areas where this training is not available.

The benefits of understanding children's anxiety around transitions were highlighted by West et al. (2010). In a longitudinal study involving 2,000 pupils in Scotland, they found a link between difficult transitions and later depression, low self-esteem, and antisocial behaviour, although their study did not categorise results by SEN status or neurodivergence and therefore the distinctive picture for autistic children was not apparent. Much of the research looking at the mental health implications of difficult transitions is based on empirical survey data (Hannah & Topping, 2012; West et al., 2010). Of those studies that include the voices of the autistic children in the research, the most common method is the semi-structured interview which can be challenging for participants who are less able to verbalise their responses (Harrington et al., 2014; Nind, 2008). As a result the evidence base is missing representation of many of the more vulnerable children and therefore is not able to provide a holistic picture of the experience of autistic children.

The transition from primary to secondary school is a challenging one which every child must face. There is a lack of data to link badly managed transitions to poor mental health outcomes for autistic children, however there is evidence for that link in population studies more generally (Jindal-Snape et al., 2020; Waters et al., 2012). This evidence, alongside the data provided by qualitative researchers who have listened to the perspectives of autistic children experiencing the transition (Fortuna, 2014), is sufficient to suggest that more needs to be done to support the transition from primary to secondary school for autistic children for the sake of their emotional and academic wellbeing.

2.5 Conclusions and Implications from the Literature Review

The literature I have reviewed suggests that - while progress has been made in the framing of autism in research to include the priorities and voices of autistic people - autistic girls and women are under-identified and therefore under-represented within this literature. Their lack of inclusion has implications for support, which may not adequately address the specific needs of autistic girls and women. Consequently, research should target their needs to address the imbalance between autistic males and females in the evidence base. Participatory research methods are expedient in providing a framework to promote the inclusion of autistic voices within research and to ensure autistic priorities are advanced.

Although there is a good deal of evidence to support the assertion that the transition for autistic children between primary and secondary school can be challenging, there is a paucity of research assessing the effectiveness of specific strategies to improve it. Moreover, much of the evidence about transitions is from quantitative research and the perspectives of parents and/or teachers, but not of autistic children.

With the social model of disability emphasising the need for structures and procedures to adapt to the needs of the individual, rather than the other way around, it is important that the onus for change is not on autistic young people adapting to fit their environment, but that the environment provided for them is appropriate to meet their needs.

What is missing, therefore, are the voices of autistic girls talking about their transition experiences, and the consideration from their own perspectives of the efficacy of resources and strategies to support transitions. Addressing this gap will form the basis of this research and will do so within a framework that aims to support and promote the sharing of autistic girls' voices. Accordingly, the following research questions were developed to guide this research:

1. How can creative data collection and analysis methods be used to promote the voices of autistic girls?
2. What do autistic girls feel are the barriers to a successful transition from primary to secondary school and how can these be addressed?
3. What are the challenges and benefits of including autistic girls in participatory research?

Chapter 3 - Supporting Autistic Voices through Creative Methods

Introduction

This chapter includes consideration of how creative data collection methods can support autistic children in sharing their experiences of educational transitions. Firstly there is an exploration of how creative methods can be used to support children share their views and experiences, with particular consideration of how these methods can benefit autistic children. The chapter continues by exploring how the sharing of embodied experiences can enhance our understanding of the way people view their lives. Body Mapping is introduced as a creative method that offers a flexible way of sharing embodied experiences. This chapter concludes with a review of Body Mapping literature followed by an examination of the advantages and challenges of using Body Mapping in this research.

3.1 Use of Creative Methods to Support Autistic Children to Share their Voices

Using creative methods within research can allow those who may find it challenging to participate in traditional research methods - such as interviews or focus groups -to be heard (Krisson et al., 2021). Creative methods necessarily allow for and build in adaptability to support different communication styles, and they support greater contextualisation of responses than methods such as surveys (Ridout, 2017). In practice, creative methods are often used to support more traditional semi-structured interviews which can be beneficial as they can provide a focus for the discussion and help children to illustrate their views (Beresford et al., 2004). Brown (2021) cautions that it is important not to assume that creativity will automatically mean that participants have a role in the research over and above the provision of data. However, the use of creative methods can support inclusion in research for autistic children by empowering participants to have greater control over their participation (Brown, 2021).

There is a small but growing body of literature that endorses the use of creative research methods to support the sharing of autistic-lived experiences. For example, Winstone et al. (2014) used self-portraits and mirrors to support eight autistic 12–14-year-old boys to talk about self-identity and found a richer quality of data was achieved with the experimental group in comparison to the autistic boys who took part in semi-structured interviews alone. Winstone et al. (2014) characterised this ‘rich’ data as being gained through a higher level of engagement with the children undertaking the creative tasks, leading to them offering more insight into their experiences. This gave the researchers a better understanding of the children’s perspectives. In another example, Beresford et al. (2004) used craft activities and photographs alongside interviews with five autistic children aged between 6 and 14 years, exploring their experiences with social care and support services. They reported that the inclusion of creative tasks lowered the children's anxiety about the process and promoted conversation. This view was also reflected during parent interviews, during which parents were surprised at how long the children engaged with the researcher. While this research offers useful insight into how creative tasks can support autistic children's participation in research, it is limited by the inclusion of only five children, one of whom chose not to take part. Furthermore, unlike Winstone et al. (2014), there is not a control group to allow comparison with alternative methods. Despite these limitations, there is evidence to support the assertion that, by supporting interviews with creative tasks, researchers may be better able to motivate children in a non-threatening environment. However, both studies required the children to engage in verbal interviews as well as the creative task. Although the tasks were found to facilitate the interviews, these studies were only accessible to children who were also able to verbalise their answers. This necessarily limits the participation of those who are unable to or choose not to use voice and speech as their primary mode of communication, leading to a lack of representation in the literature of those who communicate in different ways (Fayette & Bond, 2017, Tesfaye et al., 2019). It is important to also explore methods which allow children alternative ways of communicating to participate in research.

To facilitate research with participants with a wide range of communication preferences, it is necessary to consider not only how the children communicate, but also how the researcher responds to and understands this communication (Ellis, 2017; Tesfaye et al., 2019). For this, it is essential to build rapport with children, and - according to research conducted to synthesise evidence of methods to capture the perspectives of children with disabilities by Tesfaye et al. (2019) - it is also advantageous to include family members in this process. They argue that the involvement of family can support the researcher's understanding of the communication preferences of the children. By integrating the communication strengths of the participants with research methods that support a variety of methods of communication, it is hoped that participation can be widened to include a more representative sample of the autistic community. A consideration of some of the methods that might facilitate this follows.

Photovoice is one method which may enable young people who may otherwise be excluded from participation to engage inclusively with others (Carnahan, 2006). Photovoice involves participants taking photographs of people, places, or objects that they find important and using those as the basis for exploration. The benefits include more actively engaging the young people in participating with the research (Povee et al., 2014) and, within a participatory framework, can also help to address the power imbalance in the relationship between researcher and participant by giving the participant more ownership of the process (Ha & Whittaker, 2016). Photovoice as a method to support interviews or discussions has been very successful. Hoy et al. (2018) used it with five autistic children to explore their experiences of the transition from primary to secondary school. The children were asked to photograph areas of the school that were judged to be positive or negative for them and subsequently spoke about why these images were chosen to represent their feelings around their school in a semi-structured interview. Hoy et al.'s (2018) work exposed valuable findings about the children's feelings towards their school, which revealed the positive structures that supported their transition and where improvements could be made. Do et al., (2021) conducted a meta-synthesis of the literature involving photovoice with autistic participants which included 11 peer-reviewed articles drawn from the UK, USA, Australia, and Vietnam. They found that photovoice activities helped participants engage in a positive way, not only during the photography element of the work but during group or one-on-one discussions about the pictures participants had taken. This synthesis only included studies in which participants were able to communicate verbally about the photographs they had taken, although it was recognised that this was a limitation that was identified in five of the 11 studies and the potential of using photovoice with participants who do not communicate verbally was noted.

The photographic element of photovoice enables participants to engage in a non-verbal way, but many tasks then require discussion about the photographs taken. Photovoice can be conducted using non-verbal communication, however, by including sorting activities which involve placing pictures in categories or ranked to reflect opinion (Wang & Burris, 1997). This potential was demonstrated by Carnahan (2006) who worked with two autistic 5-year-old boys who selected 10 photographs they had taken to include in a photo-journal but did not engage in verbal communication about their choices. Here, the boys were engaged in the activity, made their choices, and shared their journals with their peers. This enabled them to effectively communicate their perspectives and interests with others without having to rely on verbal communication.

While photovoice can support autistic children to contribute their perspectives to research, the use of photography limits participants to one art form. Moreover, photovoice does not support participants to talk about events in the past, as photographing places and people they no longer have access to could be problematic. Moreover, capturing emotions in photography can be difficult without specific equipment and training. Providing participants with more flexibility in creative approaches could allow for a wider range of responses, including greater exploration of memories and emotions.

One creative method which may include photography but also allows more flexibility for participants is collaging. Collaging involves selecting visual materials and placing them on a supporting surface. Collage can offer more variety in response, as photographs can be used but supplemented with other materials such as found images from newspapers or magazines, fabric, and words. Participants can choose where to place different elements in relation to one another to create meaning (Ridout, 2014). As an example, Penelope Dunbar, an autistic artist and creative researcher, described how collaging helps her communicate meaning in a way that relies on sense rather than words (Delafield-Butt et al., 2021). She views it as a way of being self-reflexive and finds the process essential to her well-being and a way of creating synthesis between her body and mind. The challenge with using collage as data comes in the ability of the researcher to interpret the images created: methods to support the autistic person to communicate their intended meanings must be included. Nonetheless, the flexibility of collaging allows more variety in response relative to photovoice activities and could be enhanced by using the method to explore embodied experiences which would add an additional opportunity for meaning making within the activity.

3.2 The Value of Sharing Embodied Experiences.

The theory of embodied cognition argues that ‘the body is intrinsically connected with subjectivity and shapes the way we experience the world, each other, and ourselves’ (Bolsden, 2018, p. 895). The mind and body both interact with the environment, and the role of embodied experiences in cognitive processes has been recognised as important for our understanding of how people experience the world (Wilson, 2002, Wilson & Golonka, 2013). An exploration of embodied experiences considers how the physical environment contributes to the way an individual responds and interacts with other people and their surroundings. For some, a consideration of embodied experience helps to create and shape narratives and therefore can support our understanding of ourselves and our environment (Menary, 2008). For others embodied cognition provides a framework to better understand differences in cognition and how experiences shape feelings and support us to express them (Rucinska et al., 2021). An exploration of what is meant by embodied experiences and how consideration of them added value to this research is offered below.

Embodied experiences draw on theories of embodied cognition – an approach that rejects Descartes’ 17th century theory of Dualism which argued that the mind was entirely disembodied (Foglia & Wilson, 2013). Instead, it is argued that cognition is influenced by our physical experiences. Foglia and Wilson (2013) described how the body ‘intrinsically constrains, regulates, and shapes the nature of mental activity’ (p. 319). There are many conflicting ideas of how the relationship between brain and body works, and the degree of connection (Wilson, 2002), but there is evidence from empirical studies which support the relationship between them (Wilson & Golonka, 2013; Winkielman et al., 2009). For example, when participants in a study thought about the future, they leaned forwards, thinking about the past they leaned back (Miles et al., 2010). A study of the English language points to the relationship between our physical experiences and the way we think. Lakoff and Johnson's (1979) book about cognitive linguistics considered how metaphors represent our embodied cognition. For example, love is considered to be a physical force. We 'fall' in love, 'gravitate' towards one another and 'sparks fly'. Similarly, we can be 'itching to get started' and 'giddy with excitement'. Further to Lakoff and Johnson's (1979) book, the notion of embodiment in cognition became the subject of considerable interest not only to cognitive scientists, but those looking at better understanding individuals lived experiences in other fields (McNerney, 2011).

To consider the implications of understanding embodied experiences of pupils in education, Bengtsson (2013) analysed the work of Merleau-Ponty (1968) who proposed a theory of experience based on an embodied experience of life lived in a 'world of things and people' (Bengtsson, 2013 p. 41). Bengtsson (2013) considered how small children perceive the world differently due to their height, physical abilities, and experience, and this leads them to create different meanings from the world than adults. To understand experiences of education, Bengtsson (2013) proposed that it was important to consider the embodied perspectives of children and teachers. For example, the perception of the size of a classroom for a small child will differ from that of a teacher, and this will impact how they will interact both physically and emotionally with the space. In addition to the consideration of physical space on embodied experiences, De Jaegher and Di Paolo (2007) emphasised the importance of including interactions with others, arguing for participatory sense-making which includes both mental and bodily interactions with others as being important for understanding social cognition. By including embodied experiences and the way those experiences are shaped by social interactions, a rich picture of lived experiences can be developed.

While most literature exploring embodied cognition is concerned with the general population, there is a small number of studies that consider how the concept applies to autistic people. Bolsden (2018) explored the importance of embodied experiences for autistic people who experience sensorimotor differences such as difficulties with proprioception. Through a phenomenological analysis of Tito Mukhopadhyay's *How Can I Talk If My Lips Don't Move* (Mukhopadhyay, 2011), Bolsden (2018) investigated how an understanding of the differences in the way the author physically experienced the world, provided us with a better understanding of his lived experiences. For example, by rotating under a ceiling fan, Mukhopadhyay was able to feel control over his limbs so, when a power cut prevented the fan from working, he would feel distress. Rucinska et al. (2021) described an observation of a 12-year-old autistic boy, Noah, interacting with this psychotherapist. In this observation Noah was using figurines to re-enact an argument he had with his mother. Noah moved the figurines to represent the movements he and his mother made in the argument showing how representation of the embodied experience helped him to make sense of the interaction. Noah then described how his mother built a wall around herself when they argued. Noah was clearly able to understand and use metaphor in this interaction. Rucinska et al. (2021) argue that by using a framework of embodiment, a very different understanding of autistic people's imagination and understanding of metaphor is revealed. While these studies offer an interesting and in-depth account of the power of considering embodied experiences at a case study level, evidence supporting its use in larger more experimental studies is missing from the literature. There is, however, some useful theoretical work to consider.

De Jaegher (2013) proposed an enactive account of autism which argued that embodied experiences have an important role to play in better understanding the cognition of autistic people. De Jaegher (2013) considered the importance of understanding how autistic people make sense of their world with reference to differences in perception, movement, and experiencing emotions. Traditional theories of autism such as theory of mind and weak central coherence were described as 'piecemeal' (p. 1) as they considered cognition, communication, and perception separately with no reference to embodied experiences. By contrast, in her theory of enaction De Jaegher (2013) sought to consider these elements in an integrated way. Important to this theory was 'participatory sense-making' (p. 6) which considered how, in social interactions, meaning is created not only by the participants response to the researchers, but also in the processes of interaction which include the rhythm that is created within it. In this way, social interactions involve participating in the sense-making of one another. De Jaegher (2013) proposed differences in the sense-making process for autistic people due to sensory and perceptual differences. As a result, she promoted the importance of identifying these processes in autistic individuals when designing interventions, including finding ways to incorporate intense interests and repetitive behaviours. This consideration of the design of interventions can also be applied to the design of research.

By attending to the way that autistic people make sense of the world through their embodied experiences and interactions, a better understanding of the specific needs of autistic people and how to support them could be supported. For this research a consideration of the impact that gender has on embodied experience is also important. Embodiment in girls is experienced with a greater awareness of the external gaze than that of boys (Piran, 2016). Girls are more vulnerable to negative feelings about body image (Lindberg et al., 2007) which can negatively impact both academic and physical performance (Moradi & Huang, 2008). This self-consciousness is particularly prevalent at puberty (Lindberg et al., 2007) which coincides with the transition from primary to secondary school. Research looking at the gendered experiences of space and embodiment in schools in Britain and Finland reports observations of boys taking up more physical space around the school and being the focus of more teacher attention, whereas girls are expected to remain still and quiet and are therefore more likely to be challenged if they differ from this norm (Gordon, 1996). These differences in the embodied experiences of boys and girls are therefore worthy of consideration. Menary (2008) argued that any narrative is grounded in the physical experience of it, so to understand somebody's perspective it is necessary to understand their embodied experiences. Therefore, if asking autistic children to share their experiences of education, supporting them to include narratives that speak to their embodied experiences might lead to a more in-depth and nuanced picture. Selecting a method which supports the sharing of embodied experiences was central to the design of my research. The method chosen was Body Mapping which will be introduced and explored below.

3.3 Body Mapping – an Introduction and Exploration

Body Mapping combines the creative and communicative freedoms offered by collaging, the structure and framework of photovoice, and adds the opportunity for participants to ground their experiences in an embodied way by linking them with a figurative representation of themselves. This section will consider Body Mapping as a method, the literature that supports its use in other populations and why it may be an effective method to use in supporting autistic children to share their views on their transition experiences within a participatory framework.

Body Mapping has its origins in the study of sexual health, originally developed to discover how women in Jamaica understood their reproductive physiology (MacCormack & Draper, 1987). It enables investigation of the embodied experiences of participants through a series of exercises based around the creation of a life-sized representation of the body. Once the body map has been created, a conversation around the creation of the map ensues and participants are encouraged to share their thoughts and choices about what they have included. While this conversation often requires participants to verbalise their choices, there are other methods that can support the sharing of ideas that will be detailed below.

Much of the Body Mapping work conducted since 2007 has used a guide created by Solomon (2007) to inform research design which was based on a series of workshops held with women living with HIV/AIDS in Tanzania, Africa. The workshops aimed to support participants to understand and explore their experiences. The first stage was to draw around the participant's body on a large piece of paper or card. Participants then created images on or around the body to represent different events, emotions, or ambitions. In Solomon's (2007) research this included the participants creating symbols to represent where they were born, where they live now and their journey between those places. They also created a symbol that represented their power, considering where on the body they felt this power to be. At each step in the process participants were asked to consider the symbolism of their choices in terms of colour, image, and placement on the body. By considering where images were place participants were encouraged to represent their embodied experiences. For example, when considering where to place their power symbol, participants may have chosen to place it on the head to represent mental power, the arms to represent physical power or the heart to represent emotional power. This added an extra level of meaning to the image that would not be found through the symbol alone and supports the consideration of the connection between the participants' physical presence and their emotions.

For Solomon's (2007) research, the power of using Body Mapping came from the impact the process itself had on the participants. Through Body Mapping, participants were able to reflect on their life stories and to consider how their lived experiences had made them the people they had become. This was achieved by allowing participants to respond creatively to the prompts they were given, therefore providing the space and time to explore how they felt about situations they had faced. For the people living with HIV/AIDS in Solomon's (2007) work, this helped them to consider the impact of the virus on their physical as well as emotional selves. This was particularly empowering for participants who described 'Living with X' (p. 2) rather than living with HIV. This distinction meant that the participants were able to use their body map to reflect on the aspects of their lives that were important to them aside from their HIV status, and to also consider the impact of receiving their diagnosis. Body Mapping allowed this reflection to be very personal, as each aspect of their lives was represented relative to the part of the body that it signified. This method may also have provided the opportunity for more creative autonomy than might have been possible through using a method such as photovoice, as participants were not limited to photographing objects or places they could access. With Body Mapping, participants were able to represent both real places, people, or artefacts as well as imaginary or symbolic ones.

Gastaldo et al. (2012) extended Solomon's method with the inclusion of a 'testimonio' (p. 10) which involves participants narrating a personal account of their body map which is then transcribed and included with the map. The personalised testimonio provided insights from the participants themselves about their choices when creating their body maps and was therefore a helpful addition when using the method to gather data. While this method of producing the testimonio requires participants to verbalise their accounts, a similar exploration of the work could be developed as a written document or by asking participants to physically identify key ideas within their maps. Gastaldo et al.’s (2012) work focused on the experiences of undocumented migrant workers in Canada who had to fit participation in the research around punishing work schedules and, therefore, a verbal testimonio was most appropriate due to the reduced available time. While Solomon (2007) allowed five full days for the process, Gastaldo et al. (2012) were only able to allocate three hour-long sessions but, by including the testimonio, they were still able to gather participants’ detailed explanations and reflections of the choices made when constructing the body map. Consideration of the allocation of time for different elements of the tasks is important to ensure that participants are given appropriate time to reflect on each aspect.

Subsequent research has seen the methods described by Solomon (2007) and Gastaldo et al. (2012) being adapted in other ways. De Jager et al.’s (2016) systematic review included 22 articles representing 19 distinct studies of which seven originated in Canada, four in South Africa and three in Australia. Six of the 19 articles focused on HIV/AIDS with others covering largely health-related topics. The articles in this review are evaluated using a ten-point list of elements derived from Solomon’s (2007) guide. This evaluation was not designed as a critique of the research but to compare the operationalisation of Body Mapping in different projects. Of the 19 articles included, six contain all the elements described suggesting the use of Body Mapping is flexible and that adaptations are possible within the framework. De Jager et al.’s review (2016) suggested that although Solomon (2007) provided a clear methodological framework for carrying out Body Mapping, adaptations can be made to ensure that the procedure works for different populations in line with Solomon’s (2007) original intention ‘Body Mapping can be used by anyone … in many different ways’ (p.2). The strengths and limitations of using Body Mapping as a method to explore events and opinions as experienced by participants are described below.

3.3.1 Advantages to using Body Mapping to elicit the voices of participants

Body Mapping is a flexible method that can adapt to the strengths and preferences of participants. I believe it can offer greater autonomy in how tasks are completed which can, to some extent, address the imbalance of power inherent in more traditional ways of conducting research. It can encourage a deeper level of thought and reflection through the time provided for the activities and has been shown to have therapeutic value for participants considering challenging topics.

Furthermore, it offers the opportunity for a consideration of embodied experiences. Each of these advantages is expanded upon below.

Balance of Power. The balance of power in research has traditionally been skewed on the side of the researcher who sets the agenda (Barnes, 1996; Oliver, 1992). Creative methods which offer a range of ways to contribute can increase participants' autonomy over the way they engage with research, and this can change the power dynamics - particularly within a participatory research design (Brown, 2021). Where Body-Mapping differs from other creative methods is in how flexible it can be in supporting a variety of preferences. Whereas photo-voice is dependent on taking pictures of accessible locations and objects, Body Mapping can include photographs but also drawings and words which can portray more abstract concepts or locations, and objects that are not available to photograph. Using poetry or creating diaries requires participants to have literacy skills: Body Mapping can include words but does not have to. This gives participants the power to complete the tasks in ways that interest them and suit their individual needs and abilities, which arguably creates more space for authentic contributions on participants' own terms.

Time for Reflection. In a systematic review of arts-based methods used with children between seven and 12 years old, Driessnack and Furukawa (2011) reflected that using drawing in addition, or as an alternative, to interviews provides children with 'the time and opportunity to tap into their internal, sensory cues and then use these cues to organize their thoughts *before* they are asked to share them' (p. 4). In other words, the inclusion of creative expression as part of a task offers the opportunity for a different kind of thinking than that which happens during verbal interviews. Brown (2021) considered the contribution of creative and arts-based methods in participatory research and argued that 'through their powers for expression, evocation and illumination, the arts lend themselves towards exploring experiences and expressing feelings and emotions or other concepts that would be otherwise difficult to verbalise' (p. 4). Again, this is a facet of many types of creative research, but I would argue that Body Mapping is different in the flexible framework it provides for the development of thoughts and ideas provided by the tasks. Although few studies using Body Mapping have achieved the full five-day workshop as outlined in Solomon's (2007) facilitation guide, most examples take place over a sustained period which allows the participants space and opportunity to develop their ideas as well as to develop a relationship with the researcher. An example of this is Boydell et al.'s (2018) study involving experiences of six young people with psychosis in Australia. Initially the intention was to run the task over three 2-hour sessions, however - at the request of the young people who wished for more time to complete the tasks - the allocation was amended to four 3-hour sessions. This additional time not only provided a richness of data for the researchers, it was also shown to have a positive impact on the well-being of the participants (Boydell et al, 2018).

Positive Consequences of Participation in Body Mapping. Orchard (2017) describes the Body Mapping process as 'transformative' (p. 2) both for herself and her participants. In a Canadian study investigating the experiences of 11 HIV positive adults, Orchard (2017) reflected that the process empowered participants to open up about elements of their lives that they had previously kept hidden and supported them to address and communicate challenging issues. Participants reported that the technique 'really made me feel better' (p. 70) and 'helped me look at myself in a different way' (p. 80). Orchard posited that this was partially due to the way the method enabled a transfer of power from the researcher to the participant and imparted value on their contribution. Similarly, in Lys et al.'s (2018) study of Body Mapping with girls living in the Northwest Territories in Canada to investigate their knowledge and understanding of sexual health issues, participants reflected that 'introspective stuff is hard' (p. 1192) but felt that Body Mapping helped them to understand more about themselves as they were given the time and space to reflect. One peer leader who helped facilitate the research reflected: 'I think it's an invaluable facilitation tool to even out the playing field for participants who find naming the source of their pain, trauma, or violence difficult' (p.1192). Another peer leader reflected how the process allowed queer participants to feel that they were taking back ownership of their bodies through creating their body maps which were otherwise 'often criminalised' (p. 1193). Although other creative methods enable self-reflection and self-expression, these descriptions of the embodied and transformative power of Body Mapping suggest that it is a method that can be a beneficial and empowering process in its own right.

Embodied Experiences in Body Mapping. Body Mapping enables focus to be drawn to the embodied experiences of participants by encouraging reflection of experiences in relation to the body (de Jager et al., 2016). For example, Body Mapping has been used to consider the physical and emotional embodied impact of dialysis (Ludlow, 2012), family planning (Harries et al., 2019), sexual health (Lys et al) and working in tobacco production (Gamlin, 2011). By using Body Mapping in these projects, researchers reported that it was possible to broaden the depth of understanding about participants' experiences and enable them to communicate embodied experiences. Harries et al. (2019) argued this was because 'our experience of the world is multisensory' (p. 9). Body Mapping has also been used explicitly for gaining an understanding of embodied experiences. Sweet and Escalante (2015) explored how women's fear of violence can be better understood in planning public geographical spaces. This study used Body Mapping amongst other methods with women in New York City, Mexico City, Barcelona, and Medellin. The Body Mapping workshops required participants to map images or words that represented feelings about their experiences in the city on their body outlines. One participant drew sturdy boots on their map to show the need to 'run away from danger in the city and for kicking harm doers' (Sweet & Escalante, 2015, p. 1837).

Vincent also (2014) used Body Mapping to help understand participants' feelings of identity in relation to the spaces they inhabit. She describes the decision-making process around where to place different elements on the maps: 'Where to put family and friends – in heart or spine as a source of support? Would a love of popular culture reside in words we speak (mouth) or music we listen to (ears)?' (Vincent, 2014, p. 375). Both Sweet and Escalante (2015) and Vincent (2014) used Body Mapping to better understand how their participants felt about their external physical environment and how this related to their personal embodied experiences. By linking the external and personal in this way they were able to gain a deeper understanding of the experiences of their participants. These examples persuaded me that Body Mapping could provide opportunities to support the sharing of the embodied experiences of children in my research, and potentially allow a greater depth of exploration of their time in school. I was keen to explore its potential in this regard. However, I was also aware of potential challenges with applying the Body Mapping method and explore these next.

3.3.2 Challenges of using Body Mapping

The well-evidenced advantages for using Body Mapping to explore people's experiences summarised above provide a strong rationale for its use in exploring children's experiences of educational transitions. However, there are some challenges that need to be considered - firstly to ensure that the methods of data collection and analysis are reasoned and justified, and secondly to ensure that the process is carried out ethically in a way that is beneficial to all involved.

Methodological considerations in Body Mapping. Although Body Mapping has been used therapeutically for some time, primarily in health promotion research, it is still a relatively new method of data collection for gaining insights into experiences (Gastaldo et al., 2012) and is not yet substantively interrogated in the literature. While consideration of how Body Mapping is an appropriate method to answer research questions is clear in some cases - for example the links between therapy and research (Boydell et al., 2018) and the benefits of the participatory nature of the method (de Jager et al., 2016) - many studies do not explore the rationale for using the technique (Gamlin, 2011) or they include only a brief explanation of the benefits of the method but do not apply it to their own study (Senior et al., 2014). Moreover, there is a lack of detail in the literature about how the data included in body maps are analysed. Some studies do not state their methods of data analysis at all (Davy et al., 2014; Gamlin, 2011; Senior et al., 2014). Although thematic analysis is reported as the chosen method in many studies, there is a lack of depth in the type of thematic analysis used and the justification of this in relation to the stated research questions. In many cases it is reported that thematic analysis is used, with no reasoning given for this choice or reflexivity into its implications (Boydell et al., 2018; Harries et al., 2019).

Nonetheless, some studies using visual methods of analysis provide a clearer rationale and justification of their choices. For example, Skop (2016) used Body Mapping to explore the experiences of 25 participants who had a diagnosis of fibromyalgia in Canada. Skop (2016) offered a clear description of the rationale for choosing Body Mapping, detailed the process of conducting the study, and gave a considered justification for the constructivist grounded theory approach that is applied, stating it was chosen 'because this approach assumes that participants experience a multitude of realities' (p. 37). This is a level of detail which would benefit the scientific rigour of other studies and will be important for informing my own approach.

Neither of the published guides to Body Mapping methodology (Gastaldo, 2012; Solomon, 2007) have prescribed how data analysis should be conducted, so it is important for those using Body Mapping to clearly justify their choice of analytic methods and reflect on how their position in relation to the research will have an impact on the findings. De Jager et al. (2016) recognised that Body Mapping, while established as a therapeutic tool, still requires development in terms of reporting within academic journals. It is important to establish the rationale both for the use of Body Mapping as a research method in my own research, and the choice of analytic method used to interrogate my resulting data.

Ethical considerations in Body Mapping. Alongside the benefits of the therapeutic nature of Body Mapping comes a responsibility for the researcher. Boydell et al. (2012) detailed a workshop held for professionals working in health research which focused on the ethical implications of arts-based research. Key concerns that arose from Boydell et al.'s (2012) workshop included the potential for participants to find the process 'unsettling' or 'disturbing' (p. 11). They suggested that the process of creating art, which is a product of the Body Mapping task, is an experience that can provoke emotional and sensory reactions and therefore can open participants up to negative experiences. Gastaldo et al. (2012) also considered the importance of supporting participants in choosing how much to reveal of their lives. In Gastaldo et al.'s (2012) study, this was important as the undocumented migrant workers who participated had the real possibility of deportation if their identities were revealed. In my own research, exploring experiences of transitions may cause participants to remember stressful and upsetting experiences and so it is important to consider the implications of the tasks for the participants when designing arts-based research.

Ethical considerations in arts-based research such as Body Mapping can be challenging, particularly due to the collaborative nature of much of the work (Orchard, 2017). Body Mapping began as an interactive experience (Solomon, 2007), where the maps were created individually but discussed as a group so members could ‘support and inspire’ one another (p. 3). While there are examples of Body Mapping being completed with researcher and participant only (Dew et al. 2018; Ludlow, 2012), this reduces the power of the method as a supportive way to share stories. Completing Body Mapping as a group was something I felt was important for the development of the method in this research, and therefore strategies to ensure group tasks were conducted in a supportive and ethical manner were essential. Supporting participants to share only what they are comfortable with during group work is vital as is the issue of confidentiality: it is more difficult to ensure in group tasks than in sessions just between a researcher and participant. The ethical implications of this research must be carefully considered.

Body Mapping aims to harness embodied experiences and, due to the creative nature of the method and its inclusion within a participatory framework, is a good method to promote the authentic voices of participants. The literature suggests that the Body Mapping process may be beneficial not only for providing a source of rich data for the research, but also for the wellbeing of participants. For example, one participant commented “I found Body Mapping quite healing” (Boydell et al., 2018 p.252), and another that - in comparison to participating in survey-based research - “this was more meaningful” (Orchard, 2017 p.22). One of the participants in Lys et al., 2018) stated “This does get you to understand yourself better” (p. 1,191).

Overall, this method provides a promising approach because of its success in drawing out the experiences of participants as well as the potential impact of participation for them. The chapter offers arguments in support of Body Mapping as a research method that can support autistic children to share their experiences of educational transitions. The added layer of depth that can be added to our understanding of autistic children’s thoughts and opinions about school, through including their embodied experiences, has also been introduced. Informed by the literature, the next chapter will detail the pilot study that was conducted to explore further how Body Mapping could be used with autistic children to give us a rich and nuanced understanding of their views.

Chapter 4 – Pilot Study into the Use of Body Mapping to Explore Children's Experiences of Educational Transitions

Introduction

This chapter details my pilot study in which Body Mapping methodology was trialled with a small group of children including those with an autism diagnosis. This pilot study aimed to evaluate Body Mapping as a method of data collection and, specifically, as a method for exploring educational transition experiences. This study was also designed to inform the use of Body Mapping as a method in a larger participatory project to develop resources to support transitions with autistic young people as co-researchers, which is introduced in Chapter 5. Both the utility of the method and its adaptability for use in different circumstances are considered. The chapter ends with a reflection of the strengths and limitations of Body Mapping as a method for empowering children to share their embodied experiences of educational transitions. The research questions for the pilot study were:

1. In what ways can Body Mapping be used to support children to share their thoughts and ideas around the issues of transitions?
2. What are the advantages and limitations of Body Mapping as a method for enabling the voices of children?

There are currently no published studies looking at the use of Body Mapping with autistic children. There is a Doctoral study being conducted at the University of New South Wales, Australia, using Body Mapping to consider the qualities of friendships in autistic young people, but at the time of writing this study is still ongoing. Although Dew et al., (2018) included autistic participants in their study, they were part of a group with complex support needs and no distinction was made in the results or discussion between the needs of the autistic and non-autistic participants, preventing identification of data specific to autistic participants. Consequently, any advantages or limitations to the method in relation to autistic abilities or differences were unable to be extrapolated. This study therefore adds to the body of knowledge about Body Mapping as a method by investigating its use with autistic children.

Initial plans for this research involved a school-based study incorporating Body Mapping and drama work. Two schools had expressed an interest in being involved; one of which, a mainstream primary school, was already known to me as I had worked there prior to embarking on my PhD. The other, a primary special school, was part of the ACoRNS network. I had been visiting this school weekly to familiarise myself with the staff and students. Due to the Covid-19 lockdown in March 2020, both schools regretfully and understandably had to pull out of the project as many students were home-learning and the school sites were closed to all but essential personnel. I therefore adapted my project and removed the drama element which required in-person group work. This pilot work took place over two phases: an initial small-scale trial of the method, followed by a more substantive pilot study. Both the trial and pilot phases of this study were conceived during a time of uncertainty around the progression of the Covid-19 pandemic and were designed to adapt to the prevailing situation.

4.1 Trial Phase

The purpose of this trial phase was to gauge children's engagement with completing Body Mapping tasks and to ensure the process was designed accessibly. While Body Mapping has been used with children in research such as Gamlin et al.'s (2011) study looking at how seven to nine-year-old Mexican children's bodies are affected by their involvement in tobacco farming, there is little in the literature about using it with children under the age of 16 and no evidence of Body Mapping being used to explore children's thoughts and feelings about school. This trial therefore sought to discover how Body Mapping could be used to support children in sharing experiences of educational transitions prior to embarking on the pilot study with autistic children and those with SEN. The findings from this phase of the research informed the final design for the pilot study (section 4.2).

4.1.2 Testing the resources

The first stage of the trial involved a rehearsal of the Body Mapping tasks to ensure the instructions provided in the packs were easy to follow, and that the resources were adequate for the task. This involved completing the tasks in person with two children (Ages 7 and 12 - see Table 1). These children were known to the research team and this process was covered under the ethical approval of the trial phase as described in section 4.1.5. The activity was completed in the participants' home with a parent available to support if necessary. I introduced the activity and read out the tasks as provided in the written instructions and supported with the use of materials – such as opening paint lids - when needed. The tasks followed the same format as the main trial phase (see Table 3) and the participants were given the same pack of materials (see Figure 2).

Table 1

Participant Characteristics for Trial Phase

Sex	Age	Transition Focus
Male	7	Infant to junior school
Female	12	Primary to secondary

Both children showed engagement in the tasks and experimented with a variety of materials. The instructions as written required a minimum of clarification and were amended accordingly. It took around one hour to complete the tasks which was a period that both children were comfortable with. I reflected that some children may not focus for an hour, therefore dividing the tasks into shorter segments for children who may need it would be beneficial. Both children were able to speak about the choices they had made based on the questions provided.

Having conducted this rehearsal of the tasks, I was confident that the materials and information I had prepared to send out to participants would enable the Body Mapping activities to be completed, and therefore moved on to recruit participants for the trial phase.

4.1.3 Recruitment

Participants were recruited via snowball sampling from families known to me and one of my supervisors. An email was sent and interested parties were asked to contact me via email. Two information sheets were sent to potential participants, one written for the child, and one for the parent. Parents were asked to provide consent, and children assent for participation (see section 4.1.5. and Appendix A). Due to the necessity to change the format of this research due to the Covid-19 pandemic, and delays in gaining research governance approval, this process took longer than initially planned: packs were sent to families in late August 2020. This unfortunately limited the recruitment of participants that were able to complete the tasks prior to transitioning to their new schools/colleges.

In total, four participants were recruited. Three were girls who were about to transition to secondary school, the fourth a boy who was transitioning to sixth form college (see

Table 2). Two of the participants completed the process, one undertook parts of the body map but not the interview and one did not want to engage with any part of the process.

Table 2

Participant Characteristics for Trial Study

Sex	Age	Transition Focus	Status
Female	11	Primary to secondary	Complete
Female	11	Primary to secondary	Unfinished
Female	11	Primary to secondary	Did not participate
Male	16	Secondary to college	Complete

4.1.4 Method

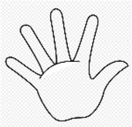
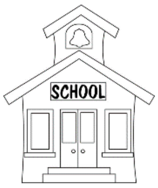
Participants were sent a box of materials through the post which included a roll of paper long enough to allow the drawing of a life-sized outline of their body, and a variety of craft materials including colouring pens, paints, coloured pipe cleaners, and emoji faces (see Figure 2).

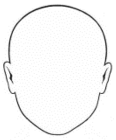
Figure 2 - Body Mapping materials

They also received instructions to share with their parent or guardian that were divided into three sessions (see Table 3). This was to avoid them feeling it was an overwhelming task that needed to be completed all at once.

Table 3

Body Mapping tasks for Trial Phase

Session 1	
1. Lie down on the piece of paper. Get your grown up to draw around your shape. 2. Choose a colour to go around the outline of your body so it stands out. Think carefully about which colour you choose. You might choose more than one colour. Whatever you choose should represent something about you. 3. Now it is time to decorate your hands. Fill the spaces where your hands are with images and colours that represent you. They might be drawn or images that you cut out and stick on. If the hands didn't come out very well in your outline you can draw them again. 4. Choose a place on your piece of paper where you would like to represent your home. It could be inside your body or outside. Think about why you might put your home in this particular place. Decide how you would like to show your home. You could use pens or paints, or you might like to find some pictures to stick on to your body map. Maybe you would like to include some of your favourite things about being at home on your image.	  
Session 2	
1. Your primary school is going to go onto your body map next. Think about where you would like to put it. You can choose how you would like to show your school. You can use any of the resources in your box or other things that you have at home. 2. Once you have finished your primary school image, you need to find a way to connect your primary school with home. You might use straight lines or wiggly ones or something other than lines. Think about what your choice might say about how you feel when you go to school in the morning and when you come home again in the afternoon. 3. Now it is time to think about your new school. You haven't started yet so you might not know much about it. That is ok. Find a way to show your new school and decide where it will go on your map. 4. How will you connect home to your new school? Will it be the same as the connection between home and primary school? It is up to you to choose how you would like to show the connection.	 

Session 3	
1. Think about the people around you who support you. Choose who you would like to include on your body map and where you would like to place them. You can choose as many people as you like. You might like to draw people or to write their names. Think about the colours or patterns you choose for the different people you include. How do these colours or patterns represent them? 2. Now it is time to fill in the face on your body map. You can choose how you would like to do this. It might be that you want to draw what you look like, or you might choose to fill it in using colours, patterns or images that represent you in another way. If you have already filled in your face, you could draw another one somewhere else on your map. 3. Your body map is finished now. The next part of the activity will be to explain what you have included on your body map and why.	 

Parents were asked to support their child to complete the tasks at home by reading the instructions and assisting where needed. Once the tasks were completed, participants were asked to answer questions about their body maps with the support of their parent or guardian and were encouraged to either provide a written response or to audio record their responses to the questions (see

Table 4). Participants were then asked to email me photographs of their completed body maps and an MP3 file with their audio responses or a document with written responses. The process for this was discussed with the parent in advance to ensure they were happy with how this should be done and offered support where needed.

Table 4

Participant Questions for Trial Phase

	Questions	**Possible prompts or examples. These might help if you are not sure how to answer.**
1.	Why did you choose *yellow* for your outline?	
2.	Tell me about the way you decided to decorate your hands?	Why did you choose *green*? Why did you draw a *football*?
3.	Why did you choose to represent your home here?	

	Questions	**Possible prompts or examples. These might help if you are not sure how to answer.**
4.	Tell me about how you chose to show your home.	What does this bit show? What does home make you feel like?
5.	Why did you choose to show your primary school like this?	
6.	Explain why you have linked your home and your primary school like this.	What does this show about how you feel when you go to school and when you come back?
7.	What are the main differences between how you have shown your primary school and how you have shown your new school?	Why are they different colours? Why are they different sizes? Why are they in different places?
8.	What are the differences in the way you have linked your primary school to your home, and how you have linked your secondary school to home?	If they are the same, why?
9.	Tell me about the people you have chosen to show on your body map. Why are they important?	Why have you represented *Mrs Anderson* like this? Why did you put *your brother* over there?
10.	What does the way you have chosen to decorate your face represent about you?	Why did you choose to use *patterns?* Why did you choose to make your eyes *sparkly?*
Words in italics are examples – substitute these with details from your own body map.		

4.1.5 Ethics

Ethical approval was obtained from the University of Southampton's Faculty of Environmental and Life Sciences Ethics Committee (Ref: 58540 Appendix A). Consent was given by the parents for their child's participation as well as assent from the children.

Physical body maps were retained by the participants. Digital data including photographs of body maps and audio recordings of the answers to the questions about their body maps were stored on a password protected computer and recordings were erased once data transcription was complete.

4.1.6 Findings and Discussion

Within this trial phase, one of the young people started creating a body map but only completed the first few tasks which did not include providing information about the transition. A second participant, while initially expressing interest in the project, chose not to complete any of the tasks having received their pack. I therefore only received photographs of completed body maps (see Figure 3 & Figure 4) and audio files of the responses to the discussion questions from two participants.

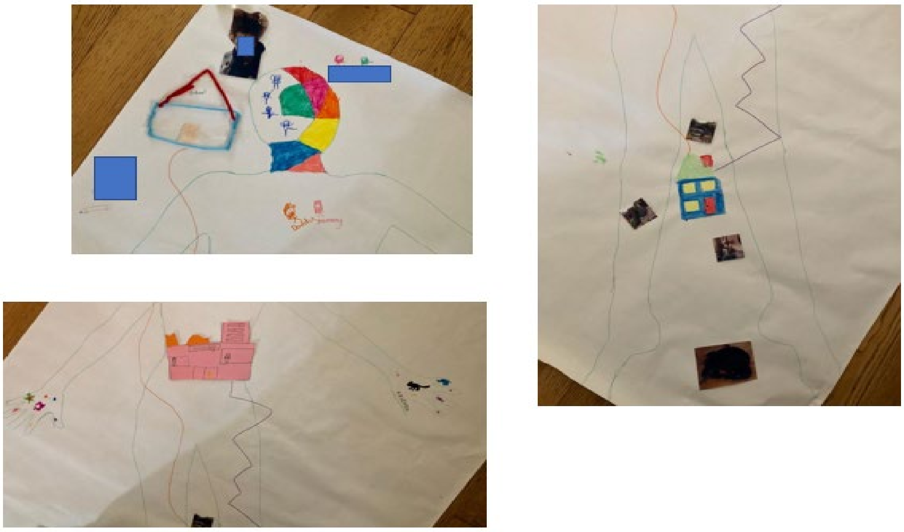


Figure 3 - Participant 1 Body Map

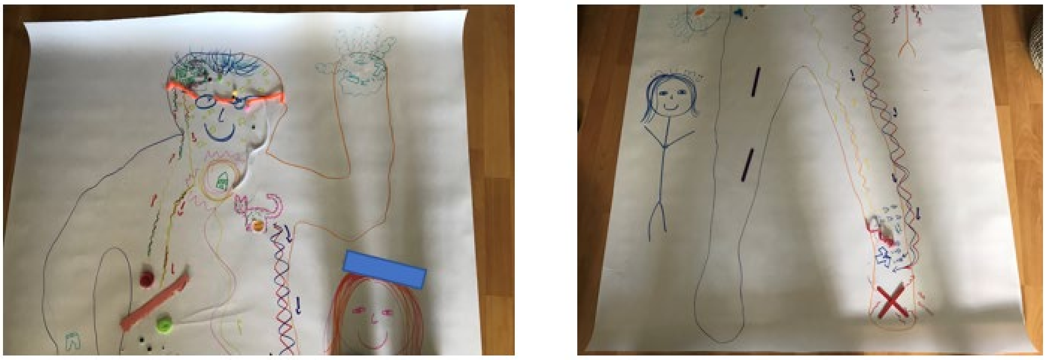


Figure 4 - Participant 4 Body Map

The descriptions of the body maps showed some clear decision-making in what to include, where and which materials to use. For example, participant 4 used marker pens expressively to show

how he felt at having to leave his old school prematurely due to Covid-19. Both participants thought about how the lines that connected home and school could represent their feelings about transitions with jagged lines signifying transitions they were worried about.

The audio files were between 6 and 7 minutes long. I compared the Body Mapping images with transcriptions of the children talking about their choices and found that there were several elements of the maps that I was unable to decipher. For example the photographs on participant 1's maps were unclear. Although they were described in the audio file as pictures of the house and garden it would have been useful to see which aspects of the house and garden were chosen. I also felt that it would have been helpful to be able to ask follow-up questions about choice of photographs. Participant 4 chose to draw one hand with cloud-like fingers. This was not explained in the audio therefore the meaning behind this choice was not clear. The omissions from the recordings led to a feeling of frustration that I was unable to ask follow-up questions. I compared this experience with the rehearsal phase in which I was present throughout the tasks and was able to discuss choices with the children while they were engaging with them. While this rehearsal phase also included the questions at the end of the tasks, having been present during the process I had a deeper understanding of the choices made than were apparent during in the recordings of the question-and-answer sessions I received. Furthermore, in the rehearsal phase the participants offered insight into their choices while they were working on the tasks which were different to the rationale they gave for those choices in the question-and-answer session. It was unclear whether this was due to forgetting what they had said previously or feeling that by asking them to explain again I was wanting a different answer. The imbalance of power in research with children can lead to the children either trying to please the researcher with their responses or fearing the consequences if they say the wrong thing (Einarsdottir, 2007). This power imbalance can be exacerbated by a lack of rapport with children (Punch, 2002). Building in opportunities to develop a relationship with the young person prior to beginning the task is therefore important for the pilot study.

It was clear that while elements of this method such as the materials provided and the activities themselves were appropriate for the research, it would be necessary for me to be more involved in the process than this trial phase allowed to support the building of rapport with the children and therefore begin to address the power imbalance.

4.1.7 Conclusions

The aims of this part of the research were to consider whether conducting Body Mapping using the provided resources and instructions, was a useful way of gathering data on school transitions. With only two complete responses, there was not enough data to usefully analyse the quality of transition information. Despite this, the trial had value in that it enabled me to rethink how to proceed with the pilot study in a way that would be acceptable, feasible, and enjoyable for participants as well as enabling me to address my research questions.

Following this trial phase, I came to three key conclusions. Firstly, not all children would be willing to participate in the Body Mapping exercises and so it would be important to consider how the tasks were introduced, and to ensure that children and young people always felt able to refuse participation without the need for explanation. Secondly, for those children who completed the task, either in person with me facilitating or with parents, I was happy that the resources and tasks I had designed were suitable for use in the pilot study as those children engaged well, reported that they enjoyed the task and were able to represent and talk about their transition experiences. Thirdly, that by not being present while the Body Mapping tasks were being completed, I was missing out on a great deal of valuable data and potentially collecting data that was unreliable due to the power balance between the researcher and the children. I concluded that rather than waiting until the body maps were complete, it would be necessary to have regular opportunities for the children to share aspects of their maps with me and the reasons for their choices if it was not possible to complete them with me present.

Having considered how to address these conclusions within the prevailing and changeable Covid-19 restrictions, a pilot study was then designed. This included an extra meeting with the child to begin the familiarisation process before starting the Body Mapping tasks and the tasks and questions being delivered by me rather than a parent.

4.2 Pilot Study

Having refined the design of the Body Mapping tasks during the trial phase of the study, the aims of the pilot were to investigate whether it would be a suitable method to support autistic young people to share their experiences and feelings about transitions. With autistic children's communication and executive function styles differing from those of non-autistic children (Gardiner, 2018), it was important to consider whether the method as experienced by children with no identified SEN in the trial phase was also beneficial in supporting autistic children to explore their transition experiences. This would be central to informing the next phase of my research. To achieve this, it was necessary to find a way to conduct Body Mapping research with myself as the researcher present, despite prevailing Covid-19 lockdown regulations. During the development of this study, I was fortunate to be put in contact with Michelle Tso, a researcher in Australia who was also trialling Body Mapping with autistic young people. She was using computer software to allow her participants to complete tasks virtually and recommended a variety of programmes that she had trialled. From this discussion I explored virtual methods and chose to include an online option using a free to access software package as well as the in-person task. I wanted to discover the advantages and disadvantages to completing the task on a computer screen rather than on a life-sized piece of paper as per the resources pack that I had posted out to participants in the trial. Crucially, this online method allowed me to be present during the completion of the task even when Covid-19 restrictions meant it was not possible to meet participants face-to-face.

While interviews with adults via Skype (an alternative online method which, like this pilot study, included audio and visual contact) have been found to be of similar length and word count as those held in person, the data has been described as less richly detailed than that gathered in face-to-face interviews (Johnson et al. 2021). It is unclear whether the same findings would apply to interviews with children. There is evidence of successfully moving quantitative studies with children online during the pandemic (Vales et al. 2021), but as yet a paucity of evidence about moving qualitative research with children online. As Body Mapping is such a visual method, it was unclear whether an online version of the task would be effective and therefore it was important for this pilot study to address this to inform the design of the second phase of this research.

4.2.1 Pilot Study Design

For this study I chose to collect data from children and parents. Body Mapping data were collected from children using two different methods: in person where the participant used craft materials to create their body maps on paper; or using video conferencing and drawing software which involved the body maps being created on a computer. In both, participants were asked to describe their choices throughout the process. The in-person task was completed in one session. The online task was divided into two sessions with the possibility of extending this if necessary. This was important because, to complete the whole task in one could be very demanding on the child’s concentration, particularly those who had been engaging in online learning during lock down. Once tasks were completed, participants were asked questions about the process. Parents were then asked for their opinions about the Body Mapping process in a follow-up interview. Thematic analysis was used to analyse the data from all participants.

4.2.2 Recruitment

Recruitment began in September 2020. Restrictions were still in place preventing meeting in person and, as my recruitment was initially via schools, it was difficult to engage participants. I contacted eight primary schools and three secondary schools via email to find a partner for the project. The email gave details of the project including the transition focus, the Body Mapping process, and that the project was specifically aiming to include autistic children. Unfortunately, no positive responses were received. I reconnected via email with the school I had previously been visiting, as well as having an online meeting with the school who had previously expressed an interest in being involved in the project. Both schools said they were unable to support research at this time, for understandable reasons. Consequently, I decided to widen the range of transitions covered in this study. I had initially intended to focus on the primary to secondary transition but the difficulty in recruitment led to inclusion of other transition stages including from school to college. This was also informed in part by the similarity in challenges described by the school to college transition literature (Nachman, 2020). I also included the transitions that took place within a school placement such as between key stages where lesson delivery and timetabling can change, and unexpected daily transitions such as classroom changes or substitute teachers. I therefore emailed eight sixth form colleges but again did not have any positive responses. As schools and colleges proved challenging to engage, I chose to use other methods of recruitment that would enable me to advertise the study directly to families. I used snowball sampling starting with contacts I had as both an ex-teacher and parent. I emailed details to my contacts asked for them to be sent on to other potentially interested parties (see Appendix B.2). Snowball sampling was a convenient method to use at a time when schools and colleges were facing the challenges of the pandemic: however, it frequently results in the participants coming from a limited geographical and socio-economic group. As the aim of this pilot study was to gauge the effectiveness of the method to uncover transition experiences rather than gain an overview of the experiences of autistic children, I felt this limitation was not prohibitive.

Another factor which supported recruitment at this stage was to open it up for children with an identified special educational need (SEN) but not necessarily a diagnosis of autism. This involved the addition of two girls who had been identified by school and parents as experiencing anxiety around periods of change and uncertainty, which negatively affected their education and well-being. By removing the requirement for an autism diagnosis, the recruitment of girls who are less likely to have received a formal diagnosis of autism (Moyse, 2021) was supported. Girls are diagnosed as autistic less often and later compared to boys (Moyse, 2021), which suggests that there are girls who struggle with transitions who may be on the autism spectrum but have not yet been diagnosed.

By making these adaptations it was possible to begin my research despite an unknown and potentially changing situation in the light of the pandemic, and in the context that many young people may have been required to isolate. The valuable lessons learned from this process supported me to design this research in a way that was robust in the face of any future disruption.

Five young people between the ages of 11-16, two girls and three boys (see Table 5) completed the Body Mapping tasks between September 2020 and January 2021. The three boys had a diagnosis of autism. The girls were both identified as having SEN which made transitions challenging for them. One of these was on the diagnostic pathway for autism. Two of the group were focusing on a transition they had recently experienced (retrospective), and the others on a transition that they were preparing for (prospective). Four group members attended mainstream secondary schools with the final participant at sixth form college. All children had one parent complete the follow-up interview. These included one father and four mothers. Interviews with parents lasted between 11 and 34 minutes.

Table 5

Participant Characteristics for Pilot Study

Name*	Sex	Age	Identified Needs	School	Transition focus	Method	Duration	Parent
Clara	F	11 y 4 m	Diagnosis pending (expecting ADHD, PDD-NOS)	Mainstream primary – secondary	Primary to secondary (prospective)	In person	50 minutes	Mum
Harry	M	14 y 1 m	Expressive developmental language disorder, Autism	Mainstream secondary	Key stage 3 (KS3) to GCSEs (prospective)	In person	1 hour 21 minutes	Mum
Malia	F	15 y 8 m	Dyslexia. Social, emotional, and mental health (SEMH) support	Mainstream secondary – 6th form college	School to college (prospective)	Online	1 hour 26 minutes	Mum
Matteo	M	16 y 10 m	Cardio Facio Cutaneous syndrome, Dyspraxia, Autism	Mainstream 6th form college (Previously special school)	School to college (retrospective)	Online	1 hour 11 minutes (59 minutes and 12 minutes)	Mum
Clive	M	15 y 5 m	Autism	Mainstream secondary	Unexpected school transitions	Online	37 minutes	Dad

Name*	Sex	Age	Identified Needs	School	Transition focus (retrospective)	Method	Duration	Parent

Note. Pseudonyms are used to ensure confidentiality.

4.2.3 Ethics

Ethical approval was obtained from the University of Southampton's Faculty of Environmental and Life Sciences Ethics Committee (Ref # 61698). Consent was provided by the parents for their interviews and on behalf of their children for the Body Mapping process (See Appendix B for ethics application form and attached documents).

Assent was also sought and received from the young people themselves. The assent/consent process included permission for the use of images of the body maps and for quotations from the interviews. All data was anonymised, and pseudonyms were used. Any identifying features on the body maps were covered before being shared. Physical body maps were retained by the participants who completed the task on paper. A link to the digital body map was emailed to me at the end of the session. All digital data were stored on a password-protected computer and digital recordings were erased once data transcription was complete.

4.2.4 Methods

Having responded to the recruitment email, parents and children were sent further details of the research (see Appendix B.3 and B.4). If still keen to participate, a conversation was had with the parent and child either via email or using Microsoft (MS) Teams to discuss the educational transition focus prior to the task. This involved outlining what was meant by educational transitions and considering which transitions were most pertinent to the child at the time that data collection was taking place. The method of completion of the tasks – whether in person or online - was also decided at this time.

In-person Body Map. Two participants engaged in the Body Mapping task in person. I met with the child and parent in the participants' homes: this was permissible under prevailing Covid-19 regulations which allowed groups of under 6 people to meet indoors. In both cases the parents were known to me prior to the research being conducted: one as my son had been to nursery school with an older sibling thirteen years previously, the second was someone with whom I attended secondary school. To establish rapport, the session began with a conversation with the child about recent events pertinent to them such as the activities they had been participating in that week. The identified transition was then discussed to ensure the young person agreed with the specific focus. The plan for the session was then outlined to the child and parent and assent and consent forms respectively, were discussed including details of the use of pseudonyms, how the data would be used and the right to withdraw. Having given consent or assent, the opportunity to ask any further questions about the study was offered before beginning the task. Both children who completed the task in person requested that their parent stayed in the room throughout. Clara's session was the first conducted and, on this occasion, only the discussion at the end of the task was recorded while notes were taken for the duration of the task. Following this session, I reflected that attempting to take notes during the task limited the discussion and took my focus away from the child. Therefore, for Harry's session the entirety was audio-recorded which allowed me to fully focus on Harry and what he was doing, and I made reflective field notes once I returned home approximately one hour after the Body Mapping session.

At the start of the task, both participants were introduced to the resources available to them to complete the body map. They were told they could use as many or as few of the resources as they liked, and it was their decision as to how to use them. The first task involved drawing around the outline of the child's body on the paper and was completed with help from the parent. The tasks outlined in Table 6 were then completed.

Table 6

Body Mapping Tasks for Pilot Study

1	Draw round the outline of your body.
2	Choose a colour to go around the outline of your body so it stands out. Think carefully about which colour you choose. You might choose more than one colour. Whatever you choose should represent something about you.
3	Now it is time to decorate your hands. Fill the spaces where your hands are with images and colours that represent you. They might be drawn or images that you cut out and stick on. If the hands didn't come out very well in your outline you can draw them again.
4	Choose a place on your piece of paper where you would like to represent your home. It could be inside your body or outside. Think about why you might put your home in this particular place. Decide how you would like to show your home. Maybe you would like to include some of your favourite things about being at home on your image.
5	Your school is going to go onto your body map next. Think about where you would like to put it. You can choose how you would like to show your school. (This could be primary or secondary school depending on the context)
6	Once you have finished your school image, you need to find a way to connect it with home. You might use straight lines or wiggly ones or something other than lines. Think about what your choice might say about how you feel when you go to school in the morning and when you come home again in the afternoon.
7	Now it is time to think about your new school/college/classroom/situation. Think about what you know about your X so far. This could be to do with the subjects you are taking,

	the differences between school and college or the way you feel when you think about the move. Choose an image to represent this on your map.
8	How will you connect home toy our new school/college? Will it be the same as the connection between home and school? It is up to you to choose how you would like to show the connection.
9	Think about what helps you when you are finding things tricky. This might be intense interests, gadgets, or activities. Find a way to represent these on your body map.
10	Think about the people around you who support you. Choose who you would like to include on your body map and where you would like to place them. You can choose as many people as you like. You might like to draw people or to write their names. Think about the colours or patterns you choose for the different people you include. How do these colours or patterns represent them?

Online Body Map. An initial online meeting was set up with the child and parent. This meeting involved a conversation with the child to establish rapport as with the in-person sessions. Transitions were discussed with the child and parent to agree what the focus of the Body Mapping session would be. This involved outlining what was meant by educational transitions and asking the child and parent which transitions they felt would be most helpful to talk about. This meeting also gave us the opportunity to test the software. The first task, which was to draw the body outline and choose the colour for it, was completed at this session to ensure the child was happy using the software and sharing their screen. Drawing the body outline using this method involved drawing trousers, a T-shirt or jumper, and a face; all of which could be adapted using the software as described below. This meeting took approximately 30 minutes. A time was then agreed for the next online meeting to complete the Body Mapping task. Completing the task online over two or more sessions was particularly important for Clive who, at the time of data collection had been attending lessons online from home, and Matteo who had been working on a computer in the college library: their schools were not providing face to face teaching for them at the time of completion.

The second MS Teams meeting took place within one week of the first. This meeting began with a discussion of consent/assent forms as above. Matteo requested his parent stay throughout and support him with the task. Malia and Clive opted for their parents to leave the room but be nearby if needed. The software was then accessed, and the next task started. For each of the tasks we discussed ideas first then the participant added the drawings to their body map. All meetings were recorded using the recording function within MS Teams.

The software used - Autodraw - (Motzenbecker & Phillips, 2017) is an experimental drawing platform showcased by Google. This software was chosen as it is easily accessible on the internet and does not require downloading or any specialist equipment. It has an artificial intelligence element that allows it to guess what you are trying to draw. This means that if you struggle with drawing online you can choose from a series of offered images to make your drawing clearer (see Figure 5). This feature supported the young people who found it more difficult to draw using a mouse or a trackpad on the computer to create images felt represented what they were trying to show. Furthermore, the programme can be used to draw using a variety of colours, shapes and text tools.

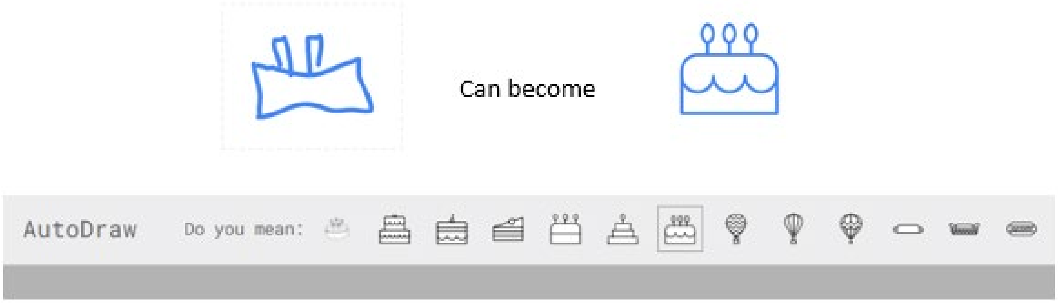


Figure 5 - Autodraw Examples

The specific tasks undertaken were tailored to the transitions that had been identified for the individual child (see Table 5). Malia chose to focus on the transition to further education (FE). Clara chose to focus on how she felt about the difference between primary and secondary. For Harry the focus was on how he felt about changing from KS3 to GCSE courses which would involve him having different teachers, a different timetable, and different pupils in his classes. For Clive it was about unexpected transitions such as a classroom change or a change in teacher. Matteo's focus was also on the transition to FE college, but he had already started at the new college so was looking back on the experience. The duration of the online Body Mapping sessions ranged between 37 minutes and 1 hour 26 minutes. Matteo's Body Mapping task was finished in an extra session one week later as he requested to end the first session after 58 minutes and finish at another time.

Questions for Participants. Once participants had completed their body maps – either online or in person, they were asked the following questions (see Table 7).

Table 7

Participant Questions for Pilot Study

	Questions
1	How did you think using Body Mapping effected the way you thought about your transitions compared to just talking about them?
2	What did you think were the good and bad aspects of using the software/craft resources?
3	Explanation was given about the alternative method of completing the tasks. They were then asked: Would you have preferred to do the task online or on paper? Why?

Questions for Parents. Parents were interviewed to gain feedback about how their children engaged with the Body Mapping task and to identify key issues relating to transitions for their children. Parents were interviewed up to one week after the Body Mapping tasks were completed. Again, the methods of the interviews were adapted to fit the prevailing lockdown guidance. The two parents whose children had completed the tasks in person were interviewed outdoors during daily permitted exercise. Both parents were happy to be recorded during a walk with a hand-held digital voice-recorder. The parents of the online participants were interviewed online over MS Teams as meeting with someone outside your household was not permitted at the time. In both interview conditions, parents were reminded of the consent form they had signed prior to their child completing the Body Mapping task. They were then given the opportunity to ask any questions before starting the interview. Parents were asked the questions below (see Table 8).

Table 8

Parent Questions for Pilot Study

	Questions	**Prompts**
1	I need to get a few details first about your child: What is their date of birth? Does your child have an identified special educational need? If yes, what is it? Does your child attend a mainstream or special school? What level of schooling are they at (secondary, college etc)?	
2	Firstly, I would like to talk a bit about the Body Mapping activity. What were the positives about doing the Body Mapping?	Use of materials? Communication style? Engagement with the tasks?

	Questions	**Prompts**
3	Were there any challenges to completing the Body Mapping?	Use of materials? Communication style? Engagement with the tasks?
4	Is there anything that you think could have been added to improve the tasks or the process?	More/different materials? Clarity of instructions? Different mode of delivery such as use of technology?
5	If you were to advise a parent going through this next year, what would you say?	

4.2.5 Analysis

Reflexive thematic analysis as defined by Braun and Clarke (2020) was used to analyse the data. Accordingly, the analysis was carried out in an inductive way with the data driving the formation of the codes and themes.

The data consisted of transcripts of the Body Mapping sessions with the children, the body maps themselves, and transcripts of the parent interviews. The familiarisation process began with transcription of the sessions and interviews from audio files. The transcripts were then checked against the recordings before being read several times more; this allowed consideration of possible links in the data to be considered. Body maps were compared to the transcriptions of the children's sessions and elements of the body map were identified in relation to the descriptions given. For example, choice of placing home next to the heart was identified both on the body map and in the transcription. Coding was completed using Nvivo software QSR International, 2020). Once familiar with the data, initial codes were generated. On revision of these, certain codes were amalgamated with others to avoid overlap, for example 'representation of the creative self' was combined with 'awareness of personal strengths' - as creativity was considered a positive attribute in all cases. The codes were then compared and collated into themes. The themes were compared again with the data, before being refined and named with 'concise, punchy' titles (Braun & Clarke, 2016, p. 93). Details of initial codes and how these were grouped into themes can be found in Appendix C.

4.2.6 Discussion

This pilot study was designed as an exploration of the use of body mapping in research rather than as a means to learn about educational transitions. Specifically, the study aimed to discover whether Body Mapping was a technique that supported children to talk about their experiences of transitions, and whether the means of delivery of Body Mapping made an impact on the efficacy of the method.

As such, the thematic analysis findings will not be presented in full here. This discussion will summarise those findings in terms of the key learnings across the themes identified and explain how they were used to inform the next phase of the research. The body mapping images are included in Appendix D

Body Mapping as a Strategy to Support Autistic Children to Reflect on Transitions. Body Mapping was successful in this study in supporting the participants to communicate their experiences and feelings. This was achieved not only through the children's choice of which images to include and where to place them, but also through the way these choices were described. A particular area of insight was shown in an awareness of their individual strengths and challenges, for example Malia's love of playing music and Matteo's difficult interactions with peers. The support given for Malia's interest in music by her school was a good example of a school using intense interests to support transitions which has been shown to be of benefit for autistic children (Wood, 2021). The importance of friendships made after transitioning to a new school, that Matteo described as helping him to overcome previous negative experiences, reflects the importance put on friendship to support successful transitions identified in case studies such as Martin et al., (2021) and more generally in a systematic review of the educational transitions literature (Nuske et al., 2019).

All the children were able to identify the people who were best able to support them with transitions. While most of the body maps included Mum in a supportive role, in most cases there was also at least one member of staff in their educational establishment who was identified. Developing relationships with staff and having an assigned mentor are important strategies for supporting effective transitions (Nuske et al., 2019). All participants were also able to reflect on strategies that they use when they are feeling challenged by difficult situations. These strategies included activities they might engage in such as spending time with pets or reading or places they may go to such as their bedroom or to a room at school where they feel comfortable and supported. This evidence supports Body Mapping as a useful method to help autistic children to talk about transitions, however it is also important - when aiming to support the voices of autistic children - to consider whether Body Mapping gave participants more agency in the data collection process than more traditional methods such as interviews might have done.

Oliver (1992) argued that ‘research has been and essentially still is, an activity carried out by those who have power upon those who do not’ (p. 110). Although the balance of power was still with the researcher in this study, my observation as the researcher was that Body Mapping gave participants agency over what they chose to share and how they shared it. By allowing the participants to have autonomy over their maps, they had some power over the data they provided. This benefit was also recognised by Dew et al. (2018) in their study using Body Mapping with young people with complex needs. They reflected how enabling the participants to decide not only how they chose to share their views on topics covered, but which topics they spoke about by choosing what to include on the map, allowed their participants to become the expert on the topic and the researcher became the ‘conduit’ (Dew et al., 2018, p. 19). Dew et al.’s (2018) study focused on life transitions and allowed the participants to choose the transition they focused on. While this study was similar in giving some autonomy over the which transition to consider, the focus on educational transitions meant that participants were not able to exercise as much choice and so they were largely guided on *what* to discuss. Where Body Mapping did provide more power to the participants was in their opportunity to choose *how* to share their ideas with me.

For example, although the Body Mapping process involved me guiding participants through the themes and ideas that need to be included on their maps, it was up to the individual how they realised the instructions. This was clear in the way participants engaged differently with the tasks. The children who created their body maps on paper were given a wide range of resources to choose from. Clara’s finished map was quite abstract with some elements being represented by areas of colour and shapes created from coloured pipe cleaners, but Harry’s included precise drawings and words. The same differences were apparent in the maps created using Autodraw (Motzenbecker & Phillips, 2017). Clive drew freehand while Malia and Matteo used the magic pencil function. Malia’s body map was densely populated with images while Clive’s was less so. Matteo and Malia both included text on their maps while Clive’s was solely images. These differences in response added an extra layer of data in that they reflected the participants preferences. It is important, however, to avoid imposing meaning onto the work without being reflexive about the impact of Double Empathy. Milton (2012) describes the assumptions of non-autistic researchers on autistic thoughts and actions as ‘often wildly inaccurate’ (p. 884). Ensuring participants are given the opportunity to share their own voices (either verbally or in another way) throughout the process and including their thoughts such as by way of a testimonio (Gastaldo et al., 2012), is an imperative part of the process.

Moreover, being reflexive in the way that data are analysed is important to address this. When moving on to using Body Mapping in the next phase of the research, including the participants within the entire process in a more meaningful way was a key focus. The addition of my reflexive journey as a source of data in the second phase of the research strengthened the analysis of the process and allowed me to further interrogate my impact as a researcher on it.

Including Body Mapping within a more participatory framework could further address the Double Empathy problem and the balance of power. My reflection on seeing the method in action is that participants need to be more involved in the decision-making and analysis of data. Orchard (2017) described how Body Mapping enabled a 'transfer of creative license and power from researchers to participants, whose work not only captures their lived experiences but is considered of equal value alongside other kinds of data' (p. 66). A major conclusion for me from this pilot study was, therefore, to incorporate Body Mapping within a more participatory framework to continue to improve the balance of power between me and the autistic children in the process.

Overall, in response to my first research question, I conclude that Body Mapping is a useful method to support autistic children to share their transition experiences and allows them some autonomy over the process in terms of what they choose to include on their body maps and how. Where the process could be strengthened is by incorporating it into a more participatory framework, where the participants would have more control over the Body Mapping tasks and the questions we might ask about them. By finding ways to include participants in the data analysis process, it would also be possible to start to address the Double Empathy problem.

Body Mapping for Enabling the Voices of Autistic Children. The second consideration about the use of Body Mapping in this study focused on whether, as a research method, it offered the potential for autistic children's voices to be promoted in research.

The way the children represented themselves on their body maps reflected an insight into their experiences and emotions that may have not been supported by more traditional methods, such as semi-structured interviews. While the formal comparison of data from interviews and Body Mapping has not been undertaken, a systematic review of studies using Body Mapping supports anecdotal evidence that the data gathered is different to that gathered from verbal interviews alone (de Jager et al., 2016). De Jager et al., (2016) propose that Body Mapping as a method provides attributes not inherent in other methods. These include its power as an arts-based method to provide a depth of information not possible with other qualitative methods, as well as the way it supports participants to consider their embodied experiences by using the image of the body at the centre of the process.

For example, Body Mapping allows participants a choice in the materials they use. Clara chose to predominantly use paints for her body map as she wanted to create large areas of colour to reflect how she strongly identified colours with people and emotions. In contrast, Harry chose to use felt-tipped pens as he wanted to be more precise with his drawings and to include more written elements to his map as he felt more comfortable working in this way. This reflected his interest in building and construction which was also represented by including a cardboard model of a bird house he had built being included on his body map. The ability to make these observations provides insights into the participants that may not have been possible without the creative element of the tasks. These observations were also supported by the descriptions from both participants of why they had chosen these materials. These benefits are, however, also available within other creative methods, particularly with the use of collaging which can involve the use of mixed materials (Ridout, 2017).

A further benefit of the Body Mapping method is that being able to intersperse talking about their experiences with periods of creating images, the participants were able to take pause and consider their responses. This was particularly apparent when working on the task with Harry. There were long periods of silence during the task while Harry was choosing materials or creating images on his map. In an interview situation, these silences may have prompted rushed answers or unnecessary clarification of the questions, the distraction of the resources meant that the pauses were a comfortable and necessary part of the process. This was supported in both in-person and online tasks, as both required the young person to make selections both of images and ways of realising them. This is similar to the benefits found in using the Mosaic approach (Clark, 2001) or interrupted interviews (Shepherd, 2015) in which semi-structured interviews are conducted in conjunction with activities such as taking photographs of important places, creating collages and sorting images into specific categories. In addition, for participants such as Harry who found verbal communication more challenging, Body Mapping enabled them to express their ideas in an alternative way by using graphic representations. For this study, however, participants were required to provide verbal reflection on their choices while completing the tasks. To give participants more autonomy over how to engage with the process, it would therefore be beneficial to be more inclusive in how they are able to reflect on their body maps. For example, Gastaldo et al. (2012) used a written testimonio created by the participant at the end of the process. It would be possible for this testimonio to be created in different ways, for example, using a sorting task to divide photographs of different elements of the map into categories as is used in some photovoice activities; a soundscape in which sounds are produced to reflect different elements of the map; or by using computer software to create a more visual testimonio which does not require detailed prose. By giving participants more choice in how they complete each element of the task, it is possible that they might also be gaining more power in the process as they will direct how they participate (Martin, 2014).

Factors such as choice of materials, chances to reflect, and opportunities to use graphic or written communication rather than just verbal, support the use of Body Mapping as an effective creative method to use. Where it potentially exceeds the possibilities of other visual methods is in the support it gives to the description of embodied experiences. The richness of the contextual information provided in the Body Mapping sessions was supported by the addition of images and colours but particularly in the positioning on the body map. Participants were able to express layers of meaning with one idea and in a way that may have been more difficult to do in spoken responses to an interview question. An example of this was when Clive spoke about how he found PE lessons challenging at school because he did not like the competitive aspect. While this was a useful observation, Clive chose to represent this on his map by drawing a monstrous looking PE teacher next to a drawing of himself running away. This gave a much clearer representation of how he felt about PE lessons than his verbal description alone. It also gave a sense of his embodied experience of wanting to escape from his PE lessons by showing him fleeing from the wicked-looking teacher. This image was placed outside the body, unlike the image he created of his family which showed him standing between and being embraced by his parents and which was placed next to his heart with a heart shape above to reflect his feelings about his family (see Appendix D.4).

By focusing the tasks on a representation of the participant's body, whether that be life-sized on paper or a representation online, Body Mapping has the potential to tie the research to experiences as lived by the participants' bodies (Dew et al., 2018). This means that participants can link the images they create to their physical as well as emotional experiences. By choosing to represent the most important features closest to, or within the body, all participants reflected on the relationships between the elements of their body map. I was initially concerned that the embodied nature of the method would be limited by completing the tasks on a screen rather than on a life-sized piece of paper, but there were no clear differences in the way participants responded. Both approaches saw participants placing home, family and support closer to their bodies and school and college further away. Both methods involved consideration of head versus heart in placing emotions within the body. The addition of emotional representation in specific places added to this. By showing some emotions being contained within the head, and some in the stomach, Matteo showed more about the impact of those emotions than he was able to do by verbally expressing them.

It would be beneficial to develop an understanding of how transition impacts participants in a sensory way using embodied representations. The value of Body Mapping to develop understanding of people's experiences within a physical space (de Jager et al., 2016) might offer the potential to encourage a better understanding of the experience of autistic young people who often experience sensory stimulation in a different way to their non autistic peers.

Flexibility of Body Mapping to Adapt to Prevailing Covid-19 Situation*.* At the time this pilot study was being conducted, the regulations surrounding contact with people outside the household were frequently changing and schools were facing closures due to outbreaks within year groups and staff shortages. It was important to consider different ways of undertaking Body Mapping to be adaptable to potential future disruption. To ensure online and in-person approaches were not only balanced in the quality and quantity of data gathered, but also enjoyable and engaging for participants, both children and parents were asked to give feedback on their thoughts about completing the tasks. Although they only experienced one method of completing the task, the alternatives were described, and they were asked to reflect on their experiences in their task as well as consider the potential pros and cons of the alternatives. Positive reflections about completing the task online included the flexibility of the software to zoom closer to the images, meaning it was possible to include as much detail as would have been included in a life-sized picture despite the image fitting on a small screen. It was also recognised that it was a more flexible way of completing the tasks in the challenging circumstances caused by Covid-19. The disadvantage of using the online version was that the experience of seeing your own life-sized body outline was lost. Although participants did still reflect on where to place images on a smaller body shape and therefore consider their embodied experience, there may be more of a disconnect between the body and an image on a screen than a tangible life-sized image on paper, but this is an observation that would require further investigation and analysis to be able to draw any firm conclusions.

4.2.7 Limitations

There are several limitations with respect to the design of this pilot study. Due to the widening of the participant pool, the transition that each participant focused on was different. This meant that it was more difficult to draw parallels between experiences than if the participants had all been describing the same transition. However, this was not felt to be detrimental as the aim of this pilot study was to consider whether the method gave agency to the children to share transitions experiences in a way that represented their unique voice, rather than to gather data to inform about a specific transition.

Although there were preliminary meetings to discuss the research, the task was completed in one session with all but one participant. Previous Body Mapping research has been conducted over five days (Solomon, 2007) or four two-hour sessions (Lys et al., 2018). These studies reported that this timeframe allowed for more depth of discussion about the focus of research than was possible over one session. This lack of depth was a feature of the current research and, when reading back over the transcripts of the sessions, I was able to identify contributions from the young people that it would have been beneficial to focus on in more depth. Additional time would allow for more considered and focused questioning as well as granting the children more time to reflect on and develop their contributions. This speaks to my development as an emerging qualitative researcher and continues to be an area in which I am reflexive.

As some parents were present throughout the task and others were not, there were also differences in the depth of feedback the parents were able to provide about their child's involvement in the tasks. Parents who were present throughout provided more information about the challenging aspects of the task whereas those who were only present for the beginning and the end tended to reflect on the positive outcomes. This may have resulted in a skewed perspective towards the positive.

4.2.8 Conclusions

This pilot study supports the use of Body Mapping as an effective and distinctive method to support autistic children to share their thoughts and experiences around transitions. Using Body Mapping, the children were able to describe their experiences and identify strategies they used to regulate the challenges they faced. They children responded positively to the Body Mapping process and were happy to share their ideas which were expressed creatively, and this positivity was reinforced by the parental perspectives. The method also supported the children to consider their educational experiences in an embodied way. I conclude, therefore, that Body Mapping is a worthwhile method to use in developing understanding about transitions for autistic young people. Through conducting this pilot study, lessons were learned about how to improve and extend the Body Mapping process in the next phase of the research. Moreover, it was possible to design the Body Mapping process in a way that was adaptable to further disruption caused by the pandemic.

The next part of this thesis will describe the substantive part of my research which involved a synthesis of the information provided in my literature review with the findings of this pilot study. It will outline how Body Mapping was used with a group of autistic girls in a participatory way to explore transition experiences. It will explore how the analysis of the data produced during this process was conducted in a way that prioritised the promotion of the autistic girls' voices to support understanding of their experiences and opinions around transitions. It will describe how this work influenced the creation of resources to be used in schools to further the understanding of autistic girls' experiences and will evaluate both the resources we created, and the process by which we created them.

Chapter 5– Building a Research Group with Autistic Girls: The Creation of Fizzacc

Introduction

In the preceding four chapters I presented my philosophy of autism research in relation to my experience as a teacher and researcher, and my support for the inclusion and promotion of autistic voices. I positioned the autistic-led Double Empathy theory as being central to this philosophy. I also reviewed the core concepts of educational transitions for autistic children, the missing voices of autistic girls in research and the impact of the social model of disability on research design, which led me to participatory research with autistic girls to further our understanding of these concepts. I presented an argument to use a Body Mapping methodology and piloted it with a group of autistic young people. My conclusions were that the method was appropriate for meeting the aims of my research, namely: to explore transition experiences through Body Mapping, collaboratively create resources to promote the understanding of autism, and consider the impact of working within a participatory framework alongside autistic girls. Accordingly, I proceeded to design a research project which brought together all the elements of my conceptual framework which include my research philosophy and the core concepts and methods summarised above.

This chapter begins by reviewing the context within which the next stage of the research sits in terms of my philosophy of research and how I decided to conduct the project. The ethical considerations involved in my participatory work are addressed. The chapter then describes how the research group for this project was created and provides an overview of the research methods and procedures. As such, this chapter serves as an introduction to the main body of this research, which is detailed in Chapters 6, 7, 8 and 9.

5.1 Research Design

The design of this research was heavily influenced by my general philosophy of working together with autistic young people to support the aim of ‘nothing about us without us’ as outlined in Chapter 1. Having established Body Mapping as a valuable method, I therefore designed a participatory research study that worked with autistic girls to explore their educational transition experiences and to develop resources to support other autistic girls’ experiences of transitions. I aimed to recruit a small group of autistic girls to join a research group to achieve these aims and with whom I would work over several months. This project addressed the gaps identified in the literature review (Chapter 3) which recognised that girls’ voices were missing from autism research and pupils’ perspectives were missing from transition research. Throughout this process I also wanted to consider the advantages and challenges of participation in the research for all members of the group. The research questions I aimed to answer in this stage of the research were:

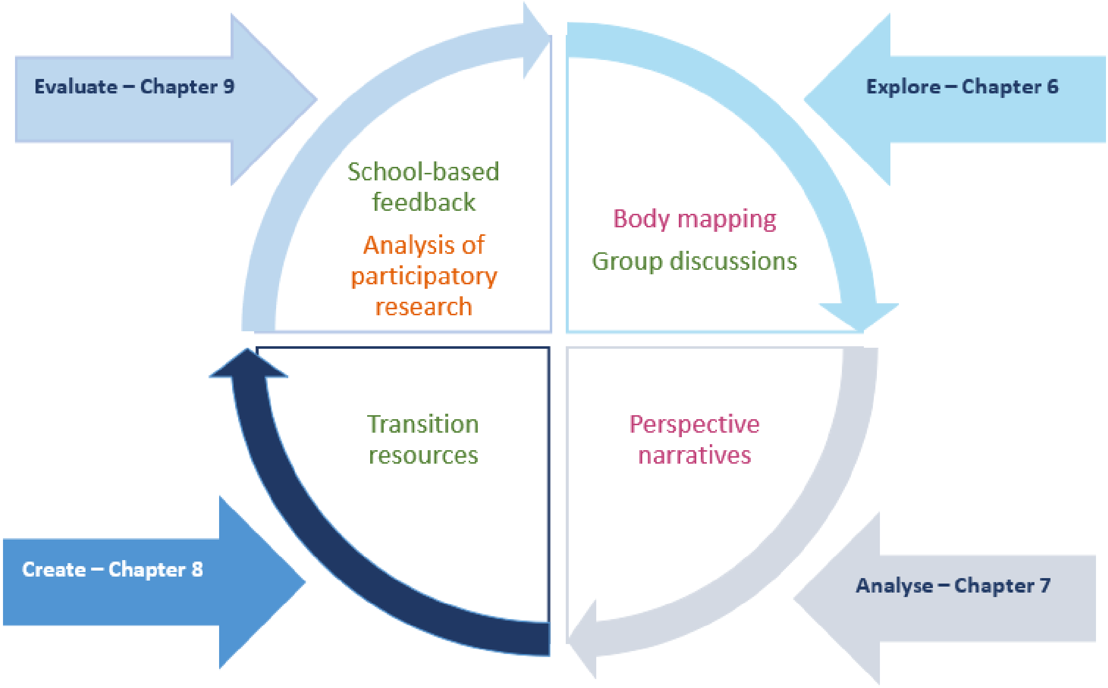
- How can creative data collection and analysis methods be used to promote the voices of autistic girls?
- What do autistic girls feel are the barriers to a successful transition from primary to secondary school and how can these be addressed?
- What are the challenges and benefits of including autistic girls in participatory research?

In Chapter 2 I explored the literature about participatory research which offered a framework to incorporate autistic young people into the decision-making process. Participatory research has been described as more 'demanding and difficult than conventional research' (Klocker, 2012 p. 151) and it can be time-intensive and therefore at odds with the structure and time limitations of a PhD (McCormack, 2004) (never mind a PhD conducted in the context of a global pandemic!). The impact of these constraints was that certain decisions about the project had to be made by me and in advance of establishing a group with whom those decisions may have been made under different circumstances. Thus, prior to setting up the research group, the decision to focus the research on the primary to secondary transition for autistic girls was already made, as was the use of Body Mapping as a tool to support the expression of views and voices of the autistic girls. While the research focus and methods can form part of the preliminary discussions within participatory research and therefore move the participatory emphasis from co-production to community-led as described in den Houting et al.'s (2021) hierarchy of participatory research, this can be challenging within the timescale of a PhD, and so I did not develop the initial focus and method with the autistic community in this research. The decision to use a participatory framework was developed as a response to my thinking about how to best research transitions for autistic children and it is important to be transparent that the research group was initially formed within parameters that I had already defined.

When designing this stage of the research I particularly aligned with the concepts of participatory action research (PAR). PAR is a methodology which prioritises active involvement of co-researchers with lived experience in research (Lenette, 2022). Where participatory research becomes PAR is in the action that results from the research undertaken, which is often more activist than academic (Raynor, 2019). This activism means that PAR is often aligned with social justice and therefore aims to address the power imbalance experienced by those who are disadvantaged and marginalised (Lenette, 2022). While there are many methods used within PAR, the ideal is that the methods chosen support collaboration with co-researchers at all stages of the process (Chevalier & Buckles, 2019). I have already outlined the limitations in relation to my own starting point, and I am aware that this project goes only a small way to address the power imbalances inherent within both the education system and social research. Nevertheless, by working together with autistic young people to produce resources which aim to make a difference to the lives of others we have worked to 'understand and improve the world by changing it' (Baum et al., 2006 p. 854).

The Inclusive Design Group at The University of Cambridge (http://www.inclusivedesigntoolkit.com/) outlines a method of designing products in an inclusive way. It states that: 'Inclusive design is about making informed design decisions, by better understanding user diversity, which helps to include as many people as possible.' To achieve this it advocates involving the end user in the design process. This aligns with PAR as inclusive design and promotes the involvement of those with lived experience as central in the process. To achieve these aims the Group produced a toolkit which divides inclusive design research into three phases: Explore, Create, and Evaluate. My approach to this project was inspired by these phases and followed a similar structure, but with the addition of an analysis phase: specifically, a novel method of data analysis was co-created which enabled us to explore understanding of transitions in a way that addressed Double Empathy.

Figure 6 illustrates the framework for my research which also shows, using colour codes, how each stage mapped to specific research questions. The project relied on each activity influencing the others. The research was thus not conducted as discrete studies but as a series of meetings in which several aspects were often addressed simultaneously. The series of activities captured under the Explore, Create, and Evaluate core elements of the Inclusive Design Framework, with my addition of participatory analysis, forms the overall structure of this next part of the thesis. Chapter 6 – Explore - details the Body Mapping tasks and discussions held during group meetings to develop our understanding of the transition from primary to secondary school. Chapter 7 – Analyse - introduces a method of data analysis that includes and promotes the voices of autistic girls in the process. Chapter 8 – Create - focuses on the process of designing and creating transition resources for schools. Chapter 9 – Evaluate - provides an analysis of the feedback we received from schools that trialled our resources before concluding with an evaluation of the process of conducting participatory research with the research group.



Research Questions:

How can creative data collection and analysis methods be used to promote the voices of autistic girls?

What do autistic girls feel are the barriers to a successful transition from primary to secondary school and how can these be addressed?

What are the challenges and benefits of including autistic girls in participatory research

Figure 6 - Framework for Conducting Fizzacc's Research **I**nspired by the Inclusive Design Toolkit **(http://www.inclusivedesigntoolkit.com/)**

5.2 Ethical Considerations

Prior to beginning this research, ethical approval was sought and granted by the University of Southampton. Two applications were required, the first (Ref # 64210) covered the participatory work with the research group of autistic young people. The second (Ref #71269) covered the evaluation of the resources from the schools. See Appendix E.1 and I.1 for ethics application forms. This section focuses on wider ethical considerations while the procedural ethics relating to informed consent are covered in the Recruitment section below.

The first consideration related to the implications of using a methodology which promotes power sharing within a research group. Having made certain top-down research decisions from the outset, I nonetheless aimed to use the opportunity to balance the power inherent in my research between the researcher and (traditionally defined) participants: this is an aim and strength of participatory research (Cumbo & Selwyn, 2021; Fletcher-Watson et al., 2019). I approached this project with a clear understanding that - although I wanted to work in a way that shared power with, and enabled agency for, the other group members – I recognised that I, was an adult working with a group of teenagers, and that we were not going to be approaching the work as equals. My power came from my age, status as a researcher (and former teacher), and that this was a project that I was leading for my PhD. The power for the young people was in their choice to share (or withhold) insights based on their lived experiences, and the opportunity for them to use their participation in the research to make a difference for other autistic young people. Throughout, it was also important when thinking about the balance of power in the project to ensure that my voice as a researcher was clear, so that my contribution to the project was defined to allow for my examination as a Doctoral candidate.

A further ethical consideration that links to the balance of power in participatory research was how to ensure the welfare of the group members in terms of providing confidentiality for the data they were sharing, whilst still enabling them to decide whether they wished to be publicly recognised for their contribution to the project. As members of a research group, it was important that the girls should have the opportunity to be recognised as co-authors and to have ownership of their work. Accordingly, I drew on the work of Vincent et al. (2017), who conducted research using a participatory framework to explore autistic young people's experiences at university using autobiographical writing. This research was undertaken by the Stratus Writers Project, a research group comprising one academic and seven autistic undergraduate students. When applying for ethical approval from their university, there were concerns from the ethics committee about the potential detrimental impacts on safety and wellbeing if the autobiographies included the students' real names. Vincent et al. (2017) argued, however, that not including the students' names when the students wished to have their names identified, would deny their right to have a voice in a matter so important to their own community and experience. As promoting the voices of underrepresented populations is an important part of participatory research, muting voices through anonymity and confidentiality procedures can serve to minimise their input in favour of the voice of the researcher (Manzo & Brightbill, 2007). Vincent et al.'s (2017) solution was to pseudonymise the data within the study, and to include the students' real names when denoting authorship. This seemed a good compromise to use within my research as it enabled me to protect the young people, and the schools they attended, whilst also recognising their contributions. Therefore, within this thesis names are pseudonymised to prevent specific data being connected to named participants including in Table 9 below. The real names of the group are included in the wider promotion of the work as co-authors.

To ensure informed consent was provided, consent forms for parents, and assent forms for the young people included a two-stage agreement, firstly for participation in the project, and then for names to be included. (See Appendix E.5 and E.6)

While the decisions described above were made prior to the recruitment of the girls, the necessity of flexibility within participatory research (Bergold & Thomas, 2012) meant that further decision-making had to wait until there was the opportunity to include the views of the research group. Recruiting a group of autistic girls who were keen to contribute to furthering knowledge of educational transitions and making a difference to future cohorts of autistic girls was therefore vital.

5.3 Recruitment

As the project required group members to create body maps and school resources, it was important to recruit a group of autistic girls who were prepared to work creatively and use their lived experiences of the primary to secondary transition to support other girls facing similar challenges. I chose to work with a group of young people in years 9 – 12 [ages 13 to 18] so that the group could reflect on their own experiences of transitions. This decision was supported by the pilot study (Chapter 4) in which older participants were able to reflect on their experiences of transitions and the strategies that can support them. By recruiting young people who had some years' experience of primary and secondary school, we were able to gather data on the benefits and challenges from both stages of education. A further rationale for choosing to work with young people who were not currently experiencing the primary to secondary transition was to avoid adding extra pressure to them at a potentially challenging time. During the pilot study, one of the young people in the trial phase who had agreed to participate changed her mind as soon as she started secondary school, and another started but did not complete the tasks. In both cases the transition was proving difficult, and the young people did not want to explore it further in their own time at home. When considering the ethical implications of working with children experiencing this transition, the International Charter for Ethical Research Involving Children (Graham & Powell, 2015) was useful, in particular to the importance of children not being harmed by their participation. I was concerned that, while Body Mapping can be therapeutic in aiding reflection on experiences, asking young people to focus on current challenging experiences may not be. Furthermore, the Charter as well as fundamental ethical principles that are embedded in British Psychological Society (BPS, 2021) and British Educational Research Association (BERA, 2018) guidelines require researchers to commit to ensuring research would benefit the children involved. It was hoped that young people in the age range I was recruiting would benefit from the experience of being involved the project by being able to refer to it in college or university applications or on a CV for job applications. For any young people going on to study in the social sciences or arts, it could also be valuable experience.

While the prevailing Covid-19 situation in 2021 when this research was being planned and conducted was improving, the uncertainty we had faced over the course of the previous 18 months prompted the decision for the project to be conducted online. The advantages of this decision were that, if needed, I could recruit young people over a wider geographical area as they would not need to attend regular sessions in a central location. Furthermore, the financial and logistical costs would be lower without travel: these were important considerations for the group members and whoever would have needed to transport them to meetings. Having conducted part of the pilot study online, I was confident that Body Mapping could work remotely. The National Centre for Research Methods (NCRM) published a guide to support researchers adapting participatory methods in response to Covid-19 (Coverdale et al., 2021) which suggested a key limitation to using online methods in research included inequalities in digital access as a barrier. It was hoped that - as children had been accessing education online for over 12 months during the pandemic - that digital access would be possible, but this could have been a limitation for participation in this project. Had any children expressed an interest in participating who were not able to access online meetings, I would have investigated alternative ways to support their participation. Coverdale et al. (2021) also recognised the reduction in opportunities for spending informal time together which often takes place at the start and end of in-person group sessions as being a further limitation to online methods. This was something I was keen to build into the structure of our online sessions by having time for wider discussions about achievements and interests.

Initially, consideration was made of the ideal number of participants to form a group that could effectively engage online, including the potential attrition of members leaving the project permanently and also ensuring that inability to attend individual sessions due to factors such as illness or other commitments would not result in lost meetings or working with only one or two young people on elements of the research that would benefit from group decisions. I therefore sought to recruit between 5 and 10 girls. Although there is little empirical evidence to recommend the ideal group size for online discussions, literature on group work in schools suggests four or five to be the optimal number (Burke, 2011). Groups of five were also found to be more democratic in a study involving undergraduate students, whereas groups of 10 tended to focus their decision-making on the opinions of the most dominant members (Fay et al., 2000). These findings are also supported by anecdotal evidence from teachers writing during the pandemic of their experiences of online learning and the use of breakout rooms (Watson, 2020).

To recruit group members, a poster was created advertising the study (see Appendix E.2). This was shared on Facebook and Twitter, on the ACoRNS website (https://acorns-soton.org.uk/wp-content/uploads/2021/06/ACoRNS-newsletter-Issue-3-June-2021-FINAL.pdf) and in the ACoRNS newsletter which is circulated to over 200 people. The poster set out two aims for the project: To design and create resources that will support autistic children with their transition from primary to secondary school, and to identify and evaluate the benefits of the process of working as a co-researcher on a participatory research project. The text of the poster targeted autistic girls who were interested in studying psychology, visual arts, graphic design, education, or journalism and promoted the development of new skills and benefits to CV or university applications. This was to highlight the advantages of participation over and above contributing to research. This was particularly important as the children would be working on a project that would support future cohorts of young people and, therefore, they would not directly benefit from the outcomes or outputs of the research. This contrasts with many participatory projects which focus on priorities that will directly impact the communities participating such as Crane et al.’s (2019) study of mental health problems in autistic young people.

Twelve secondary schools and Further Education colleges in the South Hampshire area were sent copies of the poster to display on noticeboards and smaller copies to be handed out as flyers. These were sent by post and addressed to the member of staff identified on the school website as having responsibility for SEND. As I was looking to recruit a limited number of participants, I did not initially want to share too widely and risk having more participants than I could incorporate in the study. Had the first mailing not resulted in sufficient recruitment, I would have sent it out more widely.

I received six expressions of interest in response to the poster on Twitter, the mailing to individual schools, and the information from the ACoRNS newsletter. Two group members attended the same college therefore, five different educational establishments were represented. In all cases the mailing was passed to the young person by a teacher. Respondents who expressed an interest by emailing the address included on the poster were sent information sheets for parents and young people, and consent and assent forms (see Appendix D). All six responded in favour of participating in the project and consent and assent forms were returned (see Table 9 for participant details).

Table 9 - Participatory Project Participant Characteristics

Participant	Age at start of project	School Year	Education Setting
Ellery	15	10	School
Rose	15	10	School
Abria	13	9	School
Nancy	17	13	6th Form College
Ola	17	13	6th Form College
Anwen	14	11	School

5.4 Procedure

The project was divided into two stages. The first stage entailed ten weekly one-hour group meetings. During these meeting we explored transition experiences and developed ideas for resources to support future cohorts of autistic girls. The second stage of the research was planned to involve analysis of the data from stage one and create transition resources that would be tested in schools. The exact structure of stage two was left open to allow for flexibility based on what unfolded in stage one. The decision to divide the project was made both as a reflection of my uncertainty as to how successful the group would be at working together, and in consideration of the magnitude of committing to a project for the young people. In practice, upon completing the initial ten group meetings, group members were given the option of whether they would like to continue. At this point Abria chose not to progress with the research but the others remained for the second stage of the project. Had the group not worked as well together during the initial stage, I would have had the opportunity to re-design the second part of the research and re-recruit if necessary. This ability to be reflexive and adaptable throughout the process was important for its success (Bradbury-Jones et al. 2018).

With the structure of the first section of ten meetings being considered successful by the group, the second stage followed the same pattern. In addition, there was an initial familiarisation meeting with each group member individually prior to starting the group meetings and an individual meeting for reflection on the first stage after the tenth group meeting. The next part of this chapter will give an overview of how the meetings were conducted and an outline of how the research followed the Explore, Create, Analyse, and Evaluate framework introduced earlier.

5.4.1 Familiarisation Meetings

Having received consent for participation from six girls and their parent / carer(s), a meeting was organised between myself and each young person. The option for a parent to also attend this meeting was taken up by five of the girls. This initial session was intended as an opportunity for the young person to meet me prior to the group meetings so they were familiar with me and had a better idea what to expect when meeting with the whole group. This also gave me the opportunity to find out a bit more about their communication preferences so I could plan the content and structure of the group meetings to suit all members. These familiarisation meetings took place during August 2021 in preparation for the group meetings which began in September 2021.

Initial meetings were planned with reference to Cridland et al.’s (2015) recommendations for conducting semi-structured interviews with autistic participants, which include consideration of the time and place for interviews. I offered plenty of flexibility when arranging the time and date of the initial meetings, helped by it being the summer holidays so we were not constrained by timings of the school day. All meetings took place online, as part of the familiarisation process was to ensure group members were able to access online meetings in a way that suited their preferences. Online meetings also allowed the members to choose where in their house they felt comfortable to meet and enabled them to have a trusted adult with them to support at the level they found appropriate. For some this meant their trusted adult was sitting next to them supporting on the call, while for others the adult was in the background and available only if needed. The choice was given whether to turn on cameras and whether the young person wished to participate verbally or using the chat function. All young people had their cameras turned on for this first meeting. All contributed verbally although at times parents were used as a conduit for responses with the young person expressing the answer to the parent for them to respond. For example, in advance of her familiarisation meeting, Nancy emailed to let me know that as I was a new person for her, she would be likely to be non-verbal so would have her mum alongside her to help with communication. For the first few questions Nancy whispered responses to her mum who shared them aloud. Once comfortable, Nancy then spoke directly to me. Nancy’s choice to communicate in this way was fully respected and supported.

The meeting began with a short explanation of what to expect for this individual session, including how long it would take. As recommended by Cridland et al. (2015), this information had also been shared via email in advance of the meeting along with some initial ‘warm-up’ (p. 82) questions so the members could prepare some of their answers in advance. By providing this information in advance and reiterating it at the beginning of the meeting, I aimed to alleviate anxiety that might have been caused by a lack of preparedness or uncertainty regarding what was to come (Solomon et al., 2012). By asking familiar questions to start with, and using these to develop a conversation, I aimed to start to 'build rapport' (Cridland et al, 2015, p. 85) with the group members. The questions asked included demographic information including the opportunity to give chosen pronouns, as well as what likes and dislikes they had at school or college and if they knew what they would like to do after leaving education. These questions were built on the information from the recruitment poster which detailed how the project may link to specific subjects or interests.

During these initial meetings, one of the group members requested to be referred to using the pronouns they/them which we did throughout the individual and group meetings. However, as this research focused on the experiences of autistic girls, to ensure confidentiality the pronouns she/her will be used in this document where necessary. Both this group member and their parent expressed gratitude for this consideration.

5.4.2 Group Meetings

The group meetings were held on a Tuesday evening at 7pm each week. The time and day for the group meetings was discussed during familiarisation meetings. Group members expressed a preference to meet later in the evening, so they had time to relax straight after school or college. Tuesday was a day when no group members had alternative commitments. The group members were able to choose how to engage with the discussion. Three kept cameras turned on most of the time and contributed verbally. Of the three with cameras off, one communicated via the chat only and two combined verbal input and written chat. An email was sent in advance of each meeting to outline what the meeting would include, as recommended by Cridland et al. (2015). I had planned an overall structure of the meetings in advance to ensure that we had sufficient time to both explore transitions and plan resources however the structure allowed for flexibility to adapt to the input of the group. A more in-depth description of the meetings is included in the following chapters.

Individual meetings were organised with group members to take place after the first ten group meetings. The focus of these meetings was to reflect on participation in the first part of the project and were again communicated to the group members in advance. Group members were also given information about the second part of the project which would involve analysing the transition data from the Body Mapping tasks as well as continuing with creation and evaluation of our transition resources. Group members were given the option to continue or to end their participation. Their decision was not required during the meeting, the option to inform me via email was also given. This was both to allow them time to think about whether they wanted to continue, and potentially discuss it with parents as well as to remove any pressure they may feel about giving an answer to me during the meeting. Five group members chose to continue of whom four informed me in the individual meeting and one emailed to let me know after consideration. I received an email from Abria's parent to inform me that she would not be continuing.

The second stage of group meetings followed the same format as the first with the meetings continuing on Tuesday evenings and with prior information about the structure and content of each meeting being provided in advance. Table 10 provides an overview of the individual and group meetings that shows how each element of the Explore, Create, Analyse and Evaluate framework progressed and how they overlapped. The following chapters addresses each of these elements in more detail. The information in the Evaluate column includes opportunities for evaluation as well as observations about elements of the research that are reflected on in Chapter 9.

Table 10 - ***Overview of Research Meetings for the Participatory Phases of the Project***

	Explore – Chapter 6	**Analyse – Chapter 7**	**Create – Chapter 8**	**Evaluate – Chapter 9**
Individual 1	Body Mapping task – Draw the outline of the body– consider colour and texture of the line. Prepare an introduction of yourself for the group.			Related to group evaluation of school resources. Related to evaluation of involvement in PAR.
Group 1	Body Mapping task - Design one hand to reflect something about yourself – interests, character, preferences etc.		Initial ideas of what our resources might look like and their target audience. Group name ideas.	How did the introductions impact group dynamics?
Group 2	Body Mapping task - Represent primary school on the body map. Think about where to place the image as well as what to include.			Discussed use of timer to countdown time left to finish Body Mapping task. Clearly not popular.

	Explore – Chapter 6	**Analyse – Chapter 7**	**Create – Chapter 8**	**Evaluate – Chapter 9**
Group 3	Body Mapping task - Represent secondary school on the body map. What might the placement of this in comparison to the placement of primary school suggest?			
Group 4	Body Mapping task - Represent the primary to secondary transition on the body map. Find a way to link the schools which represents how that transition went for you. Think about the choice of colours, line style and resources.			
Group 5	Body Mapping task - Create a power symbol. Where does your power come from? What images represent your power and where on the map will you place it to show the source of your power?	Data analysis card sorting exercise.		Reflection on reactions to data sorting exercise.
Group 6	Body Mapping task - (The task for this session was postponed as we wanted to continue discussing ideas for resources.)		Sharing existing transition resources. Discussing advantages and challenges of each.	Continuation of discussion rather than moving to body-mapping as a reflection of quality of interest and engagement.

	Explore – Chapter 6	**Analyse – Chapter 7**	**Create – Chapter 8**	**Evaluate – Chapter 9**
Group 7	Body Mapping task - Represent what/who supports you with difficult times at school or elsewhere. (Postponed from previous week.)		What do we want to achieve with our resources? How could we achieve this? Consideration of how each group member would like to contribute - Original artwork - Research - Written content - Graphics	
Group 8	Body Mapping task - Finishing off any elements that are incomplete.		Start individual tasks - Original artwork – Ellery & Abria - Research - Chloe - Written content – Nancy - Graphics – Ola, Rose & Anwen	
Group 9	Body Mapping task - Finishing off any elements that are incomplete.		Work on individual introduction slides for presentation Continue with individual tasks.	Discussing possibility of an in-person celebration at the end of the project.
Group 10	Body Mapping task - Represent the sensory impact of the school environment.		Review progress with presentation Discuss voice over recording Discuss next steps for the research/development of resources.	
Individual 2		Introduce idea of creating narratives out of transition experiences. Share example. Discuss what each would like to create a narrative about.		Reflection on participating in first phase of the research. Introduce next phase of research and gauge interest.

	Explore – Chapter 6	**Analyse – Chapter 7**	**Create – Chapter 8**	**Evaluate – Chapter 9**
Group 11		Share ideas for narratives. Do our narratives represent the messages we want to impart?		Discuss ideas for testing resources. Which schools to approach.
Group 12		Discuss first finished narrative – led by Ola. Is there anything we want to change or add?	Discuss True or False task – clarity of wording, have we covered everything we wanted to? Discuss lesson plan ideas.	
Group 13	Group led discussion about interests. What are they and why are they important.	Discuss second narrative – lead by Rose. Is there anything we want to change or add?		Create feedback sheets and interview/focus group schedules. Share information about first school to agree to trial resources.
Group 14		Anwen to narrate first person perspective of third narrative while I transcribe.		Update on school recruitment Finish feedback sheets.
Group 15	Group led discussion about what an ideal school would look like.	Discuss Anwen's narrative with alternative perspective. Is there anything we want to change or add?		Update on school recruitment Discuss teacher leaflet wording.
Group 16		Discuss fourth narrative – led by Ellery. Is there anything we want to change or add?		Prepare for focus groups. Lesson delivered at schools 1 & 2.
Group 17		Choose names for the narratives.		Feedback from focus groups/interviews.
Group 18		Create talking points for each narrative.		Lesson delivered at school 3 Analysis of feedback data.

	Explore – Chapter 6	Analyse – Chapter 7	Create – Chapter 8	Evaluate – Chapter 9
Group 19		Discuss fifth narrative – led by Rose. Is there anything we want to change or add?		Group evaluation of research participation.
Group 20				Finish group evaluation of research participation. Should we share the narratives on our webpage? What future uses could they have? Plan our Pizza Party.
		Analysis of the data from the trial of the resources, and analysis of the data from members responses to participating in the project took place after the group meetings had been completed.		Our Pizza Party took place at the University two weeks after the final meeting.

5.4.3 The Naming of Fizzacc

One of the aims for the first meeting was to discuss and decide on a group name. A group member suggested that we look at how we could use the first letters of our names to create a word. Fizzacc was one of the suggested words that everyone liked. When one of the members put the word into an internet search, the suggestions that came back mostly related to Pizza which the group found amusing. A vote was held to decide whether to call ourselves Fizzacc or The Pizza Gang and Fizzacc won by one vote. By giving the group a name, we began to create an identity that we were able to build on over the course of the project and so the group is referred to as Fizzacc from here.

Summary

This chapter introduced the use of a participatory action research framework to structure the next part of the thesis. It outlined the ethical considerations that informed how the research group was constructed and addressed some of the complexities inherent in designing a participatory project. The chapter then detailed the recruitment process that allowed us to create the Fizzacc group before providing a brief overview of the structure of the individual and group meetings. The next chapter will introduce the ’Explore’ phase of the research in which Fizzacc used Body Mapping and group discussion to share transition experiences.

Chapter 6 – Explore

Introduction

Having detailed the process by which Fizzacc was formed in Chapter 5, this chapter describes the 'Explore' phase of the research based on the inclusive design toolkit ((http://www.inclusivedesigntoolkit.com/). The Explore phase is described as a process of developing an understanding of the needs of all the stakeholders 'these include the end-users but also all who have something to gain or lose from the product'. The stakeholders for our product (the resources we aimed to create) included the Fizzacc members, as well as teachers and pupils at the schools where our product would be delivered. To achieve an understanding of our stakeholders, we needed to better understand autistic girls' experiences in schools. This chapter details how school experiences were explored during group meetings using Body Mapping and how we considered the needs of our stakeholders in developing resources to support the primary-to-secondary transition in schools.

6.1 Initial Familiarisation Meetings

The structure and purpose of the initial meetings are described in Chapter 5, Section 5.1. In addition to providing an opportunity to meet the girls prior to the group meetings, I also asked them to prepare to introduce themselves in the first group meeting. They could choose how to share this introduction and it was suggested that they could prepare a PowerPoint slide or write a paragraph to be read out by them or me. The initial meeting also offered the opportunity to introduce the process of Body Mapping. Images of body maps, both completed on paper, and using Autodraw software (Motzenbecker & Phillips, 2017) were shared, preferred ways of working was discussed. At this point five members expressed a preference for working on paper and one using Autodraw. After the initial meeting I received an email from the parent whose child had chosen the online method to say they had changed their mind and requested a pack of materials to be sent. A pack was posted to each group member whish included two sheets of paper measuring one meter by two meters, a set of paints, felt tipped pens, a variety of coloured paper, and a pack of craft materials including pipe cleaners, sequins, and foam shapes. Group members were encouraged to use the materials in the way that most suited them. They did not need to utilise all the resources and were able to supplement them with their own materials if they wished.

6.2 Body Mapping Procedure within Group Meetings

Body Mapping tasks were planned for seven of the ten meetings in the first phase of the research with the expectation that tasks and order could change, and that time could be needed for completing unfinished elements in some meetings. Each group session began with a discussion on the theme of the Body Mapping task (see Chapter 5, Table 10 for a list of weekly themes). Discussion prompts were open to allow the group to direct discussion towards the issues they felt strongly about. The Body Mapping task for the session was then introduced. Group members were asked to consider where they placed images on the map as well as what they chose to include. Each week, once the Body Mapping task was explained, group members moved away from their screens to complete the tasks. I remained onscreen and available to answer any questions they had. During the activity time in week 1, an online timer was shared so the group could monitor how long remained to complete the task. Feedback from the group in week 2 revealed that the timer was not helpful. It was felt to add pressure to the task and induced anxiety in some of the group, so going forwards an end time was given and a verbal reminder two minutes before the time was up which was felt to be more supportive. A disadvantage of working online was that I was unable to observe the creative process itself. It was therefore important to enable group members to share what had been included on the body maps and why after each task, allowing reflection of the decisions to be made in a timely manner. This could involve showing the image they had been working on or giving a verbal or typed description of it. They were then asked to either email their images to me or to add them to a group Padlet that had been set up for this purpose. Group members were also invited to provide a written description of their image if they wanted to.

An overview of each meeting is provided below including an image from the weekly Body Mapping tasks alongside a description provided by the creator. Some members chose not to provide a written description but contributed their thoughts about each aspect of the body map during group discussion. I have selected quotes from transcripts of the discussion to accompany the images that did not have written commentaries (identified with inverted commas). The images and descriptions were selected as they clearly demonstrate how Body Mapping supported the group's understanding of Fizzacc members' experiences. Prior to each meeting I sent an email to the group, which included information such as the link to the Padlet for uploading Body Mapping images, and the link to access the meeting and confirmation of the time and date. This email also gave the topic of the next meeting so group members would know what we would be discussing in advance.

6.3 Overview of the First Ten Group MeetingGroup meeting one focused primarily on activities to allow group members to get to know each other, sharing the introductions that group members had prepared. Nancy and Ola had prepared slides which they had sent me in advance. Ola talked through her slides while Nancy had included text which she asked me to read. Rose had sent a short script which she asked me to read. Anwen and Abria both gave verbal introductions. This activity helped the group to identify shared interests which gave them potential discussion topics outside the research conversations and helped build group cohesion.

The Body Mapping task for this session was to decorate one of the hands to represent themselves. Examples offered included images of activities they enjoyed and colours or shapes they felt represented their personality.

Week 1 – hand - Rose

I used a squiggly rainbow coloured outline because I love rainbows and I'm energetic. I've added a sloth and a crocodile because they are my favourite animals. I've drawn drama masks as I'm in a drama group and I've drawn musical notes around me and added a musical bracelet because I like singing. There's a pig as I'm Pongo the Pig in our next pantomime. The rabbit is my pet called Coffee. The heart is green and orange as they are my favourite colours. The butterfly is there because butterflies are my favourite insects and they remind me of my Nan. Chocolate is my favourite food. I've added logos from Minecraft, TocaBoca, Roblox and YouTube because these are some of my favourite games. I've drawn a dress and a sewing machine because I would like to be a fashion designer. The two faces are Ruskin from my favourite book, Krindlekrax.

Figure 7 - Body Mapping Image from Week 1

In group meeting two, members were asked to share a memory of primary school, prompting other members to contribute similar experiences both verbally and using the chat function. During this meeting I discovered that only one group member had received a diagnosis of autism during primary school. Other group members had not been identified as autistic but had been described as shy or anxious. The implications of this on the resources we were going to create were considerable. From this meeting we were clear that the resources would not be targeted at supporting specific autistic children, but to increase support and understanding more generally. This was something that Fizzacc members described as lacking at the time of transition, for example describing this as:

Abria: A really lonely, not-much-support kind of time.

This focus on awareness-raising was not what I had anticipated for the resources, which I had previously envisaged as being targeted specifically at autistic girls. This change of focus was considered in my reflexive journal:

> Only 1 out of 6 was diagnosed during primary school. Realising this makes a massive difference to what we create in terms of resources. I realise that my initial ideas were very medical model – trying to help the girls fit in to neurotypical norms. I need to go back to the philosophy and think about how we can create resources that help schools to be more

accepting and understanding of neurodivergence and it needs to be really clear about the impact on undiagnosed children (28th September 2021).

The Body Mapping task was to represent primary school. Nancy's image (Figure 8Figure 8) shows how she felt separated from the other children and how she felt she needed to choose between being herself and trying to fit in. Experiences that the rest of the group also identified with.

Week 2 – primary school - Nancy

"And watching all the other kids playing and thinking I'm on a planet of aliens. I don't understand what they're doing. I'm going to have to try and figure it out so I can fit in and pretend like I'm one of them."

Figure 8 - Body Mapping Image from Week 2

In the third group meeting members were asked to share a memory of secondary school. Again, the memories chosen prompted discussion about shared experiences, including similar strategies that schools offered which aimed to be supportive. One example was the use of exit cards which allow pupils to leave a lesson if feeling overwhelmed. While all group members had experience of these, the way they were used varied. Some had a quiet safe space they could go to others were allowed five minutes in the corridor outside the class. The group felt strongly that teachers' lack of understanding of autism meant that supportive strategies were often ineffective. This was something they were keen to address in our resources.

The Body Mapping task this week was to represent secondary school. Abria's image (Figure 9) is more abstract than Rose or Nancy's. It shows the contrast between the aspects of school she finds challenging and the positivity from staff members who make a difference. All group members felt that there were people in school who helped them.

Week 3 – secondary school – Abria

The random dark colour of cloud is just a blob of my feelings the eyes surrounded by black are halved with one eye crying and the other one not to represent how I'm alone most of the time because I like it being alone no argument no sound just me but I also don't because it is lonely. The baby bird is because I spend both my break times in the nurse's office and she is really nice and her name is XXX and the stickers are what she gave me when I had a panic attack a few weeks ago. The bracelet that is open and would fall is like a broken friendship bracelet. The weird black red lines are like my attention moving to my hand when I stab my nails into my hand. So mostly bad in school but there are positives.

Figure 9 - Body Mapping Image from Week 3

Group meeting four focused specifically on the primary-to-secondary transition. We began by discussing support available during the transition. Without having been identified as autistic, most of the group did not receive any extra support. There was awareness that it was available, but they did not know how to access it:

Nancy: I don't remember getting any extra help. I remember thinking that would have been really nice, but I didn't know how to ask for it.

We talked about how our resources needed to provide something that would be of benefit to children with an autism diagnosis and more generally, without suggesting that struggling with transition would indicate that a child might be autistic.

The Body Mapping task was to create a link between the primary and secondary school images which represented how group members felt about the transition. Although when Ellery shared her image (Figure 10) it made the group laugh, they could all relate to this feeling during their own transition experiences.

Week 4 – transition from primary to secondary – Ellery

I have drawn this as a lightning bolt as it was not a nice experience and just made me go AHHHHHHHHHHHHHHHH!

Figure 10 - Body Mapping Image from Week 4

Much of the discussion during group meeting five was taken up with a data analysis task which is addressed in Chapter 7.

The Body Mapping task was for the group to think about where their strength and power comes from, and to create a power symbol to represent that. Power symbols were included at this stage to add some positive imagery onto the body maps as many of the school-based images focused on negative experiences. A consideration of strength and power helped us identify support mechanisms we would include in our resources. While some group members chose just one image to represent power, Ellery chose several (Figure 11).

Week 5 – power symbols – Ellery

Sun - Happy little suns! I love the warmth and love sunny days.

Rainbows - because my friends make me happy and so do rainbows, so my brain made a link between the two.

Cloud on my heel - Clouds make rain and this makes rainbows. Also, rain means the field outside my *house is usually empty of people so I don't have to listen to the noise.*

Rainbow in a circle - This is because it is connecting with hearts. My circle of friends/love.

Handshake rainbow - Most of my friends are in the LGBTQ+ group and we all accept each other. I would be nowhere without my friends :)

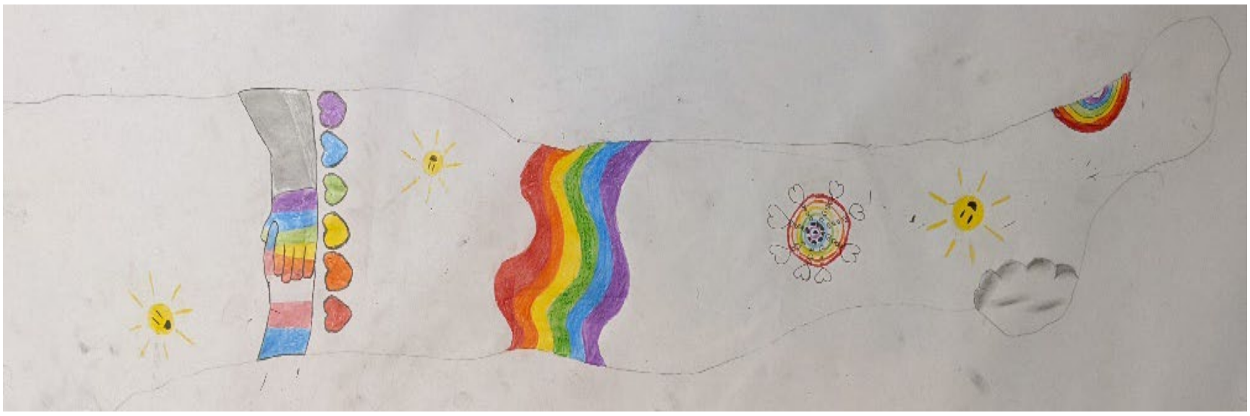


Figure 11 - Body Mapping Image from Week 5

The Body Mapping task that was planned for group meeting six was postponed as the group chose to continue a discussion about development of resources which is covered in Chapter 8.

Group meeting seven's Body Mapping task was to focus on the people or strategies that group members turn to for support. This could be in school, at home, or both. In her image Ola chose to represent things that have supported her all the way through from primary school until now (Figure 12).

Week 7 – who or what gives support – Ola

"I used to have things that are a comfort for me, like I'd have my teddy bears with me at all times and stuff like that. And I think there would be like some people that would like not be so nice about it and make fun of it and I think they weren't very good at dealing with that"

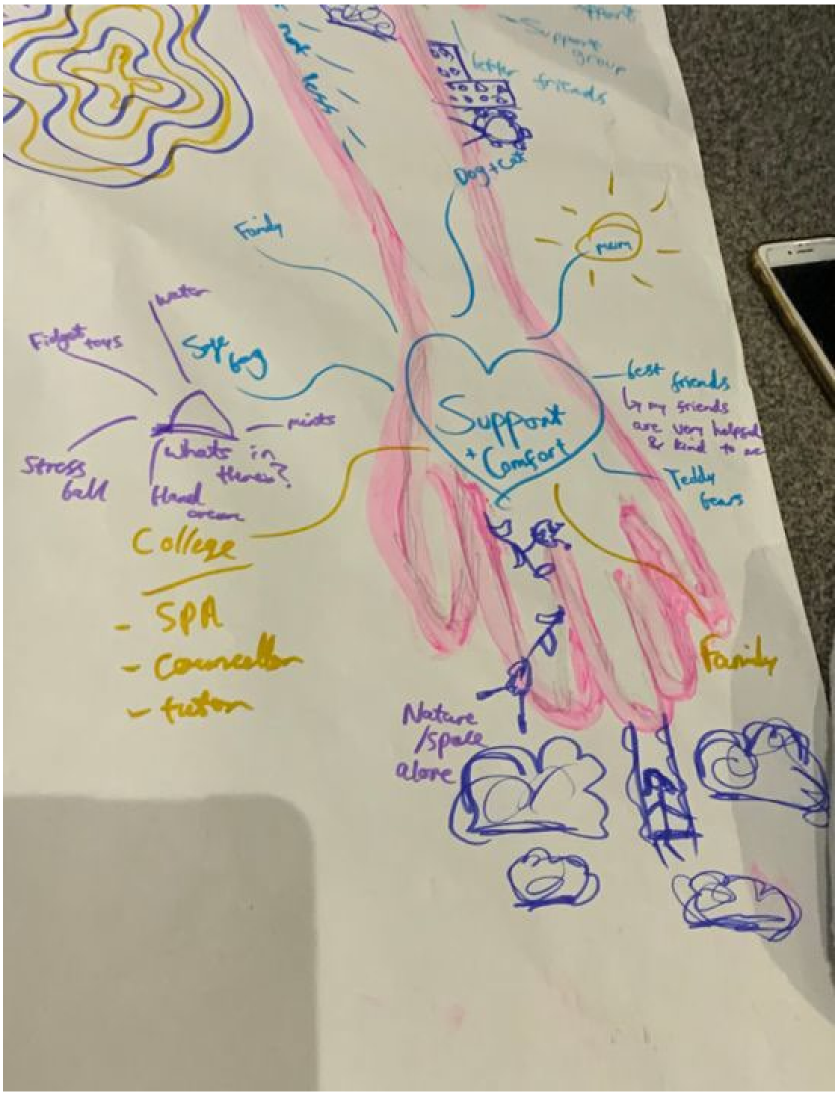


Figure 12 - Body Mapping Image from Week 7

No new Body Mapping tasks were introduced during group meetings eight or nine as we needed time to complete images from previous sessions.

Group meeting ten included the final task for the exploratory phase which was to add sensory experiences onto the body maps. The sensory environment in school was something that was challenging for all the group members at times and was therefore something we wanted to address in our resources. The sensory challenges of school came up many times over the weeks and there were many similarities in experiences. One which all agreed on was fire alarms (Figure 13).

Week 10 –sensory experiences – Rose

Sensory impact. I've drawn a fire alarm because I don't like the fire alarm going off at school.

Figure 13 - Body Mapping Image from Week 10

6.4 Individual Review Meetings

Once the ten weekly group meetings were complete, group members were asked to attend an individual review meeting with me to discuss their thoughts about participating in the research and to provide further details about their body maps. As with the previous meetings, group members were emailed in advance with an agenda, so they were aware what to expect. A request was made for each member to choose between three and five images from their body map that they felt were important, and to be prepared to share their thoughts about them. This discussion was to be the starting point to analysing the data which will be addressed in Chapter 7.

Summary

This chapter described the exploratory phase of the research in which the Fizzacc group considered their school experiences at both primary and secondary levels. By using Body Mapping to conduct this exploratory phase, we produced data both from the discussions and the body maps themselves. Chapter 7 details the process of analysing the data using novel methods which facilitated participation by Fizzacc members: a process which began once the body-mapping tasks were completed and that ran alongside the creation of resources for schools which is described in Chapter 8.

Chapter 7 – Analyse

Introduction

The inclusive design toolkit (http://www.inclusivedesigntoolkit.com/) does not include a discrete analysis phase as the focus is on the production of products and services and therefore does not prioritise deep reflection of the data produced during the process. The analysis process for Fizzacc seemed to sit between the exploratory phase (data generation) and the creative (which includes grouping and naming themes). Our analysis furthered our understanding of our data while continuing to develop our creative process. As such, this chapter is placed between Chapter 6 - Explore and Chapter 8 – Create. As shown in Chapter 5 Figure 6, we were analysing data at the same time as creating our school resources, so the analysis was not available in time to inform our resources. The implications of this are discussed in Chapter 10.

7.1 Creative Data Analysis – The Development of Perspective Narratives

The emphasis for this research was on promoting autistic girls' voices regarding their educational experiences and so, as part of the participatory process, it was important that the girls should be involved in the data analysis process. As five out of the six members had opted to continue with the second phase of ten weekly hour-long meetings, the main data analysis process took place with this group alongside the work outlined in Chapter 8. The data consisted of written or transcribed verbal descriptions that group members provided of the images included in their body maps, as well as contributions to group discussions.

Akesson et al. (2014) argued that data from arts-based research with children holds its most significant meaning in the interpretation of the data by the children themselves, and that data without explanation cannot be participatory and may even be unethical. Therefore, each group member initially analysed the data they had contributed themselves. It was important that analysis was based on the group member's own descriptions of their maps as - if I were to interpret what they had drawn - it would have become an analysis of my perceptions of their drawings rather than of the ideas, feelings, and memories that the drawings represented for them.

7.2 Piloting Different Analytic Techniques

Initially I planned to use thematic analysis (Braun & Clarke, 2020, 2021) as used in the pilot study (Chapter 4). However, I recognised that as a non-autistic researcher, I needed to be mindful of how my participation in the analysis process would impact the authenticity of it as a way of exploring these autistic girls' experiences. Moreover, I needed to consider how to conduct a meaningful thematic analysis in a participatory way with a group of autistic young people during hour-long weekly meetings, with the knowledge that our timescale would not allow us to conduct the full process together. I initially piloted an exercise in week 5 of the first phase of meetings which I hoped would help me consider how the analysis process might work. The activity I prepared aimed at supporting the group in thematically exploring the data collected so far. My aim was that the activity would prompt discussion, and I would gain a better understanding of how the group might respond to looking for patterns in their data. I hoped to then find ways to develop this procedure to inform the full analysis in the second stage of the research.

I conducted some preliminary coding of transcripts of the data from the previous four group sessions, alongside the images and descriptions of the Body Mapping tasks that had been uploaded by the group members onto the Padlet. Ideally, this would have been a process conducted with the group but - as time together was limited - I prepared codes in advance, transcribing them onto post-it notes using Jamboard software (https://jamboard.google.com) (see Figure 14).

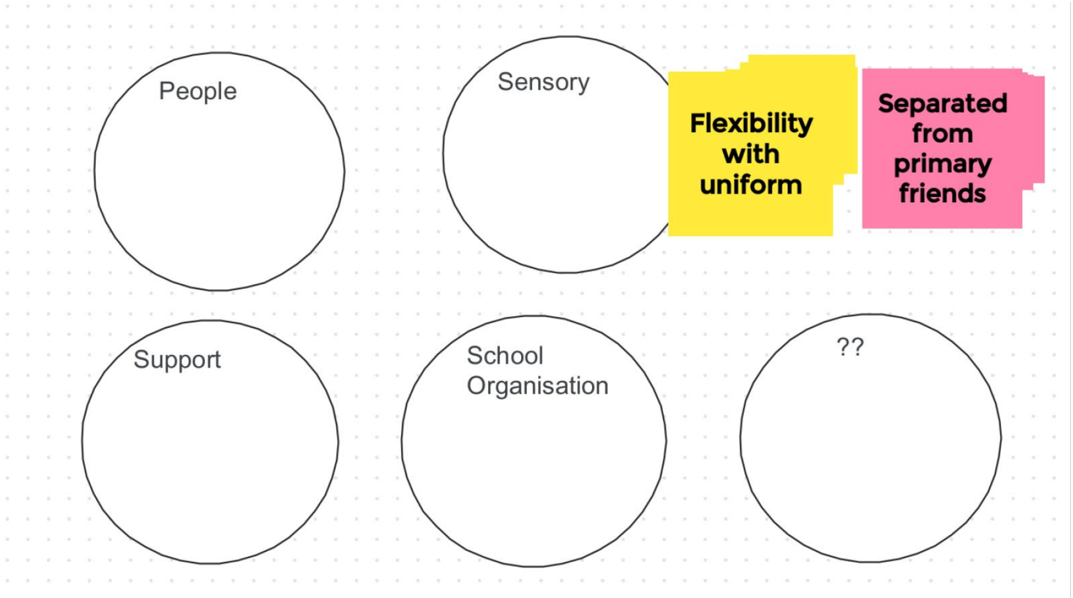


Figure 14 - Data Sorting Activity Jamboard

Codes that referred to things that group members had expressed as positive regarding educational transitions were put onto yellow post-it notes, and those that were more negative onto pink. For example, yellow post-its included statements such as 'making changes slowly step by step', 'finding a safe space' and 'teachers that understand autism'. Pink statements included 'too many people in corridors', 'not fitting into expectations' and 'not feeling included'. To begin the process of refining the data, I provided four broad categories and left a fifth blank for codes that were felt to not belong in the ones offered. These categories were based on areas of discussion we had been having as a group. The group members were asked to take it in turns to work through the pile of post-it notes and individually allocate them to the categories by clicking on the code and dragging into their chosen circle.

Ultimately, this experiment was unsuccessful. The activity, which I hoped would provoke discussion between group members, was largely completed in silence. The group all turned off their cameras and microphones, so it was difficult to gauge their reactions, but this *was* a reaction. It had been clear through lively discussions and activities in previous weeks that, when interested, the group members were all keen to contribute and would do so both verbally and in the online chat function. With this activity the silence spoke volumes. When I asked the group if they had any comments about the activity, there was no response. In addition to the categorisation activity, a further aim of this exercise was to explore how the young people would respond to looking for patterns in their data. During the process I found myself getting frustrated that some of the codes I had inserted on the post-its and seemed an obvious fit in a particular category (at least to me), the group members chose to place elsewhere. Braun and Clarke (2022) described good collaborative coding as being a process used to 'enhance understanding, interpretation, and reflexivity, rather than to reach a consensus' (p. 8). Although this was a preliminary sorting task rather than coding, I could now see that this version of how to structure a process of collaborative coding in the limited time we had available was not engaging for the group. Moreover, with the group finding it difficult to express their rationale for their choices, this process was not achieving either aim: I was unable to understand how the group members were interpreting the data, and they were finding it difficult to reflect on or articulate their choices. After this session I wrote in my reflexive journal that this did not feel like a valuable exercise for the group. Instead, I wrote that it felt like 'box-ticking – co-researchers included in data analysis session' (Reflexive journal, 19th October 2021).

7.3 Considering the Double Empathy Problem in Participatory Analysis

This pilot of analytic techniques was unsuccessful in terms of providing a framework for data analysis, but successful in prompting me to think more about communication within the group. I began to more fully consider Double Empathy (Milton, 2012), not only with respect to how we communicated as a group during meetings, but also for how we could work together to analyse data. The Double Empathy problem refers to the differences in social interaction and communication between autistic and non-autistic individuals leading to barriers in understanding. It is a 'double' problem because it is experienced by both sides of the interaction, meaning that it is not incumbent on the autistic individual to adapt their behaviour to fit in with a perceived norm (Milton, 2012). It was important that Double Empathy was directly addressed within my research, to ensure a 'true knowledge exchange' within the analysis process would be possible (Fletcher-Watson et al., 2019, p. 950). Therefore, if this research was to achieve its participatory aims, it was not only necessary to include autistic young people in a participatory way, but to also be continually mindful of how *my* understanding of their perspectives is shaped by the Double Empathy problem.

My thinking about the problem had already influenced my decision to exclude the Body Mapping pictures from the analysis process in favour of the group member's descriptions of them. It now prompted me to seek out a better way of approaching data analysis that would enhance the participatory nature of the research and prioritise and better reflect the voices of Fizzacc members. I began by removing the 'box-ticking' provided by my initial attempt at inclusive analysis and immersed myself in the qualitative literature in search of a methodology that would better fit my research. This search led me to narrative inquiry.

7.4 Exploring the potential of narrative inquiry

Narrative Inquiry is a broad term that encompasses a range of methods for data collection and analysis which centre around using stories to understand human experience. Barone (2007, p. 466) argued that:

> 'Our aim as researcher-storytellers is not to seek certainty about correct perspectives on educational phenomena but to raise significant questions about prevailing policy and practice that enrich an ongoing conversation.'

This quote strongly resonated with my aims to harness the lived experiences of autistic girls in education: to explore how practice can better support and encourage them. Promoting ongoing conversation with autistic young people and educators is key to achieving this. This section will explore narrative inquiry as a methodology, the different frameworks that exist to support its use in data analysis, and how (and why) it is relevant to this research. Moreover, the advantages of using methods of narrative inquiry to help raise significant questions about autistic girls in schools will be considered, in reference to dissemination of the outcomes of the research. Finally, I will describe how we developed our own framework of narrative inquiry for participatory data analysis, informed by Double Empathy, which we call Perspective Narrative Analysis.

Fictionalisation involves creating stories based on data and is used in narrative inquiry as a way of both exploring and presenting the data. Caine et al. (2017) explored the purposes of fictionalisation in narrative inquiry and argued that it serves three purposes: to protect the identities of participants; to harness the imagination to enrich understanding; and to create distance between self and experience. While the group working on this project all expressed a wish to have their names included when the outputs of the work were being shared, it was still important to protect their confidentiality when dealing with school-related data both for them and their schools. Narrative inquiry as a method achieved this this by allowing the fictionalising of experiences. While the stories can contain real events, any details that would allow the individuals and/or schools to be recognisable could be changed. The Fizzacc members were using imaginative ways of representing their thoughts and feelings in Body Mapping, so continuing along this imaginative trajectory to create stories based on what they were sharing seemed like a natural progression. The final purpose of narrative inquiry proposed by Caine et al (2017) - of creating distance between the self and the experiences initially felt less applicable to this project in that the members of Fizzacc did not want to distance themselves from their experiences: rather they wanted to share them to provoke change. However, on reflection, distance from the initial Body Mapping exercise and descriptions of the work was a strength of the process as by stepping back from the stories it allowed us to create narratives that resonated with the whole group, despite descriptions of events being based on the experiences of one member.

Connelly and Clandinin (1990) outlined a procedure for conducting participatory research with narrative inquiry and focused on the importance of promoting the voice of the community rather than of the researcher. They argued that giving time to listen to the stories of those with lived experience is key to achieving this. Their process involved taking data from qualitative research methods, such as semi-structured interviews, and creating narratives from them. Specifically, the researcher created the stories as a separate process after the data collection. For this project we needed to find a way to include the process of developing the stories as a group and as part of the participatory element of the research. There is precedence for this through the work of Rice et al. (2020), who described their creation of multimedia stories *with* their participants, rather than *on* or *for,* through a creative workshop process. This process resulted in the production of two- to five-minute-long videos that incorporated audio recordings of personal narratives with photographs, moving images and other artwork. Their focus was strongly collaborative, and they framed themselves as ‘storytellers’ rather than researchers in the process. Where Rice et al.’s (2020) work differs is that it was a one-stage process of creative story-making from beginning to end, as opposed to working collaboratively with the group members in this research to create stories from pre-gathered data. Therefore, a consideration of how existing frameworks for narrative inquiry could be adapted to support the data analysis process for my work was expedient. For this, I drew on the work of Caine et al. (2017), Connelly and Clandinin (1990) and Rice et al. (2020) as they all included elements (described above) which were aligned with the aims of my project.

7.4.1 Frameworks of Narrative Inquiry

Within the field of narrative inquiry, there are a few different conceptual frameworks proposed. Polkinghorne (1995) described two different types of narrative inquiry. The first he called 'analysis of narratives' (Polkinghorne, 1995 p.12), as a process whereby stories are gathered, and analysis is carried out on those stories to allow the development of themes. This is akin to using stories as data and then applying a thematic analysis to this data. The second, 'narrative analysis' (Polkinghorne, 1995 p.12), involves the researcher gathering data which they then organise into story form. This process of narrative inquiry is, therefore, one of synthesis of data rather than of separation and categorisation. My interest in the process was very much focused on the second interpretation of narrative enquiry as Body Mapping had provided authentic, deep, and rich data for analysis. The key for me was to ensure a process of data analysis that would enhance the knowledge and understanding from the source data, rather than diminish it through unnecessary division and categorisation.

An alternative perspective of narrative inquiry to Polkinghorne's (1995) was proposed by Bignold and Su (2013) who argued for two forms of narrative enquiry: epistemological - which explores lived experiences as a way of considering the nature of knowledge; and ontological, which removes the researcher from the process to delve deeper into the truth as experienced by those in the narrative. Again, Bignold and Su's (2013) proposed frameworks of narrative inquiry were useful in supporting my thinking about the processes I wanted to employ. The former, epistemological form was more aligned to my work in the way I was seeking to use narrative inquiry to explore Double Empathy and what that meant for our understanding of lived experiences of autistic girls in education. It was important to me that I not only supported the sharing of autistic voices in my presentation of the data, but that I considered how my expertise as a researcher and teacher could add to the way the knowledge and understanding of the data could be explored. Moreover, by involving the autistic young people in this process we could think about how our stories developed from the lived experiences of one group member into something that represented the views and voices of the whole group. With elements of these frameworks now informing an approach to analysis, I moved on to consider evidence from the extant literature in which similar research aims to mine had been met using narrative inquiry as a method of analysis.

7.4.2 Drawing Parallels with Existing Research

Narrative inquiry has been employed in several fields including education (Clandinin et al., 2006; Clough, 2002; Connelly & Clandinin, 1990;), and nursing (Foster, 2006; Wang & Geale, 2015) and has utilised poetry as well as prose. For example, Furman et al. (2007) used autobiographical poems by adolescents to explore identity as a source of data which were analysed thematically. This analysis prompted the creation of poems in the form of Japanese tankas to which two of the authors then responded, again through poetry. Poetry was therefore not only used as a source of data but as a method of analysis, and so fulfilled both elements of Polkinghorne's (1995) framework of 'analysis of narrative' and 'narrative analysis' (Polkinghorne, 1995 p.12). Furman et al. (2007) argued for the power of research involving participants creatively expressing their feelings, perspectives and perceptions coming from its ability to provoke emotional responses and prompt readers to reflect on the links with their own experiences even beyond the conclusions drawn by the researchers. This aspect of reflecting on the stories being shared was something that I was particularly keen to encourage in the process of developing the narratives as a group with Fizzacc. Johnson et al. (2020) also used poetry in their study to explore the lived experiences of discrimination by seven young spoken-word poets. Their project involved a group of young people aged between 16 and 25 working collaboratively to develop poems during a six-week period of seminars and workshops. Consistent with Furman et al.'s (2007) work, this project aimed to harness the power of lived experience to create poetry. However, while Furman et al. (2007) used poetry in analysis, Johnson et al. (2020) were more interested in the analysis of the process of working in this collaborative way, and therefore focused on data gathered from interviews which explored the participants' evaluation of the project and its impact on them as group members. While this strand of my research focused on using narratives as a way of analysing the body-mapping data, an evaluation of the impact of being part of Fizzacc was also conducted and is reported in Chapter 9 in line with Johnson et al. (2020).

I was also influenced by the work of McCormack (2004), whose PhD research explored how leisure was experienced by 13 women while conducting their postgraduate research. Three or four interviews, lasting between one-and-a half and two-and-a half hours were conducted with each woman. McCormack (2004) described her analysis process as 'storying stories' (p. 219). These stories were created from the interview data but in a process which also included comment and feedback from the participants. One element of McCormack's (2004) research which particularly interested me was the inclusion of an epilogue to each story: this allowed the researcher's voice to be heard within the process. The epilogue serves as an opportunity for the researcher to reflect on how the narrative addressed their research question(s), rather like the conclusion of an essay where the key messages are summarised. This process provided inspiration for how the key themes and messages about the group members' experiences in education could be highlighted within the narratives we created, and so potentially heighten their impact when disseminating the findings of the research.

7.4.3 Considering the Reader

Throughout my postgraduate research experience, I attempted to prioritise making a difference to the young people I was working with, and with their input, support other young people who were facing similar challenges in school. Therefore, it was important to consider how to disseminate our findings from the analysis. Research involving creative methods such as Body Mapping often leads to work being shown to an audience. For example, Gastaldo et al. (2012) exhibited body maps created to explore the experiences of undocumented workers in Canada at Toronto City Hall. Vincent (2014) used Body Mapping to explore participants' social history in a project carried out in conjunction with their local museum and which culminated in the body maps being converted to 3D internally-lit sculptures that were exhibited in a museum. Stories created as part of narrative enquiry are also frequently written to be shared. Johnson et al.'s (2020) spoken-word poetry was performed to a live audience who then provided feedback. Consistently, it was important to us as a group to consider who our potential audience might be when constructing narratives. Fizzacc members expressed the importance of thinking about 'what we want people to take away from it'. Group members were keen to think about how their stories could be used to change people's perceptions and understanding. Poulson et al. (2022) said that 'meaningful change can be driven by those who have a true and deep understanding of the strengths and needs from their own experiential expertise' (p. 3). Fizzacc members chose to join the project as it gave them the opportunity to use their own experiences to help create something that would engender meaningful change. For the stories we created, we decided that school staff should be a primary audience but that the stories could also be useful for parents. Whilst within the context of this research project the stories are presented as part of the data analysis process, Fizzacc is keen to further develop them and share them more widely in the future.

7.4.4 Consideration of the Quality of Narrative Research

Heikkinen et al. (2007) recognised the value in incorporating the use of narratives within action research. While their framework was based on the researcher developing the narratives in isolation rather than in conjunction with the community with lived experience, this was not applicable to my work within a participatory framework. But they do propose five principles for judging the quality of narrative in action research, and three are particularly relevant to my work. The first principle addresses considerations of reflexivity including ontological and epistemological presumptions. In my work these are addressed through Double Empathy, not only by being reflexive in the awareness that knowledge and reality for the autistic members of the group is different to mine, but by making the double-empathy problem central to the way the stories are told to highlight its importance. In the second principle, Heikkinen et al. (2007) considered dialectics, a discourse between two or more people with different viewpoints, and proposed that in the creation of narratives there is consideration of how the stories present different voices and interpretations of the situations or experiences being explored.

In deliberating how I could incorporate presentation of multiple voices and interpretation while addressing the double-empathy problem, I considered how each narrative could be created with different voices and from different perspectives. The first narrative would express the voice of an autistic young person drawing on the thoughts and experiences from the body maps but integrated in such a way as to ensure confidentiality and representation of the experiences and suggestions of the whole group. To give a coherence to these narratives, they are told from the perspective of a fictional character, Maggie - short for Margherita due to our shared love for Pizza - who also forms an important part of the transition resources created by Fizzacc detailed in Chapter 8. These stories are juxtaposed with a second narrative which tells the same story but from a narrator/outsider's perspective. The first story is told in the first person to emphasise that Maggie is an autistic girl sharing her thoughts and feelings and represents the collated voices of the autistic members of the group. The second narrative was written collaboratively by me and the group and is spoken in the third person to accentuate that this is not a voice of someone who experiences the situation first-hand, but someone who is providing a perspective which provides contrast to provoke reflection. While this second perspective is not based on real events (unlike the stories voiced by Maggie), it is based on my experience as a teacher as well as the group members' experiences with teachers.

The third significant principle Heikkinen et al. (2017) proposed was attention to how authentic and genuine the protagonists of the narrative are. With the voice of Maggie being provided by those with lived experiences of autism and refined and agreed as group, I believe we go a long way to achieving authenticity. Bignold and Su (2013) also promoted the importance of working collectively on the creation of stories; 'asking participants to comment on the representation of his or her story is an effective way of ensuring integrity in the story and so its validity' (p. 409).

Through including the narrator's voice, an added level of depth is provided which allows my lived experience as a teacher to contribute to and enhance the analysis and presentation of the data.

I believe that using the principles of narrative inquiry enabled the data produced by Fizzacc members during the body-mapping tasks to be analysed in a collaborative way which followed the principles of participatory research. Furthermore, it supported the sharing of the voices of autistic girls around their educational experiences in a way that was thought-provoking and challenging not only for us as a research group, but for future readers of the stories we created together. My experiences very much align with Clandinin et al., 2009 (p. 82) who stated that:

> 'As narrative inquirers, our lived and told stories are always in relation to or with those of our participants. We do not stand outside the lives of participants but see ourselves as part of the phenomenon under study. As narrative inquirers, we study the lives of participants as we come alongside them and become part of their lives and they part of ours.

7.4.5 Introducing Perspective Narratives

A note on the choice of terminology. Although I am using the terms *story* and *narrative* interchangeably in this chapter, I chose to use *narrative* in the title of the method as *story* could suggest 'falsehood or misrepresentation' (Polkinghorne, 1995, p.7). The key difference in the way I am using narrative inquiry relative to Clandinin et al. (2009) or Bignold and Su (2013) comes from the collation of multiple person perspectives to the narratives. I have therefore chosen to call my approach 'Perspective Narrative Analysis'.

7.5 How Perspective Narrative Analysis worked within the context of this project.

I conceived the basic framework for Perspective Narrative analysis before sharing it with the members of Fizzacc. To help clarify how the process would work, I devised an initial story as an example. This was based on two quotes from a group meeting which had been particularly thought-provoking:

> *'Being invited to parties and having friends were rare'*
>
> *'I think I got invited to a party once, but the person who the party was for didn't want to invite me, but their parent felt bad for me '*

Based on these quotes I devised a narrative to exemplify the alternative perspective. As the first-person perspective was very short, I wanted to add detail to the alternative narrative to show the group what a completed narrative might look like. All names are made up.

The narrative read:

> ‘The teacher, Mr Jenkins, watches as the gate opens and the children rush into the playground. They are trailed by parents, laden with book bags, coats and PE kits. Mr Jenkins takes a deep breath. The start of a new school year; time to establish rules and expectations. One of the children, Ruby, must already be turning nine. She is bustling around handing out purple envelopes. Mr Jenkins overhears her excitedly share:
> “It’s a pamper party! We are going to have face masks and get our nails done!”
> This is not the best start to a new term. The girls will all be beside themselves with excitement and the chances of them focusing on this morning’s numeracy activity are slim. Mr Jenkins notices Ruby’s mother pushing her towards Maggie and her grandmother. Ruby silently hands Maggie an envelope then runs off to chat to her friends. Maggie stands perfectly still with the invitation in her hand. Mr Jenkins smiles. It will be nice for Maggie to be included.

This narrative was shared with group members during the individual meetings after group meeting ten and the girls’ responses are shared in more detail below along with a detailed description of the process of creating Perspective Narratives with Fizzacc.

Figure 15 provides an overview of the stages of Perspective Narrative Analysis. The ‘analyse’ column in Table 10 shows how these processes fit chronologically with the project as a whole.

Fizzacc members chose events depicted on their body maps which they felt exemplified their experiences in school.

Stories were developed between the Fizzacc member and myself. These incorporated a description of the events chosen as data narrated in the first person to represent lived experience, alongside a description of the same events in the third person to reflect the implications of the double empathy paradigm.

Each story was shared with the group for evaluation and editing, to ensure they effectively represented lived experiences of the group. Amendments were made where necessary.

A name was chosen by the group for each story. The choice of name represented a distillation of the theme of each story.

As a group we developed questions/talking points about each story. These were to ensure that the key themes would be clear to the reader and that their perceptions would be challenged.

Figure 15 - Stages of the Perspective Narrative Process

7.5.1 Identifying Data to Analyse

Individual meetings were held online with each group member. Fizzacc members were emailed in advance to ask them to choose three or four images from their body maps which they felt were most important in the way they reflected their experiences at school. A brief description of the perspective narrative process was shared, and the explanation was supported by the example story above. I introduced the idea of group members writing up one or more of the stories behind the images they had chosen to share during the meeting, and for this story to be accompanied by a narrative written by me with input from the group, telling the story from a different perspective. For the group to analyse and share their data in an authentic way, the starting point for the process needed to be their own stories. There was discussion about which of the chosen images could form the basis of a narrative that would reflect their own experiences and the shared experiences of the group, and an agreement was reached about a basic plot to follow for the story to be created. For example, Rose chose the images of primary school, secondary school, power, and the people that support her. We talked about the pictures she had included on each of these sections. One of the most striking elements of her primary school image is that surrounding the colourful pictures is a thick, brown wall and gate (see Figure 16). When we talked about what this represented, Rose spoke about how the wall and gate being too low made her feel unsafe and, as a result, she would often hide under the desk when she was in class. Her reasons for this were not shared with her teachers. Rose felt that this would be a good story to tell as it spoke of how misunderstood she felt her behaviour was at primary school.

Figure 16 - Rose's Primary School Image

The data each group member chose to develop into a narrative was very different and represented a range of school experiences. This was recognised by the group when we were discussing the planned stories and felt to be a strength of the process.

7.5.2 Generating and Developing Narratives

Having chosen which element of their data to create a narrative about, the next stage of the process was for each member to write a draft of their story. Potential strategies to structure the writing process were discussed. Some of the group felt they would like to write their first-person narrative first, others preferred the third-person story to be created first, giving them a structure to base their story on. The group members who chose these options worked on their narratives in their own time. Two Fizzacc members chose to narrate their stories aloud while I transcribed them. Anwen's was done during group meeting 14, Ellery wanted to create hers with just me before sharing it with the group. This was done by meeting Ellery prior to group meeting 15. For these stories I edited the transcriptions for sense and structure before returning them to the authors for approval. The process of writing the narratives took five months in total. One member of the group chose not to write a story as she was preparing for exams. Another group member chose to write two. Depending on the choice of each group member, I wrote the alternative perspective of the story - either in response to what they had written or based on our discussion about what the story would be about. The events and characters in the third-person narratives were entirely fictional but were informed by my teaching experience.

It was while we were developing the narratives that I suggested we could use the character of Maggie as the voice of the first-person narrative. We had created Maggie to play a similar role for our school resources (see Chapter 8). For the narratives, she served to link the stories together as well as anonymise them. Using Maggie also helped the group members to be more objective about the narratives as they became Maggie's stories rather than their own. This was beneficial for the next stage of the process which involved sharing the stories with the rest of the group for discussion and editing.

7.5.3 Reviewing Narratives

Once both parts of the narrative had been written, these were shared with the rest of the group for discussion by reading them aloud. Some group members chose to read the first-person section of the narrative they had written while others asked me to read them. I read the third-person part of each story. While some changes to grammar and syntax were made at this point, very few changes were suggested in the plot or character development of the stories. The group members were very positive about how representative the stories were of their experiences.

Whether the stories were presented with the first-person or third-person narrative at the beginning was decided upon. Each story was considered separately, with some starting with the first-person narrative and some with the third. By varying which voice came first in each story we felt that the reader may be more likely to question their interpretation of the events as their empathy would be moving between Maggie and the other characters included. We also discussed the order in which we would present the stories. We decided to make this roughly chronological based on the age of the group member when they experienced them. For example, one story was about a primary school experience whereas the others were at secondary school, so the primary school story was presented first. As some stories were based on an amalgamation of several different events, these were allocated a place in the order that was felt to be representative of the lived experiences of the group. For example, the debates about wearing school uniform took place throughout secondary school, but we chose to include this as the second story as uniform issues were immediately apparent when moving up from primary school.

During group discussions we considered how effective the stories were at representing shared incidents as well as telling individual stories. All Fizzacc members felt they were able to identify situations they had encountered that were similar: the stories were felt to be representative of their school experiences:

Ellery: The story is so relatable. Someone stole my diary and started looking through it!

Ola: I've literally heard my teachers say the exact line about a uniform not being the height of fashion or something.

One group member felt strongly that they would like to include a story about a situation where their school experience was more positive: the initial stories were only representing challenging experiences. The positive story they wrote was based on a very specific event that was particular to this young person and did not follow the chronological story we were telling of Maggie. Despite this, we felt it was important to include the story and together we devised an introduction to explain why. The stories are presented in full in section 6 of this chapter.

7.5.4 The Next Level of Analysis – Adding Talking Points and Titles

Having completed our narratives we discussed how they represented many of the key themes that were included in the body maps and shared in our meetings. We had covered lack of understanding that behaviour is communication, sensory challenges, inaccessible structures within school, the impact of overwhelm and how it is possible for schools to get it right. At this stage the group became interested about the experience for readers of the narratives. There was concern about the clarity of our communication with potential readers. In one meeting, Anwen expressed confusion as to how the reader would understand the message we were aiming to impart with each story:

Anwen: I'm like, I guess I'm a bit confused on how like, people would understand it as much.

Ola agreed saying:

Ola: Yeah, kind of the same because there's no context.

From this confusion it was suggested that questions or statements could be added at the end of the story to encourage the reader to think about specific elements of the narrative. Our inspiration for this came from novels which include questions for book clubs at the end. This encouraged a focus on the pertinent issues for each story and facilitated discussion between us as a group, as well as providing a medium for discussion for readers of the narratives. While this process was used as part of data analysis, we recognise that it also offers potential for these stories to be used as a training tool, which is further discussed in Chapter 10.

To name our stories we searched for words or sentences that represented them in an interesting and thought-provoking way. 'Maggie and the Gate' was chosen as it sounds like the title of a picture book that Maggie might be reading and therefore gives the reader a sense of the age of Maggie when the stories begin. 'I'm Not Trying to Cause Trouble' was something that really resonated with the group. It was felt that in trying to get their needs met in school, particularly pre-diagnosis, the young people were thought to be trying to cause trouble. This lack of understanding by school staff was an important area of discussion with the group. 'I've Always Been Good at Writing about Disasters and Death' recognises that the strengths of autistic young people are often unrecognised due to the inflexibility of the school system, and the way exams are structured. 'Unthoughtful Thursday' was a response to the problems caused by well-meaning strategies that fail to achieve their goals, such as poorly designed autism training. These issues are often due to a failure to consider the thoughts and feelings of the autistic class members and their lived experiences.

Fizzacc members were very proud of the narratives we created and in Chapter 10 I discuss possibilities to further this element of our research. The narratives are now presented in their entirety before the chapter is summarised.

7.6 The Narratives

Maggie and the Gate

Maggie is eight years old. She is tall for her age with long, dark brown hair and golden skin with a dusting of freckles. She looks very like her mother, Sally, who walks her to school every morning. Sally is smartly dressed and has an efficient air about her. It is Maggie's Grandmother who collects her at the end of the day.

Maggie always speeds up when she passes the last house before the school boundary. She moves closer to her mother, tightens her grip on her hand and looks intently at the toy she is holding. It looks like she is in a hurry to get to school but doesn't look around to greet her friends like many other children are doing

When they get into the playground, Sally passes Maggie's hand to Miss Bird as if she was giving her a precious object.

"Any problems this morning?" Miss Bird asks Sally.

"No. We've had a good morning haven't we Maggie?"

Maggie brings her toy closer to her face.

"Come on then Maggie. We are going to go into the classroom, hang up your things, then have a look at a book about Sierra Sloth that I found in the library!"

As Maggie walks into the classroom with Miss Bird, she glances briefly back at the school gate where her mother is hurrying off to work.

It's time for school and my mum is calling me downstairs. I hold her hand as she opens the door and we set off down the road. As we get nearer, I start to worry about if I'll be alone at break time again today and having no friends. We arrive at school, and I see the wall and gate which isn't tall enough and I get even more anxious about someone breaking in the school. I hold my mum's hand even tighter and try not to make eye contact with the wall and gate. I go over to Miss Bird with my mum because I have no friends to talk to. Miss Bird speaks with my mum, and I hide myself behind my elephant toy. After their conversation, Miss Bird tells me about a book which I'm excited about; my mum hands me over to my teacher and I look down because I don't like looking at people's eyes or mouths. We walk into school, and I look back at the dangerous wall and gate and I think 'that is the reason why I don't feel safe in school'.

Questions/Talking points

- What kind of an impact does worry about friendships have on Maggie?

- Feeling safe at school is really important. Were they any signs in the story that Maggie didn’t feel safe?
- What assumptions might we make about Maggie from the narrative that we might change when reading the first-person account?

7.6.1 I’m Not Trying to Cause Trouble

“Maggie. I need to speak to you before you go, please.”

Miss Ahuja neatens the pile of exercise books on her desk while Maggie packs her pencil case back in her bag.

“Yes Miss?”

Maggie stands to the side of Miss Ahuja’s desk and looks intently at the pile of books.

“You know what I’m going to say Maggie, don’t you?”

Maggie sighs. “Yes Miss.”

‘That jumper is not part of our school uniform.’

“No, Miss.”

“Our uniform rules are very clear Maggie. I need to see you in proper uniform tomorrow otherwise I will have no option but to take this further. Is that clear?”

“Yes, Miss.”

“Off you go to your next lesson then Maggie. You don’t want to be late.”

Maggie takes a deep breath as she leaves the classroom. Her next lesson is upstairs in the same building. The corridors are still busy. She hoists her bag onto her back, puts her head down and keeping as close to the left-hand wall as she can, approaches the stairs.

“Maggie!”

It is Mr Jones, her head of year.

“Where is your school jumper?”

Maggie stops and looks at the floor.

“I don’t want to have to speak to you again young lady! This is the second time this week that you have not been in proper uniform. Let there not be a third strike please. I know our uniform is not the height of fashion and it isn’t as comfortable as your favourite hoodie, but rules are rules. Off you go then, don’t be late!”

By now the corridor is quieter and Maggie hurries up the stairs.

The next day Maggie is sitting in her seat in Miss Ahuja's class.

"It is good to see you in proper uniform Maggie. Thank you."

Maggie squirms in her seat and opens her book. She pulls the cuffs of her uniform jumper over her knuckles and rests her hand in her lap.

Another day of school, another day of getting told off for my uniform.

I haven't been wearing my school jumper for a while now as it makes me so uncomfortable. The textures and fit just don't sit right with me and distract me away from my work.

Recently, I've been wearing a plain black jumper instead, one that's softer and slightly bigger so I'm comfortable. In my comfy jumper, I find it so much easier to concentrate and get a lot more work done! I struggle with sensory issues a lot as certain textures and feelings especially can cause me to get upset and end with me doing no work.

It's 2pm and I've already been told off four times today for wearing a different jumper. I've tried to explain how I feel but no one seems to understand and just thinks I'm trying to dodge the school rules for no reason! I wish people listened and understood I'm not trying to cause trouble and just want to feel comfortable within school. The head of year shouted at me yesterday and said I'm on my last chance so tomorrow I'm going to have to wear the school jumper.

The next day:

I can't concentrate. I haven't done nearly enough work and are starting to get worried about catching up. Teachers keep on congratulating me for wearing my uniform like it's a miracle, when really, it's a nightmare for me.

I'm currently sat in English. I'm meant to have written a full page but instead all I can think about is how much I hate the texture of this jumper. It almost physically hurts; I can't stop focusing on it and how horrible the jumper feels around me. I'm scared this is going to get me into even more trouble for not doing work and it's making me feel really anxious and overwhelmed.

I understand a lot of students might just not want to wear a uniform, but sensory issues are a valid reason. This is something that definitely deserves to be listened to and could even be an indication towards a bigger struggle.

Questions/Talking points

- What is the point of a school uniform? What are the barriers to making it more flexible?

- What might the impact be on a young person getting told off for the same thing many times in one day?
- How do you think Maggie felt being congratulated for doing something that she knew was detrimental to her learning?
- What could the teachers have done differently that would have helped them to better understand Maggie's needs?

7.6.2 I've Always Been Good at Writing About Disasters and Death.

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.

Mum said that it was important for me to tell my teachers in advance about my autism diagnosis and how it affected me in my lessons. Even though the school had copies of my diagnosis they didn't share it with my teachers until I was in year 10 so it ended up being my responsibility to tell my teachers. Otherwise I would get into trouble for things that were out of my control. I was *worried because sometimes when people know I am autistic they start to talk to me as if I was three.*

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.

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."

"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/Talking points

- Mrs Webb says the exam system is 'inflexible and unfriendly'. How could exams be changed to be more inclusive?

- 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?
- What strategies could be used to give children like Maggie time to process questions and instructions in the classroom?

7.6.3 Unthoughtful Thursday

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.

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/Talking points

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

7.6.4 Positive Story

This story does not fit with the rest of Maggie's timeline, but we felt it was important to include it. It is as important to consider and learn from positive experiences of schools getting it right, as it is to learn from more challenging experiences. We have not written an alternative perspective as, in this case, both Maggie and her teachers have a clear understanding of her needs.

Hi. My name is Maggie and I'm autistic.

I got diagnosed last year and I had lots of help, I'm at a special school because of the help I got in year 6.

I love my school and I get to experience things that other children get to do.

I have a timetable, so I know which lessons I have for that day and I'm in a small class so it's not too busy, I go to some lessons before the corridors get busy, so I don't get anxious.

My teachers understand my needs and they help me stay calm when I'm stressed out.

I go on a minibus to and from school and I've made lots of friends and I'm loving myself more.

I'm becoming more confident each day and I AM HAPPY!!!

Questions and Talking Points

- In this story Maggie attends a special school. How could the support strategies that Maggie refers to work in a mainstream setting?
- Choose three ideas from this story that you think are key to Maggie's positive attitude to school.
- If you were to add an alternative perspective for this story, what might it say?

Summary

This chapter addressed how methods for analysing Body Mapping data were developed in a creative and collaborative way. Ideally, Body Mapping data would have been analysed prior to moving on to the 'Create' phase of the research to allow us to use the product of the analysis in the creation of resources. However, as the development of our analysis process came about in response to the interests and abilities of the group rather than as a pre-planned activity, this was not possible. Chapter 8 introduces how Fizzacc created transition resources to be used in schools which was taking place alongside the analysis described above.

Chapter 8 – Create

Introduction

The creative process of the Inclusive Design Toolkit (http://www.inclusivedesigntoolkit.com/) includes initiating ideas to create a design concept and prototypes which can then be tested. Having described the exploratory phase in Chapter 6 during which we discussed how we might address barriers to successful transition by creating resources for schools, this chapter describes the creative processes that Fizzacc undertook which aligned with the Inclusive Design Toolkit process. The creative process took place alongside the Body Mapping tasks in the first phase of the research and continued into the second phase (see Chapter 5 Table 10). It involved generating ideas for resources designed to help young people, with or without an autism diagnosis, to have a more successful transition to secondary school by educating peers and teachers about the experiences of autistic girls. These ideas were then turned into a suite of resources that we were able to take to schools and gather feedback as described in Chapter 9.

8.1 Initiating Ideas

To generate ideas, I shared some existing resources with the group so we could identify their strengths and limitations. I wanted to show a range of resources including those aimed at staff and pupils, and that addressed specific issues faced by autistic girls and women.

The first resource shared was the 'Pupil Profile' document created as part of the STEP-ASD intervention created by Mandy et al., (2016a, p.583). This was developed based on information to be discussed during a meeting between the child, their parents, a member of staff from both primary and secondary schools, and a STEP-ASD worker. It supported a more detailed 'transitions management plan' (p. 583) and was designed to be shared with secondary school staff to provide a summary of key information from the transition management plan. The first page of the document includes space for information about diagnosis, awareness of that diagnosis, and willingness to share that information with others. It included details about EHCP provision if appropriate. The second page is more descriptive and includes three sections about support needs and strategies, as well as sections for additional concerns and any triggers or dislikes. There is one small section for areas of strength, and one for known interests. Overall, the group was positive about the concept of this, and some had a similar profile created post diagnosis. However, it was felt that it should not be just for children with an autism diagnosis:

Anwen: I think all schools should do this. Like one, like every year. They should do this. Give it to everyone in the school and then more people would be diagnosed. If they had this every year.

It was felt that there should be more emphasis on positives:

Nancy: My one had a whole big box for stuff you were good at and that helped me feel better about needing support.

There was a concern that using the proforma would limit the kind of information that could be provided and there might be situations where pressure might be felt to come up with three support needs to complete all the boxes when there may only be one or two that were relevant:

Abria: I think it's quite restricting.

The second resource we looked at was a comic created as part of an ACoRNS collaborative project (https://acorns-soton.org.uk/wp-content/uploads/2022/03/School-Daze-Comic.pdf). This was produced by a team of pupils and professionals alongside a professional illustrator and tells the story of Lee Mouse's first day at secondary school. It includes tips for how to navigate challenging situations. Fizzacc felt this was a really good resource:

Rose: I think this one's much more positive than the last one because it's got pictures and you can really see yourself in the pictures.

They could see how the comic book design could be used to address different issues that children starting secondary school might face:

Anwen: I do think this is actually really cool. I think they could create more stuff like that. Like in different scenarios.

The visual nature of this was felt to be a real advantage for engaging the readers and the use of a central character to base the resource around was appreciated.

The final resource was Camouflage (Bargiela, 2019) which was created as a response to interviews the author held with autistic women. Although this is a resource focused on experiences and difficulties faced by autistic women and girls in all situations rather than transitions between schools, I wanted to share something with the group that addressed the perspective of autistic girls and women as this was an important part of the message that we wanted to share. Again, the group felt that the visual nature of the Camouflage resource was beneficial, and it prompted a long conversation between the group about their experiences as autistic girls being different to those of their male peers:

Ola: Most people when they kind of think about autism, they only really kind of think about it in boys… I think there's more of an expectation on girls to kind of have like, better manners almost. So when it comes to autism in girls, like when people who say things like, look at me when I'm talking and stuff kind of along those lines, it's almost like there's more of an expectation on girls to be kind of presenting good manners.

Nancy: I've been told that I can't be autistic because I'm a girl.

Ellery: The guys with autism in my year get special privileges and the girls get nothing.

The group all felt that it was important for them to focus the resources on the experiences of autistic girls as they felt that there is a real lack of awareness in schools about the specific challenges they face.

Having explored existing resources, Fizzacc decided that they wanted to create something visual that would raise awareness about what it is like for autistic girls in secondary school. They felt that this would not only benefit girls with an existing autism diagnosis but might also support girls who are finding school difficult and may not know why. Although our intention was not to create something that would suggest that anyone experiencing the same problems as autistic girls must be autistic, it might give a child struggling with school a prompt to seek support at home or school:

Ola: So I think it's important that whatever resource we make it is important that we make sure it's like if you feel like this could mean you have autism. But it doesn't necessarily mean that you have something like that because I think that's like misinformation.

Having decided we wanted to create something to raise awareness that used visual images, we next discussed what that might be. Anwen suggested creating a PowerPoint presentation as this would support the use of pictures which would help the audience to understand the message we were trying to convey:

Anwen: Because a lot of time when people talk about it, it goes right over my head. I think instead we should like do a PowerPoint and make like maybe a little game. So, they can get engaged instead of just going ‘what's going on?’ Because if I was in it, I would just go ‘what's actually going on? I don't understand.’ Images. Images are amazing. You can tell so much from an image.

It was also important to the group that whatever we made was freely accessible:

Anwen: Someone would be able to download it for free and be able to have their class do it.

The idea of creating a suite of resources which could be used flexibly in lesson time or tutor times, which included visuals as well as interactive elements, was discussed and agreed on. We then thought about our target audience. All members of the group agreed that the focus should be on secondary school pupils: better understanding in year 7 of the issues that were being faced post-transition was felt to be important:

Ola: Having something specially to help me in secondary school. People kind of being more aware would help the most then.

It was also felt that the resources should be aimed at both staff and pupils:

Nancy: I think it's really important for secondary school staff to have the information too, as well as primary people. So there's support and understanding on both sides of the jump.

Although we did not have time to create resources for both primary and secondary pupils, we agreed to include a leaflet that could be useful to staff from both phases as well as activities that the teachers could select from as appropriate to their class. The development of these resources is described below.

8.2 Developing a Concept

Having decided on target audience and use of PowerPoint for our presentation, we moved on to further developing our concept. To avoid the pressure of starting with a blank page which can be challenging when conducting participatory research (Seale et al, 2014), I put together a rough PowerPoint presentation which included many of the challenges in transitions and misunderstandings by teachers and peers we had discussed during Body Mapping and discussion (see Appendix F). This included a slide about meltdowns and shutdowns, an explanation of what is meant by the autistic spectrum, and information about why the experiences of autistic girls may be different to that of autistic boys. Based on the comments the Fizzacc members made about the value of being able to identify with the character of Lee Mouse in the ACoRNS comic, I suggested to the group that we base our work around a central character – Maggie. When I suggested the idea to the group, they were positive:

Ola: I really like having Maggie and because I feel like it is a really good way to represent stories, which I think, especially for young kids as well, is a really good way to get things across.

The PowerPoint I had created was shared with the group and amended where needed. For example, the group wanted to add specific information about sensory challenges, which the sample presentation included on a more general slide about difficulties in school. Once we had discussed the sample presentation, we talked about what each group member would like to work on to further develop it during future group meetings. Nancy volunteered to work on the text for the slides, Ola, Anwen, and Rose worked on developing computer images for the slides, Abria started some original hand drawn artwork, and Ellery took on the challenge of designing an image to represent Maggie. We decided that in recognition of racial disparity in autism diagnosis (Tromans et al., 2020), Maggie would have brown skin:

Ola: It's actually like anyone can have autism. I think the most important thing for me is what it says about like these set stereotypes to try and break that.

As well as the information about autism that we wanted to include in the presentation, Ola felt that it would be good to include an individual slide from each Fizzacc member to explain who we were and why we were doing this project. It was decided that this slide should include a statement from each member which responded to the heading 'one thing I want you to know about Autism'. By including these individual slides in the resources, the Fizzacc members were able to take ownership of their participation.

We finished our presentation slides during group meeting 9 in the first phase of the research. During the final meeting of this phase we reflected on our progress and discussed how we would like to create classroom-based activities to support the information in the presentation.

8.3 Creating a prototype

One of the first decisions made in the second phase of the research was to convert the presentation to a video with audio narration so schools could present it seamlessly in an assembly or lesson. It was important to the group that it was voiced by an autistic girl rather than a teacher reading out our words, so Ellery agreed to record the narration to be added as a voice over. This was done outside meeting times and was sent as an MP3 file for me to embed in the PowerPoint presentation and convert it into a video. The video can be accessed here: https://youtu.be/F2nvhAttpAU.

For each stage of this process we first discussed ideas during a group meeting. I then took these ideas and, using events and suggestions that were discussed by the group during the initial series of meetings when we were creating body maps, developed suggestion of what could be included in each resource. These were shared in the following group meeting for discussion and amendments. In this way we created all the resources as a collective with my role being distillation of ideas. This way of working meant we saved time during our group meetings as well as avoiding the challenges of the blank page as discussed above (Seale et al, 2014). We wanted to incorporate both written and more creative tasks as well as group and some individual tasks. This variety of tasks would allow teachers could select those they felt most suitable for their group as well as offer variation for the pupils.

A list of the tasks we created are in Table 11 More details of the development of each resources follows.

Table 11 ***Lesson Activities for Schools***

	Please start with the True or False task. Then choose the tasks you think most appropriate for your group.	
1	True or False task	*Teacher led – individual task*
2	Choose three things you learned about Maggie in the presentation. Which of these are similar to you and which different?	*Small group discussion or individual written task*
3	Name three ways in which Maggie's autism makes her different from someone who isn't autistic.	*Small group discussion or individual written task*
4	Why does Maggie think that autism is a superpower? What do you think makes a superpower?	*Small group discussion or individual written task*
5	Choose one of the following and design a poster that explains what it is: • Masking • The autism spectrum • Autism as a superpower	*Individual creative task*
6	Create an Autism Charter – how can we better support autistic young people in school?	*Whole class activity*

During our initial development of ideas, Anwen was keen to include a game element so we decided a true and false task should be included. I produced initial ideas for the content of the true and false questions which were shared with the group and developed collaboratively (see Appendix G.2 and G.3). Fizzacc members felt the wording was unclear on some questions, for example Ola felt that statement 7: *Autism is something that affects boys more than girls*, was unclear. It sounded like boys would be impacted more by being autistic. We therefore changed the statement to: *Boys are more likely to be autistic than girls.* I also produced initial content ideas for the staff leaflet to accompany the resources (see Appendix H). The leaflet covered the elements of the presentation in more detail and included links to further information. During the group meeting I shared a draft of the leaflet text, and it was refined and amended by the group. For example, in the ‘How can we help?’ section there was a point which stated, ‘Provide a safe space that is accessible at all times without having to ask for permission’. This was a response to the provision for safe space for different members of the group being structured differently. While the group was happy to include this strategy in the leaflet, it was not felt to be specific enough. For some, the space they were offered for a time-out was not conducive to recovering from a feeling of overwhelm. For one group member, the space offered doubled as a detention room - therefore using it felt like punishment; for another the space was not suitable in terms of sensory stimulation:

Ola: It might be kind of good to say a bit more about that. Make sure it's somewhere that's quiet and things like that. Like when I would get panic attacks, I'd be put outside like the head of year’s office, and it was just really busy.

Consequently, we added an extra sentence to say: ‘Ensure this space is a calm sensory environment’. See Figure 17 for the finished leaflet.

What you need to know about Autistic Girls in Schools

Who are FIZZACC?

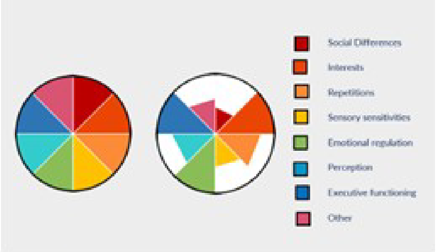
We are a research group consisting of one PhD student from the University of Southampton who has 20 years experience of teaching in secondary schools, and six autistic girls who have a lifetime of experience of autism. We believe that learning from the lived experience of autistic people themselves is the key to developing good practice. We have been working together on ideas to help teachers and other pupils better understand the experiences of autistic girls in schools as part of a project on improving educational transitions. If you would like to find out more about us and what we have been doing please go to https://acorns-soton.org.uk/2022/03/fizzacc-information/

What is Neurodiversity?

Neurodiversity recognises that human brains are all different. The term neurodivergent refers to traits and characteristics related to a number of conditions such as autism, ADHD, dyslexia and dyspraxia. People who are not neurodivergent are often referred to as neurotypical. People with neurodivergent brains add diversity which is important. Although there are challenges associated with neurodivergence these are often caused by environments that are designed for neurotypical people. There are also many strengths associated with neurodivergence.

Why do we refer to autism as a spectrum?

No two people are the same. This is true for autistic people as well as neurotypical. Because of this we refer to autism as a spectrum. Each person will have a different pattern of strengths and challenges. It is also important to remember that a person's profile will change. What is easy one day might not be the next. For this reason the terms 'high' and 'low' functioning are not helpful. 'High' functioning people often lack the support they need whereas 'low' functioning people can often miss out on opportunities due to a false perception of their abilities.



This profile shows how someone might have strengths in perception and emotional regulation but struggle with sensory sensitivities. This is not a fixed profile. It will change in different situations and on different days. It shows how the idea of autism being linear, from 'mild' to 'severe' for example, does not reflect the true picture of strengths and challenges.

Why are we focusing on autistic girls?

The perception that many people have about autism is that it is a condition associated with boys and men. This is partly based on an outdated assumption that male and female brains are different. As a result, research and diagnostic methods have focused on boys, resulting in girls and women being identified as autistic much later if at all. So why is autism not identified in girls? There are some differences in the way autistic traits look between boys and girls.

- Girls are better at hiding their autistic traits. This is often called masking or camouflaging.
- They are more likely to want to make friends and fit in. This can often lead to them copying the behaviour of their friends.
- Girls will internalise their feelings whereas boys will often 'act out'.
- Girls have interests that are considered more typical of their age for example TV shows, pop bands or animals.

Autistic strengths

- Attention to detail
- Ability to focus
- Creativity
- Acceptance of difference
- Integrity and honesty
- Ability to identify patterns in information
- In depth knowledge of specific interests

What challenges are there for autistic girls in school?

Sensory challenges. Bright fluorescent lights, the smell of school dinners, the scratchy feeling of a polyester school jumper. These are not only irritating. They can cause physical pain and make it difficult to concentrate on learning.

Meltdowns. These occur when an autistic person is in a situation that their brain can't deal with. This looks different for everyone. Some people cry, some scream and shout, some run away. This is not a choice or 'bad behaviour'. A meltdown must be allowed to run its course in a safe space and the young person should then be supported until they feel well enough to continue with their learning.

Shutdowns. These happen when there is too much information to process. The person will stop paying attention to the things that are overwhelming. This might look like rudeness with a refusal to answer questions or follow instructions. Again support should be offered in a safe space until the feeling of overwhelm comes to an end.

It is very likely that there are autistic girls at your school who have not been identified as autistic. This can make the environment even more challenging as they may not understand why things are more difficult for them.

Some words of wisdom from FIZZACC

'You can't tell if someone has Autism just by looking at them! Absolutely anyone around you could have a hidden disability so make sure to be mindful and kind to everyone. We're different not less!'

'Some children who haven't been diagnosed act "naughty" but they aren't always, they might be overwhelmed; so just TBYA – Think, Before, You, Assume.'

'Every autistic person is different - there is no one way to 'look' or be autistic, we all have different traits. Autistic people can be of any race, gender, sexuality etc. but we're all still autistic :)'

How can we help?

There are lots of things that schools can do to support autistic girls. These will support them with learning, help prevent meltdowns and shutdowns, and protect their wellbeing. These tips are also applicable to boys.

- Teach staff and pupils how to support the autistic children in their schools.
- Don't assume that what is possible for an autistic person one day will be possible another.
- It can be difficult for autistic children to explain why they are finding things challenging. Give them time to explain and check back with them regularly.
- Most autistic children want to learn. Don't assume conduct that doesn't meet your expectations is due to wilful poor behaviour. First check all other possibilities.
- Provide a safe space that is accessible at all times without having to ask for permission. Ensure this space is a calm sensory environment.
- Have flexibility in your uniform policy.
- Keep lighting low and fix faulty lighting that is flickering or buzzing.
- Remember that sensory issues can be felt as pain. If a child is in pain, they won't be able to learn so take them seriously.
- Autism in people from ethnic minority groups is often misdiagnosed. Consider this if a child from an ethnic minority group is struggling at school.
- A lot of autistic young people are proud of their autism and consider it a superpower. Help them to celebrate their abilities and harness their strengths.

How do I find out more?

Here are some links to information that might be helpful.
A comic strip which explains the autism spectrum. https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/
A really clear explanation of what is meant by neurodiversity. https://www.youtube.com/watch?v=xsfml3yVh1g
An article about The Double Empathy Problem written specifically for young people. https://kids.frontiersin.org/articles/10.3389/frym.2021.554875
An article about why the language we use when we are talking about autism is important. https://www1.racgp.org.au/ajgp/2021/march/autistic-or-with-autism
The National Autistic Society – a good source of infomation and support. https://www.autism.org.uk/
Contact FIZZACC on c.east@soton.ac.ul @ACoRNSoton

Figure 17 - Leaflet for School Staff to Accompany Resources

The impact on the group of having created tangible resources that we could share, free of charge was very important. This impact will be addressed further in the Discussion chapter of this thesis (Chapter 10). During the finalisation of the resources we began to consider how we could gather feedback on what we had created by asking schools to trial them with their pupils. This process is described in Chapter 9.

Summary

This chapter describes how Fizzacc worked together to create resources which we hoped would help pupils and teachers better understand autism and the experiences of autistic girls in schools. Having created our resources, the next stage was to recruit schools to trial them and offer feedback. Chapter 9 will begin by describing the process by which we evaluated our resources before moving on to evaluate how Fizzacc members felt about participating in this collaborative research project.

Chapter 9 - Evaluate

Introduction

The previous chapters used the elements of the Inclusive Design Toolkit (http://www.inclusivedesigntoolkit.com/) to describe how Fizzacc came together to explore lived experiences of educational transitions and use these experiences to create resources for schools. From the results of this exploration, I have described the creative element of the work including devising a novel method of data analysis which enabled Fizzacc members to take part in the analysis process and addressed issues of power, voice, and Double Empathy. This chapter provides details of the evaluation processes that form the third part of the framework. The Evaluate section of the framework involves firstly considering the review criteria for the work, before testing the products with experts and users. This chapter provides an evaluation of two different element of the research: the resources we sent out to be trialled by schools, and the process of conducting this participatory research and the impact of involvement in the project for all group members.

Evaluating Fizzacc's Resources for Schools

Having worked with Fizzacc to create resources that aimed to address problems of transition for autistic children regardless of diagnosis, it was important to us as a group to receive feedback on what we had created. A description of the process by which this evaluation was conducted now follows with an analysis of the data we collected.

9.1 Aims

Our aim was to trial our resources in a small number of schools to receive feedback on their content and structure. By doing so we wanted to ensure we were offering something that schools would find valuable in raising awareness of autism in girls. This addressed the second part of the research question as stated in Chapter 5: What do autistic girls feel are the barriers to a successful transition from primary to secondary school and how can these be addressed? More specific research questions for this work were:

1. Having watched our presentation and worked through the activities, how do teachers and pupils feel their knowledge and understanding of autism has changed?
2. How does the involvement of autistic girls in the creation of the resources make a difference to how they are received?
3. How does the delivery method of our resources engage pupils and teachers?

9.2 Recruitment

Three Fizzacc members were keen that their schools be invited to participate in the project and these schools were contacted via email. Having presented Fizzacc's work at several ACoRNS meetings and webinars, I also received messages of interest from two further schools. Disappointingly only one of the Fizzacc members' schools responded to the request, so we were left with three schools who signed up to trial the resources.

9.3 Procedure

Having established contact with each school, an online meeting was held with a facilitating member of staff to introduce the resources and discuss the best way for each school to deliver them. The resources were designed to be flexible so schools could use them as most appropriate to their curriculum. Schools were asked to inform parents and pupils in advance that the pupils would be taking part in a lesson about autism. This was to ensure that any autistic children in the classes were aware in advance and were able to prepare for the lesson if needed. Schools were asked to distribute the teacher information sheet and resources in a timely manner to allow the teachers delivering the activities to be prepared and feel able to answer questions from their pupils. The presentation was designed to be shown first followed by the activities (see Chapter 8 Table 11 for list of activities). Teachers could choose which activities to use, and the order to deliver them. The schools all chose to launch the lesson in a year-group assembly in which children watched the presentation and heard from their head of year about what they would be doing subsequently. Two schools delivered the activities during one-hour Personal, Social, Health and Economic Education (PSHE) lessons, and one during 30-minute morning tutor sessions over the period of four mornings. In each school the resources were delivered by a range of subject teachers with varying knowledge and experience of working with autistic children (see Table 12).

Table 12 ***Fizzacc Resources Trial – School Details and Procedures***

	Location of School	Delivery of resources	Mode of feedback
1	South of England	Presentation in assembly. Activities in PSHE lesson	Focus group with 10 pupils Focus group with 12 pupils Interviews with 2 teachers
2	East of England	Presentation in assembly. Activities in tutor times	Feedback forms: 160 pupils and 3 teachers

	Location of School	Delivery of resources	Mode of feedback
3	North of England	Presentation in assembly. Activities in PSHE lesson	Feedback forms: 157 pupils and 2 teachers Interview with 1 teacher

9.4 Ethical considerations

Ethical approval for this part of the project was granted (Ref #71269 - Appendix I.1). Gaining consent for the trial of resources in school required some thought, as there were different levels of consent needed for different levels of involvement. Schools were asked to email all year seven parents to inform them about the research and give the option of their child not attending the lesson. Those children asked to participate in the focus groups received a different email. An information sheet about the research - either general or focus group specific - was included with this email (see Appendix I.2 and I.3). Focus group children were identified and invited by the school and were asked if they wished to participate. Prior to starting focus groups sessions, it was made clear to the children that they did not have verbally contribute if they did not want to. This gave the children two opportunities to opt out of participation in the project. Information sheets (see Appendix I.4) were provided to the members of staff who were interviewed about the resources, and verbal consent was given prior to beginning the interviews by sharing the consent form online.

For children and staff who participated in the lesson and filled in feedback sheets, no demographic information was recorded: responses were thus totally anonymous. On the feedback sheets the instructions for completion included: ‘if there are any questions you would prefer not to answer, you can leave them blank’. This offered the option of not participating in some or all the feedback. This level of anonymity prevented the need for signed consent from the pupils who were experiencing the lesson as a normal part of their PSHE lessons, which would have been unnecessarily cumbersome for the schools to facilitate. As an ex-teacher who had delivered PSHE lessons, I had facilitated children participating in pupil voice activities as a normal and accepted part of school experience. The feedback we were gathering aligned with these processes and gave the schools involved the opportunity to learn about their pupils’ experience of the lesson as well as providing data for this study.

9.5 Data Collection and Analysis

Two schools provided written feedback using the proforma created by Fizzacc (see Appendix I.5 and I.6). Questions pertained to the research questions as stated at the beginning of this chapter and sought to gain feedback on how knowledge of autism changed through interaction with the resources, whether the mode of delivery was appropriate, and whether having autistic girls themselves involved in the creation of the resources had an impact on their influence. The third school was attended by one of the group members who was keen to be involved in the feedback process. This involved me going into the school and working alongside the Fizzacc member to run two focus groups: the first with ten pupils and the second with twelve pupils. Focus groups took place in school, the first in a classroom and the second in the school library. Each focus group lasted 50 minutes. The questions from the proforma were used to structure the discussion but allowance was made for follow up questions where appropriate. The pupils who attended the focus groups were all in year 7. They had been selected by the school as being pupils who would be likely to share their opinions of the lesson. Both groups were neurodiverse and included pupils with autistic friends and/or family, as well as those without. A member of school staff was in attendance for safeguarding purposes but sat away from the group and did not participate in the discussion. I conducted online interviews with three teachers who had delivered the activities. These took place within two weeks of the resources being used and took place at a time chosen by the teacher as most convenient. Interviews lasted between 20 minutes and 54 minutes. Focus group and interview data were audio recorded and transcribed.

Data from feedback forms, interviews and focus groups was analysed using content analysis (see Appendix J). This is described by Bengtsson (2016) as a process which 'identifies and groups categories together and seeks some understanding of [them]' (p. 8). This was a deductive analysis in that it was intended to identify views of the resources we had created rather than provide an inductive development of more general themes (Elo & Kyngas, 2007).

The first stage of analysis was to print all feedback forms and transcripts. They were cut up so each question could be analysed in turn. In line with Hseih and Shannon's (2005) outline of coding approaches for what they call 'directed content analysis' (p. 1286), codes were defined both before and during data analysis. Closed questions such as 'have you ever been taught about autism in school before?' were sorted into piles of positive and negative responses and quantified. Open questions such as 'what did you learn from the lesson?' were sorted into codes. Once complete, codes for each question were revised and amalgamated where necessary. For example, 'include information about autistic boys' and 'include autistic boys' were put together into a code entitled 'include information about/views of autistic boys'. This was necessary because in some cases the wording of the responses made it unclear in which context boys should be included. Where relevant, responses that did not specifically answer the question or that gave an opposing perspective were included in their entirety. For example, there were responses to 'what did you learn from the lesson?' that were in opposition to what the message of the lesson was, such as 'that girls are more likely to be diagnosed with autism'. Highlighting these misconceptions was useful when looking back at the resources and considering how to improve the accuracy of our messages.

While the feedback forms asked questions about the resources in general to allow for schools having approached the resources differently, interviews and focus groups were able to be more specific about how individual schools responded. Where appropriate, comments about specific tasks or the way the resources were used were included in the analysis of feedback forms. Any remarks that were made outside the structured questioning were added as separate codes.

9.6 Findings

317 forms were returned from schools 2 and 3 of which 54 were discarded as either blank or illegible, leaving 263. Of these, some had questions left blank as per the consent process that stated pupils were under no obligation to answer any or all questions.

The first questions posed in the feedback sheet referred to the first research question on how knowledge and understanding of autism had changed because of the Fizzacc resources. 37% of 263 pupils felt that they knew a lot about autism and the most common source of knowledge other than the Fizzacc resources (37%) was family (14%) and peers (12%). Only 8% felt their knowledge of autism came from school, which aligns with 80% of children reporting that they had not been taught about autism in school before. The most common responses to the question 'What did you learn from the lesson' involved masking (29%), the differences between boys and girls (25%), and that autistic people are all different (21%). 63% of pupils reported that they would change the way they interact with autistic children in their class because of the Fizzacc lesson. 3% stated that they would not, however it was unclear whether this was due to a lack of engagement in the lesson or because they felt they already interacted positively with autistic peers. The ways in which pupils felt they would change included being kinder (22%) or more understanding (13%). More specific changes included being more aware of sensory difficulties (10%) and knowing how to support with shutdowns or melt downs (6%).

In answer to the second research question about the impact of autistic girls' involvement in the developing and presenting the resources, 80% of pupils reported it made a difference with many of these stating it was because the information came from autistic girls' own experience and perspective.

The third research question concerned the delivery of the resources; pupils were asked how the lesson could be improved. 14% felt it did not need improving, 7% wanted more information included, 5% wanted autistic boys to be represented, 4% felt having an autistic person come to the school to deliver the resources would be an advantage, and 4% felt the wording of the true and false resource needed to be improved.

The focus groups' feedback on the lesson was very similar to that received from the feedback forms. Pupils felt it was an important lesson to take part in and that its content was good. Again, the pupils felt that some more specific examples of how to support autistic pupils would be helpful. The focus groups also mentioned some of the things that they felt teachers should know more about and support, such as why autistic children may be acting in a way that could seem naughty, or the impact of extreme noise levels in a classroom. One focus group member who shared that they had a diagnosis of autism talked about an experience in primary school where the class was shown a video about autism that was detrimental to the pupils' understanding:

Focus group member: Filled with misinformation about [autism] by non-autistics and a lot of people kept asking me about that, but they had the wrong information entirely.

This reinforced the importance of autism training being designed and delivered by autistic people.

Teacher feedback was overwhelmingly positive. All teachers reported that pupils were engaged with the materials and that they prompted conversation and discussion. Three tasks were particularly mentioned. The true and false task, which was found to be engaging and thought provoking, so much so that one class spent a whole hour on it:

Teacher 3: The initial true and false was brilliant because it was just such a discussion starter!

One staff member particularly liked the task which asked pupils to identify three things they had learned about Maggie and how Maggie was similar or different to themselves. This was felt to engage the pupils with the information in a way that they would not if they were to simply listen to a presentation:

Teacher 1: And what your lesson does is give students a chance for it to pass through, come out the other side and do something with it.

The third task that was singled out was the creation of an autism charter which was felt to promote positive discussion.

While two of the staff members who were interviewed were experienced teachers, one was a newly qualified teacher. This teacher was very positive about what they had learned from the lesson as well as the pupils:

Teacher 1: That's really made it clear in my mind now, looking at the kids as I said, going okay wow, that child and that child, they both have autism. One is a boy, and one is a girl, and you know, complete opposites in the way that they can present stuff so, yeah. Really, really worthwhile and really well-presented and informed, so yeah, thank you!

Staff also identified some potential barriers to the resources being adopted successfully such as teachers who are resistant to changing their practice and may have a negative view of some of the issues raised:

Teacher 2: But I think the biggest problem, and I'll say it, is those teachers that don't recognise it. You know, there are some teachers who are like no, you're not autistic.

For these staff members, a suite of resources to raise awareness may be unlikely to change their mindset. There was a concern that - as this was part of a research project - the time that the schools were willing to devote to it was above what might be allocated under different circumstances. With less time the lesson may not have the same impact:

Teacher 1: So, if we can have that amount of time again, absolutely, because it means we can go into things in more detail, have more discussions, a lot more creativity, talking etc. So yeah, as long as the school can support that with time, then definitely!

An important point was also made by one staff member about the difference in the way autistic traits are perceived being limited to differences between boys and girls. Instead, a broader conversation needs to be had about how every autistic individual is different:

Teacher 2: This is what boys are, this is what girls are, and actually, it's none of that. Um so I don't… I'm not saying that your research isn't good, I'm saying we're on a journey and at some point it's going to be that there isn't this girl and boy autistic, it's…but obviously, we need to do this now to focus on this group that are slipping through the net."

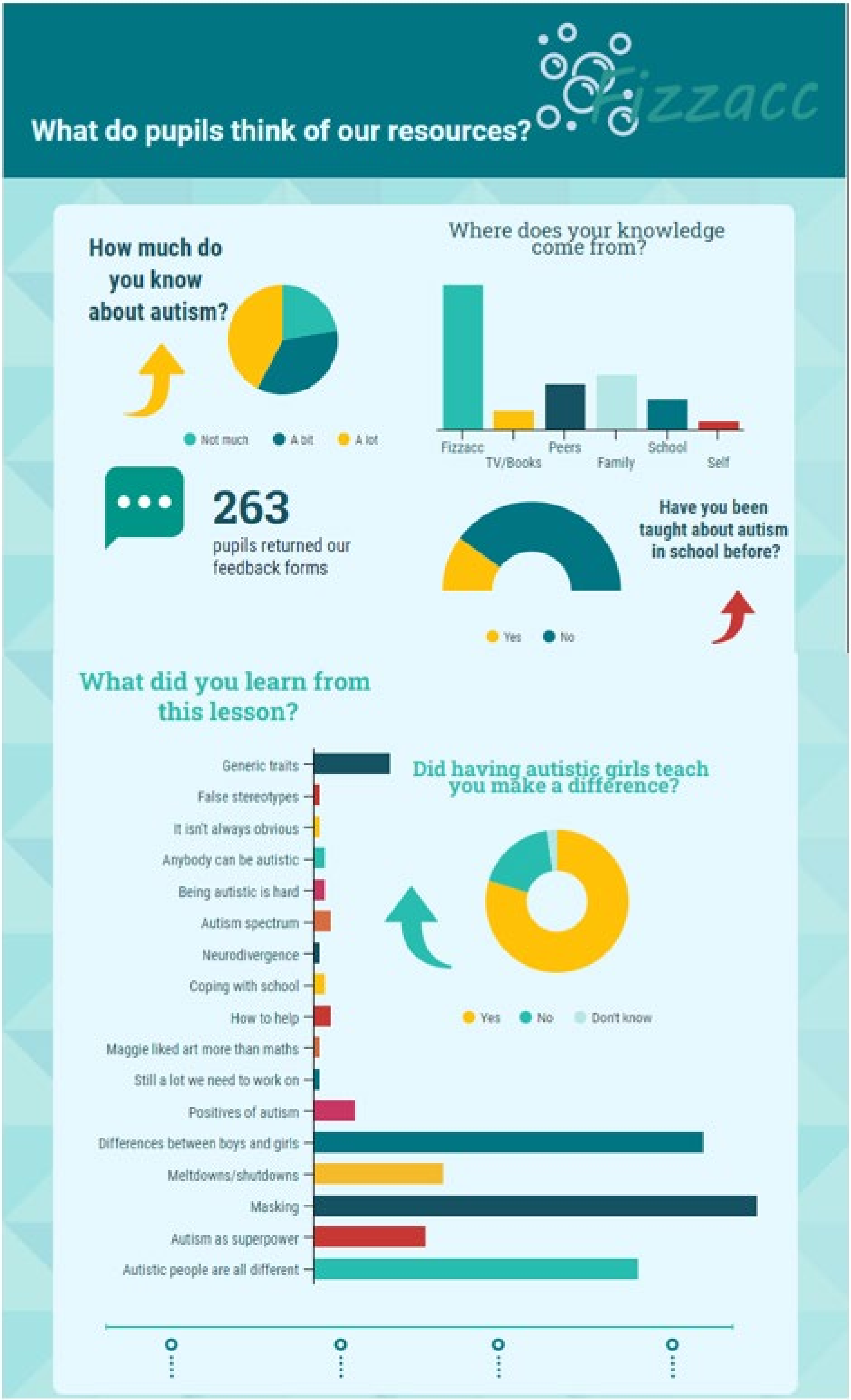
The feedback we received about our resources was overwhelmingly positive. From staff we received the comments:

Teacher 3: The material you gave was cracking!

Teacher 3: The video is utter gold! It is phenomenal!

While we recognise that not all staff members will use the resources and not all pupils will engage with them, our aim to raise awareness of the experiences of autistic girls in education has been met based on the feedback from these three schools. We are now sharing our resources more widely through the ACoRNS website https://acorns-soton.org.uk/2022/03/fizzacc-information/.

To share the feedback from the schools with Fizzacc I created an infographic. This provided a visual representation of the data which highlighted some of the key findings in an accessible way for the group (see Figure 18).



What do pupils think of our resources?

How much do you know about autism?

Where does your knowledge come from?

263
pupils returned our feedback forms

Have you been taught about autism in school before?

What did you learn from this lesson?

Did having autistic girls teach you make a difference?

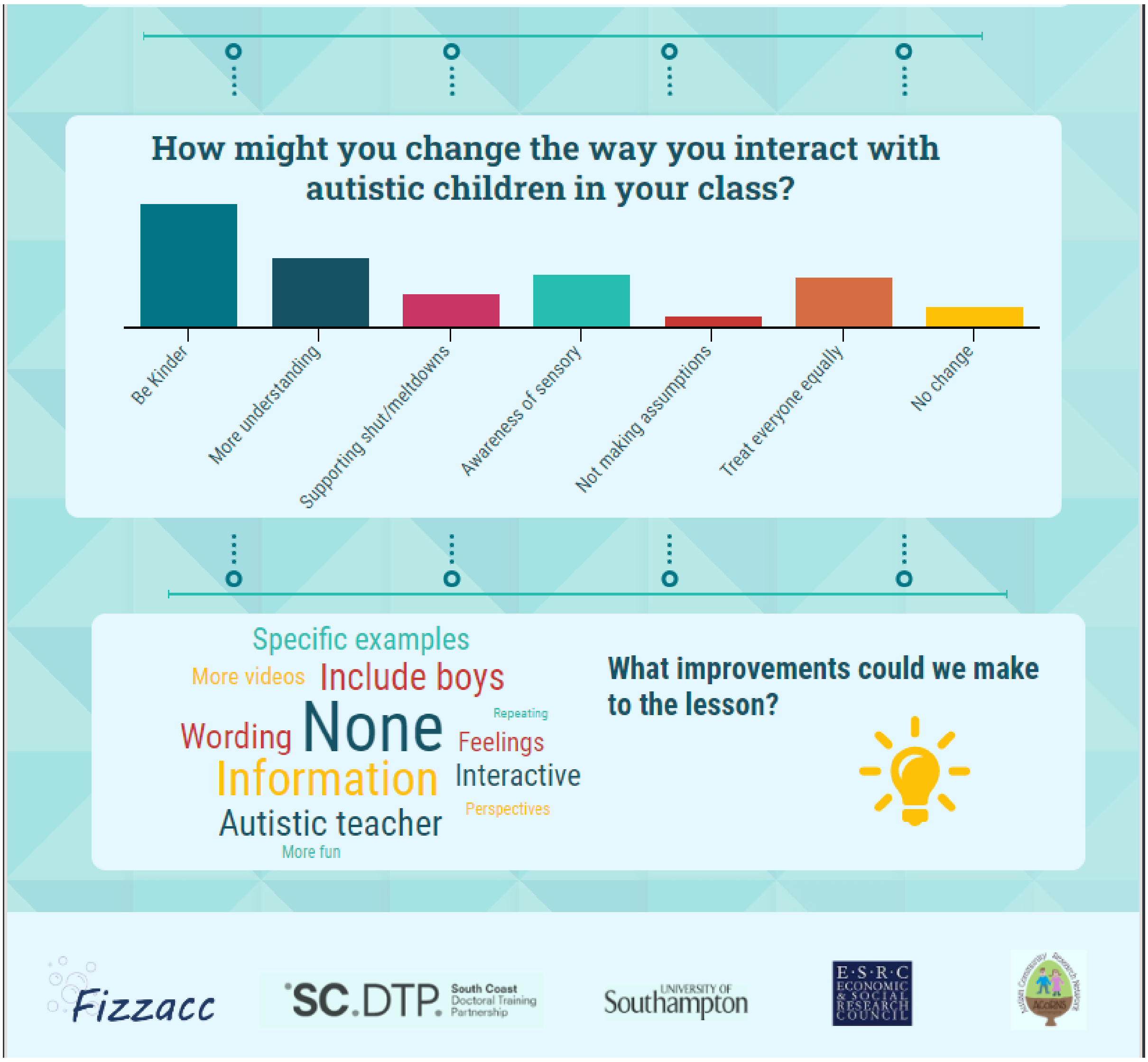


Figure 18 - Infographic Showing Results of Fizzacc Resources Trial

Summary

Ideally at this stage in the process we would have used the feedback from pupils and staff to generate new knowledge that could help us to continue to raise awareness of the challenges faced by autistic girls. This could involve adapting the resources for other groups such as primary schools or medical staff. Due to the timing constraints on postgraduate research, this was not possible and the implications of this will be discussed in Chapter 10.

The power of the resources we created was due, in a large part, to the role that the members of Fizzacc played in their creation. Had I worked alone as a researcher, I could probably have created something with more polish and developed the resources to encompass primary schools as well as secondary, but the resources would have been less impactful. Working collaboratively with autistic young people can be challenging but the rewards, based on the feedback not only from schools but from the Fizzacc members themselves, made participatory work worthwhile and this is discussed further in the following section.

Evaluating the Benefits and Challenges of Working as Part of a Creative Participatory Research Group

Having detailed how we evaluated the resources Fizzacc created in the first part of this chapter, the next stage of evaluation involves an exploration of how involvement in participatory research benefitted and challenged Fizzacc as a group, as well as influencing what we produced as an outcome of our research. This process was one of reflection on the project and although the thoughts and opinions of the young people who made up the rest of the Fizzacc group were central to it, they were not involved in the process. The decision to undertake this part of the research process independently of the group was made in response to what I believed would benefit all members of the group.

With over a year having passed since their initial involvement in the project, many of the Fizzacc members had moved on to new stages in their lives and their interest in the project had waned. They had expressed a disinterest in the process of thematic analysis as described in Chapter 7 and it would have been a significant undertaking for them to be involved in analysing this body of data or of reading and responding to my analysis. The group clearly expressed that for them, the importance of the project was in connection to sharing their message through the school resources and narratives. There had been opportunities to reflect on the process several times throughout the group and individual meetings and further reflection did not seem to be of benefit to them at this time.

In personal terms I was very aware that I was conducting this research as part of a PhD and for me, that involved both developing and demonstrating my research skills. By conducting this thematic analysis independently I was able to fully reflect both on what the Fizzacc members had discussed about their involvement in the project, but also crucially, how I reflected on this as a researcher. By working alone I was able to immerse myself in the data and the process of conducting a reflexive thematic analysis and produce a thoughtful and personal response to conducting research both for, and with, autistic young people.

The following analysis is in response to the research question as stated in Chapter 5:

- What are the challenges and benefits of including autistic girls in participatory research?

9.7 Data Collection

Data pertinent to this focus were collected throughout the process of working with Fizzacc. Some of this was as a response to explicit questioning and tasks set for the group, some as a response to how the group worked together on Body Mapping, discussion, and creating resources. Chapter 5 Table 10 provides an overview of where in the chronology of the meetings, key events took place which contributed to the data. There were two specific data collection points which will be described in more detail below.

Having completed the first phase of ten group meetings, each Fizzacc member was asked to meet individually online with me to conduct a review of the process so far (with an adult present if required). The following questions were sent via email in advance and then asked during this meeting:

1. What have you enjoyed about being a member of Fizzacc?
2. What have you found challenging about being a member of Fizzacc?
3. What did you think about doing the Body Mapping tasks?
4. Is there anything that you think could have been added to improve the tasks or the process?
5. If you could change one thing about the project, what would it be and why?
6. If someone was thinking of taking part in a project like this in the future, what advice would you give them?

The second review of the process took place during the nineteenth group meeting. This involved an evaluation of the project as a group. The following questions were shared on screen as well as verbalised and group members could either respond verbally or in the chat:

1. Did you feel you were able to contribute to the discussions and ideas as much as you wanted to?
2. How do you feel about the decisions we made and about what we created to support transitions?
3. Is there anything you wish you had said that you didn't get the chance to?
4. Is there anything you would have like to spend more time on?
5. Do you feel more confident about sharing ideas as part of a group? If yes, do you think that is true of other groups you work with as well as this one?
6. Do you feel more comfortable about talking about autism after being part of Fizzacc?
7. Was there anything you would have liked to discuss that we didn't get round to?
8. Is there anything else you think Fizzacc could do as a group?

Meetings were auto transcribed and recorded. Transcriptions were then checked against recordings and amended where necessary. Also included in the data were notes from my reflexive journal. This was a document that included a commentary about my intentions for each meeting and interview as well as reflection on how my aims were realised. From this data corpus, a data set was identified which included all instances relevant to the research question (Saldana, 2014). Data analysis took place after all group meetings had taken place.

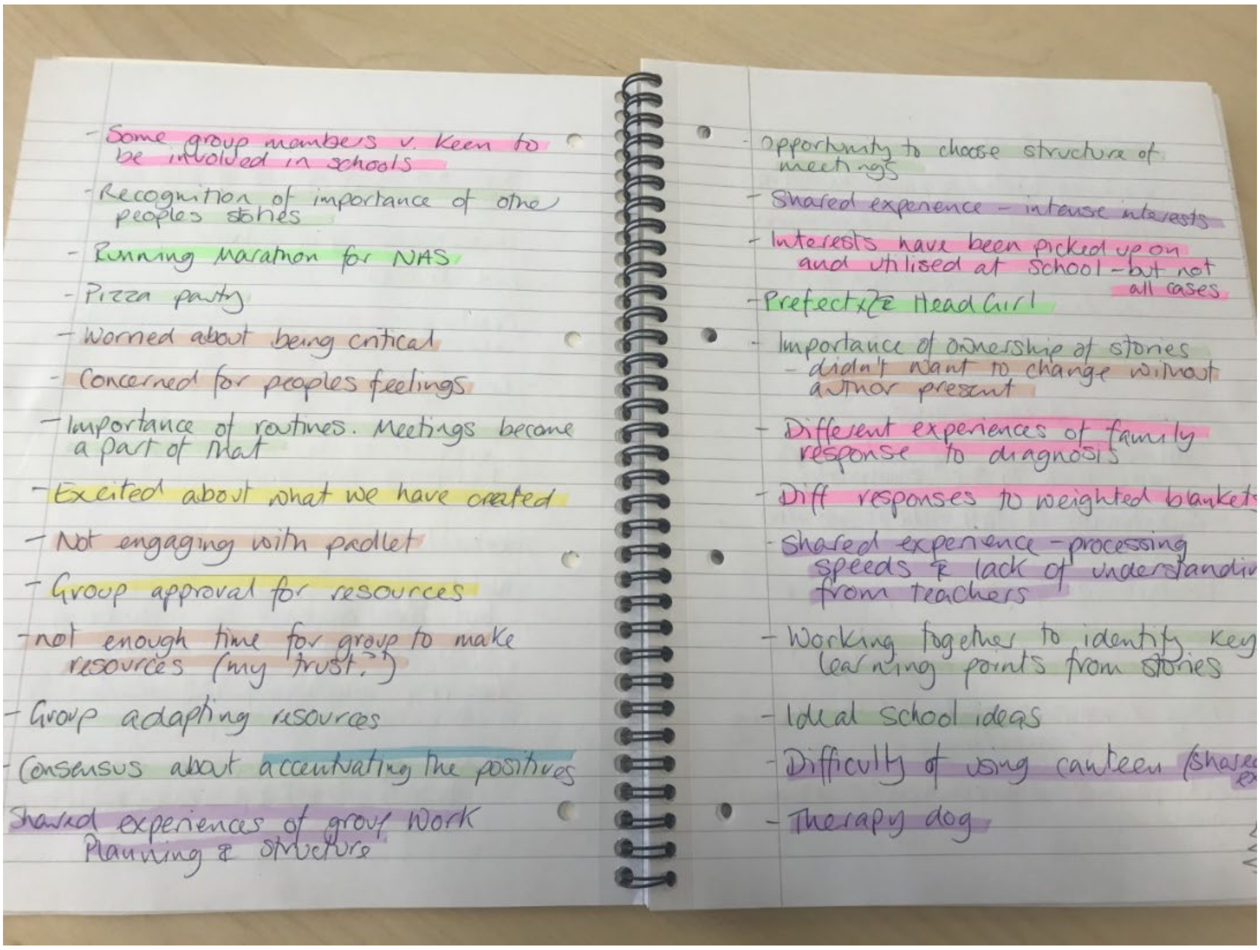
9.8 Foundation for Choosing Reflexive Thematic Analysis

The epistemological stance taken in this study is one of critical realism (Bhaskar, 2010). By considering the contributions of the Fizzacc members as their truth within the context of the participatory research group, I hoped to access Fizzacc's perceptions of participation while recognising the importance of reflexivity in doing so (Bergin et al. 2008). Data was collected describing involvement within this participatory research and it was therefore important to be critical about what the data included but also what might be missing. It was also important to recognise that the data represented experiences of participating in this research project only and was therefore not attempting to speak to a wider range of participation opportunities that may be available (Braun & Clarke, 2021).

To support this level of critical reflexion, reflexive thematic analysis was chosen as a method that would allow consideration of the lived experiences of the Fizzacc members' participation in this research. Reflexive thematic analysis (Braun & Clarke, 2006, 2020, 2022) allowed a combination of deductive and inductive analysis. Deductively, this data set was taken from the wider corpus to answer a specific research question about the challenges and benefits of including autistic girls in participatory research. Inductively, codes and themes, while not value free, were identified from the data (Braun & Clarke, 2006).

9.9 Familiarising Myself with the Data

My first stage in analysing the data was to re-read all transcripts to re-familiarise myself with the data. On the second reading I noted down anything that felt important. I wanted to spend some time thinking about the data before starting the coding process so decided to create my own body map to explore the data more critically. I therefore went through my list of ideas and used different coloured highlighters to divide them into categories for placing on a body map (see Figure 19).



- Some group members v. Keen to be involved in schools
- Recognition of importance of other peoples stories
- Running Marathon for NAS
- Pizza party
- Worried about being critical
- Concerned for peoples feelings
- Importance of routines. Meetings become a part of that
- Excited about what we have created
- Not engaging with padlet
- Group approval for resources
- not enough time for group to make resources (my trust?)
- Group adapting resources
- Consensus about accentuating the positives
- Shared experiences of group work Planning & structure

- Opportunity to choose structure of meetings
- Shared experience – intense interests
- Interests have been picked up on and utilised at school – but not all cases
- Prefect x2 & Head Girl
- Importance of ownership of stories
  - didn't want to change without author present
- Different experiences of family response to diagnosis
- Diff responses to weighted blanket
- Shared experience – processing speeds & lack of understandin from teachers
- Working together to identify key learning points from stories
- Ideal School ideas
- Difficulty of using canteen (Shared ex
- Therapy dog

Figure 19 - Highlighted ideas from data familiarisation stage

To establish where to place different ideas onto the body map I created seven categories associated with different areas of the map and spoke to their connection both to me as a researcher, and to the project as a whole (see Table 13). As this process was intended to support my familiarisation and critical engagement with the data, the categorisation was descriptive and broad and did not involve the reflexive rigour that would come in the coding stage. What the process did allow me to do was to immerse myself in the data while considering my relationship with it.

Table 13 ***Categories on the Body Map and Rationale for Positioning***

Category	Position on Body Map	Rationale
Shared experiences	Below the body	I felt these underpinned the project as finding common ground in the group helped to create the group dynamic. I therefore symbolically made the shared experiences the ground that the body was standing on.

Category	**Position on Body Map**	**Rationale**
Sharing of good news	Outside the body around the left arm and shoulder	This felt like a powerful expression of positivity in the group which was important as we were so often talking about negative experiences. I therefore placed these ideas as if they were a superhero cape flying behind the body. The notion of autism as a superpower was one that some members of the group identified with.
Emotional responses	On the heart	I was reflecting the way participants in the pilot study as well as the Fizzacc members used this position to represent images that meant the most to them. The emotional responses the group gave about participating in the project were very important to me and I responded emotionally to them.
Advantages of participatory approach	Across the left-hand side of the head, body and over both legs	The positives about participation and took up most of the body. I chose to include them inside the body as they were an intrinsic part of the research question this process is seeking to answer.
Challenges of participatory approach	On the right-hand side of the head	I suffer from right sided headaches, so that was where I chose to place challenges. While this suggests that challenges were painful, they were an important part of the process therefore remained within the body.
Group differences	Outside the body on the right-hand side next to the head	There were some differences in experiences and involvement between members of the group. I placed these outside the body on the right side near the head to represent differences not being a positive aspect of the research less important than the similarities they shared.
Thoughts about autism	On the right arm	The responses the group gave about how they thought about their autism were an important part of how they approached everyday life therefore, as I am right-handed, I placed them on the right arm.

As I was not exploring my embodied experience of the research, I chose to create this body map on A3 paper using a gingerbread man shape rather than making it a life-sized representation. Rather than copying the notes verbatim, I thought about ways to represent the different ideas in a more figurative way. This helped me to delve deeper into the meanings behind the data and to be reflexive about my response to it. For example, I chose to depict ‘involvement in data collection’ in the differences section in a spiral as this was a challenging factor to unravel during the research as we sought ways to ensure all group members could be equally involved. I wrote the word ‘uniform’ in the shared experiences section using jagged handwriting to represent the negative sensory impact of wearing uniform that was common amongst the group (see Figure 20).

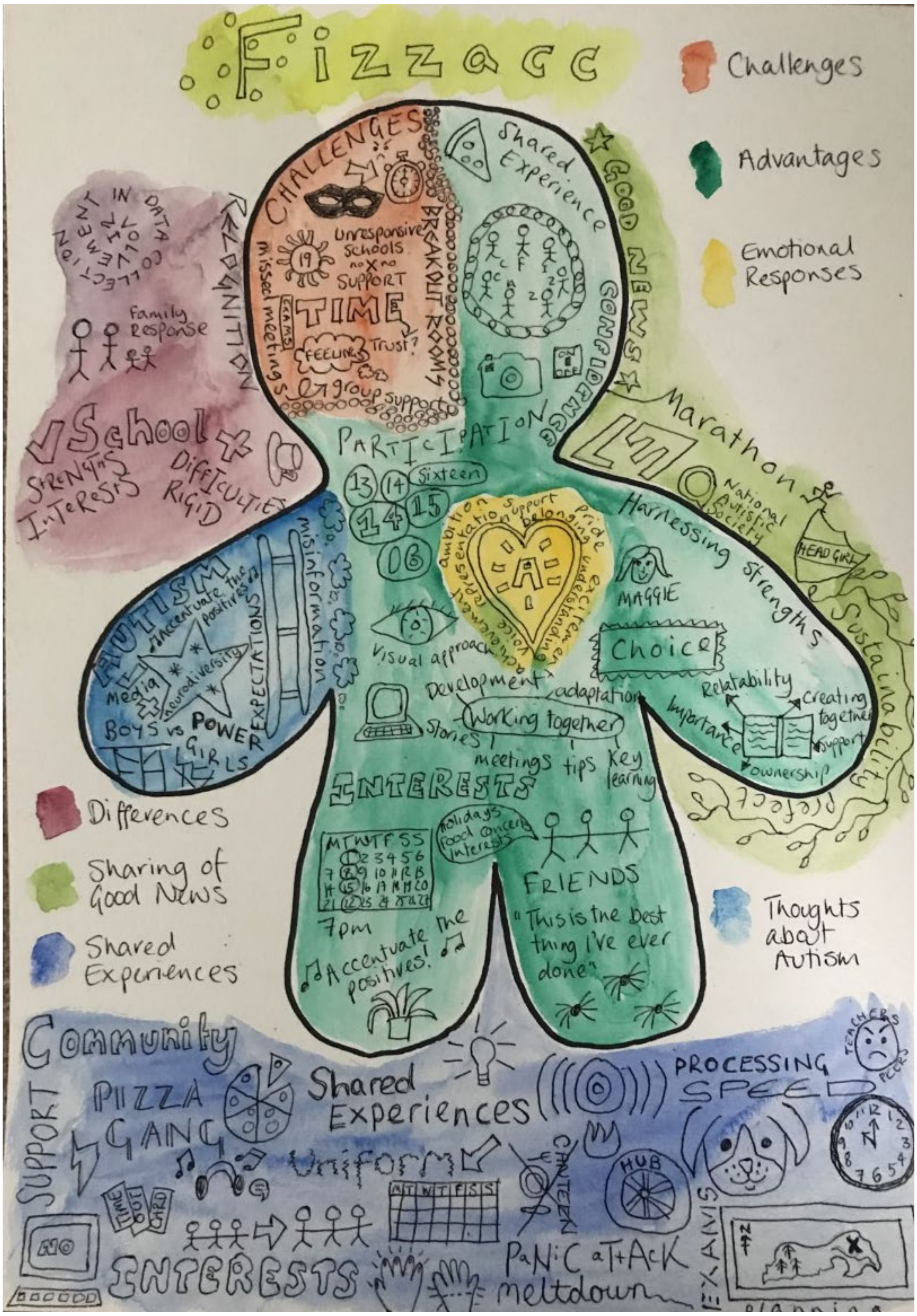


Figure 20 – My Data Familiarisation Body Map

Having completed the body map, I re-read the transcripts and my reflexive journal to ensure there were no omissions from the data familiarisation before beginning coding.

9.10 Coding the Data

Transcripts of interviews and group sessions were uploaded into NVivo for coding. As the data corpus was so broad, only the salient sections that had relevance to the research questions for this part of the project were coded in line with recommendations from Saldana (2014). Miles et al. (2018) described the first cycle of coding as 'data condensation' (p. 64) which allows for the most relevant material to be assembled in units of data that are then available for analysis. Braun and Clarke (2022) argued that it is more than that; it is about your 'analytic take' (p. 35) on the data. For this reason, the labels chosen to name codes are important and should aim to convey the meaning they represent. Having coded the data a first time by applying meaningful labels to the codes, the process was repeated. Some codes were refined where too similar, for example 'teacher assumptions' was incorporated into 'impact of adults lacking understanding and awareness'. My reflexive process in the second round of coding continued with consideration of how the codes addressed my research questions.

9.11 Generating Themes

Once happy with my second round of coding, the code labels were printed onto slips of paper to allow the next stage of analysis to be completed manually. This stage involved generating initial themes by clustering the codes into meaningful groups (see Figure 21).

Figure 21 - Manually Clustering Codes into Themes

Working manually allowed me to explore different ideas within the data; a process Braun and Clarke (2022) refer to as 'finding, losing and finding your way again' (p. 79). I ordered the codes into themes and photographed them, then repeated the process the following day and compared the results with the photographs to see if I had drawn the same conclusions. This process prompted me to justify my choices against other possibilities and therefore engage critically with the data. Once I was happy with my initial categorisation, I created a PowerPoint presentation which supported my ongoing process. I first inputted my code labels and assigned a colour for each theme (see Figure 22).

Figure 22 – Colour-Sorted Codes

I then created a page for each theme which included the name of the theme, the codes within that theme and example data extracts that exemplified that theme (see Appendix K). This process brought me back in touch with the voices of the Fizzacc members, therefore ensuring I was being reflexive about how the themes represented their perspectives. I then considered how to further refine and group my themes, resulting in two overarching themes (see Figure 23). The overarching themes are presented at the top of the figure with the sub-themes at the next level in pale blue and the codes at the bottom in grey.

	Working Together Matters	
Positive outcomes of participatory design	The power of shared experiences	Collaboration is valuable
Skills developed as a result of participation	Pressure to conform to norms	Offering advice and experience within the group
Wanting to get it right	Impact of adults lacking understanding and awareness	Eager to share good news
Pride in resources we created	Lack of support from school	Keen to be involved in all aspects
Developing knowledge and understanding of autism	Not being believed	Positivity about the group sessions
Unusual to focus on positives	Things adults have done to support me	
	Ways of coping with adversity	
	People like me	
	Value of friendships	

	Getting the Participatory Design Right	
Creative group work can be challenging	How meetings are planned is important	Creative and positive voices
Difficulties associated with Body Mapping	Importance of routing	Advantages of Body Mapping for expressing yourself
Not wanting to rock the boat	Benefits of online meetings	Glad of the opportunity to share views
	Appreciating the Body Mapping resources	Importance of the opportunity to make voice heard

Figure 23 - Thematic Map Showing Codes, Sub-themes and Themes for the Participatory Data

‘Working together matters’ speaks to the power of being in a group of people with shared experiences to explore issues that are mutually important and find ways to solve problems. ‘Getting the participatory design right’ is about how to facilitate working together. It is about the challenges associated with working creatively and collectively and what matters to group members in supporting them to participate. Both themes include evidence of both challenges and successes of the research and are detailed more fully below.

9.12 Findings – Theme 1 - Working Together Matters

When designing this research, I was keen that the work would be done collectively but had not particularly considered the implications of this. With a paucity of participatory research with autistic children described in the literature, the focus tends to be on the general benefits and aspirations of conducting participatory projects (den Houting et al. 2021) rather than an analysis of the best ways of doing so. Therefore, there was little to suggest whether working with the young people as a group or individually would be most beneficial. I was influenced by the collaborative approach described in Fletcher-Watson et al. (2019) as well as the benefit of collaboration I had observed as a drama teacher: I therefore sought to create a research group in which the young people would hopefully work together on common goals. I possibly underestimated the impact of this decision until I started to code the data: it was then that I recognised how compelling the impact of having an opportunity to meet and collaborate with other autistic young people could be. Within this main theme were three sub-themes which exemplified the advantages of participation in the Fizzacc research group, and these are discussed next.

9.12.1 The Power of Shared Experiences

The data shows that Fizzacc members, despite their individuality, had many of the same experiences in school. Many of the most powerful moments during meetings involved recognition of these shared experiences which were accompanied at times with a palpable sense of relief and wonder at the similarities. Such shared experiences supported the development of a group identity for Fizzacc and created bonds between the members.

The pressure to conform to neurotypical norms was common. This links to the propensity for masking amongst autistic girls and may have contributed to the late diagnosis of many of the group (McQuaid et al., 2022):

Nancy: Watching all the other kids playing and thinking, ‘I'm on a planet of aliens. I don't understand what they're doing. I'm going to have to try and figure out so I can fit in and pretend like I'm one of them.

While Nancy was describing her time at primary school here, the group were aware of the efforts they frequently went to in hiding their autism throughout school.

There were many experiences of adults showing a lack of understanding and awareness of autism. Some show a very generalised poor understanding based on stereotyped views of autism:

Nancy: I got diagnosed with anxiety and the psychiatrist said I can't be autistic because I have empathy.

Others were more specific to autistic characteristics such as processing speed:

Ellery: I used to get in trouble for not responding to my teachers fast enough. I didn't have the time required to process their question.

This lack of understanding unsurprisingly led to a lack of support from school, which was reported on quite a general level:

Anwen: My teachers kind of turned their back on me and didn't really teach me that well.

There were also more specific examples which were often connected to the lack of formal diagnosis leading to a lack of support. Ellery described one of her teachers refusing extra support in class:

Ellery: 'Well because there's no paper telling us you have it, we don't need to do anything so we're not going to'.

Support was often only forthcoming once the girls had reached crisis point:

Nancy: I only got picked up by student services in the end when I started refusing to go to school because I was so anxious and so overwhelmed.

While the instances of staff getting it wrong were more widespread in the data, there were some good examples of simple support strategies used by staff:

Ellery: This week my psychology teacher, let me do a presentation to the focus group rather than to the class which I really like.

Abria: All my teachers know about my situation, and I always sit in the back corner of the class.

The benefits of having an autistic member of staff to provide appropriate support were also recognised:

Ellery: One of our English teachers is autistic. She was very understanding. The best English teacher I ever had.

Potential outcomes of situations when things were not going well in school were discussed. One group member was keen to find out more about the difference between shutdowns and meltdowns and these were described from personal experience. This was an important conversation for the group who were clearly supporting one another to better-understand their autism in this moment. Some strategies to cope with adversity were not universal amongst the group although beneficial to share:

Ellery: In my mind, I kind of compare it to like a locked chest that you can't open or cactus that you don't want to touch because it's because it's sharp and will hurt you. You know? So you just leave the cactus alone.

While not all experiences were common, the importance of friendship was. Having a trusted friend or group of friends was important to all members of the group, particularly during transition:

Ola: That's probably the time that I felt most difficult with like, transitioning and making new friends and things.

Ellery: So when I managed to get to secondary school and I found people I could finally trust, it's like the world got brighter around me and there might be some hope you know.

The desire for friendship was also apparent within the group. At the end of the second meeting the girls did not want to stop talking and so, with parents' permission, arranged to continue chatting without me outside the parameters of the research. I recorded in my reflexive journal:

Chloe: A few have said they don't have any/many friends so this may be the first time they have been able to share these experiences with others who understand.

The value of having the opportunity to share experiences with other autistic teenagers was recognised and Abria reflected on how this could be useful in her school:

Abria: I wish that students with autism had like a meeting at least once a week with other students in a similar situation and could talk with each other and give opinions on how the school could help them.

This was an opportunity available to two of the group at their sixth form college and was highly-valued by them both. For Fizzacc members, discussion about shared experiences was beneficial in that it supported them to validate their experiences and learn from one another. This was also positive for the outcomes of the research. Ellery reflected on how the positive and supportive group dynamic influenced the data collected:

Ellery: So you kind of build this like community with each other while you're doing the project, you know? You're with like-minded people. It's a lot easier to share your thoughts that you wouldn't normally share.

9.12.2 Collaboration is Valuable

The process of collaborating was important and helped to build on shared experiences to create a strong group dynamic. Having a variety of ages and experiences in Fizzacc was beneficial, as group members were able to offer advice and guidance based on previous experiences. This included how to get the most out of college open days and how to find the support needed to attend concerts and festivals. The group was also keen to share good news such as successfully volunteering to speak to parents at a school event or being appointed Head Girl!

This positivity in working together was also apparent in how group members were keen to get involved in the activities --both during the weekly session, and outside of this structure. When asked which parts of the research process she would like to be involved in, Rosie responded:

Rosie: I mean, as much of it as I can really, like, I'd be happy to do it all.

The general responses to being involved in the project were also overwhelmingly positive:

Ellery: This is the best thing I've ever done.

Rosie: Loved coming to the sessions.

Ola: All of us together sort of having an input has been really nice. Definitely.

And finally, Anwen was keen to share her feelings about the group:

Anwen: You are amazing and never forget that. All unique and wonderful!

9.12.3 Positive Outcomes of Participatory Design

The benefits of participation for the Fizzacc members can also be seen in the skills and knowledge that they developed through the process. These skills were very much a product of working collaboratively and spoke of confidence, self-esteem, and empathy:

Ola: I think it's helped with my confidence…. Although I might be different to a lot of other people I still matter.

Ellery: So this project helped me see other people's perspectives on things in a way that I would understand.

Group meetings offered a space for Fizzacc members to talk about autism in a different way. The predominant focus of discourse around autism since their diagnosis was on the difficulties they were experiencing:

Ellery: When I was first told about my autism, I was only shown negatives of the condition and was told that I would live a worse life. I hated myself and my autism but, because of this project, I can see both myself and my autism in a happier note.

This project gave group members the opportunity to learn more about characteristics that were positive as well as learning about how being part of an autism community can be beneficial:

Ola: Being around other autistic people has been really helpful for me to gain a better understanding of myself.

A further benefit experienced as an outcome of participating in the project was a sense of pride in the results of our work. It was important for group members to feel that they were making a good job of the group tasks as they were aware that the products of their work would reflect on the group as a whole. Although this at times caused some stress, it resulted in a feeling of pride in the outcomes. Rosie in particular was concerned about the impact of getting things wrong:

Rosie: I'm just a bit stressed about the grammar.

Rosie: When I do big things, I tend to always make a mistake when I'm drawing.

Consequently, Rosie was particularly proud of having a product go out into the world due to the work we did:

Rosie: More people now know what it is and what it feels like, so we changed the world!

Ola reflected on how the creative nature of our resources represented Fizzac as a group in a way that more traditional materials might not have done:

Ola: I'm really happy with what we created. I really like the stories. I really like how we did that and the fact it doesn't just feel like a boring presentation.

9.13 Findings – Theme 2 - Getting the Participatory Design Right

It is important in any research project that the design of the research is carefully considered. For participatory research this can be a more complex task, particularly when this research involves vulnerable young people (Bradbury-Jones et al., 2017) and autistic young people who may need specific support to enable their full participation. Fizzacc members were forthcoming with their thoughts about what they liked about being involved in the project and what they found more challenging. I was, however, aware that some group members found it more difficult to offer negative feedback as they were concerned about causing upset. My reflexive journal also revealed where I had been successful in planning for the group and where I made assumptions and failed to understand the needs of the group. This theme was, as the previous theme, made up of three sub-themes.

9.13.1 Creative Group Work Can Be Challenging.

Despite having trialled the Body Mapping methods during the pilot study and providing more time to complete tasks as a result, there were still some challenges for group members in getting tasks finished:

Nancy: Some of them, there were too many things going on in my brain and I struggled to sort them all out and get them on the paper in the time.

This was difficult to navigate as working online meant that I was not able to see their progress unless they chose to share it in the meeting or upload it onto the Padlet. For those who did not finish in the allocated meeting time and chose to complete work in their own time, this was also difficult with other priorities to consider:

Rosie: It was a bit stressful doing it in the week and doing it my own time.

Reticence to admit to feeling challenged by some of the tasks was also manifested in concern about how work they had produced would be received. One group member would always say 'I don't know' or 'I don't mind' as their first response to being asked to make a choice. Once she had heard the responses of others, she would often then make her choice. It was important to make it clear that 'I don't know' or 'I don't mind' were perfectly valid responses and she was under no obligation to make a choice if she did not want to. As a potential alternative I used the polling function on the software we were using for our meetings which allowed group members to make anonymous choices as it was possible that her reticence to express a preference was due to being afraid to make a 'wrong' or unpopular choice. This did not seem to be the case as on both occasions this tool was used, she waited until everyone else had voted before she did. This also removed the conversation we had around the decision-making process which had been valuable as it enabled us to hear different perspectives around an issue. This reticence also manifested at times with a concern that the resources we were creating would not be well-received:

Rosie: Some people might not like it and might start blaming me for it.

Having group responsibility for the resources went some way to alleviate these kinds of concerns but it was important for me to continue to reflect on the impact for the group of sharing their experiences of challenging times.

During the group sessions I reflected on my attempts to balance the discussion by including both positive and negative aspects of their educational experiences. This was due to a concern about their well-being if the sessions were only covering their adverse experiences. Attempts were made in the planning of the sessions to avoid a focus on negativity, but these were not successful. I reflected:

Chloe: I need to be careful not to make assumptions about how they might feel, but to ask them to tell me instead.

There was a danger of pushing my agenda on the group out of a misguided attempt to shield them. There is potentially more risk involved with this when working on a group participatory project because I – as the adult researcher – had a responsibility to the group that I would protect as well as empower them (McCartan et al. 2012). My good intentions actually ignored the benefits that were realised by the group being able to reflect on their shared experiences.

9.13.2 How Meetings are Planned is Important

Routine was important to the group. Meetings were held on the same day at the same time each week and agendas were emailed in advance. There were some occasions where the group were offered a change to routine to complete unfinished tasks or move on to talk about a different topic, but these were usually rejected:

Chloe: Should we stop talking about the project for a bit and talk about the Body Mapping?
(Rosie shakes her head)

Chloe: You want to do it in the order?

Rosie: Yeah.

There was positivity from all members of the group about the meetings being held online, the main focus of which was the flexibility it offered:

Ola: Like I found it really good in the way that everything's kind of just been laid out. Like, if we're overwhelmed, and we can … like, turn our cameras off…. it just made me feel a lot more like comfortable, knowing. I had the option.

Ellery reflected on how online working supported autistic characteristics such as dislike of eye contact:

Ellery: Well, you know, in person you have to keep up to the social standards of maintain eye contact but don't stare too intensely or else, you're being weird.

While some group members were keen to meet in person towards the end of the project, they recognised the value of online working for creating the group dynamic that was achieved:

Anwen: I think every if Covid never happened, and we did this in person, I think we would all be more awkward around each other but since we've been in the comfort of our own homes, and being able to do this over computers…we're able to do this, right?

The combination between meeting online and working on the physical body maps was well received. Group members were all very excited to have taken delivery of such an enormous parcel of materials and enjoyed having options to complete their maps:

Rosie: I really loved options.

The value of having options was reflected in the variety of choices made. Some body maps were very abstract with lots of paint used, some very precise drawings with marker pens and use of text:

Ola: Having everything out and being able to have a big space to kind of like express myself on to that and how I feel about things.

As the group members had responded to a call for participants which emphasised the creative focus of the research it was important to ensure they felt their creativity was enabled in the way the project was planned.

9.13.3 Creative and Positive Voices

The importance of creative expression was also recognised when the group members were reflecting on completing their body maps:

Ellery: You can kind of see how a person’s thought process works by how they've decided to do it, you know. So you get to know a bit more about the person than you would from just speaking to them.

The power of creativity to support autistic expression was articulated by Ola:

Ola: Like if I'm just typing stuff, that's quite difficult for me. Just where I like to do like hands on kind of stuff. That might be a sensory thing actually.

The opportunity Body Mapping offers to consider embodied experiences was also referred to in the data:

Ola: I like the way everything works together and where I've placed stuff is kind of how I feel about the different situations…. kind of reflected where I've put them on me.

The data showed that positivity about sharing voices echoed the feedback on the school resources which said that there was power in hearing about autism from autistic girls themselves. This was something that the group felt was a rare opportunity:

Rosie: Well, because you might not get another chance again to say what you feel.

That autistic people want to be actively involved in all aspects of research is very apparent in the literature (Den Houting et al., 2021; Pellicano et al., 2014a; 2021). Participatory approaches value and make visible the insights of groups of people who may have had difficult or damaging relationships with adults (Bradbury-Jones et al., 2018). Being able to redistribute power to the Fizzacc members by using their voices in the research is a strength of participatory research (McCartan, 2012).

Summary

This chapter provided details of how the resources created by Fizzacc were evaluated and offered an analysis of the challenges and benefits of working as part of a creative participatory research group. Chapters 5 - 9 of this thesis described how the Fizzacc research group worked together to answer the research questions. This included the use of creative methods that have not been explored with autistic young people in the literature before, as well as the creation of a novel method of analysing data as part of a participatory project. Chapter 10 discusses the findings of the research with consideration of how they add to the body of research about autistic girls in education. The discussion will also consider what this research brings to our understanding of the use of creative participatory methods with autistic young people.

Chapter 10 – General Discussion

Introduction

I was motivated to undertake this research by newspaper headlines announcing a 'special educational needs crisis' (Jayanetti, 2019) and schools 'failing' children (Weale, 2019). My own practice as a teacher supported these views as children in my classes, particularly autistic children, were struggling to cope and access their curriculum and I lacked the training to effectively support them. The literature review in Chapter 2 identified the transition from primary to secondary school as being a particularly challenging time for autistic children (Boulter et al., 2014; Makin et al., 2017; Tobin et al., 2012). My research focused on providing a better understanding of why that was, and how children could be supported at this time. Chapter 2 also identified autistic girls' voices as being underrepresented (Watkins et al., 2014), therefore I sought to particularly highlight and promote the perspectives of autistic girls in this space. Throughout the course of my research, newspaper headlines have continued to decry the state of SEN provision with children being 'denied an education' (Corker, 2023) and accusations of 'sleepwalking into a special educational needs crisis' (Unison, 2023). Autistic children, young people and their families deserve better, and providing opportunities for them to contribute to the conversation about what needs to change is critical for that change to be meaningful.

Therefore, this research had two main aims: (1) to better understand the primary to secondary transition experiences of autistic girls and discover what girls themselves feel would best support future cohorts facing the transition; and (2) to evaluate the outcomes and impact of working on a creative collaborative project for all members of the research group. The research questions formulated to achieve these aims were:

- How can creative data collection and analysis methods be used to promote the voices of autistic girls?
- What do autistic girls feel are the barriers to a successful transition from primary to secondary school and how can these be addressed?
- What are the challenges and benefits of including autistic girls in participatory research?

These research questions also link to the four key concepts for this research as outlined in my conceptual framework (see Figure 1) which I return to here and will form the structure for the first part of this chapter with each concept being addressed in each sub-heading. The chapter then includes a consideration of the limitations of the research and the implications for future research and practice. Finally, some concluding remarks will be offered.

10.1 Philosophy of Autism Research

My introduction chapter outlined my philosophy of autism research, and this was further developed through the literature review in Chapter 2. I established the reasons for my choice of language around autism, my view of autism through the lens of the social model of disability and my recognition of the importance of prioritising autistic voices in autism research. I also defined my understanding of the neurodiversity paradigm as a strengths-based representation of natural variation. Although my overall philosophical position did not change, my understanding of these concepts developed throughout the process. Notably, I had previously underestimated the significance of receiving an autism diagnosis, which I learned a great deal about from the members of Fizzacc.

There is some debate about whether having a diagnosis of autism is a benefit or a hindrance. Arguments in favour include that diagnosis can open doors to funding and support that would not otherwise be available or supporting autistic people to better understand struggles they might have been facing (Werkhoven et al., 2021). Moreover, for some autistic adults, receiving a diagnosis has meant they no longer feel the same pressure to fit in or to mask their autism (Hens & Langenberg, 2016). Those arguing against diagnosis often talk about the negative impact of stigma and how it can lead to feeling defined by a label rather than being seen as an individual (Werkhoven et al., 2021). Difficulties in accessing a diagnosis due to factors such as class, race or financial difficulties have led to some adults choosing to self-diagnose (Sarrett, 2016). While this is criticised by some, other members of the autism community accept those who self-diagnose and recognise it as an empowering rejection of the medical model of disability (Sarrett, 2016).

The pilot study (Chapter 4) included participants without a formal diagnosis, partly to overcome the challenges of recruitment during a global pandemic but also in recognition of the gender disparity in autism diagnosis (Bargiela et al., 2016; Kim et al., 2011). The recruitment for Fizzacc members did not specify whether a formal diagnosis was required to participate, although they had all been diagnosed before starting the project. Whilst I felt it was important to be inclusive of non-diagnosed autistic children in the project, on reflection, as a non-autistic researcher I made these decisions without understanding the significance of diagnosis on the girls' experiences of education or the impact on how we would achieve our aims. With five out of the six girls receiving their diagnosis after they had transitioned to secondary school, one of the key barriers to successful primary to secondary transition was the lack of timely diagnosis preventing access to appropriate support. Improving pathways to diagnosis for autistic girls was beyond the scope of this research so we were pushed to think laterally about how best to support unidentified autistic girls with transitions. The answer identified by Fizzacc was to raise awareness of autistic girls, identify their challenges and recognise their strengths.

The implications of late diagnosis of autism in girls should not be underestimated. Work is being done to understand better the barriers to diagnosis in girls (Hamdani et al., 2023) and representations in popular media such as the BBC drama ‘A Kind of Spark’ based on the novel by autistic author Elle McNicholl (McNicholl, 2020) are helping to raise awareness. However, researchers have yet to evaluate the impact on the education and wellbeing of autistic girls in school without appropriate support pre-diagnosis. Furthermore, as identified in the literature review, the perspectives of autistic girls are just not being heard: their input in illuminating this issue within the research was so valuable and important.

Two solutions to addressing the failures of early diagnosis and lack of representation in research and educational planning seem appropriate. The first is to empower educators, parents, and clinicians to recognise autism in girls and improve diagnostic tools to better identify them. The second is more closely aligned to the social model of disability, namely, to support schools to adapt to practices that support and encourage learning for children of all neurotypes, therefore removing the barriers to successful transitions for all. In identifying how the barriers to successful transition for autistic girls can be addressed, Fizzacc answered a bigger question about how to address some elements of the special educational needs crisis itself.

10.2 Missing Voices of Autistic Girls

Having identified in my literature review that autistic girls and women are under-represented in the literature (Watkins et al., 2014), and that the experiences of autistic girls differ from those of autistic boys (Begeer et al., 2013; Wood-Downie et al., 2020), this research prioritised promoting the voices of autistic girls. Fizzacc members reported feeling that they were treated differently to autistic boys in school and that their journeys to diagnosis were negatively impacted by their gender. This reinforces findings from Hamdani et al. (2023) and Lockwood Estrin et al. (2021) whose work highlighted a lack of knowledge about autism in girls preventing timely diagnosis. Fizzacc members were very keen to prioritise the experiences of autistic girls in the resources we created for schools (see Chapter 8). This was well-received by the pupils and staff members who experienced the resources and reported that their understanding of autism in girls had increased through their participation in the project.

With my focus on raising the profile of autistic girls’ experiences, I have been challenged to justify the binary nature of female and male presentations of autism when presenting my work in conferences and seminars. Moore et al. (2022), in a systematic review looking at the intersection of autism and gender, argued that research focusing on the experiences of one gender can perpetuate stereotypes and ignore the wider issues around autism and gender such as gender non-conformity and gender diversity. While I am in accord with the importance of all genders being represented in autism research, the nature of a research project is that parameters must be drawn, and I made the decision to focus on girls specifically. I did so with the awareness that this would very possibly result in the perpetuation of stereotypes, but I have tried to be nuanced both in how the research was conducted and shared. Having worked with the Fizzacc group of autistic girls who felt strongly that they wanted to speak up about how they felt their gender affected the support they received, the importance of continuing to promote autistic girls' voices was very apparent. While this has been identified in the literature (Bargiela et al., 2016; Milner et al., 2019), more still needs to be done to ensure this has an impact on practice (McLinden & Sedgewick, 2023).

This research used a variety of novel methods to produce data about autistic girls' experiences of educational transitions that were previously missing from the literature. Through the Body Mapping Process, Fizzacc members had the opportunity to explore and discuss shared experiences with other autistic girls: an exceptional experience for most of them. By analysing the data collected during Body Mapping using the Perspective Narrative Approach we were able to address the Double Empathy Problem. Our approach encouraged readers of our work to consider the impact of their own perspectives when experiencing the girls' stories and question their own assumptions. Narrative analysis encourages readers of research stories to question their understanding of lived experiences (McCormack, 2004) and encourages researchers to look more deeply into the meanings behind the data (Caine et al., 2016): the use of Perspective Narrative analysis is distinctive in the way it encourages both processes. We hope to further develop this work and publish the stories presently. The girls' voices were also promoted through the school resources that were created as part of this project, both in terms of the content and quite literally as the presentation is voiced by a group member. These resources reflect what Fizzacc members felt would best address the barriers they identified to successful transitions for future cohorts of autistic girls, namely the lack of knowledge and understanding by secondary school staff and pupils and the structural barriers to neurodivergent children being supported and included in school.

Through all the opportunities for promoting the voices of autistic girls, one message had been clear: the barrier is lack of knowledge and understanding. Structural change is needed in schools to provide an inclusive education for all genders, those with and without a diagnosis and of all neurotypes (McLinden & Sedgewick, 2023). The girls were able to clearly identify small steps that could be made to begin this change including flexibility around uniform, provision of and access to quiet spaces, and better training for staff on autistic strengths and challenges. This directly mirrors the finding of the NAS (2023) Education Report which highlights teacher understanding, sensory overload, exams, peer understanding, bullying, and transitions as the key issues for autistic children in mainstream schools.

10.3 Participatory Research

Participatory Research strives to promote the voices of stakeholders and is something in which at least some autistic people want to be involved (den Houting et al., 2021; Pellicano et al., 2014a). The Participatory Autism Research Collective (PARC) at London South Bank University, created in 2015, promotes participatory research as an important and ethically-driven approach to conducting research that challenges the status quo (Milton et al., 2019). The number of studies in the autism research literature that use participatory methods is increasing, and evidence of the views of autistic participants about the process of engaging with these studies is emerging (Hummerstone & Parsons, 2022; Scott-Barrett et al., 2022; Ward et al., 2022). This research sought to contribute to this body of literature by conducting participatory research with autistic children and eliciting their views about the process. Furthermore, it did so with the use of creative methods based on Body Mapping that are novel to autistic children and focuses specifically on the experiences of autistic girls.

A significant contribution of this research lies in the in-depth understanding gained of how a participatory research process can be sustained over time, and the learning gained from our successes and failures. Fizzacc first met as a group in September 2021 and our final group meeting was in June 2022. The opportunity to work with the group over the course of 20 hour-long meetings spanning a period of nine months meant the group was able to benefit from feeling part of something meaningful. It is rare that a participatory study with young people is conducted over such a sustained period. Other similar studies have been far shorter, for example Costley et al.'s (2022) study into the anxiety of autistic children in secondary schools with six autistic researchers was completed over the course of three meetings. Scott-Barrett et al. (2022) worked with 12 autistic primary school children using multi-modal methods to explore their perceptions of the school environment over five weekly meetings. The extended period of contact enabled us to build relationships within the group which were important for the members to feel confident to share their experiences. Building trusting relationships requires time but is important for the group to feel supported and valued (Pickard et al., 2021).

With face-to-face interactions being impossible during Covid, it was necessary to adapt my research from a school-based in-person design to something that would be more adaptable to uncertain and changing circumstances. Working online was not something that appealed to me, and I was uncertain how successful I would be at engaging online with autistic children. As a drama teacher I had always relied on physical expression to communicate and respond to others and therefore felt stifled by this new way of working. Initially I did not consider the potential benefits of online working for the young people. Computer-based communication supports many autistic people to communicate in ways they may be unable to elsewhere (Gillespie-Lynch et al., 2014). Not only can online technologies help with access to others who share similar interests, it allows for a variety of communication preferences and can help to avoid some of the social challenges that can be faced offline (Benford & Standen, 2009). While the pilot study gave me confidence in my ability to communicate effectively online, working with Fizzacc prompted me to recognize the advantages of working in this way for the benefit of my autistic group members. Fizzacc reported benefits in having choices in communication: they could choose whether to speak, type or listen and this could be different each week or within the same meeting. This meant that on occasions group members joined the meeting not feeling they wanted to participate, and so had their camera and microphone turned off. Later they felt they wanted to contribute and were able to do. If the meetings had been in person, they may have missed the entire meeting in these circumstances. The choice of how to participate in meetings therefore not only gave Fizzacc members agency in the manner of their contribution but enabled them to be more engaged in the process due to greater attendance at meetings. This was something they reflected on in their own evaluation as a particular strength of the project. The success of the group meetings and the positive response to working online challenged my assumptions as a non-autistic researcher. I assumed that face-to-face meetings would be the ideal procedure and would provide richer data as all group members would contribute if we were in the same physical space. This assumption was based on my preferences and experience and did not consider the differences in communication preference of the other group members. Taking time to reflect on my assumptions was imperative and emphasized the importance of flexibility in participatory design (Pickard et al., 2021).

The importance of using methods that are inclusive is important for ensuring that young people are not excluded from research (Bradbury Jones et al., 2018). Brown (2021) recognised that arts-based methods can support a change in power dynamics if designed accordingly. While methods such as Photovoice can give agency and control to the young person in their choice of what, when and how to take photographs (Bradbury Jones et al., 2018) within the hierarchy of participatory research proposed by den Houting et al. (2021) this alone would not be enough to move research from ‘doing for’ to ‘doing with’ (p. 149) as it would not necessarily provide agency in what was being researched and how. Therefore, selecting the most advantageous methods to promote the voices of autistic children in this research was imperative to the success of the project. This research sought to use creative methods collaboratively with autistic children, to represent and promote their voices in a way that addressed the Double Empathy Problem which is imperative for reflecting on how the views and experiences of autistic young people are understood by, and communicated to others (Hummerstone & Parsons, 2022).

The use of Body Mapping as a method to explore the experiences of the Fizzacc members supported different communication preferences (Ridout, 2017) by including data from verbal, written, and graphically represented ideas. The advantages of Photovoice for communicating ideas (Carnahan, 2006; Ha & Whittaker, 2016; Povee et al., 2014) and collage for flexibility of responses (Delafield-Butt et al., 2021; Ridout, 2014) were incorporated into the Body Mapping process. Fizzacc members included both drawn and written elements on their body maps as well as using different materials to better represent their responses. Furthermore, Body Mapping allowed for consideration of the group members' relationships to their environment and physical reactions to events through consideration of their embodied experiences (De Jager et al., 2016).

Body Mapping also allowed for differences in processing speed. During tasks there was time to consider what to include both before and during the creative process and to return to ideas multiple times during the sessions, which would not have been possible in an interview or discussion situation (Driessnack & Furukawa, 2011). This is an important advantage of using Body Mapping with autistic participants, which has previously not been mentioned or explored in the literature.

Body Mapping with autistic young people was described by Dew et al. (2018) in their study involving participants with complex support needs. They reported that Body Mapping was a useful method to elicit the views of their participants, but they did not reflect on any differences between the autistic participants' responses to those with other support needs. A further study which focused solely on autistic young people was conducted by Britton et al. (2020) who used Body Mapping to elicit the feelings of participants in a surf therapy intervention. Their Body Mapping took place on the beach immediately before or after surfing and involved the young people using found objects on the beach to populate body maps created by drawing round them in the sand as well as using coloured pencils to represent their reactions to surfing on body outlines drawn on paper. These body maps were completed in 15 – 20 minutes and represented a snapshot of how the young person was feeling at that moment in time. This study compared the Body Mapping data with interview data and found that Body Mapping elicited a 'richer and more textured experience and how and where these emotions are felt in the body as physical sensations' (Britton et al., 2020 p. 12). My research adds to the Body Mapping literature by focusing specifically on the experiences of autistic girls within a participatory framework. Additionally, Fizzacc used Body Mapping as a method to represent a depth of experience over a sustained period such as that developed by Solomon (2009) to investigate the experiences of women with HIV. The data produced during the Body Mapping data was also analysed collectively by the group as part of the participatory process, thereby extending knowledge about how the method can be further developed and applied.

Indeed, one of the most novel contributions of this research lies in the development of an approach to analysis that sought to address Double Empathy. When first considering using Body Mapping within this research, I investigated methods for analysing visual art data but could find no framework that would avoid my non-autistic assumptions about the body maps clouding the results. It was therefore important that Fizzacc members were central to the analysis process and the recognition of the dichotomy between the experiences of the other Fizzacc members as autistic young people experiencing education, and my experiences as a non-autistic teacher, was instrumental in the development of Perspective Narrative analysis. By developing the analysis process collaboratively during group meetings, the Fizzacc members had agency over what was included in the process and how it was conducted. Had I been working alone, the work would have lacked authenticity and the Double Empathy Problem would not have been addressed. Pellicano et al. (2021) said: 'Involving autistic partners in the research process, especially in its implementation, can play a crucial role in enhancing autism research' (p. 1). This is an argument which Fizzacc's work clearly supports.

The thematic analysis presented in Chapter 9 offers insights into how Fizzacc members felt about the project. It showed how the project gave the group new perspectives on what it means to be autistic by focusing on what the group felt were the positive aspects of autism and how beneficial being part of a neurodivergent community could be. The power of connecting with an autistic community has been shown to be beneficial to well-being (Botha et al., 2022) and it is something that most of the Fizzacc participants had not had access to previously. Moreover, this sense of community contributed to the empowerment of the group evidenced through their comments about the power of recognising themselves in the narratives written by other group members. Pickard et al. (2021) found that the opportunity for autistic people to work together on participatory projects was empowering. My status as an adult and the researcher who instigated the project prevented the power dynamic in Fizzacc from being evenly balanced but having six autistic members of the group working together on the project went some way to redress this balance. It is important to recognise that it is not in the gift of the researcher to imbue power on young people, rather that the power that the young person already has can and should be amplified through participatory research (Bradbury Jones et al., 2018). Lundy et al., (2011) conceptualised the inherent power in young people by considering their rights as set down in the United Nations Convention on the Rights of the Child (1989) and argued that these rights mean that researchers (who do hold power) have the responsibility to promote and support children and young people's views.

Participation in this project also allowed the Fizzacc members to feel a sense of achievement. This was particularly powerful in how the group felt when hearing the feedback from the schools who had trialled our resources. This reflects Hummerstone and Parsons (2022) who argued that while co-designed methods are important for including the views of autistic young people, they need to be conducted in conjunction with meaningful action to 'increase autism awareness to change attitudes and educational practices (p. 70)'. Our school resources were not only co-produced by Fizzacc but designed to make an impact on the school experiences of future cohorts of autistic girls. Consequently, the resources are freely available for access and download from the ACoRNS website (https://acorns-soton.org.uk/2022/03/fizzacc-information/), and other schools have subsequently expressed interest in using the resources.

The participatory framework we were working in gave group members the authority and expertise to describe their lived experiences and gave them the opportunity to reflect on the impact of their participation in the project. Our research very much chimes with Scott-Barrett et al. (2022) who used multi-modal methods to engage autistic children in research about their school environment and reflected on 'respectful research practices and processes' (p. 28). They highlighted the importance of participatory research as offering a flexible way of working which promotes what is meaningful for young people and encourages a strength-based approach, in a similar way to the research conducted with Fizzacc. Furthermore, Scott-Barrett et al. (2022) emphasised the importance of considering the Double Empathy Problem (Milton, 2012) in communicating the autistic young people's perspectives and recognising their value. Our work included these aspects and went further by developing a new way of analysing data encompassing different perspectives on their lived experiences. Furthermore, by using creative methods and enabling a variety of communication styles, this research offered flexibility in terms of how participation and engagement was supported. Fizzacc also promoted the views and expertise of our members through how we chose to create, evaluate, and share our school resources.

Using a participatory design was challenging and time-consuming, particularly as part of a PhD (Klocker, 2012; Pickard et al, 2021). It was necessary to consider how every decision would impact how the group engaged with the research process, and it added an extra layer of responsibility to get it right for the Fizzacc members, their families and my supervisors as well as for myself. However, for me the benefits far outweighed the demands. This study is, to the best of my knowledge at the time of writing, the first to use Body Mapping within participatory research and highlights its value as a creative, flexible, and empowering way to work collaboratively with autistic young people.

10.4 Transitions

When I set out on my research trajectory, one of my aims was to improve transition experiences for autistic girls. From working with Fizzacc, however, I came to understand that my vision of creating resources that would support autistic girls through the transition was ill-conceived and that the challenges of transitions are more complex and wider reaching. For autistic children, the transition from primary to secondary school can be a challenging time and children should be supported to experience the transition positively (Nuske et al. 2019). Resources such as the STEP-ASD programme (Mandy et al., 2016a) are potentially beneficial for addressing key issues around transitions - such as the importance of good home-school communication (Hoy et al., 2019; Neal & Frederickson, 2016) or planning individualised support (Dann, 2011; Hughes et al., 2013; Stoner et al., 2007). However, the kinds of strategies that primary schools put in place such as transition visits and visual supports will have little impact if the secondary school that the child is transitioning into lacks awareness of autism and, specifically for this project, awareness of autistic girls. Furthermore, use of programmes to support autistic children with the transition from primary to secondary school, rely on the young people having been identified as autistic for them to benefit from the support. Identification or diagnosis is often delayed in girls due to the differences in presentation of autistic traits (Lockwood Estrin et al., 2021), therefore many girls are facing the transition without support because they are moving to secondary schools who are not aware of their needs (Cridland et al. 2013). With five of the six members of Fizzacc not having been diagnosed as autistic until after their transition to secondary school, the transition needs to be supported by better understanding of autism in girls and better provision in both primary and secondary schools.

We know that many autistic children are being let down by the school system in the UK (DHSC and DfE, 2021). The number of autistic children being permanently excluded from school is increasing (Guldberg et al., 2019) and teaching staff report a lack of confidence in the training they had received to support autistic children in their classrooms (Ambitious about Autism, 2013). A 2021 survey of 605 autistic pupils found that only 26% felt happy at school (NAS, 2023). With schools failing to provide an education that meets the needs of autistic children, there are clear implications for transitions as, no matter how well planned the transition is, if the environment a child is transitioning into is inadequate the child is unlikely to feel settled and ready to learn.

Fizzacc members were very clear about the impact of staff awareness and understanding on the provision of education to meet their needs. All group members could identify situations where schools were making a positive impact on their ability to learn. However, they could all identify barriers to learning created by ignorance or indifference and they felt teachers lacked the training necessary to offer appropriate support. To try to overcome the poor provision and lack of understanding, the group reflected on how they would often mask their autistic traits to avoid conflict. Masking has been shown to be more prevalent in girls and can be detrimental to mental health (Wood-Downie et al, 2021b). With a better understanding of autism in girls, teachers could potentially recognise the signs of masking and understand masking as communication that the young person is not feeling able to be their authentic self in school.

Fizzacc members identified some very simple strategies provided by their schools that were beneficial in navigating school environments that could be challenging. These challenges can be due to the school environment and structures failing to support autistic children with sensory sensitivity (McAllister & Sloan, 2018). Some members used ear defenders to manage the sensory impact of noisy classrooms and corridors. Some were allowed to use disabled toilets which avoided crowds and the need to queue. The use of a variety of ‘time out’ cards was also shared although the benefits of these were mixed as some enabled the use of well-designed quiet spaces they could freely access while others only allowed them five minutes in the corridor. In one school the room provided for time out doubled up as the detention room so had negative connotations. The group valued the opportunity to hear how other group members were supported, and this enabled them to reflect on how things could be improved within their own schools. These reflections formed an important part of the school resources we designed and align with the recent education report from the NAS which identifies the same barriers to effective education (NAS, 2023).

As well as considering specific aspects of their own schools’ provision, Fizzacc members reflected on education more broadly. They felt that secondary schools focused on grades to the detriment of the individual and their mental health. The group felt that schools had this the wrong way round and that focusing more on mental health would lead to better exam results: the reverse was not true. There were also concerns about the structure and content of exams being inappropriate for autistic students. This was reflected in the Perspective Narrative story ‘I’ve Always Been Good at Writing About Disasters and Death’ in which Maggie struggles with some of the questions in her English exam despite being a top set student. The inaccessibility of GCSE papers has been recognised by the Autism Education Trust who have produced guidance and recommendations for examination boards (AET, n.d.). This highlights the use of ambiguous language in questions, the difficulty of questioning that relies on inference and the way exam papers are structured and laid out.

Research suggests that the quality of educational provision for autistic students is failing to meet their needs due to lack of training for staff, environments being inaccessible, and the focus on teaching and assessment failing to recognise the challenges faced by autistic girls (AET, n.d; Ambitious about Autism, 2013; APPGA & NAS, 2017; Guldberg et al., 2019; DHSC and DfE, 2021; NAS, 2023). Supporting autistic children at primary school to transition into a secondary school which is not equipped to understand or cater for their needs was felt by Fizzacc to be counterproductive. They argued that raising awareness and understanding of school staff and peers in secondary schools would be the most beneficial strategy for improving transition experiences. This reflects the social model of disability (Oliver, 1986) in that it should not be incumbent on the child to adapt to their new school environment, rather that the school should better understand and accommodate their needs (Ravet, 2011). Moreover consideration of the neurodiversity paradigm (Legault et al., 2021) would suggest that schools should adapt to support all neurotypes. Therefore, Fizzacc chose to create resources to support transitions that aimed to inform staff and pupils about the experiences of autistic girls in schools and how to support them. This research is novel in that it focuses specifically on the transition experiences of autistic girls and does so by promoting the voices of autistic girls themselves in adding to our understanding of this potentially challenging period in an autistic child's life.

10.5 Limitations

10.5.1 Participatory Problems

As with many participatory research projects, there were some compromises that had to be made in the way the work with Fizzacc was realised. The decision to use Body Mapping was made prior to commencing the project, which prevented Fizzacc members from being involved in the choice of method. While it would have been ideal to allow members of the research team to be active participants in all decision-making (den Houting et al, 2021), it was not possible for this project. The age and inexperience of the other Fizzacc members meant that making informed decisions about research methods would have used too much of our limited time together. As such it was necessary for me to have made some decisions without the input of the group.

While the influence that Fizzacc members had over data analysis and the way resources were designed and created meant that they had power over elements of the project, the group dynamic was always influenced by the differences between us. As an adult who had conceived the project, I was always the de facto 'leader' of the group. Den Houting et al. (2021) reported that community partners recognised that researchers typically held control over the decision-making processes in participatory research. For this research, the balance of power was always going to be tipped towards me due to the lack of equity between the ages and life experiences of group members.

10.5.2 Representation of Autistic Voices

The voices represented in this research were from girls who were able to provide verbal or written contributions to group discussions, therefore they represent a small section of the autistic community. Autistic young people who communicate using other methods - such as sign-language or other augmentative and alternative communication (AAC) tools such as picture boards or computer apps - are far less likely to have their first-person perspectives heard (Lewis-Dagnell et al., 2023; Tesfaye et al., 2019). Recruitment for the project targeted those able to use video conferencing software verbally or using text, as my lack of online research experience led me to working with young people similar to those I had previously taught. Having worked in mainstream schools, I felt I knew how to approach and encourage this population. Prior to COVID-19 lockdowns I had been establishing a relationship with a special school and investigating ways of supporting children with more complex support and communication needs to participate in my research. This relationship necessarily halted once schools were closed to all but essential staff and vulnerable children in March 2020. This required a change in focus for the research which was adaptable to changing COVID-19 situations and led to working with autistic children who were able to access online group meetings. This is something that would have been challenging with the children I had been getting to know prior to the pandemic. Lewis-Dagnell et al. (2023)'s systematic review uses Lundy's (2007) framework for consideration of children's participation in research to view the existing literature aiming to promote the voices and perspectives of children with complex needs, reflecting that this area of research is underrepresented in the literature. Lundy's (2007) framework considers: Space – the opportunity for the child to express their views; Voice – use of methods which facilitated children to participate; Audience – listening to the child's views; and Influence – using the child's views, as appropriate, to effect change. vThe impact of the pandemic meant that space and voice were far more difficult to achieve for children with complex needs. While there is evidence of projects with children successfully moving online, these involve children who can communicate with a researcher using video conferencing (Herbert, 2020). The National Centre for Research Methods (NCRM, n.d) produced a wealth of useful resources during the pandemic to support with ideas of how to adapt research methods to support the continuation of research despite lockdowns and self-isolation. However, none of the papers they shared referred to research with participants with complex needs. While my work with Fizzacc was valuable and added to our understanding of autism from the perspective of autistic girls, it did not help to redress the balance of autism research under-representing autistic people who do not speak or have complex needs (Bradbury Jones et al., 2018; Lewis-Dagnell et al., 2023).

10.6 Implications for Research and Practice

10.6.1 Promotion of Autistic Girls' Voices.

The challenges of transition from primary to secondary school are defined in the literature (Nuske et al., 2019). However a large proportion of what we know about transitions comes from parent and teacher opinion (Deacy et al., 2015; Peters & Brooks, 2016; Tobin et al., 2012) and there is little recognition of the potential differences between the experiences of boys and girls. Indeed, in one qualitative study which involved semi-structured interviews with five boys and one girl, the authors chose to refer to all the participants as 'he' to ensure anonymity, therefore preventing any consideration of potential differences in experience (Neal & Frederickson, 2016). My research not only considers the experiences of only autistic girls, but it also promotes their voices in the telling of their stories and therefore contributes a perspective to our understanding of the challenges of transitions that has been missing from the literature. Moreover it addresses the intersectionality between autism, childhood, and gender which work together to marginalise the voices of autistic girls over and above other autistic people (Cascio et al., 2020). This also addresses wider concerns within autism research about whose knowledge is considered valid, with tensions existing between non-autistic researchers' perceptions of research and those of autistic stakeholders (den Houting et al., 2021). Milton (2014b) argued for researchers to: 'appreciate the distinctive knowledge autistic people possess and to build more constructive ways of relating to it' (n.p.). To address this, I sought constructive and creative ways to involve autistic girls in sharing their distinctive knowledge so that all neurotypes could engage and relate to it.

10.6.2 Body Mapping supported as a method for encouraging voice in autistic children

Body Mapping has been used in many fields as both a therapeutic and research tool (de Jager et al., 2016). Although examples of it being used with autistic young people are beginning to emerge (Britton et al., 2020; Dew et al., 2018), this project is novel in that it supports the use of Body Mapping to facilitate a sustained process of embodied exploration within a participatory project. It therefore adds to the toolbox of creative methods that can be used to support autistic participants to engage with research. This research saw Body Mapping being used with children who were able to share their experiences verbally or in writing. My initial exploration of the method was as something that could help those without those skills to share their thoughts on educational transitions. As a method that encourages understanding of embodied experiences, and can include a variety of sensory elements, it has the potential to be used with autistic people who communicate using AAC or in other ways. One of the advantages of Body Mapping is that (with consent) the maps can be exhibited, supporting the promotion of the perspectives of the creators regardless of their communication preferences (Gastaldo et al., 2012; Vincent, 2014).

10.6.3 Educational Resources

Fizzacc created a set of resources that can be accessed by schools, free of charge, to use in educating their pupils about autism. The schools who trialled the resources were all intending to include them in their regular curriculum. The resources have also been shared more widely via workshops and seminars, and an online site which offers resources approved by autistic professionals (Epic Autism Resources (padlet.com)). This moves my research beyond reporting on transition experiences for autistic children to a more emancipatory position which aims to make a difference in practice, therefore bridging the gap between the research and the experiences of young people in the classroom (Guldberg, 2017; Parsons, 2021). Future evaluation of the impact of the resources on the understanding and awareness of staff and pupils would be a welcome priority.

10.6.4 Perspective Narrative Analysis

In developing Perspective Narratives to analyse our Body Mapping Data I strongly feel that we found a way to share the voices of autistic young people and promote understanding of their educational experiences. The following quote from Clough (2002) powerfully summarises the strengths that I suggest the Perspective Narratives Analysis approach encapsulates:

‘The fictionalisation of educational experience offers researchers the opportunity to import fragments of data from various real events in order to speak to the heart of social consciousness – thus providing the protection of anonymity to the research participants without stripping away the rawness of real happenings.’ (p.8).

While we created the process to address the complexities of analysing data with autistic girls in a participatory way and in recognition of Double Empathy, it is a method that could be adopted by other researchers, particularly those working with groups whose voices are seldom heard and understood. Our Perspective Narrative Analysis approach will be included as a chapter in a Creative Data Analysis Textbook which is due to be published in 2023 (Kara et al. n.d.). Furthermore, Perspective Narratives also have the potential to be used more broadly for education and training purposes. For example, they could be developed into a book for wider publishing and dissemination, and narratives could be developed that address autistic young people’s experiences of hospitals, social care, or the criminal justice system to widen the audience. This would be beneficial for promoting the challenges autistic people encounter when accessing a variety of services, while considering the impact of Double Empathy on the understanding of non-autistic staff. Fizzacc’s narratives have already been used as part of a module for trainee social workers and to inform a school governing body in re-writing uniform policy.

10.7 Concluding Remarks

This research began as a response to the SEND crisis in English schools as outlined in the Introduction. My experience in the classroom reflected research about the growing number of children in schools in England who were being failed by the education system due to lack of support. The impact this was having on children and the staff - who were working so hard to manage an impossible situation - was devastating. I recognised that part of the problem was lack of teacher knowledge and understanding and therefore sought to address this in my research. Three and a half years since I first started to think about this research, very little has changed as evidenced by the SEND review (DoE & DHSC, 2022) and NAS Education Report (NAS, 2023).

While my research only addresses a very small part of a very large problem, it is nevertheless an important contribution, as Fizzacc member Abria said: ‘we are a little part of a big picture’. By including autistic girls’ voices in the dialogue about school transitions, this research contributes to the existing body of knowledge about transitions and extends it by including embodied representations of the lived experiences of autistic girls. Furthermore, it provides support for the use of creative participatory methods for supporting the sharing of experiences for autistic children. This is not only beneficial for the outcomes of the research itself but also had a positive impact on those who participated.

As this research prioritised promoting the voices of autistic girls, I would like to conclude with a quote which sums up the feeling I had about working with Fizzacc:

Ola: To be a part of something that I know can help even more people is just a really lovely thing to do.

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Appendices

Appendix A Ethics Information for Trial Phase

A.1 Application

ERGO II Ethics application form – Psychology Committee

1. Applicant Details

1.1 Applicant name	Chloe East
1.2 Supervisor	Hanna Kovshoff, Sarah Parsons
1.3 Other researchers / collaborators (if applicable): *Name, address, email*	

2. Study Details

2.1 Title of study	Using body-mapping to discover children's feelings about their transition from primary to secondary school
2.2 Type of project (e.g. undergraduate, Masters, Doctorate, staff)	Doctorate

2.3 Briefly describe the rationale for carrying out this project and its specific aims and objectives.

The transition between primary and secondary school has been shown to be a particularly difficult time for children and their families. The children are required to engage with a very different environment both physically and structurally (Jindal-Snape, Vettraino, Lowson & McDuff). For parents this can also be a confusing time as they are required to support their children while often lacking the necessary knowledge and understanding of the school that their child is moving to (Nuske et al). Moreover, given the Covid-19 lockdown, children in year 6 have not had what would be typical planned transitions. This project aims to gather information which will be used to facilitate discussions of feelings around transitions between parents and children to support them to manage the transition process more easily. We also will use the data to develop further tools to support educational in the future for other groups of children.
Aims:

- To trial the use of Body Mapping to gather data about how year 6 children feel about the transition they are experiencing
- To understand whether Body Mapping as a tool can be used to stimulate discussion and gather data
- To find out which aspects of the transition process children and their families would appreciate support with and how this support can be delivered.

2.4 Provide a brief outline of the basic study design. Outline what approach is being used and why.

This study will involve both creative data collection methods and semi-structured interviews. This is to support all stakeholders to express their feelings and opinions. There will be two separate data collection periods:

1. Body Mapping to be conducted with year 6 children at home with their families. Body Mapping is a method of data collection that has been used with a number of vulnerable populations to support discussions around feelings. It involves participants creating a life-sized representation of their body on paper, onto which they write, draw or stick images that represent their feelings around given topics. This body map can then be used as the basis for discussion about their feelings.
2. Semi-structured interviews with parents who have gone through the transition process with their children. This data will inform the creation of the transition tool along with the data collected from the children.

2.5 What are the key research question(s)? Specify hypotheses if applicable.

- How can the use of Body Mapping techniques support children to voice their opinions about transitions?

- How do children feel about their transition to secondary school?

- What do parents feel about Body Mapping as a tool to support their child’s transition to secondary school?

3. Sample and setting

3.1 Who are the proposed participants and where are they from (e.g. fellow students, club members)? List inclusion / exclusion criteria if applicable.

Participants will be year 6 children and their parents.
All activities will be conducted in the participants own homes.
A parcel of materials will be sent to participants with written instructions on how to complete the tasks. They will have around 6 weeks to complete the activities after which they will photograph the results and send the photos and a copy of the discussion (either written or verbal recording) back to the researcher via email. (See Body Mapping instructions v1.)

Interviews will take place via Microsoft Teams or email after the children have settled into their new school. (See Parent interview schedule v1.)

3.2. How will the participants be identified and approached? Provide an indication of your sample size. If participants are under the responsibility of others (e.g., parents/carers, teachers) state if you have permission or how you will obtain permission from the third party).

Families will be invited to participate via snowball method from individual contacts provided by the researcher and supervisors. The first contacts will be families known to the researcher and supervisors through being involved with primary schools as either a parent, or a previous member of staff. These initial contacts will share the information allowing prospective participants to email the researcher for further information. No email addresses will be shared without consent. A copy of the email is attached (Participant email v1.)

Sample size will be 20 children and their parent/s. Up to 10 of these children will have an autism diagnosis.

Parents will give their consent and children their assent to participate.

3.3 Describe the relationship between researcher and sample. Describe any relationship e.g., teacher, friend, boss, clinician, etc.

N/A

3.4 How will you obtain the consent of participants? (*please upload a copy of the consent form if obtaining written consent***) NB. Consent form is not needed for studies collecting data online.**

All adult participants will be issued with an information sheet and a consent form prior to the interviews. The children will receive an information form and assent form, their parents will receive an information form and consent for the children to participate. (See Child info sheet v1., Parent info sheet v1., Assent_consent form v1.)

3.5 Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

Parent participants will be able to give informed consent for themselves and their children. Children will be asked to give assent for their participation. The forms (attached) are designed to be accessible to the particular participant group.

4. Research procedures, interventions and measurements

4.1 Give a brief account of the procedure as experienced by the participant. Make it clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear the total demands made on participants, including time and travel. *Upload copies of questionnaires and interview schedules to ERGO.*

Please see attached interview schedule and Body Mapping instruction sheets.

4.2 Will the procedure involve deception of any sort? If yes, what is your justification?

No

4.3. Detail any possible (psychological or physical) discomfort, inconvenience, or distress that participants may experience, including after the study, and what precautions will be taken to minimise these risks.

Parents: There is a small possibility of psychological discomfort or distress for parents discussing a potentially difficult time in their child's life.
At the beginning of the interviews, participants will be reminded that they can ask to terminate the interview at any time or not answer any question they find uncomfortable. No reason needs to be given. Participants will also be reminded that they can withdraw from the study up until December 31st, 2020 by which time all interviews will be concluded. This information is also included on the information sheet.

Children: There is a small possibility that children may feel upset talking about issues surrounding transitions. As they will be completing the tasks with a parent, they will be able to be supported with this. The instructions make it clear that they can work through the activities at their own pace and their assent form makes it clear that they don't have to complete the tasks if they don't want to. The instructions also include suggestions for parents to help their children including links to organisations that offer support.

4.4 Detail any possible (psychological or physical) discomfort, inconvenience, or distress that YOU as a researcher may experience, including after the study, and what precautions will be taken to minimise these risks. If the study involves lone working please state the risks and the procedures put in place to minimise these risks (please refer to the lone working policy).

N/A

4.5 Explain how you will care for any participants in 'special groups' e.g., those in a dependent relationship, are vulnerable or are lacking mental capacity), if applicable:

Children involved in the project will be completing the tasks with a parent.

4.6 Please give details of any payments or incentives being used to recruit participants, if applicable:

Participants will be able to keep any of the materials left at the end of the task and will be able to keep their completed body map.

5. Access and storage of data

5.1 How will participant confidentiality be maintained? Confidentiality is defined as non-disclosure of research information except to another authorised person. Confidential information can be shared with those already party to it and may also be disclosed where the person providing the information provides explicit consent. Consider whether it is truly possible to maintain a participant's involvement in the study confidential, e.g. can people observe the participant taking part in the study? How will data be anonymised to ensure participants' confidentiality?
In any written information or reports, confidentiality will be maintained by giving each participant a pseudonym. Demographic information containing identifying information of each participation will be stored separately from anonymised interview transcripts. This information will be gathered at the parental interview stage and will ask for details of their child's SEN and school status, their geographical location and their ethnicity. Paper copies of information will be kept separately in locked filing cabinets which only the research team can access, and digital files will be stored separately on university computers using encryption and password protection.

5.2 How will personal data and study results be stored securely during and after the study. Who will have access to these data?
Only members of the research team will have access to the raw data. Hard copies of data will be stored securely in a locked filing cabinet and digital data will be kept on a university server. Digital files will be deleted following anonymised transcription.

5.3 How will it be made clear to participants that they may withdraw consent to participate? Please note that anonymous data (e.g. anonymous questionnaires) cannot be withdrawn after they have been submitted. If there is a point up to which data can be withdrawn/destroyed e.g., up to interview data being transcribed please state this here.
The information sheets will clearly state the date by which participants may withdraw consent. This will be the date at which point data transcription is expected to be complete.

6. Additional Ethical considerations

6.1 Are there any additional ethical considerations or other information you feel may be relevant to this study?
No

Appendix B Ethics Information for Pilot Phase

B.1 Application

ERGO II Ethics application form – Psychology Committee

5. Applicant Details

1.1 Applicant name	Chloe East
1.2 Supervisor	Hanna Kovshoff, Sarah Parsons
1.3 Other researchers / collaborators (if applicable): *Name, address, email*	

6. Study Details

2.1 Title of study	Is Body Mapping a useful method of data collection to use with children with special educational needs (SEN) and autism?
2.2 Type of project (e.g. undergraduate, Masters, Doctorate, staff)	PhD

2.3 Briefly describe the rationale for carrying out this project and its specific aims and objectives.
Young people with SEN – and particularly autistic children - can find it challenging to participate in traditional methods of qualitative research such as interviews (Harrington & Foster, 2013). Although some success has been found with methods such as photovoice (Carnahan, 2006), talking mats (Cameron & Murphy, 2002) and collage (Shepherd, 2015), there are limitations in the depth of response allowed – particularly if the child is non-verbal. Body Mapping is a technique which has been used with a variety of populations such as HIV+ women in Africa (Solomon, 2007) and youths experiencing psychosis in Australia (Boydell et al., 2018). It allows participants to engage in a creative task which explores their embodied experience of a particular part of their lives. This method provides a framework for a variety of communication styles and draws on autistic children's visual thinking and creativity. This study will investigate the use of Body Mapping with young people from 11 to 18 years old and will include children with a variety of SEN including autism. The Body Mapping task will focus on school-based transitions as these will form the focus of the next study in the project (ethics will be applied for to cover the second study in a separate application). Different methods will be used to conduct the Body Mapping tasks to investigate whether strategies that comply with different levels of Covid restrictions impact on the quality and depth of data and on the value of the experience of the young people in undertaking the task. The results will impact on the design of my next study. Aims: • To evaluate the use of Body Mapping as a research method with children with SEN including autistic children. • To identify the strengths and challenges of different approaches to Body Mapping.

- To elicit the voices of children in the development of knowledge about school-based transitions.

2.4 Provide a brief outline of the basic study design. Outline what approach is being used and why.

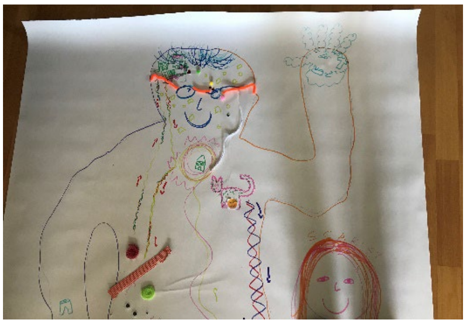
See Body Mapping instructions document for a full description of the tasks.

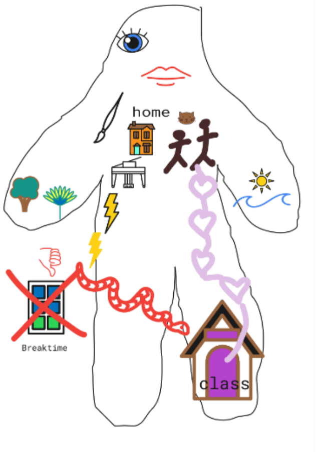
The task will involve participants creating a representation of their body on paper (see figure 1) or on a computer (see figure 2), onto which they write, draw or stick images that represent their feelings around given topics. The task will take approximately 2 hours to complete. After the body map is finished the children will share their thinking behind their body maps using their preferred communication style. This may be verbally, written or using pictorial support such as a talking mat. They will also be asked how they felt about participating in the activities.

The task will be conducted in three different ways.

5. Participants will be sent a pack in the post which will contain all the materials to complete the task. They will be able to complete in their own time. Once the tasks are complete, they will email photographs of the finished body map and a recording – either audio or written – of the responses to the questions.
6. Participants will come to a local venue (e.g. scout hut or village hall). The researcher will guide them through the task. Photographs will be taken of the completed body maps and an audio recording will be taken of the responses to the questions. A Parent will be in attendance during the task if appropriate. If a parent is unable to attend the body outline will be drawn freehand. There will be fewer than 6 people in attendance. Adults will wear masks. Hand sanitiser will be used during and after the task. Temperatures will be taken on arrival. Each child will be given their own pack of materials. Any resources left at the end of the session will either be taken home by the child or disposed of.
7. Participants will complete the task using Autodraw. This is a computer drawing programme which is freely available on the internet. They will complete the task while sharing their screen with the researcher via Microsoft Teams. They will be able to talk through their decisions while completing the task. The conversation will be recorded, and copies of the completed map will be downloaded.

Figure 1	**Figure 2**
In person or by post version	*Online version*





Participants will be allocated to one of the methods. This allocation will depend on geographical location (lockdown rules in some areas will not allow for travel there) and what the current rules are for the area local to the researcher. The discussion about the task will include an opportunity to get their feedback on how they feel about the alternative methods of completion.
A follow up interview will be conducted with parents via telephone or teams within two weeks of the task to gain a wider perspective of the child's response to the task.

2.5 What are the key research question(s)? Specify hypotheses if applicable.

- Do young people enjoy and engage with the process of Body Mapping? What are the benefits to them of participation?
- Is Body Mapping an effective way to support children to think about and share their thoughts and feelings?
- What are the most useful resources to use?
- Does the use of different methods impact on the quality of experience or depth of data?
- How long does the process take? Is it better to complete it in one session or more?
- How is it best to conduct the discussion part of the task?
- Does the data provide a rich source of information about transitions?
- How do the children feel about transitions they have experienced and the support they have received?

7. Sample and setting

3.1 Who are the proposed participants and where are they from (e.g. fellow students, club members)? List inclusion / exclusion criteria if applicable.

The children will be aged between 11 and 18 and will include children with an autism diagnosis and children who have SEN which makes transitions more challenging. Parental interviews will be held with one or both parents depending on availability.

3.2. How will the participants be identified and approached? Provide an indication of your sample size. If participants are under the responsibility of others (e.g., parents/carers, teachers) state if you have permission or how you will obtain permission from the third party).

Families will be invited to participate via snowball method from individual contacts provided by the researcher and supervisors. The first contacts will be families known to the researcher through being involved with schools as either a parent, or a previous member of staff. These initial contacts will share the information allowing prospective participants to email the researcher for further information. No email addresses will be shared without consent. A copy of the email is attached. Sample size will be between 5 and 10 children. It is hoped that the final number will be towards the upper end, but studies have been conducted with 6 young people (Boydell et al, 2018) and 7 young people (Dew et al, 2018).

Parents will give their consent and children their assent to participate.

3.3 Describe the relationship between researcher and sample. Describe any relationship e.g., teacher, friend, boss, clinician, etc.

None

3.4 How will you obtain the consent of participants? (*please upload a copy of the consent form if obtaining written consent***) NB. Consent form is not needed for studies collecting data online.**

The children will receive an information form and assent form, their parents will receive an information form and consent for their child to participate. Forms are attached.

3.5 Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

Parent participants will be able to give informed consent for their children. Children will be asked to give assent for their participation. The forms (attached) are designed to be accessible to the particular participant group and will be explained verbally at the beginning of the project.

8. Research procedures, interventions and measurements

4.1 Give a brief account of the procedure as experienced by the participant. Make it clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear the total demands made on participants, including time and travel. *Upload copies of questionnaires and interview schedules to ERGO.*

Please see attached interview and Body Mapping schedules.

Full procedures for conducting the task by post are included in the Body Mapping instructions document.

For in person or online versions of the task the following will apply:

Young people will have the task explained to them and will be asked to initial the assent form to confirm they are happy to participate. They will be reminded that the session will be audio recorded.
If conducting the task in person the young person will be familiarised with the resources provided.
If online the online drawing tool will be introduced: https://www.autodraw.com/
Body Mapping tasks for a young person facing school to college transitions will involve the following instructions:

1. Draw round the outline of your body. This will be done by someone in their own bubble if available. If not, a freehand life-sized drawing will be made. On Autodraw they will draw a gingerbread style figure.

2. Choose a colour to go around the outline of your body so it stands out. Think carefully about which colour you choose. You might choose more than one colour. Whatever you choose should represent something about you.

3. Now it is time to decorate your hands. Fill the spaces where your hands are with images and colours that represent you. They might be drawn or images that you cut out and stick on. If the hands didn't come out very well in your outline you can draw them again.

4. Choose a place on your piece of paper where you would like to represent your home. It could be inside your body or outside. Think about why you might put your home in this particular place. Decide how you would like to show your home. Maybe you would like to include some of your favourite things about being at home on your image.

5. Your school is going to go onto your body map next. Think about where you would like to put it. You can choose how you would like to show your school.

6. Once you have finished your school image, you need to find a way to connect it with home. You might use straight lines or wiggly ones or something other than lines. Think about what your choice might say about how you feel when you go to school in the morning and when you come home again in the afternoon.

7. Now it is time to think about your new college. Think about what you know about your college so far. This could be to do with the subjects you are taking, the differences between school and college or the way you feel when you think about the move.

8. How will you connect home to college? Will it be the same as the connection between home and school? It is up to you to choose how you would like to show the connection.
9. Think about what helps you when you are finding things tricky. This might be special interests, gadgets or activities. Find a way to represent these on your body map.

10. Think about the people around you who support you. Choose who you would like to include on your body map and where you would like to place them. You can choose as many people as you like. You might like to draw people or to write their names. Think about the colours or patterns you choose for the different people you include. How do these colours or patterns represent them?

11. Now it is time to fill in the face on your body map. You can choose how you would like to do this. It might be that you want to draw what you look like, or you might choose to fill it in using

colours, patterns or images that represent you in another way. If you have already filled in your face you could draw another one somewhere else on your map.

(Instructions for different transitions are included on the body map instructions document.)

If the task is being conducted in person, the discussion will be recorded via Dictaphone throughout the task. Online the session will be recorded. Any questions not addressed during the task will be asked at the end. If in person, the body map will be photographed once completed. The young person will then be able to take the body map home. On Autodraw the young person will be asked to share the final image with the researcher by sending a link via email.

4.2 Will the procedure involve deception of any sort? If yes, what is your justification?

No

4.3. Detail any possible (psychological or physical) discomfort, inconvenience, or distress that participants may experience, including after the study, and what precautions will be taken to minimise these risks.

There is a small possibility that children may feel upset talking about issues surrounding transitions. They will be able to stop the session or interview with no questions asked and their parents will be in attendance if appropriate.
Measures will be put in place for social distancing and handwashing where the task is completed in person. A risk assessment with specific information for individual venues will be completed.

4.4 Detail any possible (psychological or physical) discomfort, inconvenience, or distress that YOU as a researcher may experience, including after the study, and what precautions will be taken to minimise these risks. If the study involves lone working please state the risks and the procedures put in place to minimise these risks (please refer to the lone working policy).

A risk assessment for the hazards associated with COVID 19 has been carried out and the measures put in place by individual venues will be adhered to. This will include hand washing, wearing of masks and maintaining a 2m distance. A risk assessment for the posting of research materials has also been carried out.

4.5 Explain how you will care for any participants in 'special groups' e.g., those in a dependent relationship, are vulnerable or are lacking mental capacity), if applicable:

Young people will be able to request to finish the task at any time. Younger children and those who may require extra support will have a parent in attendance throughout the task.

4.6 Please give details of any payments or incentives being used to recruit participants, if applicable:

N/A

5. Access and storage of data

5.1 How will participant confidentiality be maintained? Confidentiality is defined as non-disclosure of research information except to another authorised person. Confidential information can be shared with those already party to it and may also be disclosed where the person providing the information provides explicit consent. Consider whether it is truly possible to maintain a participant's involvement in the study confidential, e.g. can people observe the participant taking part in the study? How will data be anonymised to ensure participants' confidentiality?

In any written information or reports, confidentiality will be maintained by giving each participant a pseudonym.
Demographic information containing identifying information of each participation will be stored separately from anonymised interview transcripts. Paper copies of information will be kept separately in locked filing cabinets which only the research team can access, and digital files will be stored separately on university computers using encryption and password protection.

5.2 How will personal data and study results be stored securely during and after the study. Who will have access to these data?

Only members of the research team will have access to the raw data.

Hard copies of data will be stored securely in a locked filing cabinet and digital data will be kept on a university server. Digital files will be deleted following anonymised transcription.
Images of the body maps and interview transcriptions will be anonymised. Agreement for the use of the images and responses will form part of the consent process prior to the task. (See assent_consent form)

5.3 How will it be made clear to participants that they may withdraw consent to participate? Please note that anonymous data (e.g. anonymous questionnaires) cannot be withdrawn after they have been submitted. If there is a point up to which data can be withdrawn/destroyed e.g., up to interview data being transcribed please state this here.

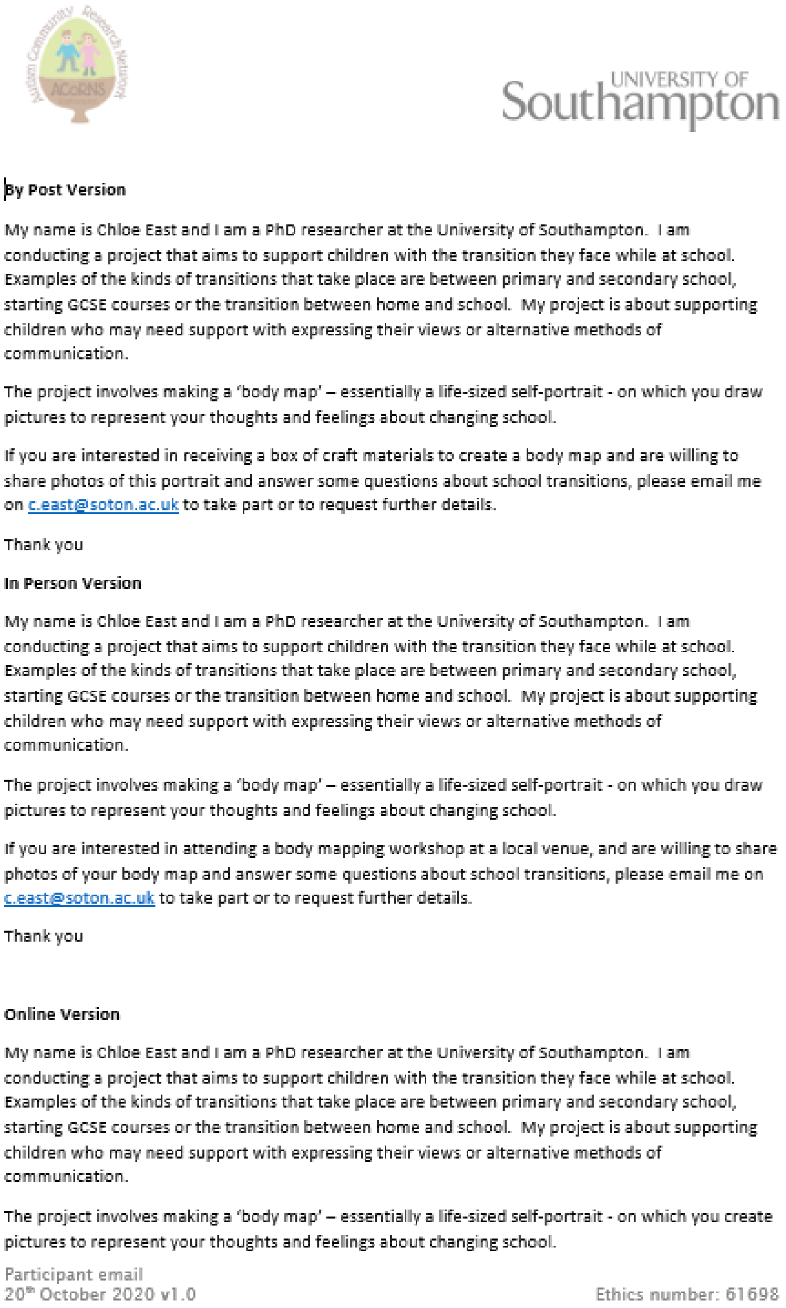
The information sheets will clearly state the date by which participants may withdraw consent. This will be the date at which point data transcription is expected to be complete. Participants will be reminded verbally of this before the start of any data collection session

6. Additional Ethical considerations

6.1 Are there any additional ethical considerations or other information you feel may be relevant to this study?

No

B.2 *Initial Recruiting Email*



UNIVERSITY OF Southampton

By Post Version

My name is Chloe East and I am a PhD researcher at the University of Southampton. I am conducting a project that aims to support children with the transition they face while at school. Examples of the kinds of transitions that take place are between primary and secondary school, starting GCSE courses or the transition between home and school. My project is about supporting children who may need support with expressing their views or alternative methods of communication.

The project involves making a 'body map' – essentially a life-sized self-portrait - on which you draw pictures to represent your thoughts and feelings about changing school.

If you are interested in receiving a box of craft materials to create a body map and are willing to share photos of this portrait and answer some questions about school transitions, please email me on c.east@soton.ac.uk to take part or to request further details.

Thank you

In Person Version

My name is Chloe East and I am a PhD researcher at the University of Southampton. I am conducting a project that aims to support children with the transition they face while at school. Examples of the kinds of transitions that take place are between primary and secondary school, starting GCSE courses or the transition between home and school. My project is about supporting children who may need support with expressing their views or alternative methods of communication.

The project involves making a 'body map' – essentially a life-sized self-portrait - on which you draw pictures to represent your thoughts and feelings about changing school.

If you are interested in attending a body mapping workshop at a local venue, and are willing to share photos of your body map and answer some questions about school transitions, please email me on c.east@soton.ac.uk to take part or to request further details.

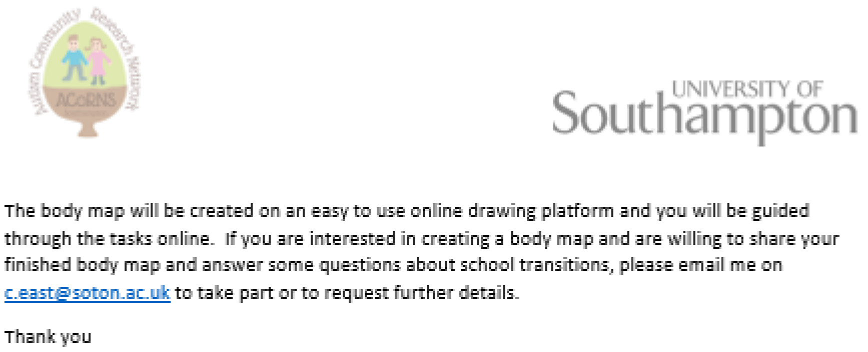
Thank you

Online Version

My name is Chloe East and I am a PhD researcher at the University of Southampton. I am conducting a project that aims to support children with the transition they face while at school. Examples of the kinds of transitions that take place are between primary and secondary school, starting GCSE courses or the transition between home and school. My project is about supporting children who may need support with expressing their views or alternative methods of communication.

The project involves making a 'body map' – essentially a life-sized self-portrait - on which you create pictures to represent your thoughts and feelings about changing school.

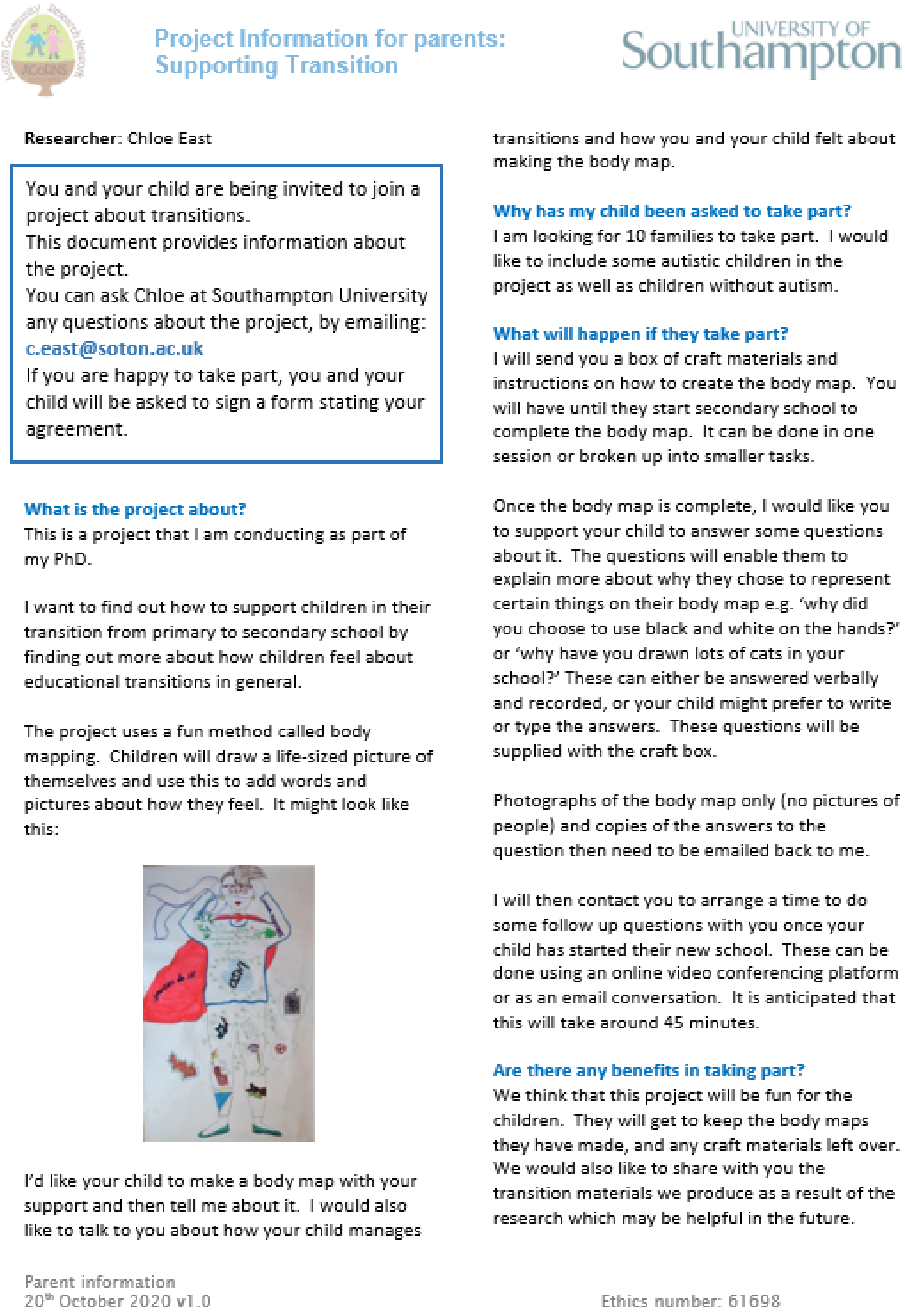
Participant email
20th October 2020 v1.0 Ethics number: 61698



The body map will be created on an easy to use online drawing platform and you will be guided through the tasks online. If you are interested in creating a body map and are willing to share your finished body map and answer some questions about school transitions, please email me on c.east@soton.ac.uk to take part or to request further details.

Thank you

B.3 Parent Information Sheet



Project Information for parents: Supporting Transition

Researcher: Chloe East

You and your child are being invited to join a project about transitions.
This document provides information about the project.
You can ask Chloe at Southampton University any questions about the project, by emailing: c.east@soton.ac.uk
If you are happy to take part, you and your child will be asked to sign a form stating your agreement.

What is the project about?

This is a project that I am conducting as part of my PhD.

I want to find out how to support children in their transition from primary to secondary school by finding out more about how children feel about educational transitions in general.

The project uses a fun method called body mapping. Children will draw a life-sized picture of themselves and use this to add words and pictures about how they feel. It might look like this:

I'd like your child to make a body map with your support and then tell me about it. I would also like to talk to you about how your child manages transitions and how you and your child felt about making the body map.

Why has my child been asked to take part?

I am looking for 10 families to take part. I would like to include some autistic children in the project as well as children without autism.

What will happen if they take part?

I will send you a box of craft materials and instructions on how to create the body map. You will have until they start secondary school to complete the body map. It can be done in one session or broken up into smaller tasks.

Once the body map is complete, I would like you to support your child to answer some questions about it. The questions will enable them to explain more about why they chose to represent certain things on their body map e.g. 'why did you choose to use black and white on the hands?' or 'why have you drawn lots of cats in your school?' These can either be answered verbally and recorded, or your child might prefer to write or type the answers. These questions will be supplied with the craft box.

Photographs of the body map only (no pictures of people) and copies of the answers to the question then need to be emailed back to me.

I will then contact you to arrange a time to do some follow up questions with you once your child has started their new school. These can be done using an online video conferencing platform or as an email conversation. It is anticipated that this will take around 45 minutes.

Are there any benefits in taking part?

We think that this project will be fun for the children. They will get to keep the body maps they have made, and any craft materials left over. We would also like to share with you the transition materials we produce as a result of the research which may be helpful in the future.

Parent information
20th October 2020 v1.0

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Are there any risks involved?

Not really. If your child is not happy about taking part they do not have to continue.

What data will be collected?

We will:

- keep a copy of your answers to the questions asked
- keep photographs of your child's body map and a record of their thoughts about it
- send you a summary of what we find out
- make that summary available on our website for other people to read

How will we safeguard your data?

Your names will be removed from all your data and replaced with a participant number for identification. Hard copies of transcripts or photographs will be kept in a locked filing cabinet. Data stored digitally will be kept on university computers using encryption and password protection. 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 we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential.

Will anyone else know they have taken part?

No-one will know you have taken part in the project. We will not include your son / daughter's name in anything we write about the project.

Do we have to take part?

No. This is your child's decision as well as yours and we don't mind either way. If you decide to take part, and you are happy for them to take part, we will ask you both to sign a consent form.

What happens if I change my mind?

You can change your mind at any time before April 30th 2021 without giving a reason. If you do, your data, including photographs of body maps, will be deleted. Please just let me know. My contact details are: c.east@soton.ac.uk

What will happen to the results of the research?

We will write a short report to put up on our website. There may also be a longer report that we want to write about the project to let other people know what we have found out. This may include quotes from you or your child which will be anonymised. If we share pictures of your child's body map, we will cover any identifying details.

What do I do if I want to take part?

Just email me on c.east@soton.ac.uk and I will send you the craft pack and all the instructions.

Where can I get more information?

Please ask me if you have any questions about the project: c.east@soton.ac.uk

You can also contact my supervisor - Hanna Kovshoff at the University: H.Kovshoff@soton.ac.uk or telephone: (023) 8059 4593

What happens if there is a problem?

If you have any concerns about the project please speak to me first.

If you are still unhappy or have a complaint, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

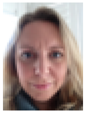
By law, The University of Southampton has to protect and use the information collected in this project in specific ways. This can sound very formal and complicated.

The main thing to know is that we treat any information very carefully. There is detailed information about this that we have to let you know, and this can be found on the next page.

Thank you very much for taking the time to read this.

Project Information for parents: Supporting Transition

Chloe East



More details about Data Protection and Privacy that we have to tell you

- The University of Southampton carries out research with the greatest care and consideration.
- We have to have a good reason ('lawful basis') for asking for your personal information.
- The good reason is that we are doing research that we think other people might be interested in and could help them.
- This means that when you agree to take part in a research study, we will only use information (data) about you in the ways that you have been told about in this project information sheet.
- We will not use your information for any other purpose.
- The University's policy about how we use information about you can be found on its website here: [https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page] and there is more information about keeping your details private here: [https://www.mrc.soton.ac.uk/web2/files/2013/04/privacy.pdf].
- Please ask the research team if you have any questions or are unclear what information is being collected about you.
- 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 Southampton will keep information about you for 10 years after the study has finished. After this, any link between you and your information will be removed.
- If you have any questions about how your information (data) is used you can find more information here: [https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page]
- If you need more help or information, please contact the University's Data Protection Officer by email: data.protection@soton.ac.uk.

In Person Version

What is the project about?

I'd like your child to make a body map and then tell me about it. I would also like to talk to you about how you feel your child manages

What will happen if they take part?

We will agree a location for the task to take place. This will be a village hall or scout hut local to you.
The venue will be cleaned and I will wear a mask throughout the task. You and your child will be given hand sanitiser to use and you will be required – if appropriate – to wear a mask. Your child can choose whether or not they wish to wear a mask. A risk assessment for each venue will be completed in advance and I can send you a copy of this if you wish.
To complete the body map, your child will have an outline drawn of their body on a piece of paper. They will then be given craft materials to use to represent different aspects of home and school. The craft materials will be individual to them and they may keep any that are left at the end.
Once the body map is complete, I will ask some questions about it. The questions will enable them to explain more about why they chose to represent certain things on their body map e.g. 'why did you choose to use black and white on the hands?' or 'why have you drawn lots of cats in your school?' I will record the answers to the questions on a voice recorder.

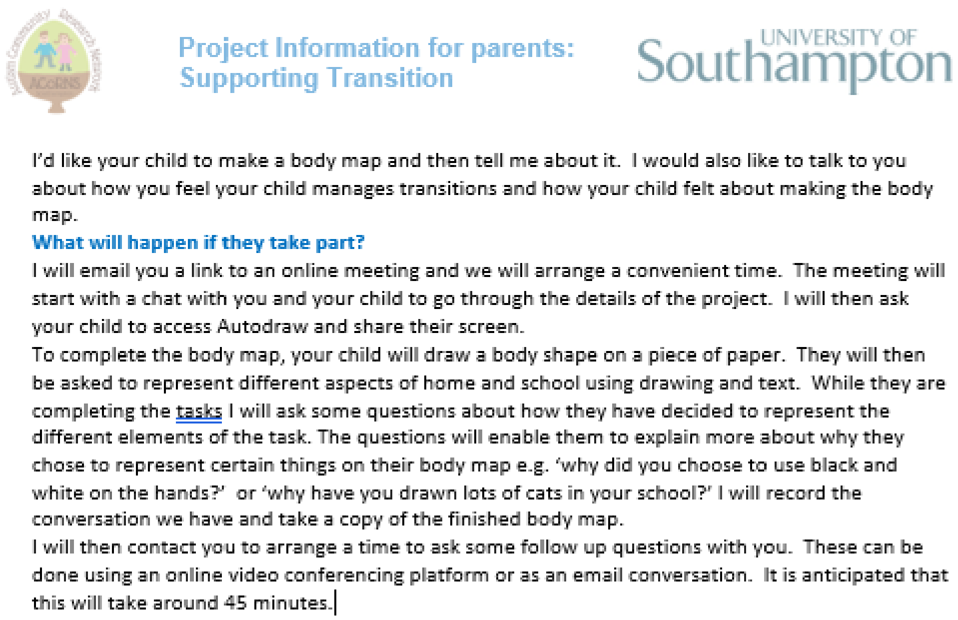
I will take photographs of the body map once it is finished and then you can take it home along with any unused materials.

I will then contact you to arrange a time to ask some follow up questions with you. These can be done using an online video conferencing platform or as an email conversation. It is anticipated that this will take around 45 minutes.

Online Version

What is the project about?

The project uses a fun method called body mapping. Children will create a picture of themselves and use this to add words and pictures about how they feel. It might look like this:



Project Information for parents: Supporting Transition

I'd like your child to make a body map and then tell me about it. I would also like to talk to you about how you feel your child manages transitions and how your child felt about making the body map.

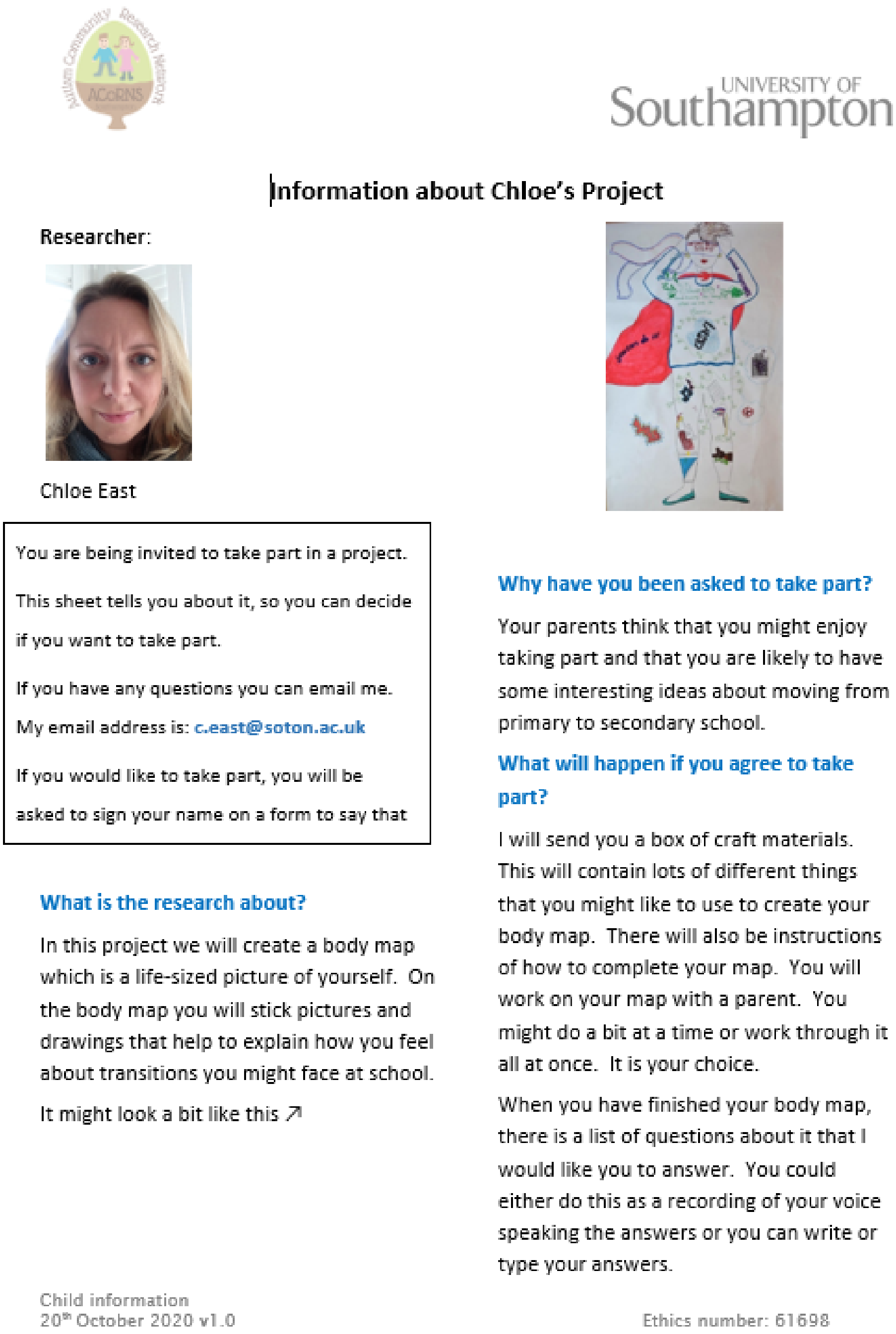
What will happen if they take part?

I will email you a link to an online meeting and we will arrange a convenient time. The meeting will start with a chat with you and your child to go through the details of the project. I will then ask your child to access Autodraw and share their screen.

To complete the body map, your child will draw a body shape on a piece of paper. They will then be asked to represent different aspects of home and school using drawing and text. While they are completing the tasks I will ask some questions about how they have decided to represent the different elements of the task. The questions will enable them to explain more about why they chose to represent certain things on their body map e.g. 'why did you choose to use black and white on the hands?' or 'why have you drawn lots of cats in your school?' I will record the conversation we have and take a copy of the finished body map.

I will then contact you to arrange a time to ask some follow up questions with you. These can be done using an online video conferencing platform or as an email conversation. It is anticipated that this will take around 45 minutes.

B.4 Child Information Sheet



Information about Chloe's Project

Researcher:

Chloe East

You are being invited to take part in a project.

This sheet tells you about it, so you can decide if you want to take part.

If you have any questions you can email me.

My email address is: c.east@soton.ac.uk

If you would like to take part, you will be asked to sign your name on a form to say that

What is the research about?

In this project we will create a body map which is a life-sized picture of yourself. On the body map you will stick pictures and drawings that help to explain how you feel about transitions you might face at school.

It might look a bit like this ↗

Why have you been asked to take part?

Your parents think that you might enjoy taking part and that you are likely to have some interesting ideas about moving from primary to secondary school.

What will happen if you agree to take part?

I will send you a box of craft materials. This will contain lots of different things that you might like to use to create your body map. There will also be instructions of how to complete your map. You will work on your map with a parent. You might do a bit at a time or work through it all at once. It is your choice.

When you have finished your body map, there is a list of questions about it that I would like you to answer. You could either do this as a recording of your voice speaking the answers or you can write or type your answers.

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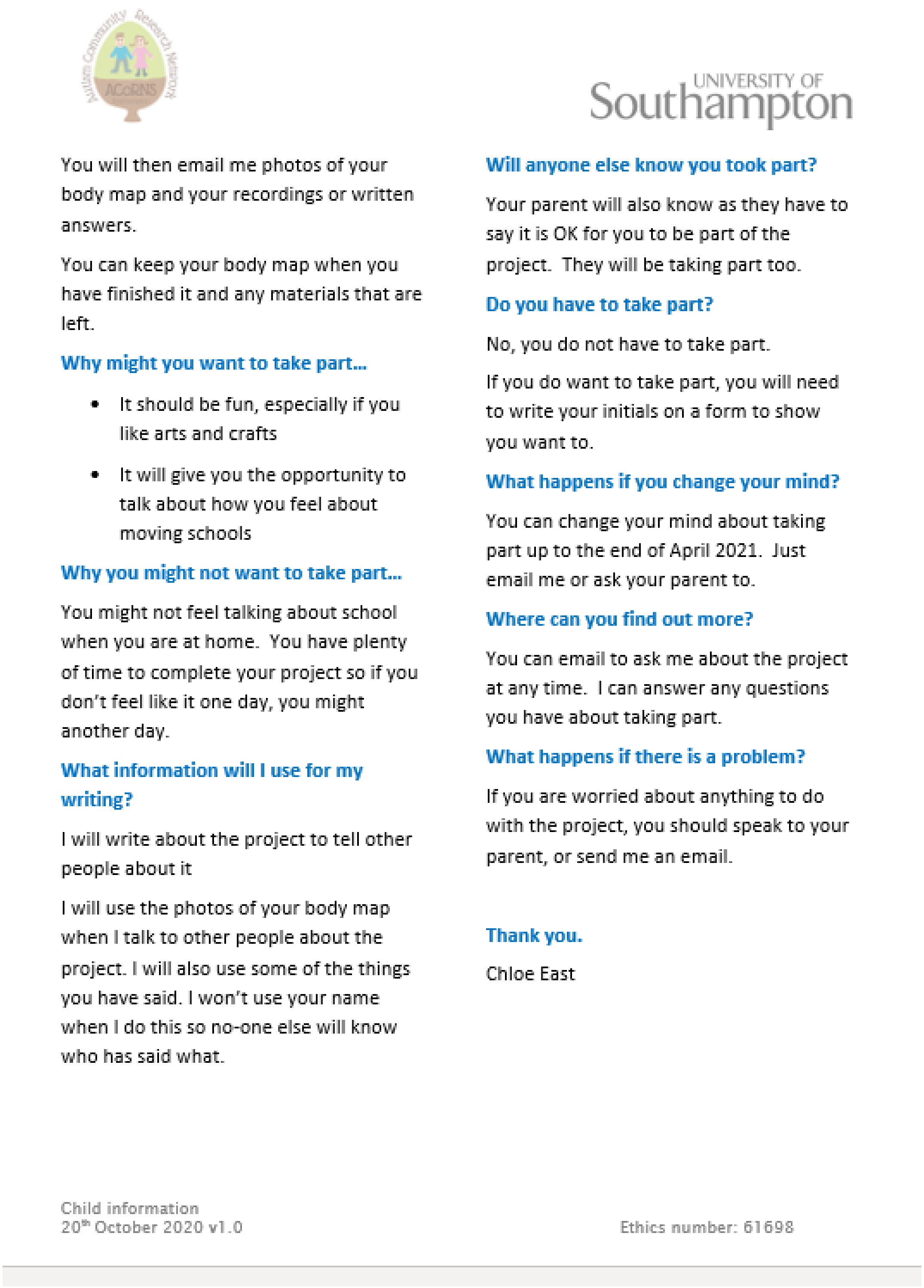


You will then email me photos of your body map and your recordings or written answers.

You can keep your body map when you have finished it and any materials that are left.

Why might you want to take part…

- It should be fun, especially if you like arts and crafts
- It will give you the opportunity to talk about how you feel about moving schools

Why you might not want to take part…

You might not feel talking about school when you are at home. You have plenty of time to complete your project so if you don't feel like it one day, you might another day.

What information will I use for my writing?

I will write about the project to tell other people about it

I will use the photos of your body map when I talk to other people about the project. I will also use some of the things you have said. I won't use your name when I do this so no-one else will know who has said what.

Will anyone else know you took part?

Your parent will also know as they have to say it is OK for you to be part of the project. They will be taking part too.

Do you have to take part?

No, you do not have to take part.

If you do want to take part, you will need to write your initials on a form to show you want to.

What happens if you change your mind?

You can change your mind about taking part up to the end of April 2021. Just email me or ask your parent to.

Where can you find out more?

You can email to ask me about the project at any time. I can answer any questions you have about taking part.

What happens if there is a problem?

If you are worried about anything to do with the project, you should speak to your parent, or send me an email.

Thank you.

Chloe East

Child information
20th October 2020 v1.0

Ethics number: 61698

In Person Version

What will happen if you agree to take part?

You will come with a parent, to the venue we have agreed which will be cleaned before you arrive. I will be wearing a mask and will have cleaned my hands. I will give you some hand sanitiser to use when you get there and take your temperature. You can wear a mask if you want to. Your parent can stay with you but does not have to hear what you say or see your body map if you don't want them to.

You will create your body map using materials that are just for you. You can keep whatever is left at the end and take it home for future projects.

You will start off by having an outline of your body drawn on a piece of paper. You will then be asked to represent different things on this piece of paper. They don't need to be drawings, you can represent things however you like.

When you have finished your body map, there is a list of questions about it that I would like you to answer. I will ask you the questions and use a voice recorder to record your answers.

Online Version

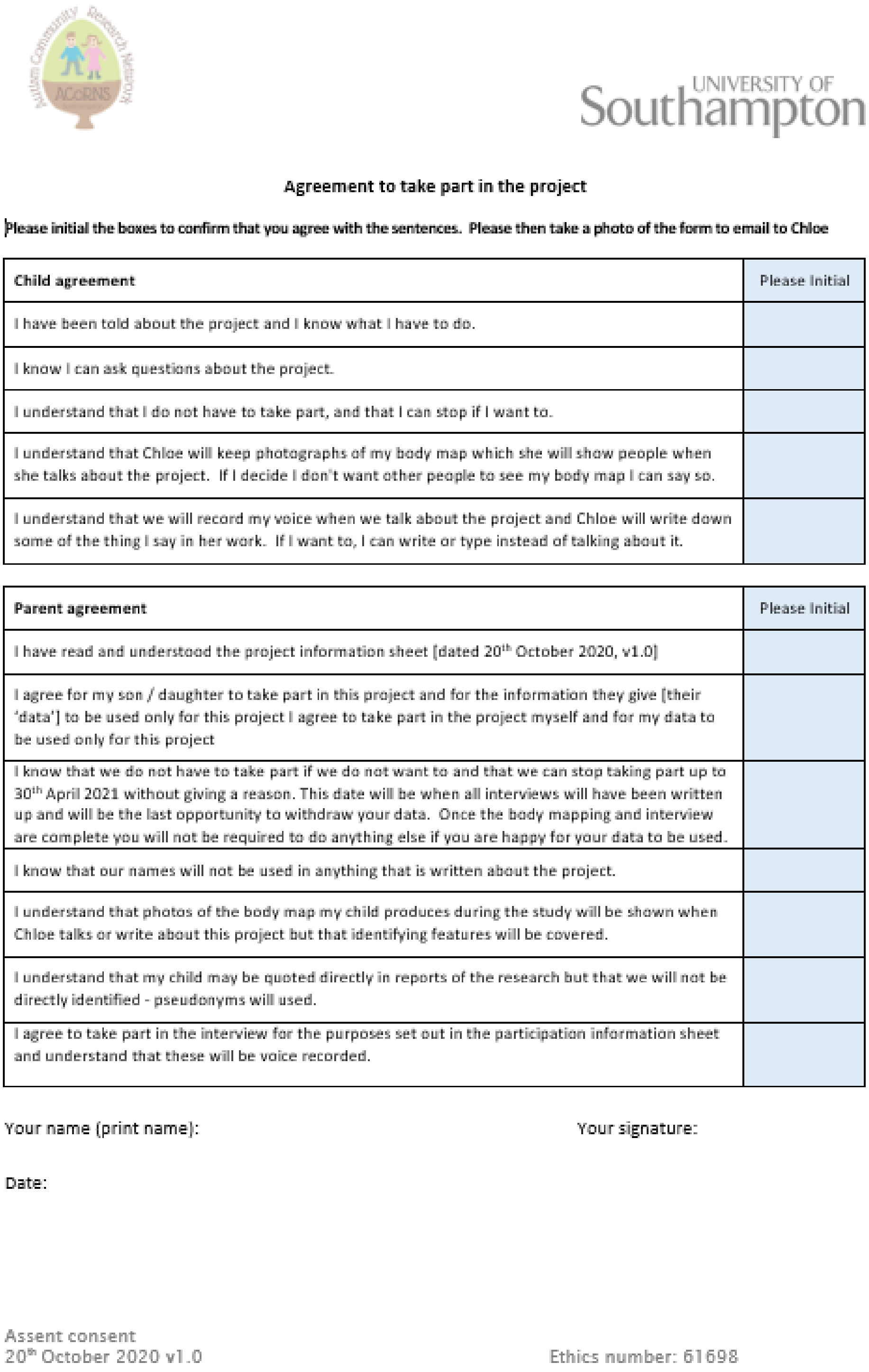
What will happen if you agree to take part?

I will email a link to your parents for an online meeting. I will have a chat with you and a parent for a few minutes about what you will be doing for the task. You will then connect to autodraw and share your screen. I will give you some instructions about different things to represent on your body map. I will ask you questions while you are completing the tasks. The conversation we have will be recorded and I will keep a copy of your finished map.

Why might you want to take part…

- It should be fun, especially if you like using different computer programmes
- It will give you the opportunity to talk about how you feel about transitions

B.5 Assent/Consent Form



Autism Community Research Network ACoRNS

UNIVERSITY OF Southampton

Agreement to take part in the project

Please initial the boxes to confirm that you agree with the sentences. Please then take a photo of the form to email to Chloe

Child agreement	Please Initial
I have been told about the project and I know what I have to do.	
I know I can ask questions about the project.	
I understand that I do not have to take part, and that I can stop if I want to.	
I understand that Chloe will keep photographs of my body map which she will show people when she talks about the project. If I decide I don't want other people to see my body map I can say so.	
I understand that we will record my voice when we talk about the project and Chloe will write down some of the thing I say in her work. If I want to, I can write or type instead of talking about it.	

Parent agreement	Please Initial
I have read and understood the project information sheet [dated 20th October 2020, v1.0]	
I agree for my son / daughter to take part in this project and for the information they give [their 'data'] to be used only for this project I agree to take part in the project myself and for my data to be used only for this project	
I know that we do not have to take part if we do not want to and that we can stop taking part up to 30th April 2021 without giving a reason. This date will be when all interviews will have been written up and will be the last opportunity to withdraw your data. Once the body mapping and interview are complete you will not be required to do anything else if you are happy for your data to be used.	
I know that our names will not be used in anything that is written about the project.	
I understand that photos of the body map my child produces during the study will be shown when Chloe talks or write about this project but that identifying features will be covered.	
I understand that my child may be quoted directly in reports of the research but that we will not be directly identified - pseudonyms will used.	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that these will be voice recorded.	

Your name (print name):

Your signature:

Date:

Assent consent
20th October 2020 v1.0

Ethics number: 61698

B.6 Child Debrief

Thank you!

Title: Feasibility study to find out what are the successes and challenges with using body mapping

Aims: To see whether using body mapping helps us to understand how you feel about transitions you experience at home and at school.

What will happen now?

Your body map, and your answers to my questions will help me to know how to use body mapping in my research. If it is successful, it will help me to understand how we can best support young people, like you, in their move from primary to secondary school.

Your answers will be kept confidential; your name will be kept secret so no one will know who answered our questions.

If you have any more questions for me or would like to hear more about my study when I've finished it, you can contact me at any time:

Chloe East: c.east@soton.ac.uk

Thank you for helping with this research.

Signature: ________________________________ Date: ___________________

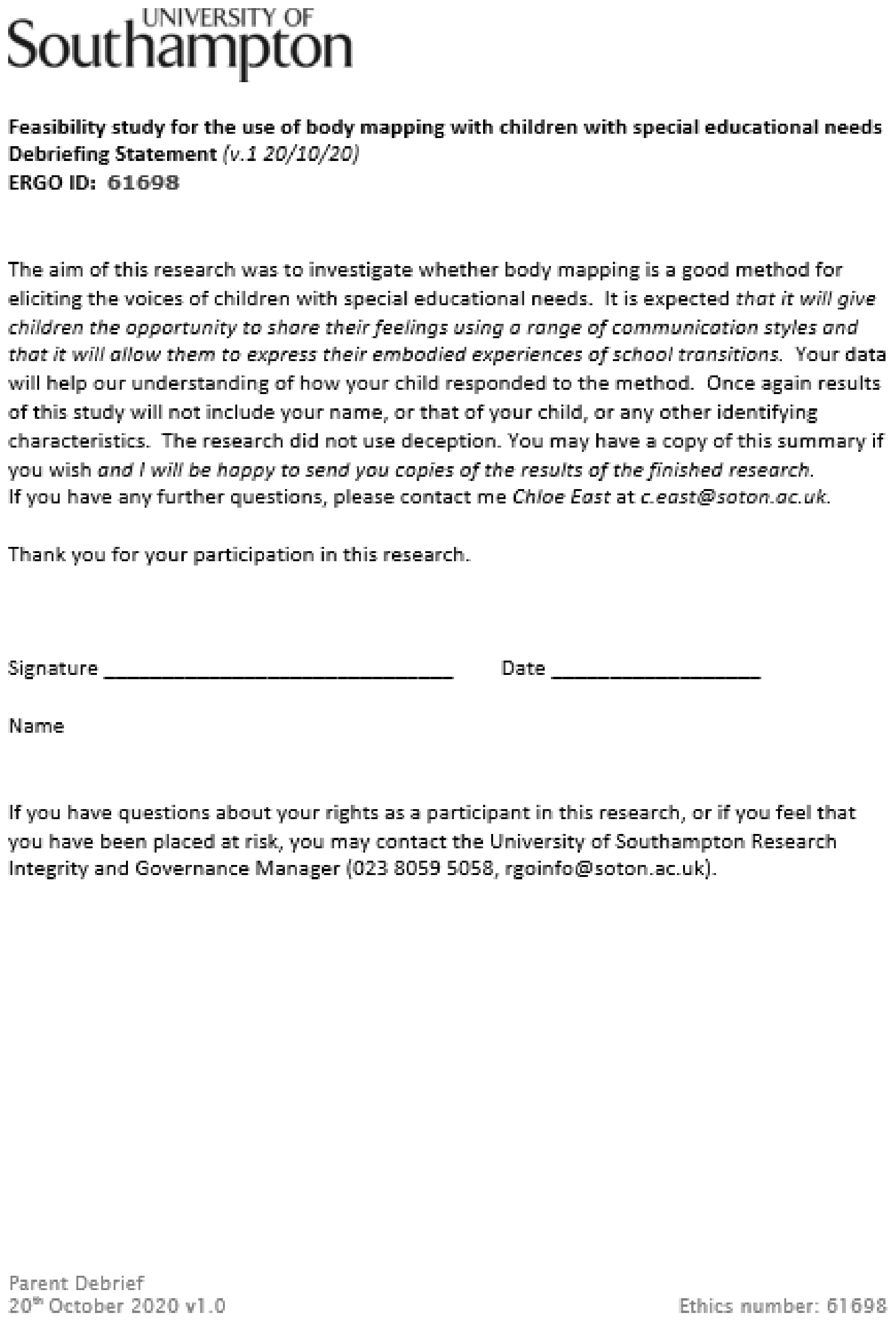
Name: ________________________________

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Child debrief
20th October 2020 v1.0

Ethics number: 61698

B.7 Parent Debrief



UNIVERSITY OF Southampton

Feasibility study for the use of body mapping with children with special educational needs
Debriefing Statement *(v.1 20/10/20)*
ERGO ID: 61698

The aim of this research was to investigate whether body mapping is a good method for eliciting the voices of children with special educational needs. It is expected *that it will give children the opportunity to share their feelings using a range of communication styles and that it will allow them to express their embodied experiences of school transitions.* Your data will help our understanding of how your child responded to the method. Once again results of this study will not include your name, or that of your child, or any other identifying characteristics. The research did not use deception. You may have a copy of this summary if you wish *and I will be happy to send you copies of the results of the finished research.*
If you have any further questions, please contact me *Chloe East* at *c.east@soton.ac.uk*.

Thank you for your participation in this research.

Signature _______________________________ Date ___________________

Name

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Parent Debrief
20th October 2020 v1.0 Ethics number: 61698

Appendix C Pilot Study Development of Codes and Themes

C.1 Generation of Codes for Child Data

Representation of Self		
Representative positioning on the body	(Chose to draw a light bulb to represent learning) RESEARCHER: So, tell me about putting it also, in your body. Why have you chosen to put it in your body rather than in a space? CLIVE: Because I feel it's quite a part of me. RESEARCHER: Are the worst things about school going to be inside your body as well or are they going to be outside? CLIVE: They're going to be outside. RESEARCHER: OK, tell me why you decided to put him inside your body. CLIVE: Because he’s is an important person to me. I’ve got it up on my shoulder like towards my head sort of thing because it's always on my mind. Music’s always in my like on my mind whether I’m listening to it through my headphones at school whether I’m actually playing my tuba. Whether I’m sorting sheet music out. It's always. Always in my head. (About college) MALIA: I want to put it further away from my body. because I’m not quite there yet. (About home) It’s a spacious area in the body and I’ve lived here nearly all my life so it might be near my heart. (About choosing GCSEs) Probably on my head because I’m starting to think about them.	Embodiment – using the space inside the body to represent the things that are important. In this case learning. Showing how the good is represented close or within the body. The further away something is drawn the worse it is. Using the space near the head to represent something that is always on her mind. Pushing away the things she is unsure about. She doesn’t want to deal with them yet so keeps them at a distance. Use of the heart. In 4/5 maps home was drawn near the heart.

	MATTEO: I know. Annoyed, irritated, sad, sensory overload, angry. RESEARCHER: And where in your body might you feel those feelings? MATTEO: I think in the head because that is where you think of things so you would be thinking those feelings in your head.	Opposite of earlier – as tricky issues are tackled they are positioned on the head to show they are being thought about. Difficult emotions are in the head because that is where those thoughts take place.
Colours to represent emotions	What do you think that grey represents? MALIA: The uncertainty. And the not knowing. And like the not the not really happy times. I think that that's what grey represents on here. Orange is going to be confusion and blue is going to be good. yellow because its like a happy colour, purple is a, hmm, fierce colour. Red is also a fierce colour. red which is angriness RESEARCHER Why are you writing those words in red? MATTEO: Because red is an angry colour so it the colour of those feelings.	Clearly explained rationale for choice of colour. Colours described by child who talks about people and places having colours attached to them in her mind. Clearly articulates which colour is which emotion but less about to say why. Allocating a colour to difficult feelings.
Literal Representations	I probably will put green around it because we've got a big garden. White! Red and white. RESEARCHER: Why red and white? MATTEO: Saints! Southampton football club. RESEARCHER: Aha! MATTEO: It's the red and white barmy army!	Some choices are more representative of what is being shown. That is true of images and colours.

Response to completing the task	CLIVE: I think that the primary target in this situation should be people of my age. CLIVE: I feel that for me it would be more difficult but for other Autistic kids it may have been easier. RESEARCHER: Can you explain that a bit more to me? That's a useful, useful thing to say well. CLIVE: My autism isn't really that different from a normal brain function, so, I find it easier to converse with others. However, some people's autism affects them greatly so, they aren't really that good at really doing anything with other people outside their family group. So, I feel that for those children. They should have their parents explain to them what's going on, but for kids like me who's autism doesn't seriously affect them. Yes, you should do it. RESEARCHER: Super, that's helpful. Do you? Do you think you would be more honest with somebody that you don't know very well? Or do you think it's just more interesting? CLIVE: I'd say would be interesting. I think doing it with someone else other than mum is quite nice because then I'm more likely to like fully put everything. It's also sometimes like if I feel like I'm doing something like wrong. If I'm getting um, If I'm getting annoyed with like how I'm drawing it. I sometimes get a bit antsy so Mum, because I only live with Mum, Mum's like the one that kind of gets the, gets the antsy from me (unclear) argument so. So, doing it with someone other than Mum is quite useful. CLIVE: I think I've preferred this method to the original. RESEARCHER: OK, why? Why is that?	Consideration of how the person delivering the task impacts the experience.

	CLIVE: Because I much prefer drawing to general arts and crafts. I like, I like hands on crafting. I quite like the idea of like the crafty version, but then also this way was also useful as well because I'm still using like that creative, quite creative side of it so yeah. Kind of half and half. I think drawing was a better way. It's a bit more active. So. And it can make you. It could make you get your brain working and you don't fall asleep because it's so boring. It was good.	Reflections on mode of completion based on the activity they enjoy more.
Insight into strengths and challenges		
Reflecting on specific emotions for specific places	Like if I'm in a like a bad, either like a bad mood or like I'm upset I could go to the Guinea Pigs. Animals in general are just calming. Because I tend to be very tired. And a bit kind of, like miserable. It's like I don't particularly want to leave the house because it's nice and warm. I'm going to a really cold school. Where I'm like made to do things I know I need to do. But then going from school to home I'm very happy. Why is it not liking my smiley faces? Always. So very happy because it means I get to chill. Like when I'm going home I get to chill. I can kind of do what I want, sort of thing. I don't have to necessarily follow instructions. I do, but not, like as intense. Because I'm angry quite a lot at home. My heart is happy, mainly happy	This doesn't feel like a very distinct code. Maybe incorporate it somewhere else.

Awareness of personal challenges	CLIVE: Well, most of them it's because they have different interest to me, such as goofing off, buying things, texting on their phones. Those who do have similar interests don't really understand how I am. Except C. He does. Are there any things that you could put on there that you don't like and find a way represent what you don't like? MALIA: Ha ha – school work. I will draw a book and then that can be like a school book. RESEARCHER: Are there any particular subjects that you dislike more than others? MALIA: Science. Science and English. RESEARCHER: Why is that? MALIA: Because being dyslexic? It’s very - they’re wordy, significantly more wordier OK so why can a sloth describe your home to school journey? MALIA: Because I tend to be very tired. And a bit kind of, like miserable. It's like I don't particularly want to leave the house because it's nice and warm. I’m going to a really cold school. Where I’m like made to do things I know I need to do. MATTEO: No. I used to be, I used to be like the famous kid if you know what I mean. I used to be the one that, I used to be the one that everyone used to know. Used to be like (unclear) used to happen all the time in RS shall I have your photo? All the time they used to want to take photos and stuff and pictures and all that.	Not being understood by many others. Challenges of school work Reflecting on emotions in connection to going to school. Recognition of how this makes the transition from home to school more challenging A really difficult time in a previous school. Maybe the positive move away from this school set him up for a more positive response to the transition to college?
Awareness of personal strengths	CLIVE: I feel that for me it would be more difficult but for other Autistic kids it may have been easier. RESEARCHER: Can you explain that a bit more to me? That's a useful, useful thing to say well.	

	CLIVE: My autism isn't really that different from a normal brain function, so, I find it easier to converse with others. However, some people’s autism affects them greatly so, they aren't really that good at really doing anything with other people outside their family group. So, I feel that for those children. They should have their parents explain to them what's going on, but for kids like me who's autism doesn't seriously affect them. Yes, you should do it.	Suggests that his autism has a lesser impact on him than that of others.
	And kind of how strong I am. So, like it also links in with my tuba. Like how strong I have to be to like march with my tuba.	Finding positive attributes and feeling pride in them. How extra-curricular activities can provide benefits. – Intense interests?
	So, I’m in charge of music across lower and upper.	Pride in being given responsibility.
	maths is really good. Maths is a good subject because it's helps the better my maths is, the more better my music is. Because there's a lot of maths in music. My maths teacher came to my music lesson today. I played her my GCSE composition so far and she said, she said to me. You know there's so much music in the way that you've kind of thought about it and done stuff.	Pride in ability
	the last two years I got merits and distinctions which are good in Speak Out.	Pride in ability – particularly important due to S&L difficulties (expressive developmental language disorder).
	I’m quite prepared. And I think it will be good for me and I like things being organised, having a book for most lessons.	Awareness of strengths that will be of benefit to the transition
	MATTEO: BA. I did a theatre thing with them online in the summer. It was dancing, singing and acting. It was really fun. I would like to do that again. We did a performance online. I used to be in	

	XXX Choir and XXX Choir. We did a big performance at the XXX Hall. RESEARCHER: What is it about singing that you particularly enjoy? How does it make you feel? MATTEO: I love singing. It gives me joy.	How extra-curricular activities can provide benefits
Importance of Friends	It's helped me make a lot of friends. So, I made a lot of friends through like music and just being in ensembles because it means I'm surrounded by people. So, I'm out being social. I used to play rugby. And I used to play for a team so again it's like the social aspect. What on earth have I done there? So, it's just kind of like the social aspect of it. Because I'm with my friends	Importance of being social A bit of a limited code. Maybe merge? Add to support section?
Negative aspects of transition	Because I'm not either. It's not because I'm not kind of there yet. Or my mind is like choosing not to think like that far ahead in the future, I, I tend because like when my dad and stuff it's like he would always tell me something and then he wouldn't do it. So, I've kind of taught myself not to like think, like to ahead in the future or get too, like too excited for something that might not happen? I know college will happen but I've kind of taught my brain not to think too far ahead. The red is I'm late, I've got everything wrong. The green is I'm trying my best but it's not all the time working and the yellow is it doesn't matter really, um, how there, if there's anything which I don't need to do. Like sometimes I forget to make my lunch, but I can just go and buy lunch if I don't make it on time.	Not wanting to think about difficult things. Not wanting to think about difficult things Recognising things that can go wrong

	MATTEO: Excited really because I knew I had friends in there and I use to think that. I used to always feel excited because I knew I had friends there and nothing could really go wrong. At least until I met LM and then I thought (loud noise). RESEARCHER: Is that someone that was annoying? MATTEO: More than annoying. She used to be …. Me and her was like Saints and Pompey. That's how bad. You know what that means don't you? RESEARCHER: How about if you are doing something you really like – like at the train station – and you have to leave to do something that you don't like doing so much. What might that make you feel like? MATTEO: I know. Annoyed, irritated, sad, sensory overload, angry.	How particular people can make things difficult. Emotions that might be felt as part of a difficult transition.
Positive aspects of transition	Bad subjects gone. PARENT: Yeah. I think that was what was different wasn't it about OS when you moved wasn't it? Because I think, um. MATTEO: Because everyone was alike if you know what I mean. PARENT: Everyone was alike. Yeah. I think so. RESEARCHER: Yes? How did you feel when you were going to school in the mornings? Did you feel happy and excited? MATTEO: Excited really because I knew I had friends in there and I use to think that. I used to always feel excited because I knew I had friends there and nothing could really go wrong. PARENT: Are you? Are you quite confident when you are going to college? Do you feel similar when	Finding things to look forward to Reflecting on a positive change to a more suitable environment. Away from a negative one. Importance of knowing what to expect and that there were friends to support.

	you are going to college as when you were going to OS? (Matteo writes 'yes' on the screen). RESEARCHER: So, one more thing Matteo. When you first started going to college when you first started doing that transition when you were going from one to the next, what kind of feelings did you have? MATTEO: I was excited because beforehand I thought I already knew where I was going there and I always knew what it was like because beforehand I did a transition so I knew what it was like so I just thought to myself I know what I'm up against I'm quite prepared. And I think it will be good for me and I like things being organised, having a book for most lessons.	Being well prepared for the transition
Means for supporting Transitions		
People who support	RESEARCHER: What would you say the things that make it home rather than just 4 walls. CLIVE: Well. I have a love. I have loving parents there. RESEARCHER: Fabulous so, when you're feeling these tricky feelings. When you're in a situation where you're having a transition that is hard. Who or what would you say helps you the most? Are there any particular things that you know that you can do that make you feel better? Or are there any particular people that you go to that will make you feel better? CLIVE: Well, it's usually my teachers. But if not them, then my fellow pupils. RESEARCHER: OK, is there anybody specifically you can think of that you could add to your body map that would show us your support?	Teachers first then pupils. Initial support is people rather than quiet space etc.

	CLIVE: My one true friend at W – C. RESEARCHER: So, where are you going to put C? CLIVE: I'm going to put him here? RESEARCHER: OK. It looks like Charles is waving. Is he waving? CLIVE: Yes. RESEARCHER: OK, tell me why you decided to put him inside your body. CLIVE: Because he's is an important person to me. RESEARCHER: Do you think your school understands you pretty well and is pretty good at being supportive? CLIVE: Well, some of them are. Mostly either teachers, the SENCO, a few of the students who are closer to me. CLIVE: Well, most of them it's because they have different interest to me, such as goofing off, buying things, texting on their phones. Those who do have similar interests don't really understand how I am. Except C. He does. Who are the people that you think support you the most? MALIA: But Mum. Mum yeah. And then LSAs? So Dad as well My tutor and Mummy. Who is going to help you if you've got those feelings? Or what is going to help you? HARRY: My mum. Miss H and K and they are the people that have helped me move to secondary school. MATTEO: Oh. He's like, he's just my best friend forever to be	Limited number of friends but important. Importance of friendship. Identification of specific people at school. Adults first. Mum common important figure. Tutor and Mum. Mum Primary class teacher and ELSA at receiving secondary.

	honest he's just such a nice boy. He's been my, he's been so nice to me and all that. We used to play football all the time in school and all that. To be honest I haven't really seen him in a while. The last time I saw him was my birthday in July. That was the last time I saw him there.	Limited number of friends but important
	PARENT: So does that mean that friends was important to you at school? MATTEO: Yeah. Friends. Because if it wasn't for friends.	
	MATTEO: Because if it wasn't for friends in school, like school wouldn't be the same. It would just be like. It would be boring. If you like couldn't have friends in school it would be really boring, it would be like you can't do anything.	
	RESEARCHER: Thinking about a time when you have felt those feelings, what kinds of things help you to feel better and make those feelings go away. MATTEO: I don't know. I can't remember. I haven't felt them for a long time so I'm not sure. RESEARCHER: Is there an activity or an object that helps? Something like listening to music, fiddling with something, a person who helps you? MATTEO: Probably mum.	
	RESEARCHER: Are there any other people that you think have helped you a lot with transitions? MATTEO: J (support worker) helped me to walk to school by myself. I didn't use to be able to walk to school, but J helped me to. He helped me with lots of things. I have done lots of fun things with James and I'm looking forward to being able to see him again.	Mum Support worker
	MATTEO: Mr B was my LSA from year 2 to year 6. He helped me	

	with lots of things and I still see him sometimes. I went to a football match with him and other things.	Support worker
Types of support	CLIVE: It's a place where I can find sanctuary. It's really relaxing. And it's just something other than like school-work. Just a sense of kind of helping someone. It's just kind of the sense of like I've done something for someone. because I do a lot of colouring because it's like really relaxing. So, I do a lot of kind of colouring, drawing, um. Just because it's nice and relaxing to like if I've had a stressful day at school, I can come home and colour. Do you tend to listen to music with headphones at home or do you listen with your mum? MALIA: No headphones. I like Yankee candles. Yes. because you can get some very nice smelling Yankee candles. Some of them can be very relaxing, RESEARCHER: Yeah? It seems that home is a very relaxing place. That your main focus when you're at home is to be relaxed. So, I do a lot of music in my day to day life. And it's actually something that kind of keeps me going at school. Then actually I have to put a cup of tea in there first. RESEARCHER: Do you have cups of tea at school? MALIA: Yes. I do. RESEARCHER: Is that an important part of your day?	Importance of home Baking – activities. Voluntary work colouring Music Importance of home. Music

	MALIA: Yeah. I don't have it all the time, but. Some of the time I'll have like upset at school. Either I'll get one from like the Hub or if I'm very lucky Miss C, one of the upper school LSA's will make me a cup of tea. because I get in at like quarter to eight. Would you say that your Guinea Pigs are calming? Or are they entertaining or are they….? MALIA: Yeah, very calming. Like if I'm in a like a bad, either like a bad mood or like I'm upset I could go to the Guinea Pigs. Animals in general are just calming.	Animals
	Because I listen to a lot of music to like if things are hard. To like calm down or just to kind of get away from everything. And then I do a lot of colouring, but how do I draw these colours? Any people that support you or any things that support you? MALIA: So my. Guinea – oh I can't spell. My Guinea. My Guinea pigs.	
	would probably try to get through school and just go on the screen for the rest of the day.	Computer games
	know what I need to do, and I usually just do it and I do it on time.	
	They've just reassured me we've had lots of talks	Emotional support
	gave me special stuff	Feeling of being special.
	MATTEO: BA. I did a theatre thing with them online in the summer. It was dancing, singing and acting. It was really fun. I would like to do that again. We did a performance online. I used to be in XXX Choir and XXX Choir. We did a big performance at the SXXX Hall.	Performing

	RESEARCHER: What is it about singing that you particularly enjoy? How does it make you feel? MATTEO: I love singing. It gives me joy.	

C.2 Refining Codes into Themes for Child Data

Theme	**Codes**	**Description**
Representation of self *'I want to put it further away from my body. because I'm not quite there yet.'*	Choice of images Colours to represent emotions Literal representations Representative positioning on the body Response to completing the task	This is about how Body Mapping is used to represent themselves and their experiences and feelings. It includes issues about embodiment. This theme supports Body Mapping as a good tool to use for this research.
Insight into strengths and challenges *'I love singing. It gives me joy.'*	Awareness of personal challenges Awareness of personal strengths Importance of friends (Moved to support theme) Negative aspects of transition Positive aspects of transition Representing creativity (Moved into strengths code)	This is about the insight that the participants have about themselves. They are articulate and aware of their strengths and limitations both in general and in relation to transitions.
Means for supporting transitions *'If it wasn't for friends….'*	People who support Types of support	This is about the features that the participants have identified as being supportive when it comes to transitions.

C.3 Generation of Codes for Parent Data

Pros and Cons of Modality		
Online vs Paper	with the platform you were using there was an infinite zoom on there wasn't there? So, he could fit… he could zoom in until he had enough space to put, to draw what he wanted where we wanted it to go, which you couldn't do on paper.	Flexibility of software

	if a pack like that turned up I am not sure where he would have done that in our house. To lay out 6 feet of paper somewhere and then just knowing what he can be like with paint, we would have had to put down drop cloths and everything all over the place. If there's things that could be knocked over and stain and stuff like that so... Yeah, that would be a concern.	Difficulties of negotiating space and resources with paper task
	I think possibly if it hadn't been for covid, she might have chosen that she enjoyed the Body Mapping the auto draw, but I think if it hadn't been for Covid she might have gone for the whole crafty thing.	
	we are not the most arty or creative family and I thought that might be a barrier for him and I was surprised to find it wasn't	Paper task not a barrier to completion for non-arty participant
	I think that he's quite a visual learner, so I think the fact that it's visual and on the screen and it stays on the screen. I think that probably then helped him to be able to refer back to some of the other things that he. Um? Some of the other ideas that you had before.	
	I think this way he needed quite a lot of support from me to try and get what he was wanting on to the paper. Whereas I can see that if it was a larger and more real thing then that would've been good for him.	Necessity for support with online version that may not have been the case with paper.
	I think in person there would be more opportunity for him to actually be able to speak. He would well. He would have felt that there was more opportunity for him to be able to speak. Um. And to kind of go into a bit greater depth of what he. Um. How we felt and, and things	
	He kind of comes back to the; what can I spell? what can I do? how can I write it? rather than the whole getting the whole essence of it out.	

		Resources creating barrier. Unclear whether this would have been the same with paper version. Speaks to complexity of the task with lots going on at once.
Parent vs Researcher	I think you would get a very different response. If you got me or his mother to do it, than if you were doing it, there are some things people are happier talking to strangers about. And some things they are happier talking to their relatives about, and that's going to vary with people.	Different but not necessarily better?
	I think you got more openness from her because it wasn't me.	Openness
	She doesn't hide anything from me, but she might not have felt quite as able or found it as easy to be open and honest and stuff.	Honesty
	The one observation I had was a lot of that came because he was having a conversation with somebody other than me.	A different person to talk to stimulates different conversation
	it would be the conversation with somebody other than his normal communication support whoever that might be his parent or whoever. I don't think we would have got as much out of it if he had done the whole thing with me. I think we would have got a lot less	A definite comment in favour of researcher leading task rather than parent
Benefits of Taking Part		
Pride	He said he was quite proud of his picture So, he showed me the picture and he pointed out a few of the things as to why he drew them, or what he thought so that was quite good. He was quite proud of what he produced and wanted to show me. He didn't talk about all of it, but he was quite chuffed.	Clear benefit to have produced artefact that induces pride

	She was very proud to show off what she'd done I think it's really nice to have something there that's visual that you can kind of then potentially even look back on and think actually right. you know, I, I made that and that was that was that was a, a really detailed look into how I was feeling at that particular moment in time,	Pride in creating something that could have lasting meaning.
Enjoyment	He definitely enjoyed doing it. So, he enjoyed the process. She really enjoyed doing it and felt really relaxed.	
Ongoing Communication	If anything, it provided some more conversations with Malia and I after, as you know, opened up more conversations. She chose to talk to me about what she put on there. Mum, you know why I put that? Or you know she didn't go into all of it 'cause I didn't say she had to, but she chose to tell me some of it. so he showed me the picture and he pointed out a few of the things as to why he drew them, or what he thought so that was quite good. It's something I could get her to do so she could do it to let me know what was going on or something. some of the things that have come out of that conversation have led to subsequent conversations since that would be really helpful so perhaps	Stimulated continued conversation which could be beneficial. Important to think about implications of this if the task brings up more challenging issues. Signposting to support will be important. Considering using the technique to help with future difficult conversations. Helpful as has stimulated further conversation.

	beyond even what you were aiming for it to do it has done so it has been really helpful.	Link benefits and challenges as there are overlaps
Challenges of Taking Part		
Choices	I was fascinated by some of the choices he made one of the things he struggles with is making choices and making decisions and depending on his mood or the time of day or everything else that's going on in his life at the time that can be as simple as what to eat for breakfast so I was worried that he was going to struggle to make the choices about what to say, what to talk about and what materials to use.	Pros and cons of choices. Despite this comment participant was quite decisive about how to complete tasks
Abstract task	Across the range of the autistic spectrum you've got differing levels of concreteness. I would say he's quite good at being abstract. Understanding the boundary between self and other and things like that. I think I can see that being an issue. So, it might not be just an autistic issue, it might just be a; some people can do it, and some people just live a very concrete life and don't consider that sort of thing. It was good for Matteo to try it as a prompt, for Matteo to try and think about where he might have feelings and, and to try and link those things together. It's something that he would find particularly difficult. You probably would notice when he answered questions that that he, he couldn't understand where those feelings were within his body, so it was good for him to try and do that, but I think it's something that he would find really, really tricky.	Parental concern about children's ability to access abstract nature of the task. Despite this all participants completed all tasks. There are no wrong choices with how to complete tasks so no expectations about how literal or abstract it was necessary to be. The inclusion of the figure at the centre of the map means that decisions have to be made about where to put things which may also have taken the pressure off.

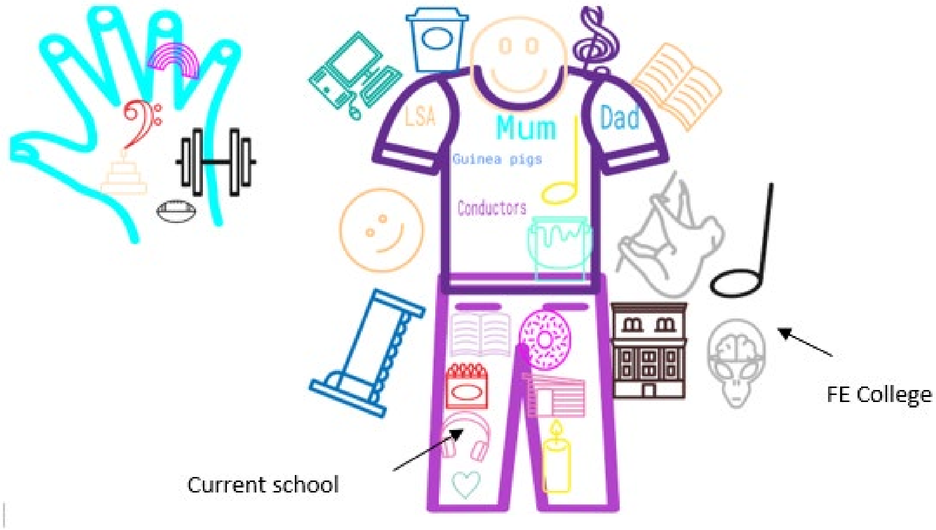
	He does find kind of this arts and this sort of slightly more abstract way of thinking really hard	
Supporting Communication		
Distraction from questions	He's also introverted, so that becomes quite the effort after a while. And so, I think that the drawing probably gave him a bit of an outlet for the introversion as well. I really liked the sound of it because it was a really good way of gaging thoughts and feelings without the child, necessarily whatever age of the child, realizing what they were doing? I felt it was a really clever way to get somebody to talk. I think because she was doing something creative, she felt more relaxed and … Just able to, sort of, she felt more. A sort of an interview where someone else was helping to make that visual would be, would be good. I think for him to imagine something,	Adding the drawing task took the pressure off answering questions. More time to think rather than having to answer straight away. Possibility of someone else doing the drawing while participant answered the questions to support with overload of tasks and resources
Engagement/Focus	You got him to just sit here and talk to you for 40 minutes. You gave him something else to focus on that wasn't a person. Yeah, I think because I think if he if he wasn't [engaged], you have known that because he would have wanted to stop. So, you know if he if he really doesn't like something he will, he will kind of just say no I've had enough now thanks. The fact that he kept going for quite a long time he that that's a good sign.	Adding creative task increased focus.

C.4 Refining Codes into Themes for Parent Data

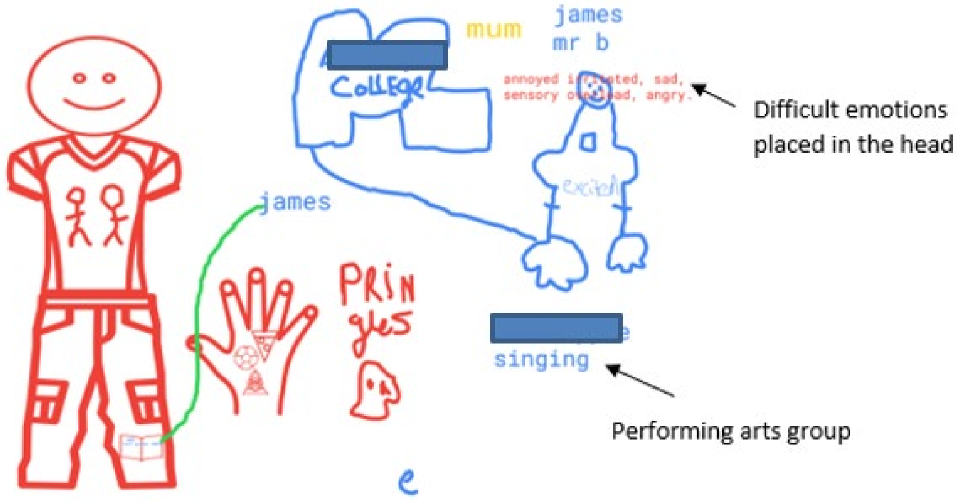
Theme	**Codes**	**Description**
Pros and cons of modality *'a lot of that came because he was having a conversation with somebody other than me.'*	Online vs paper Parent vs researcher	This speaks to the way the research is designed. Is one method superior to the other? Is it important to have the researcher's input? This follows on in part from the initial pilot study and reinforces the importance of researcher input rather than having parents lead the task then feed-back.
Benefits and challenges of taking part		
Benefits *'She was very proud to show off what she'd done.'*	Pride Enjoyment Ongoing communication	Did the participants value taking part? Parental perspective on this quite honest. Positive feedback, particularly in how it was the start of a conversation in some cases rather than a stand-alone task.
Challenges *'He does find kind of this arts and this sort of slightly more abstract way of thinking really hard.'*	Choices Abstract task	Recognition that what was being asked was difficult in some cases. Despite this all participants were able to complete all tasks successfully. Maybe underestimated by parents? Or due to a lack of parental understanding about what was wanted from the task.
Supporting communication *'I felt it was a really clever way to get somebody to talk.'*	Distraction from questions Engagement/focus on task	Positive feedback about this supporting the participants to engage in the questions. Having something to slow the conversation, cover thinking time and take the pressure off eye contact etc seemed to be helpful. In some cases the length of time the participant focused on the task was more than expected.

Appendix D Pilot Phase Body Mapping Images

D.1 Malia's Body Map



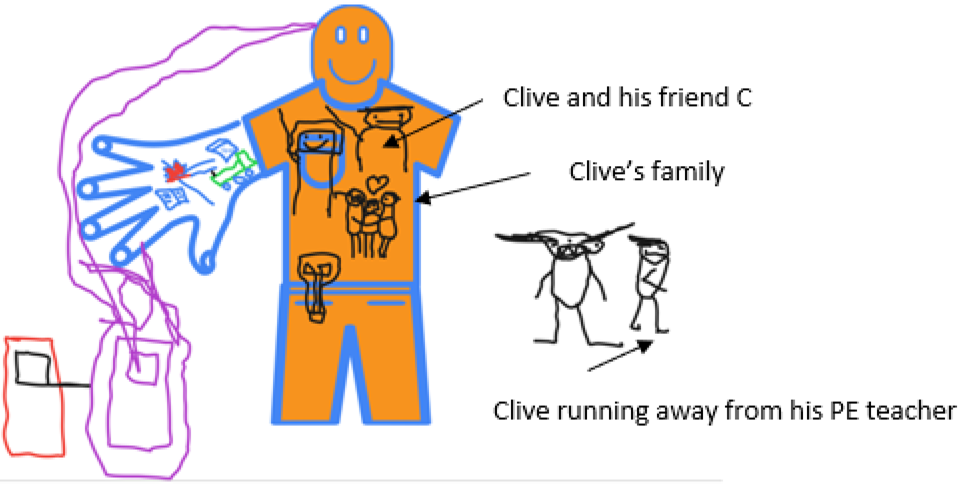
D.2 Matteo's Body Map



D.3 Clara's Body Map

Link between home and primary

D.4 Clive's Body Map

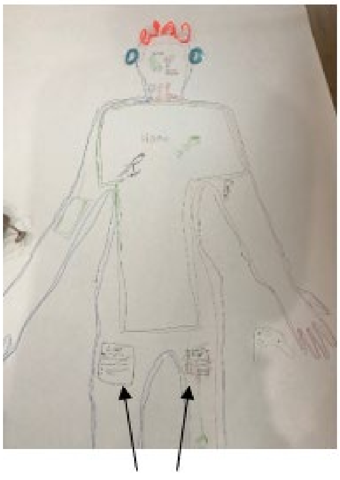


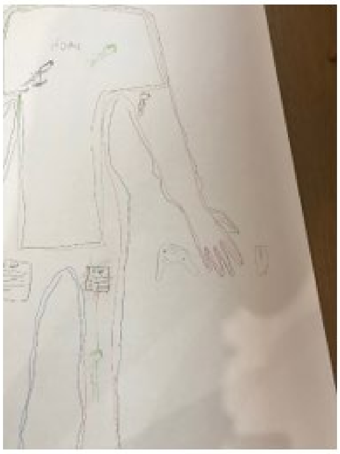
Clive and his friend C

Clive's family

Clive running away from his PE teacher

D.5 Harry's Body Map





Appendix E Ethics Information for Substantive Project

E.1 Application

ERGO II Ethics application form – FELS Committee

9. Applicant Details

1.1 Applicant name	Chloe East
1.2 Supervisor	Hanna Kovshoff, Sarah Parsons
1.3 Other researchers / collaborators (if applicable): *Name, address, email*	n/a

10. Study Details

2.1 Title of study	A participatory project to creatively support autistic children's transitions from primary to secondary school
2.2 Type of project (e.g. undergraduate, Masters, Doctorate, staff)	Doctorate
2.4 Proposed start date (must match date stated in ERGO)	3.5.21
2.5 Proposed end date (must match date stated in ERGO)	31.12.22

2.6 Briefly describe the rationale for carrying out this project and its specific aims and objectives.

It is estimated that the prevalence of autism is one in 54 (Maenna et al., 2020). With around 644,000 children in year 6 in 2019, this means that over 10,000 autistic children transitioned to secondary school in England in September 2020.

The transition to secondary school can be very challenging for autistic children (Nuske et al., 2019). It can lead to problems with mental health (Fortuna, 2014; Hannah & Topping, 2012). Despite the evidence to suggest the challenging nature of transitions, there is little research looking at resources that can support them.

Autistic girls are underdiagnosed and underrepresented in the literature (Gould, 2017; Lai et al., 2015). Many girls mask their differences (Bargiela et al., 2016), often in an attempt to fit in socially (Tierney et al., 2016). The difference between autistic and neurotypical girls is particularly challenging during the development of the complex social relationships that establish during adolescence (Cridland et al., 2014). This means that the challenges of the primary to secondary transition for many autistic girls are different to those experienced by autistic boys therefore this project will investigate transitions from the perspective of autistic girls.

The social model of disability argues that society disables individuals by failing to offer the necessary provisions for them (Oliver, 1992). The neurodiversity movement supports this assertion and focuses on autism as a difference, not a deficit (Milton & Bracher, 2013). Together they advocate for the importance of including disabled voices in research. This project will use a participatory design to ensure the voices of autistic children are central to it and will incorporate the use of creative methods to support the voices of young people who may have different communication preferences.

Aims:

1. To develop creative resources to support the primary to secondary transition in a co-constructed project with autistic young people.
2. To understand the views and experience of autistic young people participating as co-researchers in a research project.

Objectives:

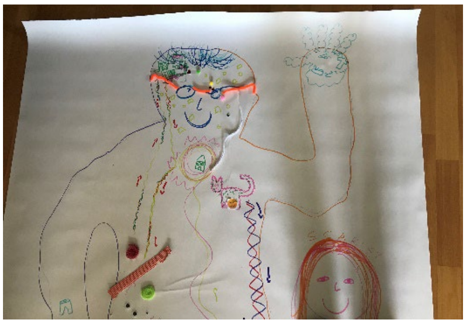
1. To work in participation with autistic YP in a collaborative and creative way
2. To design resources that can support autistic children to have a more positive experience in the transition from primary to secondary school which draws on the experiences of the co-researchers.
3. To reflect on the experiences of working on a participatory project for all members.

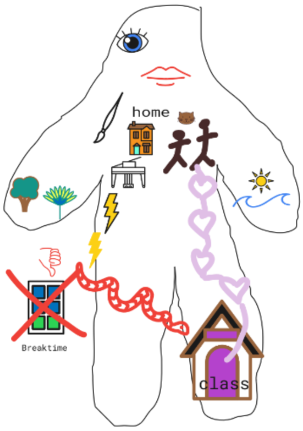
2.7 Provide a brief outline of the basic study design. Outline what approach is being used and why.

This study comprises a participatory research design to produce the transition resources, with qualitative methods used to capture the experiences of co-researchers through their participation. These qualitative methods will include semi-structured interviews, focus groups and use of Body Mapping. (Evaluation of the resources created will also be undertaken but the methods for this will be designed as part of the project and will therefore be outlined in a future ethics application.)

Body Mapping is a creative process which involves participants creating a representation of themselves onto which they draw picture or symbols to represent events or emotions. Participants will be able to do this either using an online drawing tool: https://www.autodraw.com/ or on paper. See below for example body maps. All participants will be sent a pack of materials that they can use for the task.

Participants will be asked to represent themselves, their schools, and their memories of the primary to secondary transition as they experienced it.





2.8 What are the key research question(s)? Specify hypotheses if applicable.

1. What are the experiences of autistic girls of the transition from primary to secondary school?
2. What do autistic girls think would support the transitions of other young people?
3. What are the views of autistic girls on co-researching as part of a participatory project?

The next part of the project to be addressed in a future ethics application will look at how effective the resources created in supporting the transitions from primary to secondary school for autistic children are.

11. Sample and setting

3.1 Who are the proposed co-researchers and where are they from (e.g. fellow students, club members)? List inclusion / exclusion criteria if applicable.

Between 5 and 10 autistic girls between the ages of 11 and 18 (school year 7 – 12). Co-researchers will be in mainstream education and following a mainstream curriculum.

3.2. How will the co-researchers be identified and approached? Provide an indication of your sample size. If co-researchers are under the responsibility of others (e.g., parents/carers, teachers) state if you have permission or how you will obtain permission from the third party).

Project posters will be displayed online, including social media sites, and on community noticeboards. (See attached document).

Project posters and information packs will be sent to local schools and 6th form colleges.

The information pack includes:
Project outline
Co-researcher information sheet
Initial questionnaire

3.3 Describe the relationship between researcher and sample. Describe any relationship e.g., teacher, friend, boss, clinician, etc.

None

3.4 How will you obtain the consent of co-researchers? (*please upload a copy of the consent form if obtaining written consent***) NB. Consent form is not needed for studies collecting data online.**

All co-researchers will be required to sign a consent form before taking part in the study. A consent form will be emailed with the information sheet prior to the first session. Participants will need to complete this and either email back a copy. Any participants who do not have the technology to do this will have a form posted to them with a stamped addressed envelope to return the completed form. Any co-researchers below the age of 16 will complete an assent form and their parent will sign a consent form for their child to participate. Consent and assent forms attached.

3.5 Is there any reason to believe co-researchers may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

No. Under 16’s will also require parental consent.

12. Research procedures, interventions and measurements

4.1 Give a brief account of the procedure as experienced by the co-researcher. Make it clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear the total demands made on co-researchers, including time and travel.
Upload copies of questionnaires and interview schedules to ERGO.

Once a young person expresses an interest in the project, I will ensure they have a copy of the information pack. This include a co-researcher information form, consent/assent forms and an initial questionnaire (See attached files).

Co-researchers will then be invited to an initial individual meeting on Microsoft Teams where the lead researcher will outline the parameters of the project and the way it will be structured. At this point they will complete their assent/consent forms. Clear details of the first group meeting will be given so co-researchers know what to expect. Co-researchers will be able at this point to share preferences to how they participate in the first group meeting. This may be with or without camera and communicating via the microphone or chat function.

As this is a participatory project the framework for the meetings will be generated by the group after the first group meeting. The plan below is a suggested structure which is subject to change. The plan for the subsequent meeting will be developed at the end of each session and sent out to co-researchers at least three days in advance.

Meeting 1:

- welcome and introductions
- ensure all co-researchers are clear on participation in the research and are aware that they can leave the project at any time
- confirm aims and objectives for the project
- discuss and agree a schedule for meeting during the project
- discuss different roles within the project
- discuss any information to be gathered before next meeting
- complete first Body Mapping task
- create an agenda for the next meeting

Each subsequent meeting will involve participating in a Body Mapping task as well as some discussion work. See attached interview schedule.

It is anticipated that there will be a maximum of 10 meetings together over a 3-month period, that will take place online and be for a maximum of 60 minutes. However, this will be discussed by the working group and may be adjusted according to the preferences of the group.

At the end of this stage of the project, each co-researcher will be invited to take part in an individual qualitative interview (see attached interview schedule). This will give them the opportunity to feedback on their experiences as a co-researcher.

Co-researchers will be invited to attend in person group meeting at the University at the end of the group online sessions accompanied by a parent or guardian. This will be an opportunity for the YP to share their body maps with the group as well as to celebrate their achievement at completing this stage of the research. Refreshments will be provided. Information about dietary and allergy requirements will be collected and adhered to and detailed information about the venue and programme for the evening will be sent. See attached documentation. The meeting will take place at the university in Building 44. It will be held in the evening to fit around school and work requirements and will be scheduled for 2 hours. Any health and safety requirements of the venue will be adhered to. All Covid-19 regulations will be adhered to. All attendees will be asked to take a lateral flow test prior to the event if appropriate at that time. A risk assessment for this is attached to this application.

Co-researchers will be then given the opportunity to participate in the next stage of the project which will involve data collection and analysis on the resources created by the group. It will be made clear that they are under no obligation to participate in the next stage of the project. They will not be asked to give an answer straight away but to respond to an email if they would like to participate. A separate ethics application will cover the next part of the project and will include a further consent process.

4.2 Will the procedure involve deception of any sort? If yes, what is your justification?

No

4.3. Detail any possible (psychological or physical) discomfort, inconvenience, or distress that co-researchers may experience, including after the study, and what precautions will be taken to minimise these risks.

There is a small possibility of psychological discomfort or distress by co-researchers discussing their experiences of transitioning to secondary school. If this occurs, they will be directed to appropriate support such as parents, school, or college support services.

The information sheet explains that should co-researchers feel psychological discomfort or distress during the program, or if they find the project inconvenient, they are free to withdraw from the study at any time without needing to explain.

Co-researchers will also be reminded that they can withdraw from the study up until the qualitative interview has been recorded.

4.4 Detail any possible (psychological or physical) discomfort, inconvenience, or distress that YOU as a researcher may experience, including after the study, and what precautions will be taken to minimise these risks.

There is a small possibility of psychological discomfort or distress of the researcher during the program if co-researchers find it difficult to reach agreement on aspects of the project. Additionally, the researcher may be inconvenienced by co-researchers not attending meetings or fulfilling tasks as agreed. This risk will be minimised by arranging debriefing sessions with supervisors as necessary.

4.5 Explain how you will care for any co-researchers in ‘special groups’ e.g., those in a dependent relationship, are vulnerable or are lacking mental capacity), if applicable:

Any co-researchers under 16 will require a parent to consent to their involvement in the project as well as completing their own assent form.

4.6 Please give details of any payments or incentives being used to recruit co-researchers, if applicable:

n/a

5. Access and storage of data

5.1 How will co-researcher confidentiality be maintained? Confidentiality is defined as non-disclosure of research information except to another authorised person. Confidential information can be shared with those already party to it and may also be disclosed where the person providing the information provides explicit consent. Consider whether it is truly possible to maintain a co-researcher's involvement in the study confidential, e.g. can people observe the co-researcher taking part in the study?

In any written information or reports, confidentiality will be maintained by giving each co-researcher a pseudonym. Therefore, it will not be possible to link specific data to specific co-researchers in written information or reports. However, co-researchers will be given the choice to be identified as a member of the working group in the resource or any publications associated with the resource if desired. Any co-researchers under the age of 16 will need parental consent for this identification.

Demographic information containing identifying information of each co-researcher will be stored separately from anonymised data sets. Paper copies of information will be kept separately in locked filing cabinets which only the research team can access, and digital files will be stored separately on university computers using encryption and password protection.

5.2 How will personal data and study results be stored securely during and after the study. Who will have access to these data?

Only members of the research team will have access to the raw data including Voluntary Research Assistants who will sign a confidentiality agreement.

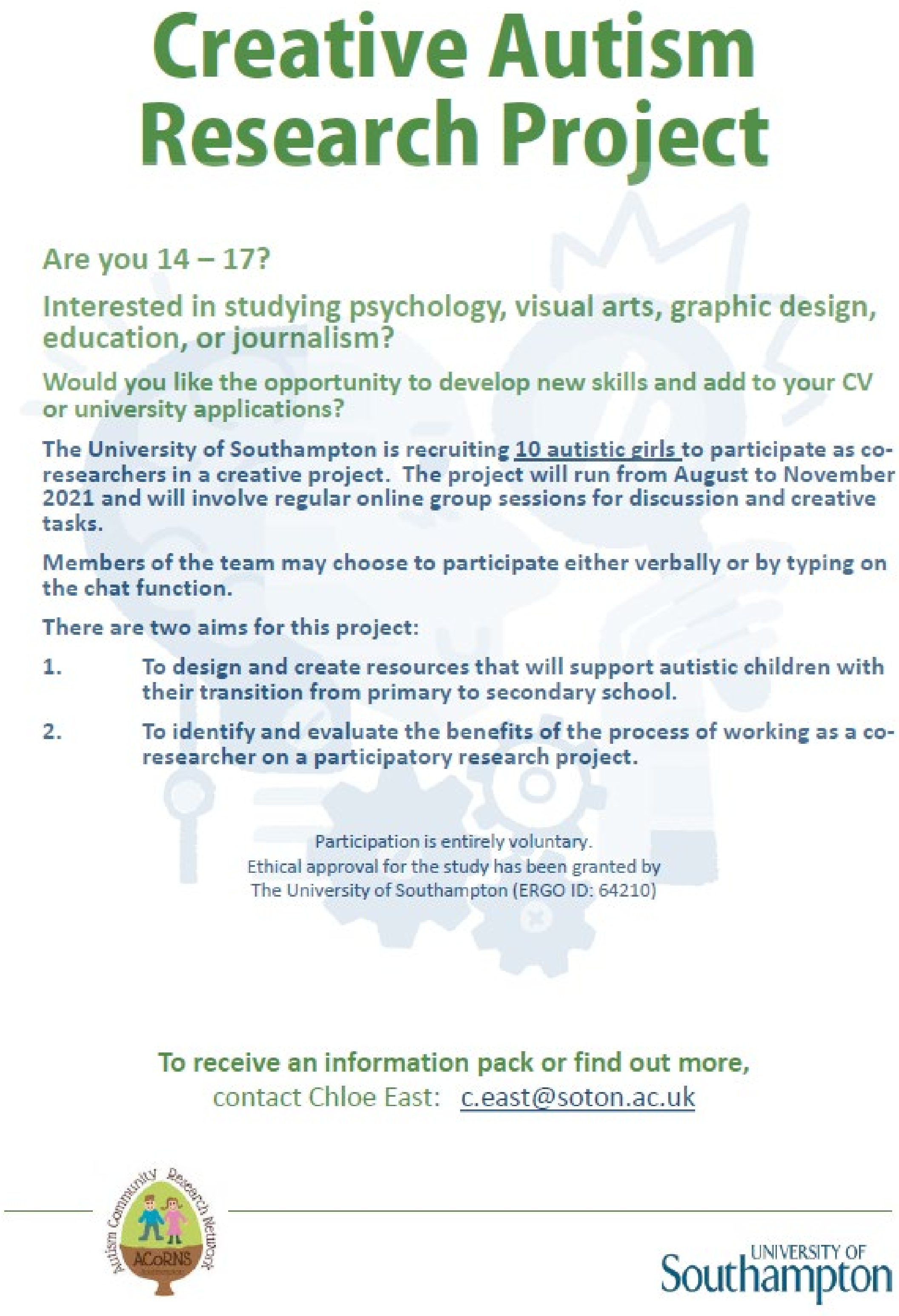
Personalised hard copies of data will be stored securely in a locked filing cabinet and digital data will be kept on a university server.

5.3 How will it be made clear to co-researchers that they may withdraw consent to participate? Please note that anonymous data (e.g. anonymous questionnaires) cannot be withdrawn after they have been submitted. If there is a point up to which data can be withdrawn/destroyed e.g., up to interview data being transcribed please state this here.
The information sheet will clearly state that co-researchers may withdraw consent at any time in the study up until the qualitative interview has been recorded. Co-researchers who choose to complete the next part of the project will sign a new assent/consent form for that stage (to be included on amendment to the project once the data collection process has been designed).

6. Additional Ethical considerations

6.1. Are there any additional ethical considerations or other information you feel may be relevant to this study?
No

E.2 Recruitment Poster



Creative Autism Research Project

Are you 14 – 17?

Interested in studying psychology, visual arts, graphic design, education, or journalism?

Would you like the opportunity to develop new skills and add to your CV or university applications?

The University of Southampton is recruiting 10 autistic girls to participate as co-researchers in a creative project. The project will run from August to November 2021 and will involve regular online group sessions for discussion and creative tasks.

Members of the team may choose to participate either verbally or by typing on the chat function.

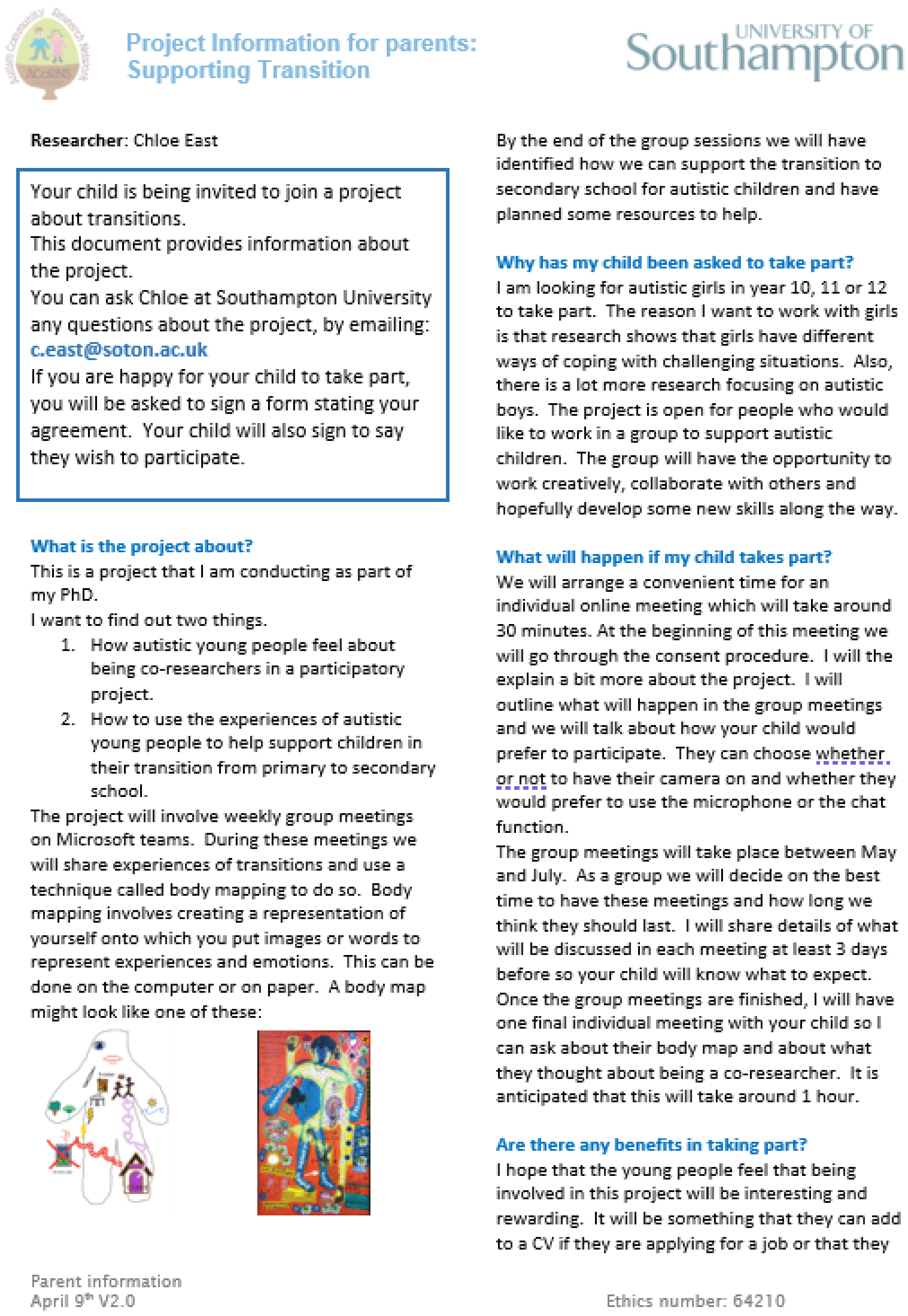
There are two aims for this project:

1. **To design and create resources that will support autistic children with their transition from primary to secondary school.**
2. **To identify and evaluate the benefits of the process of working as a co-researcher on a participatory research project.**

Participation is entirely voluntary.
Ethical approval for the study has been granted by
The University of Southampton (ERGO ID: 64210)

To receive an information pack or find out more,
contact Chloe East: c.east@soton.ac.uk

E.3 Parent Information Sheet



Project Information for parents: Supporting Transition

Researcher: Chloe East

Your child is being invited to join a project about transitions.
This document provides information about the project.
You can ask Chloe at Southampton University any questions about the project, by emailing: c.east@soton.ac.uk
If you are happy for your child to take part, you will be asked to sign a form stating your agreement. Your child will also sign to say they wish to participate.

What is the project about?

This is a project that I am conducting as part of my PhD.
I want to find out two things.

1. How autistic young people feel about being co-researchers in a participatory project.
2. How to use the experiences of autistic young people to help support children in their transition from primary to secondary school.

The project will involve weekly group meetings on Microsoft teams. During these meetings we will share experiences of transitions and use a technique called body mapping to do so. Body mapping involves creating a representation of yourself onto which you put images or words to represent experiences and emotions. This can be done on the computer or on paper. A body map might look like one of these:

By the end of the group sessions we will have identified how we can support the transition to secondary school for autistic children and have planned some resources to help.

Why has my child been asked to take part?

I am looking for autistic girls in year 10, 11 or 12 to take part. The reason I want to work with girls is that research shows that girls have different ways of coping with challenging situations. Also, there is a lot more research focusing on autistic boys. The project is open for people who would like to work in a group to support autistic children. The group will have the opportunity to work creatively, collaborate with others and hopefully develop some new skills along the way.

What will happen if my child takes part?

We will arrange a convenient time for an individual online meeting which will take around 30 minutes. At the beginning of this meeting we will go through the consent procedure. I will the explain a bit more about the project. I will outline what will happen in the group meetings and we will talk about how your child would prefer to participate. They can choose whether or not to have their camera on and whether they would prefer to use the microphone or the chat function.
The group meetings will take place between May and July. As a group we will decide on the best time to have these meetings and how long we think they should last. I will share details of what will be discussed in each meeting at least 3 days before so your child will know what to expect.
Once the group meetings are finished, I will have one final individual meeting with your child so I can ask about their body map and about what they thought about being a co-researcher. It is anticipated that this will take around 1 hour.

Are there any benefits in taking part?

I hope that the young people feel that being involved in this project will be interesting and rewarding. It will be something that they can add to a CV if they are applying for a job or that they

Parent information
April 9th V2.0

Ethics number: 64210

could include on a college or university application form. Your child can decide if they would like their name to appear as a co-researcher on any materials published as a result of the project. Your permission will be required for this. Their data will be linked to a pseudonym so if they choose to be named it will not be possible to tell which data is theirs.

Are there any risks involved?

Not really. If they had a difficult time during their transition to secondary school, they may feel upset talking about it. It is up to your child how much they share with the group. Group members will be encouraged not to discuss the information shared in the group sessions to anyone else but this cannot be guaranteed. Organisations that they may want to talk to will be shared on the Team page.

What data will be collected?

We will:

- Make a record of your child's name and date of birth. These will be kept securely for our records and will not be linked to your child's data.
- record the group sessions to keep a record of the ideas we generate. These recordings will be deleted once they have been transcribed.
- keep a copy of the body map
- keep a record of the young people's views of being a co-researcher
- send them a summary of what we find out
- make that summary available on our website for other people to read

How will we safeguard your data?

Your child's name will be removed from all your data and replaced with a pseudonym for identification. Hard copies of transcripts or body maps will be kept in a locked filing cabinet. Data stored digitally will be kept on university computers using encryption and password protection. 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 we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your child's information, as a research participant, strictly confidential.

Will anyone else know my child has taken part?

No-one will know they have taken part in the project unless they choose to. We will not include your child's name in anything we write about the project if they don't want us to, but if they would like to have their name included as co-researcher they can do. Your permission will need to be given for them to be named on the research.

Do they have to take part?

No. This is a decision for you and your child and I don't mind either way. If they decide to take part, I will ask you both to sign a consent form.

What happens if I change my mind?

You can change your mind at any time before 31st August 2021 without giving a reason. If you do, your child's data, including transcripts of what will be deleted. Please just let me know. My contact details are: c.east@soton.ac.uk

What will happen to the results of the research?

We will write a short report to put up on our website. There may also be a longer report that we want to write about the project to let other people know what we have found out. This may include quotes from your child which will be anonymised. If we share pictures of your child's body map, we will cover any identifying details.

What do I do if I want to take part?

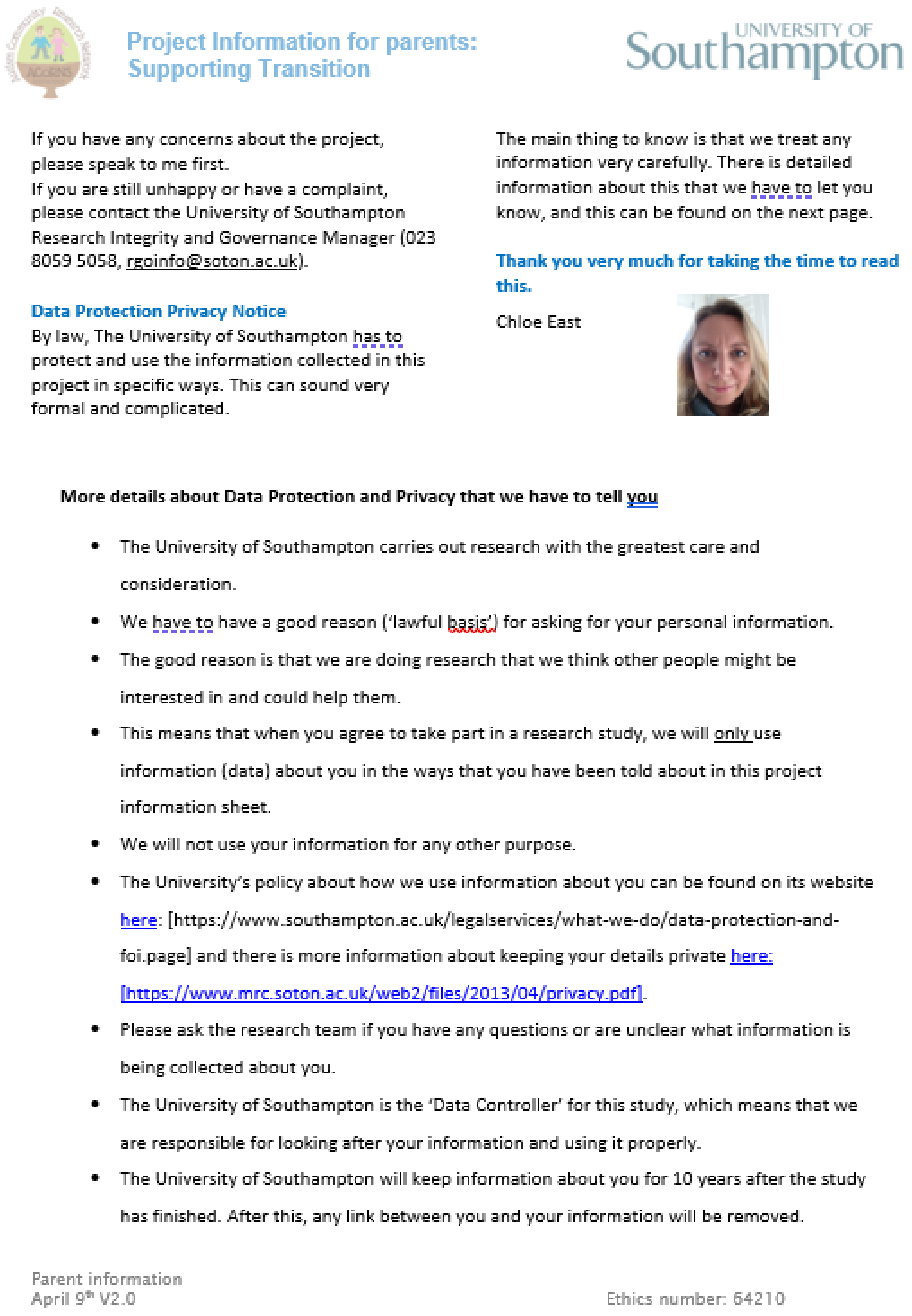
Just email me on c.east@soton.ac.uk and I will be in touch to arrange the first meeting.

Where can I get more information?

Please ask me if you have any questions about the project: c.east@soton.ac.uk

You can also contact my supervisor - Hanna Kovshoff at the University: H.Kovshoff@soton.ac.uk or telephone: (023) 8059 4593

What happens if there is a problem?



Project Information for parents: Supporting Transition

UNIVERSITY OF Southampton

If you have any concerns about the project, please speak to me first.
If you are still unhappy or have a complaint, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

By law, The University of Southampton has to protect and use the information collected in this project in specific ways. This can sound very formal and complicated.

The main thing to know is that we treat any information very carefully. There is detailed information about this that we have to let you know, and this can be found on the next page.

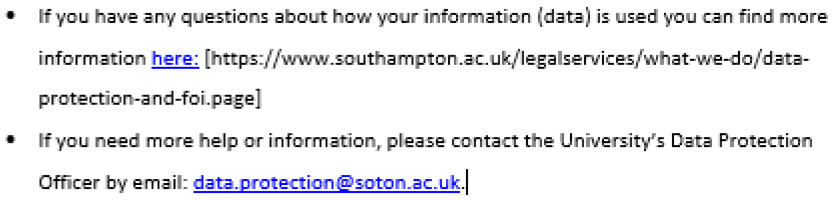
Thank you very much for taking the time to read this.

Chloe East

More details about Data Protection and Privacy that we have to tell you

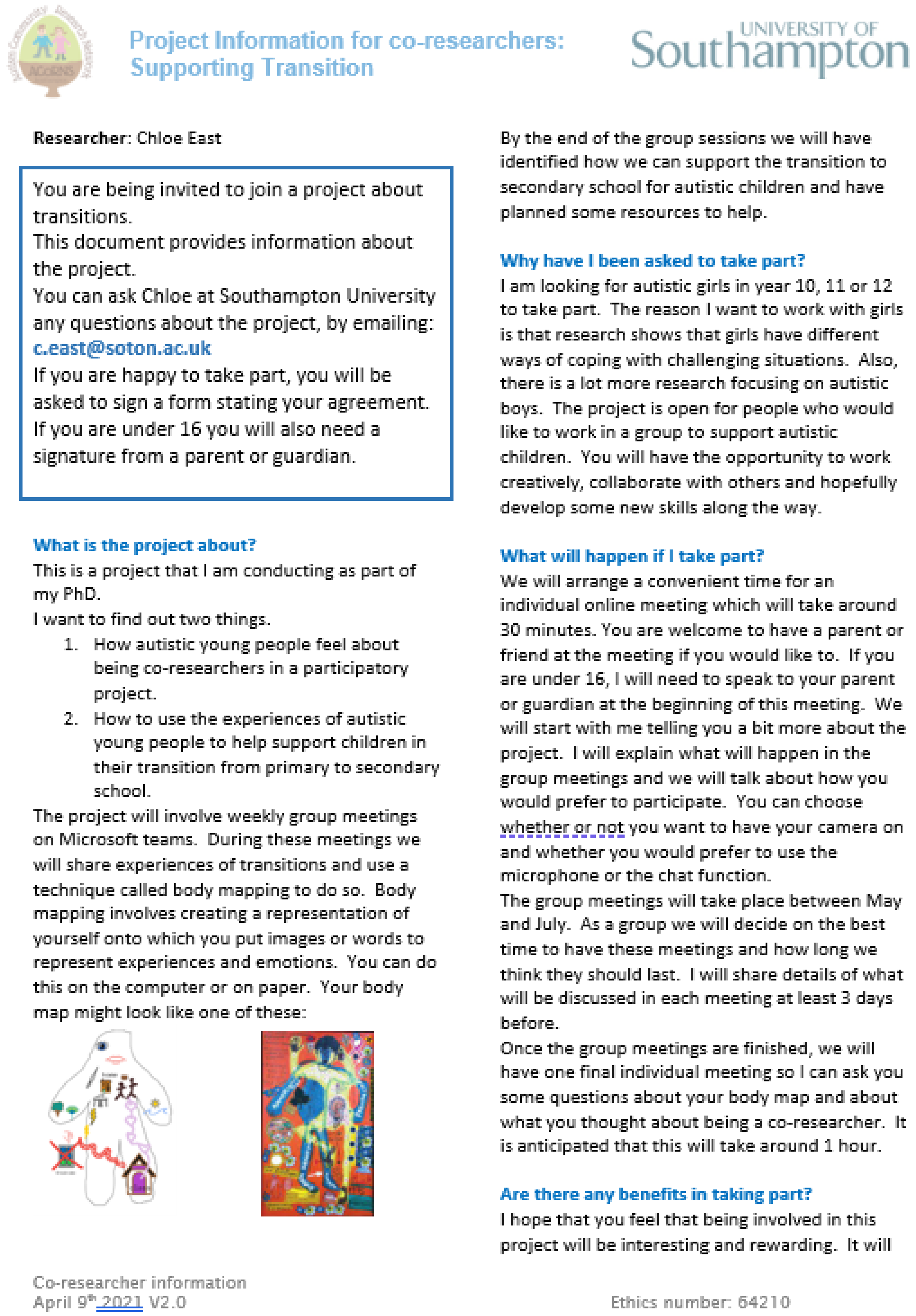
- The University of Southampton carries out research with the greatest care and consideration.
- We have to have a good reason ('lawful basis') for asking for your personal information.
- The good reason is that we are doing research that we think other people might be interested in and could help them.
- This means that when you agree to take part in a research study, we will only use information (data) about you in the ways that you have been told about in this project information sheet.
- We will not use your information for any other purpose.
- The University's policy about how we use information about you can be found on its website here: [https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page] and there is more information about keeping your details private here: [https://www.mrc.soton.ac.uk/web2/files/2013/04/privacy.pdf].
- Please ask the research team if you have any questions or are unclear what information is being collected about you.
- 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 Southampton will keep information about you for 10 years after the study has finished. After this, any link between you and your information will be removed.

Parent information
April 9th V2.0 Ethics number: 64210



- If you have any questions about how your information (data) is used you can find more information here: [https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page]
- If you need more help or information, please contact the University's Data Protection Officer by email: data.protection@soton.ac.uk.

E.4 Child Information Sheet



Project Information for co-researchers: Supporting Transition

Researcher: Chloe East

You are being invited to join a project about transitions.
This document provides information about the project.
You can ask Chloe at Southampton University any questions about the project, by emailing: c.east@soton.ac.uk
If you are happy to take part, you will be asked to sign a form stating your agreement.
If you are under 16 you will also need a signature from a parent or guardian.

What is the project about?

This is a project that I am conducting as part of my PhD.
I want to find out two things.

1. How autistic young people feel about being co-researchers in a participatory project.
2. How to use the experiences of autistic young people to help support children in their transition from primary to secondary school.

The project will involve weekly group meetings on Microsoft teams. During these meetings we will share experiences of transitions and use a technique called body mapping to do so. Body mapping involves creating a representation of yourself onto which you put images or words to represent experiences and emotions. You can do this on the computer or on paper. Your body map might look like one of these:

By the end of the group sessions we will have identified how we can support the transition to secondary school for autistic children and have planned some resources to help.

Why have I been asked to take part?

I am looking for autistic girls in year 10, 11 or 12 to take part. The reason I want to work with girls is that research shows that girls have different ways of coping with challenging situations. Also, there is a lot more research focusing on autistic boys. The project is open for people who would like to work in a group to support autistic children. You will have the opportunity to work creatively, collaborate with others and hopefully develop some new skills along the way.

What will happen if I take part?

We will arrange a convenient time for an individual online meeting which will take around 30 minutes. You are welcome to have a parent or friend at the meeting if you would like to. If you are under 16, I will need to speak to your parent or guardian at the beginning of this meeting. We will start with me telling you a bit more about the project. I will explain what will happen in the group meetings and we will talk about how you would prefer to participate. You can choose whether or not you want to have your camera on and whether you would prefer to use the microphone or the chat function.
The group meetings will take place between May and July. As a group we will decide on the best time to have these meetings and how long we think they should last. I will share details of what will be discussed in each meeting at least 3 days before.
Once the group meetings are finished, we will have one final individual meeting so I can ask you some questions about your body map and about what you thought about being a co-researcher. It is anticipated that this will take around 1 hour.

Are there any benefits in taking part?

I hope that you feel that being involved in this project will be interesting and rewarding. It will

Co-researcher information
April 9th 2021 V2.0

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be something that you can add to a CV if you are applying for a job or that you could write about on a college or university application form. You can decide if you would like your name to appear as a co-researcher on any materials published as a result of the project. Your data will be linked to a pseudonym so if you choose to be named it will not be possible to tell which data is yours.

Are there any risks involved?

Not really. If you had a difficult time during your transition to secondary school, you may feel upset talking about it. It is up to you how much you share with the group. Group members will be encouraged not to discuss the information shared in the group sessions to anyone else but this cannot be guaranteed. Organisations that you may want to talk to will be shared on the Team page.

What data will be collected?

We will:

- Make a record of your name and date of birth. These will be kept securely for our records and will not be linked to your data.
- record the group sessions to keep a record of the ideas we generate. These recordings will be deleted once they have been transcribed.
- keep a copy of your body map
- keep a record of your views of being a co-researcher
- send you a summary of what we find out
- make that summary available on our website for other people to read

How will we safeguard your data?

Your name will be removed from all your data and replaced with a pseudonym for identification. Hard copies of transcripts or body maps will be kept in a locked filing cabinet. Data stored digitally will be kept on university computers using encryption and password protection. 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 we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential.

Will anyone else know I have taken part?

No-one will know you have taken part in the project unless you want them to. We will not include your name in anything we write about the project if you don't want us to, but if you would like to have your name included as co-researcher you can do. If you are under 16 we will need to get permission from a parent or guardian to use your name.

Do I have to take part?

No. This is your decision and I don't mind either way. If you decide to take part, I will ask you to sign a consent form. If you are under 16 a parent or guardian will also need to sign.

What happens if I change my mind?

You can change your mind at any time before 31st August 2021 without giving a reason. If you do, your data, including transcripts of what you have said and images of your body map, will be deleted. Please just let me know. My contact details are: c.east@soton.ac.uk

What will happen to the results of the research?

We will write a short report to put up on our website. There may also be a longer report that we want to write about the project to let other people know what we have found out. This may include quotes from you which will be anonymised. If we share pictures of your body map, we will cover any identifying details.

What do I do if I want to take part?

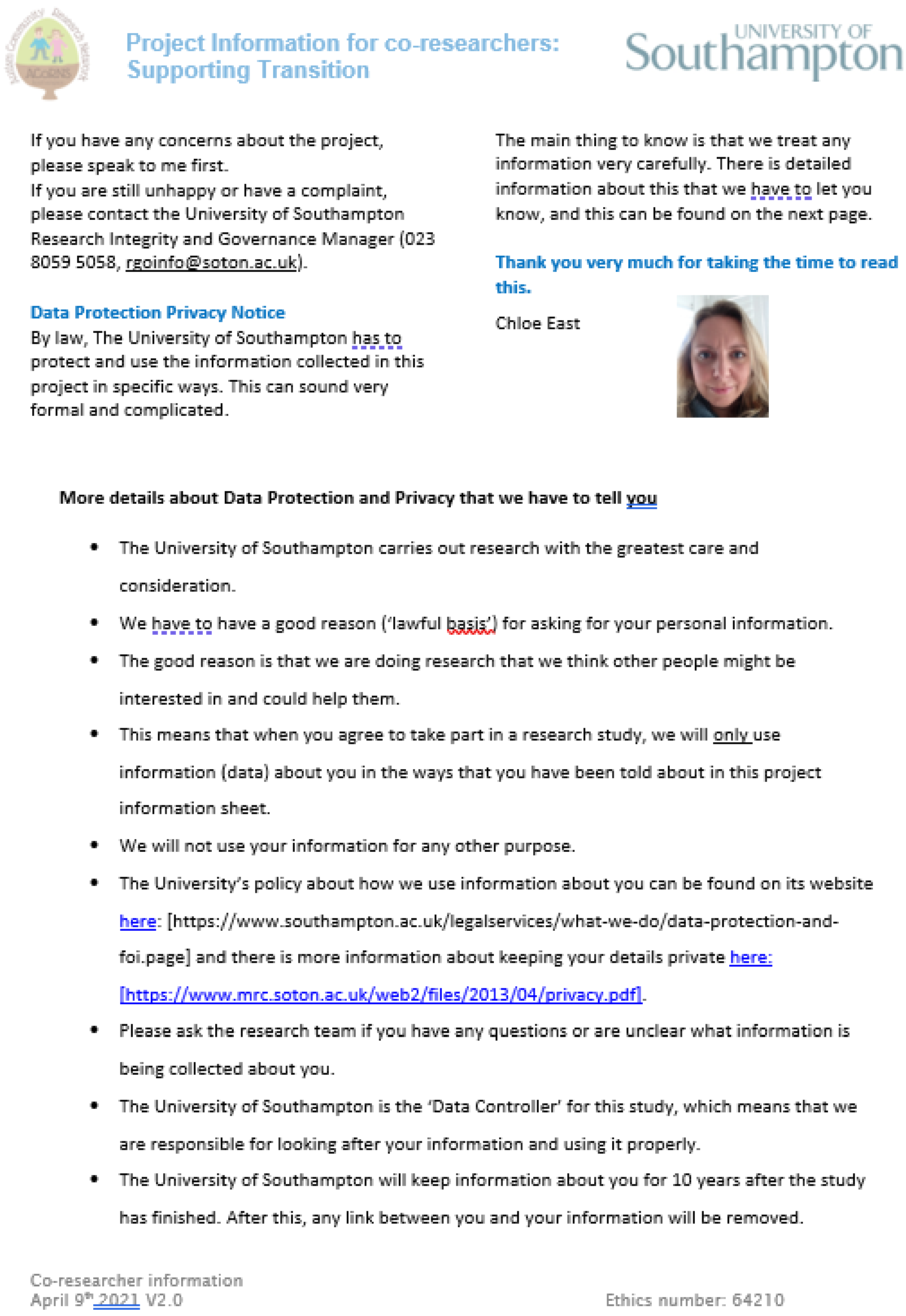
Just email me on c.east@soton.ac.uk and I will be in touch to arrange the first meeting.

Where can I get more information?

Please ask me if you have any questions about the project: c.east@soton.ac.uk

You can also contact my supervisor - Hanna Kovshoff at the University: H.Kovshoff@soton.ac.uk or telephone: (023) 8059 4593

What happens if there is a problem?



Project Information for co-researchers: Supporting Transition

UNIVERSITY OF Southampton

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Thank you very much for taking the time to read this.

Chloe East

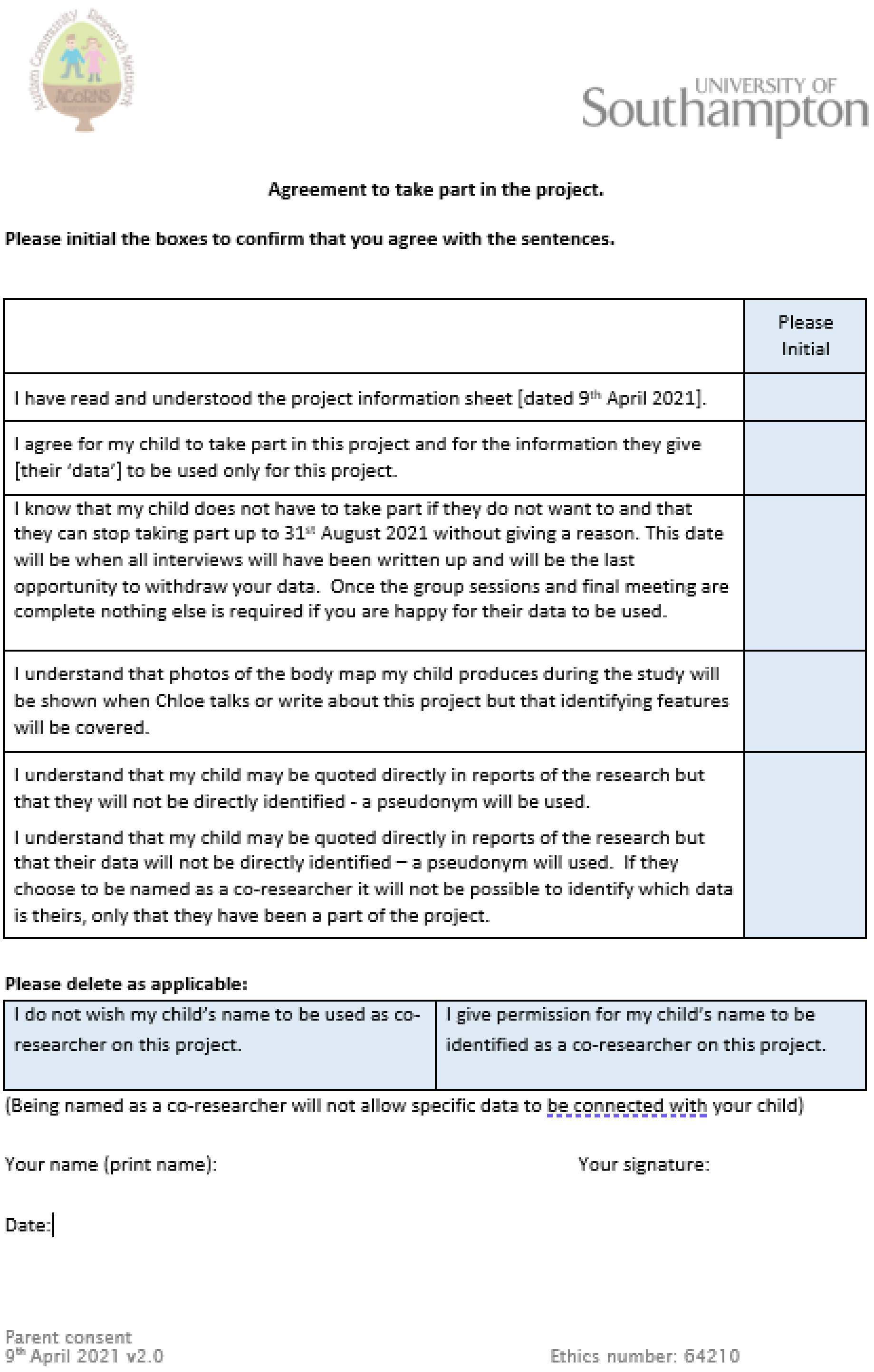
More details about Data Protection and Privacy that we have to tell you

- The University of Southampton carries out research with the greatest care and consideration.
- We have to have a good reason ('lawful basis') for asking for your personal information.
- The good reason is that we are doing research that we think other people might be interested in and could help them.
- This means that when you agree to take part in a research study, we will only use information (data) about you in the ways that you have been told about in this project information sheet.
- We will not use your information for any other purpose.
- The University's policy about how we use information about you can be found on its website here: [https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page] and there is more information about keeping your details private here: [https://www.mrc.soton.ac.uk/web2/files/2013/04/privacy.pdf].
- Please ask the research team if you have any questions or are unclear what information is being collected about you.
- 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 Southampton will keep information about you for 10 years after the study has finished. After this, any link between you and your information will be removed.

Co-researcher information
April 9th 2021 V2.0

Ethics number: 64210

E.5 Parent Consent Form



Agreement to take part in the project.

Please initial the boxes to confirm that you agree with the sentences.

	Please Initial
I have read and understood the project information sheet [dated 9th April 2021].	
I agree for my child to take part in this project and for the information they give [their 'data'] to be used only for this project.	
I know that my child does not have to take part if they do not want to and that they can stop taking part up to 31st August 2021 without giving a reason. This date will be when all interviews will have been written up and will be the last opportunity to withdraw your data. Once the group sessions and final meeting are complete nothing else is required if you are happy for their data to be used.	
I understand that photos of the body map my child produces during the study will be shown when Chloe talks or write about this project but that identifying features will be covered.	
I understand that my child may be quoted directly in reports of the research but that they will not be directly identified - a pseudonym will be used. I understand that my child may be quoted directly in reports of the research but that their data will not be directly identified – a pseudonym will used. If they choose to be named as a co-researcher it will not be possible to identify which data is theirs, only that they have been a part of the project.	

Please delete as applicable:

I do not wish my child's name to be used as co-researcher on this project.	I give permission for my child's name to be identified as a co-researcher on this project.

(Being named as a co-researcher will not allow specific data to be connected with your child)

Your name (print name):

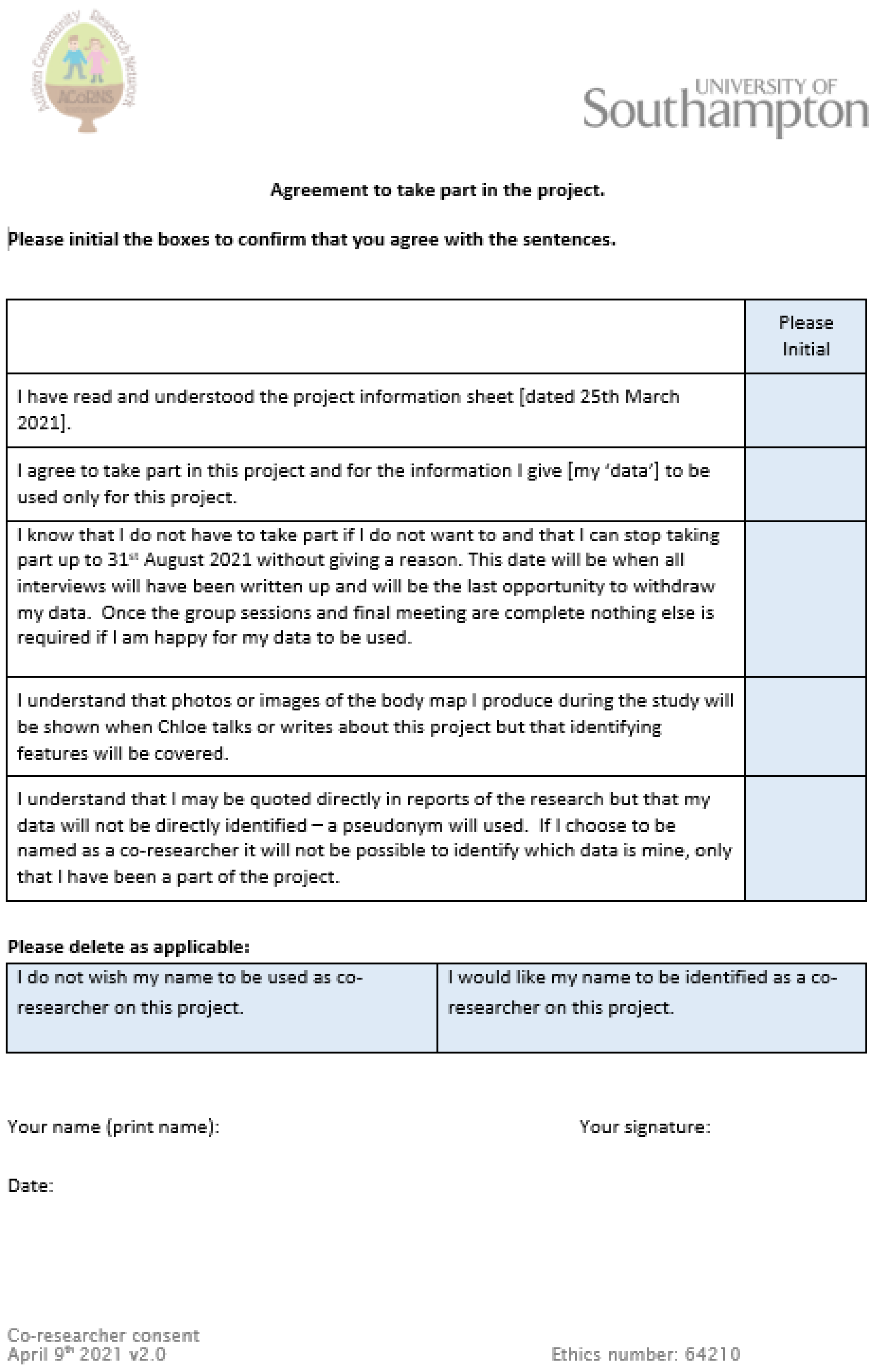
Your signature:

Date:

Parent consent
9th April 2021 v2.0

Ethics number: 64210

E.6 Child Assent Form



Agreement to take part in the project.

Please initial the boxes to confirm that you agree with the sentences.

	Please Initial
I have read and understood the project information sheet [dated 25th March 2021].	
I agree to take part in this project and for the information I give [my 'data'] to be used only for this project.	
I know that I do not have to take part if I do not want to and that I can stop taking part up to 31st August 2021 without giving a reason. This date will be when all interviews will have been written up and will be the last opportunity to withdraw my data. Once the group sessions and final meeting are complete nothing else is required if I am happy for my data to be used.	
I understand that photos or images of the body map I produce during the study will be shown when Chloe talks or writes about this project but that identifying features will be covered.	
I understand that I may be quoted directly in reports of the research but that my data will not be directly identified – a pseudonym will used. If I choose to be named as a co-researcher it will not be possible to identify which data is mine, only that I have been a part of the project.	

Please delete as applicable:

I do not wish my name to be used as co-researcher on this project.	I would like my name to be identified as a co-researcher on this project.

Your name (print name):

Your signature:

Date:

Co-researcher consent
April 9th 2021 v2.0

Ethics number: 64210

Appendix F Fizzacc Presentation Ideas

We are FIZZACC!

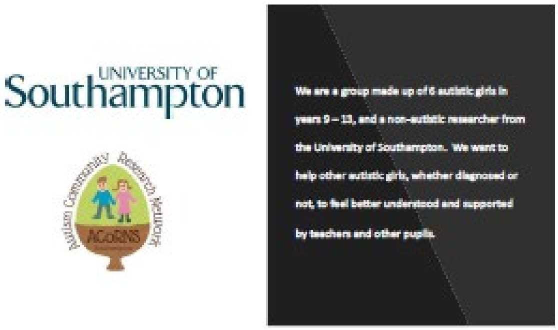
What is autism?

What it is ✓

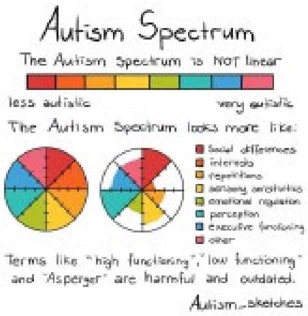
- A neurodevelopmental difference (different brain wiring), a natural variation
- Affects every aspect of a person's being: how they perceive, experience, interact with and interpret the world
- A minority neurology
- Lifelong

What it isn't ✗

- A learning disability
- An illness or disease
- Bad behaviour/wilful defiance
- Bad parenting
- Affects only children



We are a group made up of 6 autistic girls in years 9 – 13, and a non-autistic researcher from the University of Southampton. We want to help other autistic girls, whether diagnosed or not, to feel better understood and supported by teachers and other pupils.



Autism Spectrum

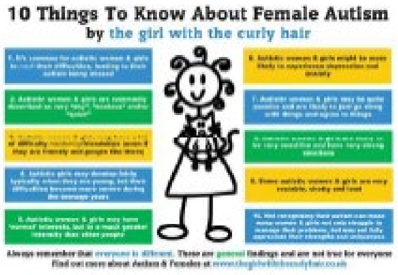
The Autism Spectrum is NOT linear

The Autism Spectrum looks more like:

Terms like "high functioning", "low functioning" and "Asperger" are harmful and outdated.

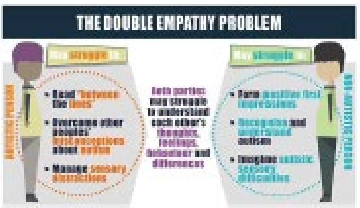
Autism_sketches

Neurodiversity

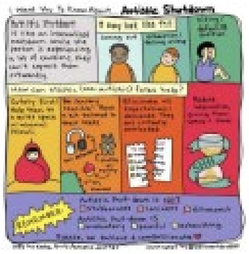


10 Things To Know About Female Autism

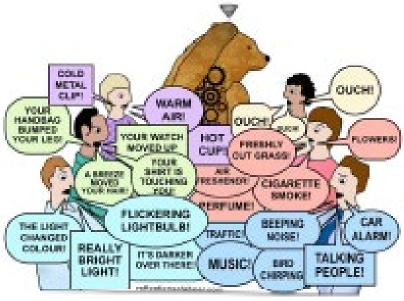
by the girl with the curly hair


THE DOUBLE EMPATHY PROBLEM
May struggle to:
AUTISTIC PERSON
Read "between the lines"
Overcome other peoples' misconceptions about autism
Manage sensory distractions
Both parties may struggle to understand each other's thoughts, feelings, behaviour and differences
May struggle to:
Form positive first impressions
Recognise and understand autism
Imagine autistic sensory difficulties
NON-AUTISTIC PERSON


AUTISTIC MELTDOWNS

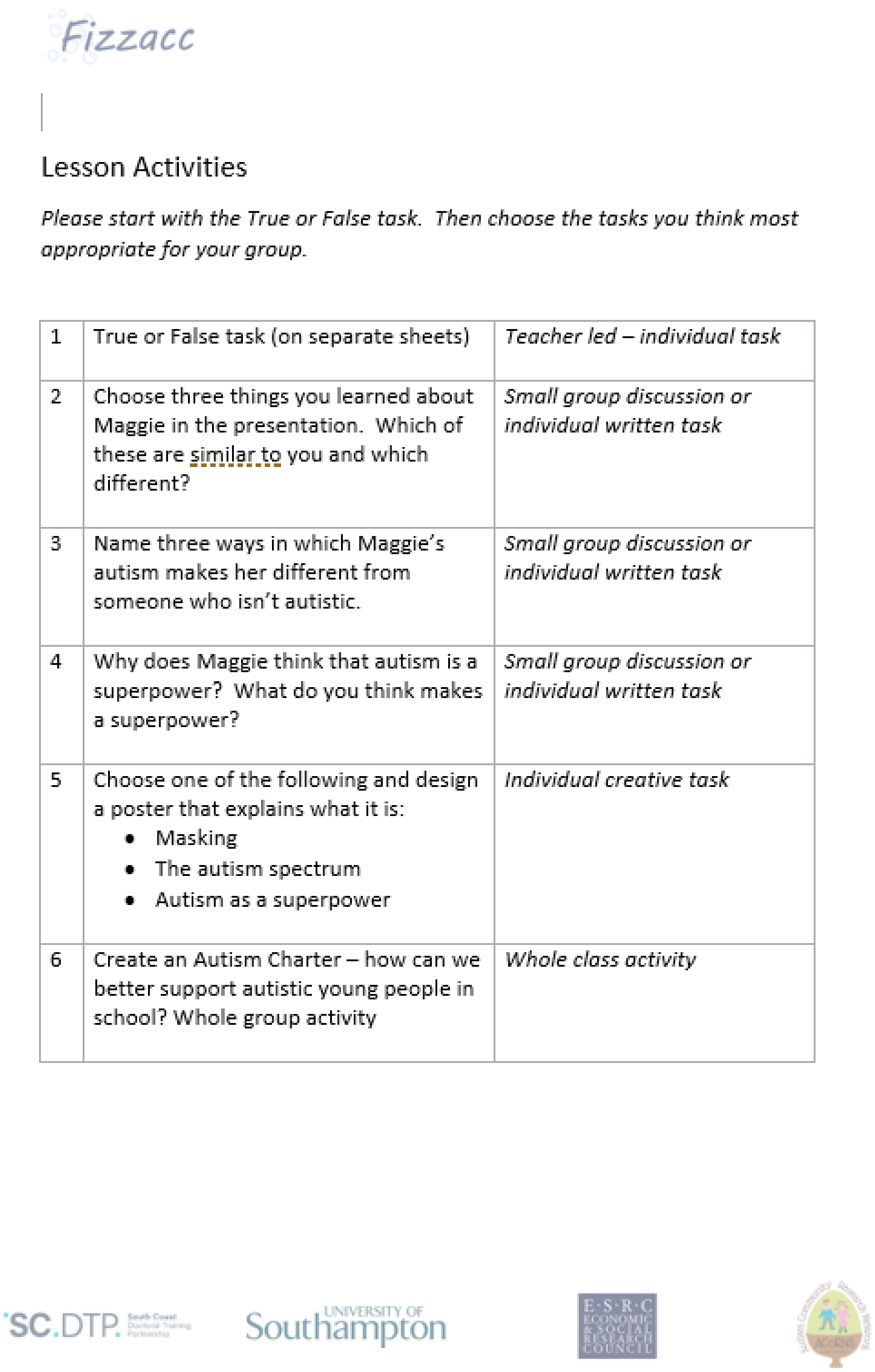

I Want You To Know About: Autistic Shutdowns


10 myths about Autism


COLD METAL CLIP!
YOUR HANDBAG BUMPED YOUR LEG!
WARM AIR!
OUCH!
YOUR WATCH MOVED UP
OUCH!
OUCH!
HOT CUP!
FRESHLY CUT GRASS!
FLOWERS!
A BREEZE MOVED YOUR HAIR!
YOUR SHIRT IS TOUCHING YOU!
AIR FRESHENER!
CIGARETTE SMOKE!
PERFUME!
FLICKERING LIGHTBULB!
THE LIGHT CHANGED COLOUR!
REALLY BRIGHT LIGHT!
IT'S DARKER OVER THERE!
TRAFFIC!
BEEPING NOISE!
CAR ALARM!
MUSIC!
BIRD CHIRPING
TALKING PEOPLE!

Appendix G School Resources

G.1 Lesson Activities



Fizzacc

Lesson Activities

Please start with the True or False task. Then choose the tasks you think most appropriate for your group.

1	True or False task (on separate sheets)	*Teacher led – individual task*
2	Choose three things you learned about Maggie in the presentation. Which of these are similar to you and which different?	*Small group discussion or individual written task*
3	Name three ways in which Maggie's autism makes her different from someone who isn't autistic.	*Small group discussion or individual written task*
4	Why does Maggie think that autism is a superpower? What do you think makes a superpower?	*Small group discussion or individual written task*
5	Choose one of the following and design a poster that explains what it is: • Masking • The autism spectrum • Autism as a superpower	*Individual creative task*
6	Create an Autism Charter – how can we better support autistic young people in school? Whole group activity	*Whole class activity*

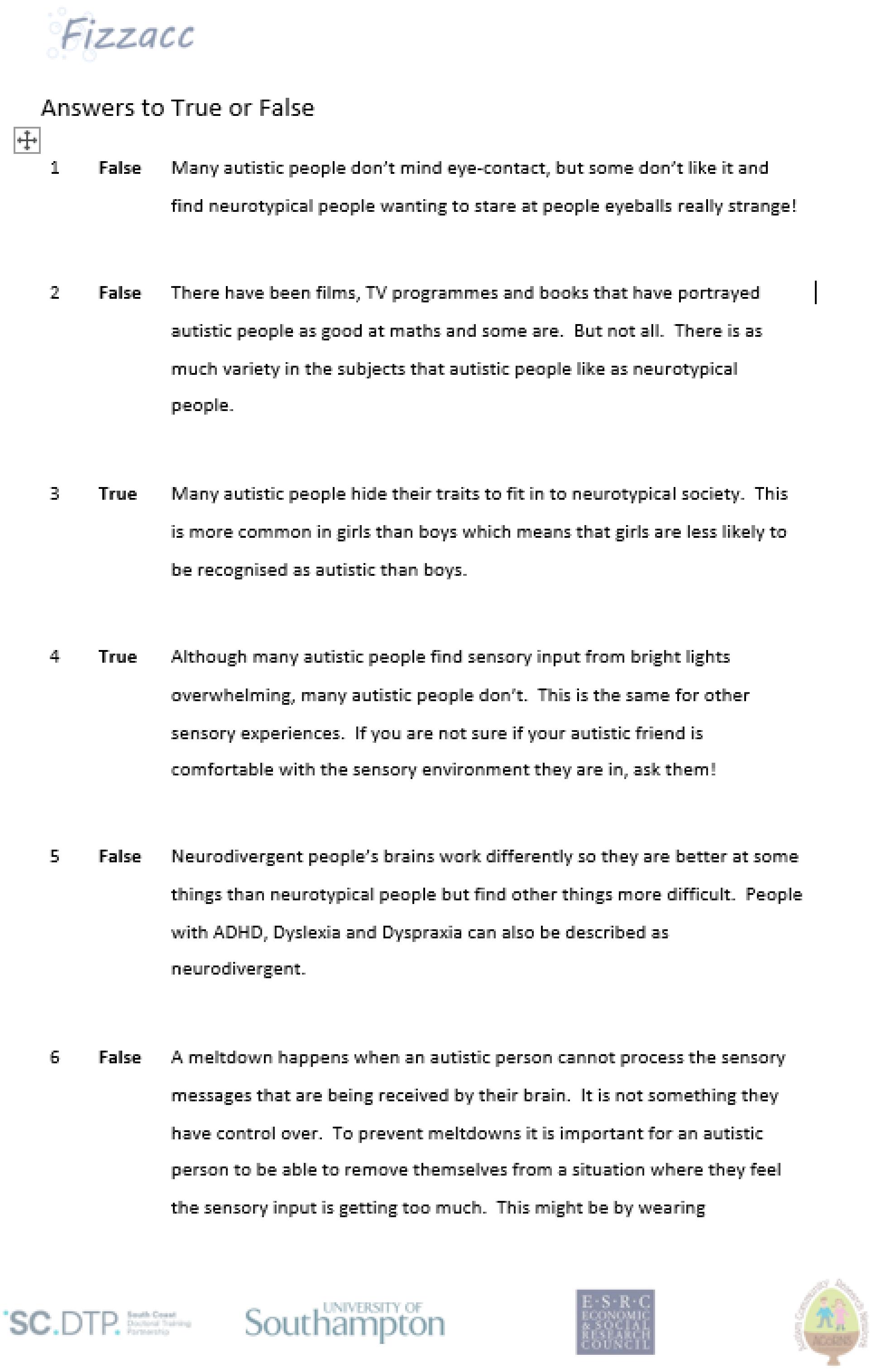
G.2 True or False Questions

Fizzacc

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

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

G.3 True or False Answers



Fizzacc

Answers to True or False

1	**False**	Many autistic people don't mind eye-contact, but some don't like it and find neurotypical people wanting to stare at people eyeballs really strange!
2	**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.
3	**True**	Many autistic people hide their traits to fit in to neurotypical society. This is more common in girls than boys which means that girls are less likely to be recognised as autistic than boys.
4	**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!
5	**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.
6	**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

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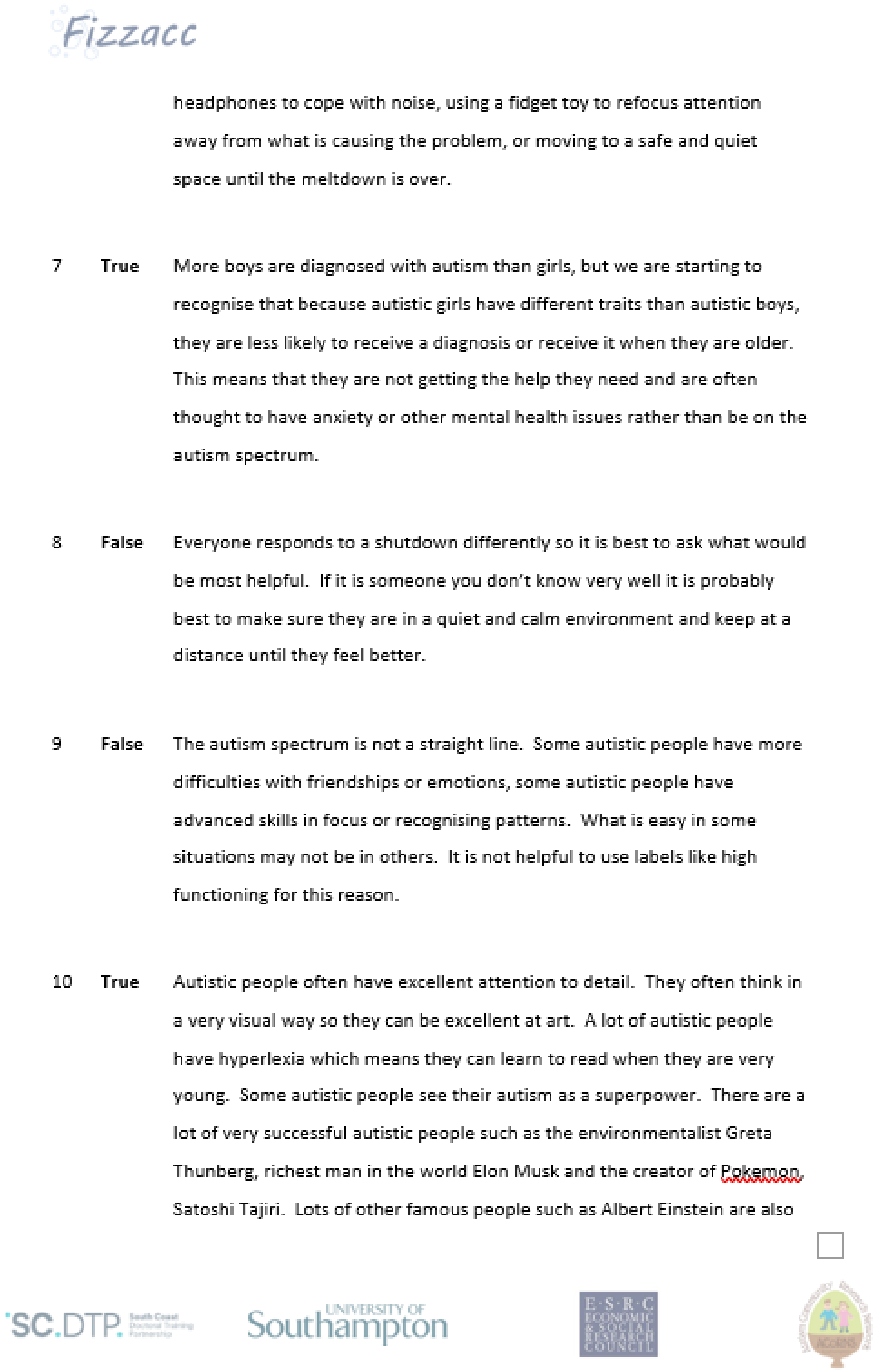

Fizzacc

		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.
7	**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, 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.
8	**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.
9	**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.
10	**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, richest man in the world Elon Musk and the creator of Pokemon, Satoshi Tajiri. Lots of other famous people such as Albert Einstein are also

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Autism Community Research Network ACoRNS

Appendix H Initial Leaflet Ideas

What you need to know about Autistic Girls in Schools

What is Neurodiversity?

Neurodiversity recognises that human brains are all different. The term neurodivergent refers to traits and characteristics related to a number of conditions such as autism, ADHD, dyslexia and dyspraxia. People who are not neurodivergent are often referred to as neurotypical. People with neurodivergent brains add diversity which is important. Although there are challenges associated with neurodivergence these are often caused by environments that are designed for neurotypical people. There are also many strengths associated with neurodivergence.

Autistic strengths

- Attention to detail
- Ability to focus
- Creativity
- Acceptance of difference
- Integrity and honesty
- Ability to identify patterns in information
- In depth knowledge of specific interests

Why do we refer to autism as a spectrum?

No two people are the same. This is true for autistic people as well as neurotypical. Because of this we refer to autism as a spectrum. Each person will have a different pattern of strengths and challenges. It is also important to remember that a person's profile will change. What is easy one day might not be the next. For this reason the terms 'high' and 'low' functioning are not helpful. 'High' functioning people often lack the support they need whereas 'low' functioning people can often miss out on opportunities due to a false perception of their abilities.

Why are we focusing on autistic girls?

The perception that many people have about autism is that it is a condition associated with boys and men. This is partly based on an outdated assumption that male and female brains are different. As a result, research and diagnostic methods have focused on boys resulting in girls and women being identified as autistic much later if at all. So why is autism not identified in girls? There are some differences in the way autistic traits look between boys and girls.

- Girls are better at hiding their autistic traits. This is often called masking or camouflaging.
- They are more likely to want to make friends and fit in. This can often lead to them copying the behaviour of their friends.
- Girls will internalise their feelings whereas boys will often 'act out'.
- Girls have interests that are considered more typical of their age for example TV shows, pop bands or animals.

What are some of the challenges for autistic girls in school?

Sensory challenges. Bright fluorescent lights, the smell of school dinners, the scratchy feeling of a polyester school jumper. These are not only irritating. They can cause physical pain and make it difficult to concentrate on learning.

Meltdowns. These occur when an autistic child is in a situation that their brain can't deal with. This looks different for everyone. Some people cry, some scream and shout, some run away. This is not a choice or 'bad behaviour'. A meltdown must be allowed to run its course in a safe space and the young person should then be supported until they feel well enough to continue with their learning.

Shutdowns. These happen when there is too much information to process. The young person will stop paying attention to the things that are overwhelming. This might look like rudeness with a refusal to answer questions or follow instructions. Again support should be offered in a safe space until the feeling of overwhelm comes to an end.

What can we do to help?

There are lots of things that schools can do to support autistic girls. These will support them with learning, help prevent meltdowns and shutdowns, and protect their wellbeing. Here are some suggestions:

- Teach staff and pupils how to support the autistic children in their schools.
- Don't assume that what is possible one day will be possible another.
- Most autistic children want to learn. Don't assume that failure to behave as you expect is due to poor behaviour until you have checked all other possibilities.
- Provide a safe space that is accessible at all times without having to ask for permission.
- Have flexibility in your uniform policy.
- Keep lighting low and fix faulty lighting that is flickering or buzzing.
- Remember that sensory issues can be felt as pain. If a child is in pain, they won't be able to learn so take them seriously.
- Autism in people from ethnic minority groups is often misdiagnosed. Consider this if a child from an ethnic minority group is struggling at school.
- A lot of autistic young people are proud of their autism and consider it a superpower. Help them to celebrate their abilities and harness their strengths.

How do I find out more?

Here are some links to information that might be interesting.

This is an article written about the recent diagnoses received by some prominent women in television.

https://www.theguardian.com/society/2021/nov/20/melanie-sykes-christine-mcguinness-people-late-diagnosis-autism

A comic strip which explains the autism spectrum.

https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/

A really clear explanation of what is meant by neurodiversity

https://www.youtube.com/watch?v=xsfml3yVh1g

An article which explains what is meant by The Double Empathy Problem written specifically for young people.

https://kids.frontiersin.org/articles/10.3389/frym.2021.554875

An article about why the language we use when we are talking about autism is important

https://www1.racgp.org.au/ajgp/2021/march/autistic-or-with-autism

The National Autistic Society – a good source of information and support

https://www.autism.org.uk/

Appendix I School Resource Evaluation

I.1 Ethics Application

ERGO II Ethics application form – FELS Committee

13. Applicant Details

1.1 Applicant name	Chloe East
1.2 Supervisor	Hanna Kovshoff, Sarah Parsons
1.3 Other researchers / collaborators (if applicable): *Name, address, email*	n/a

14. Study Details

2.1 Title of study	Understanding the impact of sharing educational transition resources created by the FIZZACC Research Group
2.2 Type of project (e.g. undergraduate, Masters, Doctorate, staff)	Doctorate
2.4 Proposed start date (must match date stated in ERGO)	1.3.22
2.5 Proposed end date (must match date stated in ERGO)	31.12.22

2.6 Briefly describe the rationale for carrying out this project and its specific aims and objectives.

The transition to secondary school can be very challenging for autistic children (Nuske et al., 2019). It can lead to problems with mental health (Fortuna, 2014; Hannah & Topping, 2012). Despite the evidence to suggest the challenging nature of transitions, there is little research investigating the resources used to support or plan for transitions, and even fewer studies have aimed to evaluate resources that created with and by autistic children themselves.

Whilst autistic boys are often thought to outnumber girls at a commonly reported ratio of 4:1, more recent work has highlight that uutistic girls are underdiagnosed and underrepresented in the literature (Gould, 2017; Lai et al., 2015). Many girls engage in active strategies to mask their differences (Bargiela et al., 2016), often in an attempt to fit in socially (Tierney et al., 2016). The differences between autistic and neurotypical girls may be particularly challenging during the development of the complex social relationships that establish during adolescence (Cridland et al., 2013). This means that the challenges of the primary to secondary transition for many autistic girls are different to those experienced by autistic boys therefore this project will investigate transitions from the perspective of autistic girls.

This project builds on a previous research study where I led a group of co-researcher autistic girls to co-create a set of resources to support educational transitions and which highlight their experiences and what they wanted people to know about being an autistic girl. This next stage of the project will aim to understand more about the co-researchers' experiences creating and disseminating the resources and will also consider the thoughts of teachers and pupils on how they feel about learning about autistic girls' experiences in education from a co-constructed resource.

Aims:

1. To understand more about how involvement in a participatory research project was experienced by autistic girls
2. To understand how the resources designed and created by the autistic girls can support raising awareness of how they experience education.

Objectives:

4. To work in participation with autistic girls in a collaborative and creative way
5. To reflect on the experiences of working on a participatory project for all members.
6. To consider how school staff and pupils respond to learning from resources created in a co-constructed project.

2.7 Provide a brief outline of the basic study design. Outline what approach is being used and why.

This study comprises a participatory research design to evaluate the impact of the transition resources created with the participants in a previous study (see ERGO 64210). (Resources are still being developed – working documents are attached)

Throughout this application the girls who are part of the FIZZACC (as it has been named) research group will be referred to as **co-researchers**. Teachers and pupils recruited to provide data about the resources will be referred to as **participants**.

Co-researchers have been working together on the first stage of the project since August 2021 and have expressed that they would like to continue with the next stage. They will be issued with new information sheets and consent forms accordingly (attached).

The resources co-created in the first part of this research include a power point presentation, information sheet, and guidance on activities that can be used to further explore the experiences of autistic girls in school.

Between 3 and 6 Partner schools will be recruited to trial the resources. The schools will deliver the resources to their pupils in either a tutor time, assembly or citizenship/PSHE lesson as appropriate for the individual establishment.

Data will then be collected by the researcher and volunteer members of the co-researcher team.

Teachers will be interviewed either in person or online as most convenient to them. Interviews will be conducted by the lead researcher and where appropriate, one other member of the co-researcher team. Interviews will be recorded and transcribed. Other members of the research team will have the opportunity to view the recordings as part of the data analysis process.

A topic guide is included (see attached documents).

Pupils attending the participating schools will take part in discussions about the resources as part of a whole class activity or focus group. This will be arranged to suit individual school requirements. Parents will be informed of the lesson in advance via email and will have the opportunity to request that their child does not participate.

Whole class activity: Discussions will be led by the class teacher. Pupils will have the opportunity to discuss their responses to the learning and will then record their answers on pro-forma (see interview schedule). Pupils will be reminded that they are under no obligation to answer any questions they do not wish to, they can hand back a blank sheet so their decision will not be made public.

Focus group activity: Discussions will be led by the researcher with support from the class teacher. Any discussions taking place in the school of a member of the research team may also be facilitated by that co-researcher. These discussions will be audio recorded. Identifying details will not be taken of children who contribute (only the year group they are in will be recorded). Children will be asked to volunteer thoughts and opinions verbally or in writing if they wish to, but it will be made clear to them that they will not be obliged to.

By clearly informing pupils that they are under no obligation to respond to the questions, this gives both parents and children the opportunity to opt out of participation without prejudice.

2.8 What are the key research questions? Specify hypotheses if applicable.

1. How could working in participation with autistic young people help to change practice in schools?
2. What is the impact on autistic girls of participating as part of a research project?

15. Sample and setting

3.1 Who are the proposed participants and where are they from (e.g. fellow students, club members)? List inclusion / exclusion criteria if applicable.

Teachers working in primary or secondary schools in England.

Children aged between 10 and 13 who attend primary or secondary school in England.

3.2. How will the participants be identified and approached? Provide an indication of your sample size. If co-researchers are under the responsibility of others (e.g., parents/carers, teachers) state if you have permission or how you will obtain permission from the third party).

Participants

Schools will be identified by members of the research team and approached via email. We would seek to work with between 3 and 6 schools, with 6 – 10 teachers and 20 – 30 pupils providing feedback on the resources via focus groups and 100 – 200 via written responses.

3.3 Describe the relationship between researcher and sample. Describe any relationship e.g., teacher, friend, boss, clinician, etc.

As we will be recruiting from local schools, we may work with an establishment which is either the current, or past school of one of the co-researchers. These schools will only be contacted if the co-researcher is keen for this to happen.

3.4 How will you obtain the consent of Participants (*please upload a copy of the consent form if obtaining written consent***) NB. Consent form is not needed for studies collecting data online.**

Teachers will receive and information form about the project and will be asked to sign a consent form.

Pupils will be able to consent by contributing to the verbal or written feedback. Parents will have the opportunity to withdraw their child from the session if they wish to. (See parent information sheet).

3.5 Is there any reason to believe participants may not be able to give full informed consent? If yes, what steps do you propose to take to safeguard their interests?

No.

16. Research procedures, interventions and measurements

4.1 Give a brief account of the procedure as experienced by the participant. Make it clear who does what, how many times and in what order. Make clear the role of all assistants and collaborators. Make clear the total demands made on participants/co-researchers, including time and travel. *Upload copies of questionnaires and interview schedules to ERGO.*

Liaison with each school will determine how best to deliver the resources according to their timetable and staffing. It may involve the presentation being used in an assembly setting or classroom. The activities may be done with the children in a tutor period or a lesson. Staff will be able to choose from the available resources, which are most appropriate to use with their classes. Teachers will be required to do some preparation in advance of delivering the lesson – maximum of 30 minutes.

Once the presentation and activities have been done, teachers and pupils will be involved in providing feedback. This may be done online or in person (If visiting schools in person, current covid regulations will be followed and sensible precautions will be taken including use of lateral flow testing where appropriate).

Follow up data collection with teachers will take no more than one hour and will take place at a time convenient to the teacher, either online or in person. Pupils involved with follow up data collection via focus group will do so subsequent to receiving the lesson and during the school day as appropriate to the individual establishment. (e.g. during a tutor period or citizenship/PSHE lesson). Again this will take no more than one hour. Pupils giving written feedback will do so as part of their lesson

4.2 Will the procedure involve deception of any sort? If yes, what is your justification?

No

4.3. Detail any possible (psychological or physical) discomfort, inconvenience, or distress that co-researchers may experience, including after the study, and what precautions will be taken to minimise these risks.

The information sheets explains that should participants feel psychological discomfort or distress during the research, or if they find the project inconvenient, they are free to withdraw from the study at any time without needing to explain.

4.4 Detail any possible (psychological or physical) discomfort, inconvenience, or distress that YOU as a researcher may experience, including after the study, and what precautions will be taken to minimise these risks.

It is unlikely that any discomfort, inconvenience, or distress will be experienced in connection with this study. This will be monitored during regular meeting with the supervisory team.

4.5 Explain how you will care for any co-researchers in 'special groups' e.g., those in a dependent relationship, are vulnerable or are lacking mental capacity), if applicable:

Participants will be reminded at the beginning of the process that they are under no obligation to answer any questions that they do not wish to answer and that they can leave the interview/focus group at any time of leave any spaces on the feedback sheet blank. A member of staff from the host school will be required to be on hand to support if necessary. The lead researcher has 20 years' experience as a teacher and therefore has expertise at working with children.

4.6 Please give details of any payments or incentives being used to recruit co-researchers, if applicable:

n/a

5. Access and storage of data

5.1 How will co-researcher confidentiality be maintained? Confidentiality is defined as non-disclosure of research information except to another authorised person. Confidential information can be shared with those already party to it and may also be disclosed where the person providing the information provides explicit consent. Consider whether it is truly possible to maintain a co-researcher's involvement in the study confidential, e.g. can people observe the co-researcher taking part in the study?

In any written information or reports, confidentiality will be maintained by referring to participants as Teacher 1, Pupil 1 etc.

Demographic information containing identifying information of each participant/co-researcher will be stored separately from anonymised data sets. No identifying information will be collected from pupils involved in discussions/focus groups apart from year group. Written feedback will not be named. Paper copies of information will be kept separately in locked filing cabinets which only the research team can access, and digital files will be stored separately on university computers using encryption and password protection.

5.2 How will personal data and study results be stored securely during and after the study. Who will have access to these data?

Only members of the research team will have access to the raw data including Voluntary Research Assistants who will sign a confidentiality agreement.

Personalised hard copies of data will be stored securely in a locked filing cabinet and digital data will be kept on a university server.

5.3 How will it be made clear to co-researchers/participants that they may withdraw consent to participate? Please note that anonymous data (e.g. anonymous questionnaires) cannot be withdrawn after they have been submitted. If there is a point up to which data can be withdrawn/destroyed e.g., up to interview data being transcribed please state this here.

Participants

The information sheet will clearly state that participants may withdraw consent at any time in the study up until one week after the interview.

6. Additional Ethical considerations

6.1. Are there any additional ethical considerations or other information you feel may be relevant to this study?
No

I.2 Pupil Lesson Information Sheet

Project Information Sheet: Supporting Autistic Girls in School

University of Southampton

Researcher: Chloe East

You are being invited to take part in a 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 you would like more information before you decide whether you wish to take part in this research. Please talk to your parent/guardian and if you would prefer not to take part please email (ADDRESS TBC).

What is the project about?

This is a project that I am conducting as part of my PhD. It builds on work that I have been doing with a research group called FIZZACC which includes myself and 6 teenage autistic girls. We have been exploring the experiences of autistic girls during the transition from primary to secondary school and have decided that raising awareness of what autistic girls experience, might help other girls in the future. We have created a presentation and some other resources about the experience of being an autistic girl at school. Having created our resources we want to find out whether they help teachers and pupils to better understand the experiences of autistic girls in school.

Why have I been asked to take part?

You have been asked to take part as your school is participating in the project.

What will happen if I take part?

Your will watch a presentation about autism in (NAME OF CLASS) and do some work in class based on what you have watched. At the end of the lesson you will be asked to give some written feedback about the lesson. You won't have to put your name on the feedback so nobody will know what you have said.

Are there any benefits in taking part?

I hope that it will give you the opportunity to learn more about what it is like for autistic girls in school.

Are there any risks involved?

Not really. If you feel upset or worried about any of the information in the lesson you can talk to (NAME TBC).

What data will be collected?

We will:

- Take in the feedback sheets you have completed but they will not be named.
- send your school a summary of what we find out so you can see what you have contributed to
- make that summary available on our website for other people to read

How will we safeguard your data?

Your feedback sheets will be kept in a locked filing cabinet. Data stored digitally will be kept on university computers using encryption and password protection. 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 we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take

Feedback information
February 22nd 2022 v1.0

Ergo ID: 71269

part, you don't need to do anything. If you don't want to attend the lesson please email (ADDRESS TBC). If you attend the session but don't want to answer the questions on the feedback sheet you can leave them blank.

What happens if I change my mind?

You can change your mind at any time up to (DATE TBC). Once you have handed in your feedback sheet you will not be able to change your mind as the sheets will be anonymous.

What will happen to the results of the research?

We will write a short report to put up on our website. There may also be a longer report that we want to write about the project to let other people know what we have found out. This may include quotes from you which will be anonymised. The results of this research will also be included in my PhD thesis.

What do I do if I want to take part?

Just email me on c.east@soton.ac.uk and I will be in touch to arrange the meeting.

Where can I get more information?

Please ask me if you have any questions about the project: c.east@soton.ac.uk
You can also contact my supervisor - Hanna Kovshoff at the University: H.Kovshoff@soton.ac.uk or telephone: (023) 8059 4593

What happens if there is a problem?

If you have any concerns about the project, please speak to me first.
If you are still unhappy or have a complaint, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

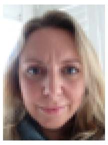
Data Protection Privacy Notice

By law, The University of Southampton has to protect and use the information collected in this project in specific ways. This can sound very formal and complicated.

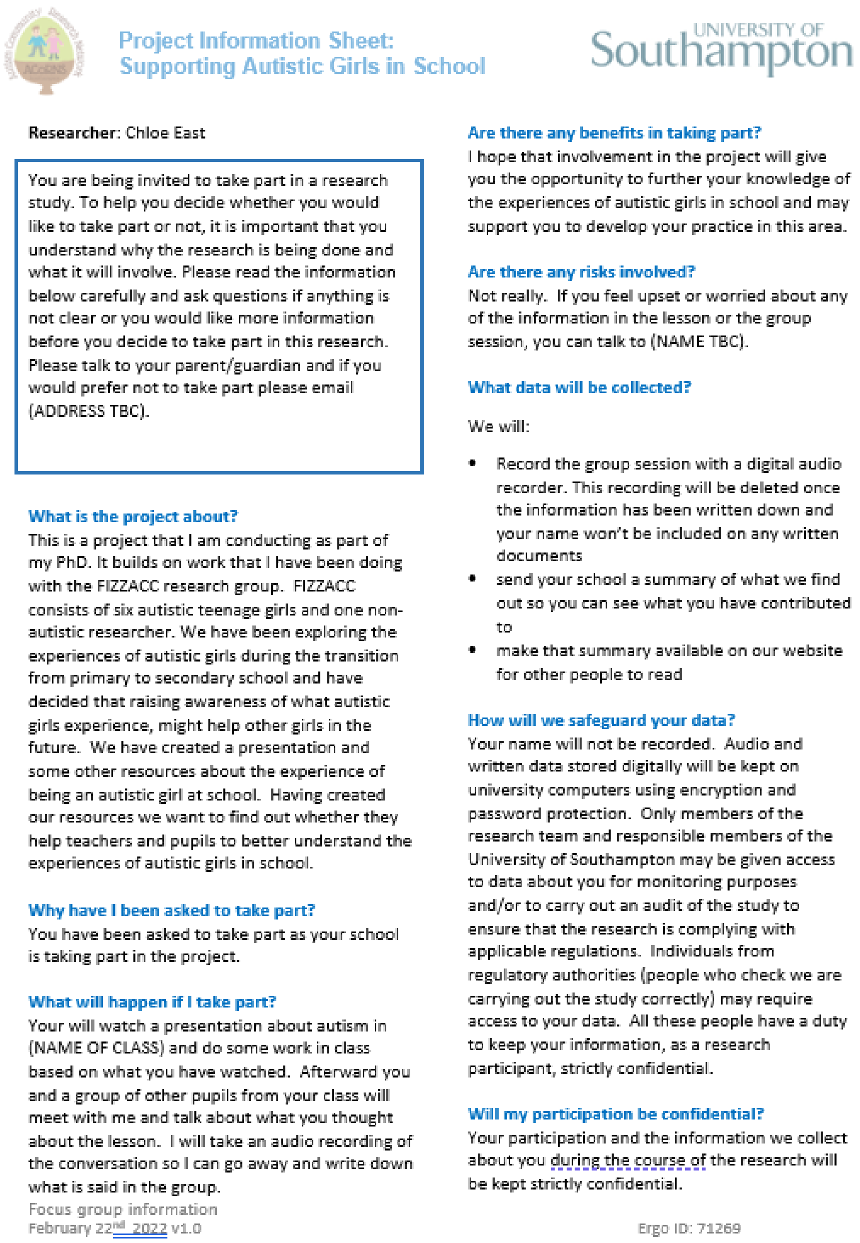
The main thing to know is that we treat any information very carefully. There is detailed information about this that we have to let you know, and this can be found on the next page.

Thank you very much for taking the time to read this.

Chloe East



I.3 Pupil Focus Group Information Sheet



Project Information Sheet: Supporting Autistic Girls in School

UNIVERSITY OF Southampton

Researcher: Chloe East

You are being invited to take part in a 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 you would like more information before you decide to take part in this research. Please talk to your parent/guardian and if you would prefer not to take part please email (ADDRESS TBC).

What is the project about?

This is a project that I am conducting as part of my PhD. It builds on work that I have been doing with the FIZZACC research group. FIZZACC consists of six autistic teenage girls and one non-autistic researcher. We have been exploring the experiences of autistic girls during the transition from primary to secondary school and have decided that raising awareness of what autistic girls experience, might help other girls in the future. We have created a presentation and some other resources about the experience of being an autistic girl at school. Having created our resources we want to find out whether they help teachers and pupils to better understand the experiences of autistic girls in school.

Why have I been asked to take part?

You have been asked to take part as your school is taking part in the project.

What will happen if I take part?

Your will watch a presentation about autism in (NAME OF CLASS) and do some work in class based on what you have watched. Afterward you and a group of other pupils from your class will meet with me and talk about what you thought about the lesson. I will take an audio recording of the conversation so I can go away and write down what is said in the group.

Are there any benefits in taking part?

I hope that involvement in the project will give you the opportunity to further your knowledge of the experiences of autistic girls in school and may support you to develop your practice in this area.

Are there any risks involved?

Not really. If you feel upset or worried about any of the information in the lesson or the group session, you can talk to (NAME TBC).

What data will be collected?

We will:

- Record the group session with a digital audio recorder. This recording will be deleted once the information has been written down and your name won't be included on any written documents
- send your school a summary of what we find out so you can see what you have contributed to
- make that summary available on our website for other people to read

How will we safeguard your data?

Your name will not be recorded. Audio and written data stored digitally will be kept on university computers using encryption and password protection. 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 we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Focus group information
February 22nd 2022 v1.0

Ergo ID: 71269

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you don't need to do anything. If you don't want to attend the lesson please email (ADDRESS TBC). If you attend the session but don't want to answer the questions in the group session it is fine not to volunteer any answers.

What happens if I change my mind?

You can change your mind at any time up to (DATE TBC). Once the group session is finished you won't be able to withdraw your data as it will be anonymised.

What will happen to the results of the research?

We will write a short report to put up on our website. There may also be a longer report that we want to write about the project to let other people know what we have found out. This may include quotes from you which will be anonymised. The results of this research will also be included in my PhD thesis.

What do I do if I want to take part?

Just email me on c.east@soton.ac.uk and I will be in touch to arrange the meeting.

Where can I get more information?

Please ask me if you have any questions about the project: c.east@soton.ac.uk

You can also contact my supervisor - Hanna Kovshoff at the University: H.Kovshoff@soton.ac.uk or telephone: (023) 8059 4593

What happens if there is a problem?

If you have any concerns about the project, please speak to me first.
If you are still unhappy or have a complaint, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

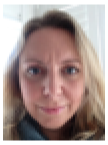
Data Protection Privacy Notice

By law, The University of Southampton has to protect and use the information collected in this project in specific ways. This can sound very formal and complicated.

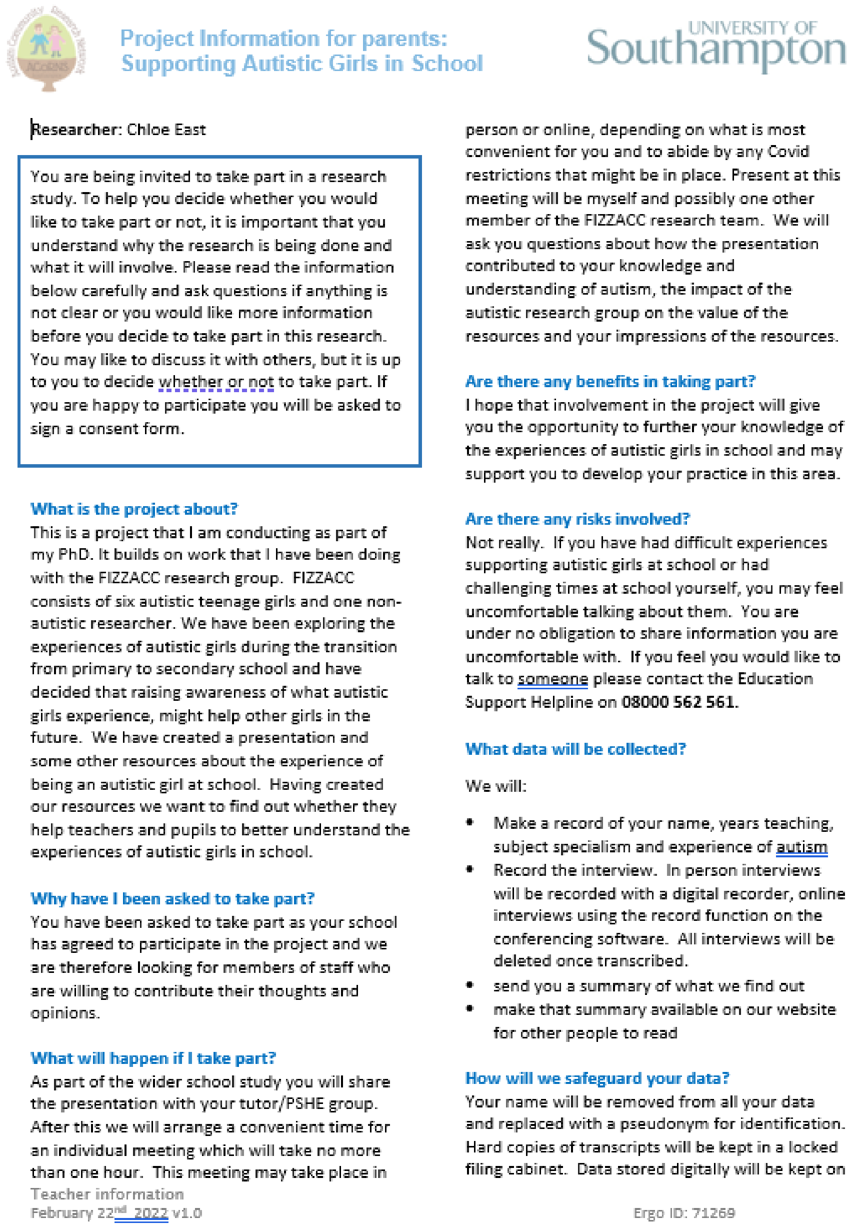
The main thing to know is that we treat any information very carefully. There is detailed information about this that we have to let you know, and this can be found on the next page.

Thank you very much for taking the time to read this.

Chloe East



I.4 Teacher Information Sheet



Project Information for parents: Supporting Autistic Girls in School

UNIVERSITY OF Southampton

Researcher: Chloe East

You are being invited to take part in a 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 you would like more information before you decide to take part in this research. You may like to discuss it with others, but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the project about?

This is a project that I am conducting as part of my PhD. It builds on work that I have been doing with the FIZZACC research group. FIZZACC consists of six autistic teenage girls and one non-autistic researcher. We have been exploring the experiences of autistic girls during the transition from primary to secondary school and have decided that raising awareness of what autistic girls experience, might help other girls in the future. We have created a presentation and some other resources about the experience of being an autistic girl at school. Having created our resources we want to find out whether they help teachers and pupils to better understand the experiences of autistic girls in school.

Why have I been asked to take part?

You have been asked to take part as your school has agreed to participate in the project and we are therefore looking for members of staff who are willing to contribute their thoughts and opinions.

What will happen if I take part?

As part of the wider school study you will share the presentation with your tutor/PSHE group. After this we will arrange a convenient time for an individual meeting which will take no more than one hour. This meeting may take place in person or online, depending on what is most convenient for you and to abide by any Covid restrictions that might be in place. Present at this meeting will be myself and possibly one other member of the FIZZACC research team. We will ask you questions about how the presentation contributed to your knowledge and understanding of autism, the impact of the autistic research group on the value of the resources and your impressions of the resources.

Are there any benefits in taking part?

I hope that involvement in the project will give you the opportunity to further your knowledge of the experiences of autistic girls in school and may support you to develop your practice in this area.

Are there any risks involved?

Not really. If you have had difficult experiences supporting autistic girls at school or had challenging times at school yourself, you may feel uncomfortable talking about them. You are under no obligation to share information you are uncomfortable with. If you feel you would like to talk to someone please contact the Education Support Helpline on **08000 562 561**.

What data will be collected?

We will:

- Make a record of your name, years teaching, subject specialism and experience of autism
- Record the interview. In person interviews will be recorded with a digital recorder, online interviews using the record function on the conferencing software. All interviews will be deleted once transcribed.
- send you a summary of what we find out
- make that summary available on our website for other people to read

How will we safeguard your data?

Your name will be removed from all your data and replaced with a pseudonym for identification. Hard copies of transcripts will be kept in a locked filing cabinet. Data stored digitally will be kept on

Teacher information
February 22nd 2022 v1.0

Ergo ID: 71269

university computers using encryption and password protection. 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 we are carrying out the study correctly) may require access to your data. All these people have a duty to keep your information, as a research participant, strictly confidential.

Will my participation be confidential?
Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Do I have to take part?
No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?
You can change your mind at any time before 31st July 2022 without giving a reason. If you do, your data, including transcripts will be deleted. Please just let me know. My contact details are: c.east@soton.ac.uk

What will happen to the results of the research?
We will write a short report to put up on our website. There may also be a longer report that we want to write about the project to let other people know what we have found out. This may include quotes from you which will be anonymised. The results of this research will also be included in my PhD thesis.

What do I do if I want to take part?
Just email me on c.east@soton.ac.uk and I will be in touch to arrange the meeting.

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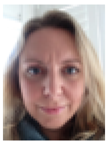
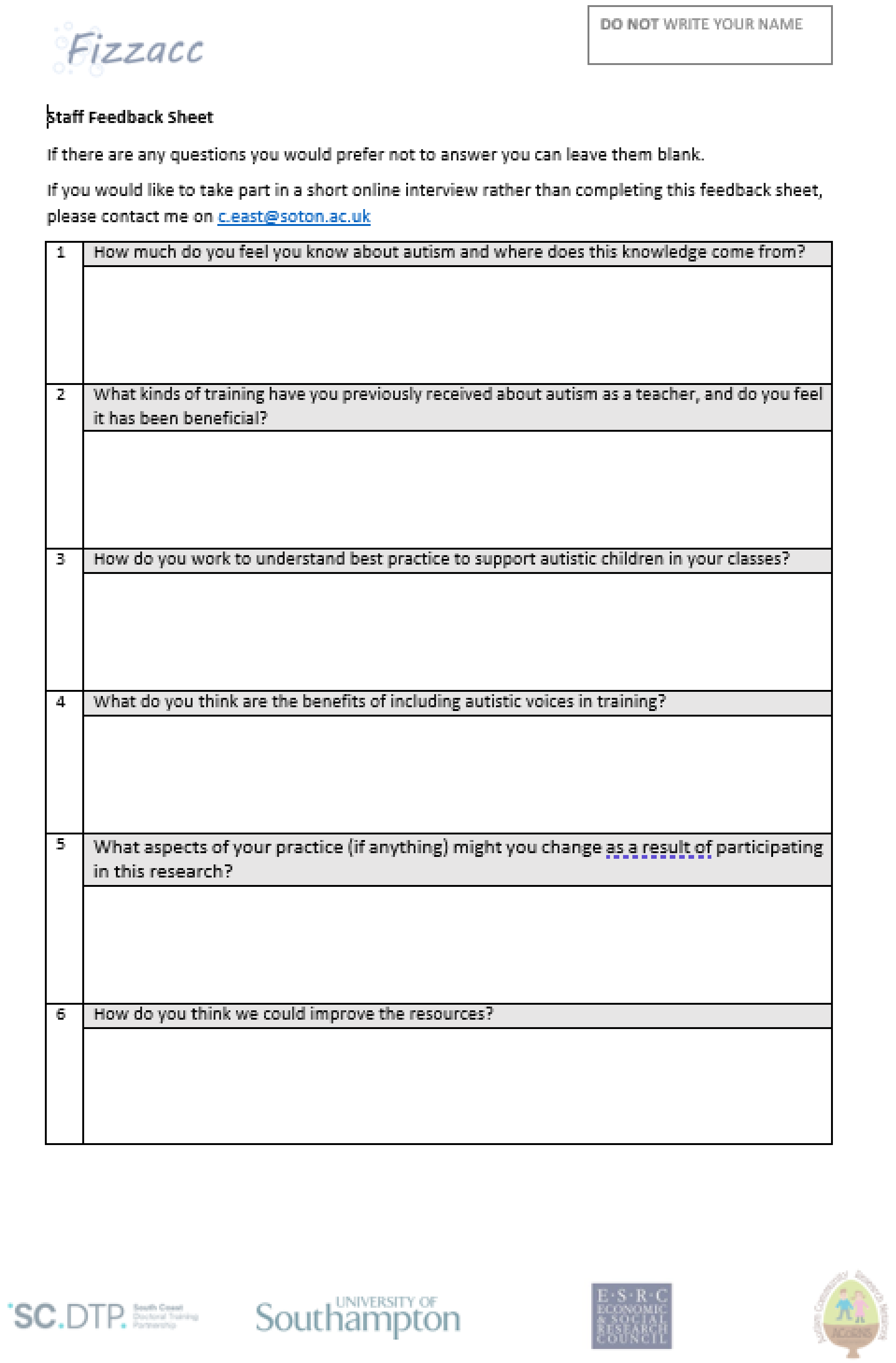
Thank you very much for taking the time to read this.

Chloe East



I.5 Staff Feedback



Fizzacc

DO NOT WRITE YOUR NAME

Staff Feedback Sheet

If there are any questions you would prefer not to answer you can leave them blank.

If you would like to take part in a short online interview rather than completing this feedback sheet, please contact me on c.east@soton.ac.uk

1	How much do you feel you know about autism and where does this knowledge come from?
2	What kinds of training have you previously received about autism as a teacher, and do you feel it has been beneficial?
3	How do you work to understand best practice to support autistic children in your classes?
4	What do you think are the benefits of including autistic voices in training?
5	What aspects of your practice (if anything) might you change as a result of participating in this research?
6	How do you think we could improve the resources?

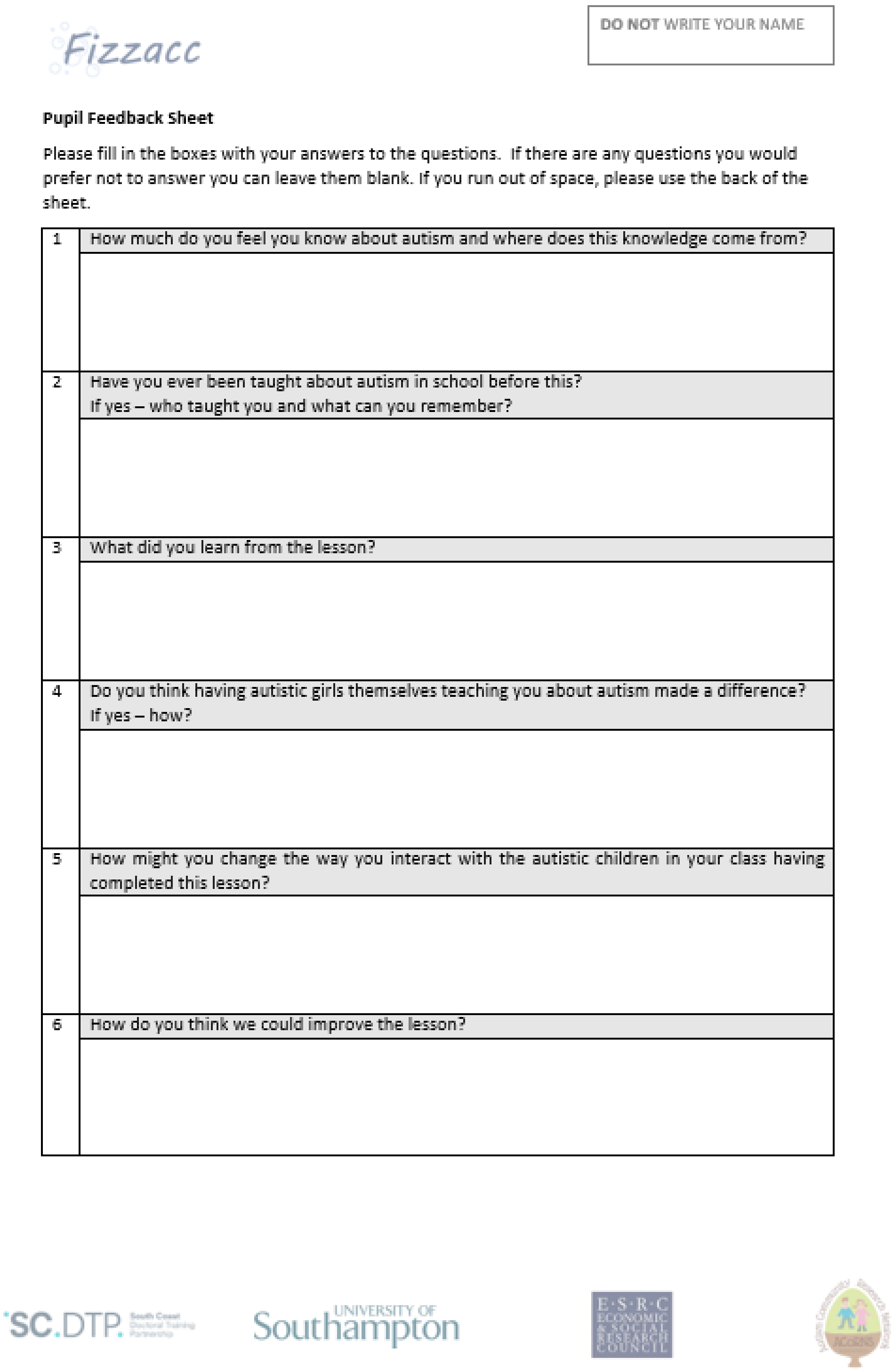
SC.DTP. South Coast Doctoral Training Partnership

University of Southampton

E·S·R·C Economic & Social Research Council

Autism Community Research Network ACoRNS

I.6 Pupil Feedback



Fizzacc

DO NOT WRITE YOUR NAME

Pupil Feedback Sheet

Please fill in the boxes with your answers to the questions. If there are any questions you would prefer not to answer you can leave them blank. If you run out of space, please use the back of the sheet.

1	How much do you feel you know about autism and where does this knowledge come from?
2	Have you ever been taught about autism in school before this? If yes – who taught you and what can you remember?
3	What did you learn from the lesson?
4	Do you think having autistic girls themselves teaching you about autism made a difference? If yes – how?
5	How might you change the way you interact with the autistic children in your class having completed this lesson?
6	How do you think we could improve the lesson?

Appendix J Content Analysis Data

How much do you feel you know about autism and where does that knowledge come from?							
How Much?		Fizzacc	TV/Books	Peers	Family	School	Self
Not much	51	17	0	3	1	6	0
A bit	80	37	3	9	6	5	1
A lot	96	35	7	16	23	9	4
Not specified	35	8	3	3	2	1	2
		97	13	31	37	21	7

<table>
<tr><th colspan="4">Have you ever been taught about autism in school before?</th></tr>
<tr><td>Yes</td><td>53</td><td>No</td><td>210</td></tr>
<tr><td>What can you remember?</td><td colspan="3">I can remember that autism can appear in boys and you can see it in them more than you can see it in girls</td></tr>
<tr><td></td><td colspan="3">How to treat autistic kids</td></tr>
<tr><td></td><td colspan="3">Just before Easter we had a week at school about neurodiversity and our form tutors told us about it</td></tr>
<tr><td></td><td colspan="3">I remember in year 6 our teacher talking about neurodiversity and autism</td></tr>
<tr><td></td><td colspan="3">I remember some stereotypes we looked at</td></tr>
<tr><td></td><td colspan="3">In primary we learnt different types of it and I can remember that you may not always know if someone has autism so be careful and don’t bully</td></tr>
<tr><td></td><td colspan="3">I knew their brains work in different ways but they still have great talents</td></tr>
<tr><td></td><td colspan="3">Yes, that they are a bit difference</td></tr>
<tr><td></td><td colspan="3">Yes its different ways people think</td></tr>
<tr><td></td><td colspan="3">I have been taught they are all different</td></tr>
<tr><td></td><td colspan="3">You need fidgets to help concentrate</td></tr>
<tr><td></td><td colspan="3">That they have a hard time focusing</td></tr>
<tr><td></td><td colspan="3">Yes, that autistic people can see more</td></tr>
</table>

What did you learn from the lesson?	
Generic traits	13
Stereotypes not true	1
It isn’t always obvious when someone has autism	1
Anybody can be autistic/you can’t control it	2
Being autistic is hard/can be challenging for autistic people	2
Spectrum - terminology	3
Neurodivergent – terminology	1

Coping with school	2
How to help	3
Maggie liked art more than maths	1
That there is a lot we still need to work on this	1
Positives of autism	7
Differences between boys and girls	66
Meltdowns/shutdowns	22
Masking	75
Autism as a superpower	19
Autistic people all different	55
Incorrect or irrelevant Statements That girls more likely to be diagnosed with autism That autistic people tend to be very good at a specific subject How horrible people can be I learnt that there are different levels of autism I learnt that it's more common for boys to have autism and autistic people are more neurodivergent They need more help That autistic people have something wrong with there brains which gives them less understanding of things Boys are more likely to be autistic Autism is more common in boys The odds of certain things	10

Do you think having autistic girls themselves teaching you about autism made a difference? If yes, how?	
Yes	208
No	47
Don't know	6
Yes – comes from their own experience/perspective (majority of responses) Helps to learn about masking (4) Highlights differences between boys and girls (12) More accurate Specific traits Removes stereotypes 'Yes. I am a girl. I don't know where I am on the spectrum. I've never been diagnosed before' 'Yes, because I know I am not alone with autism and now I know more about it' 'Yes, because I didn't really understand what autism was until now'	
No – could have come from anyone with autism Would have been better to hear from boys too.	

'No. I don't think any teachers are autistic'

How might you change the way you interact with the autistic children in your class having completed this lesson?	
By not making assumptions	6
More understanding	33
Know how to support with shut downs/melt downs	16
Awareness of sensory – space/noise	25
Be nicer/kinder	58
Treat everyone the same	24
I won't change	10
Negative responses 'I will not stare at them for a long time' 'I'm not sure but I think I would feel bad for them' 'Act young' 'Not much because I don't think my mates are autistic'	

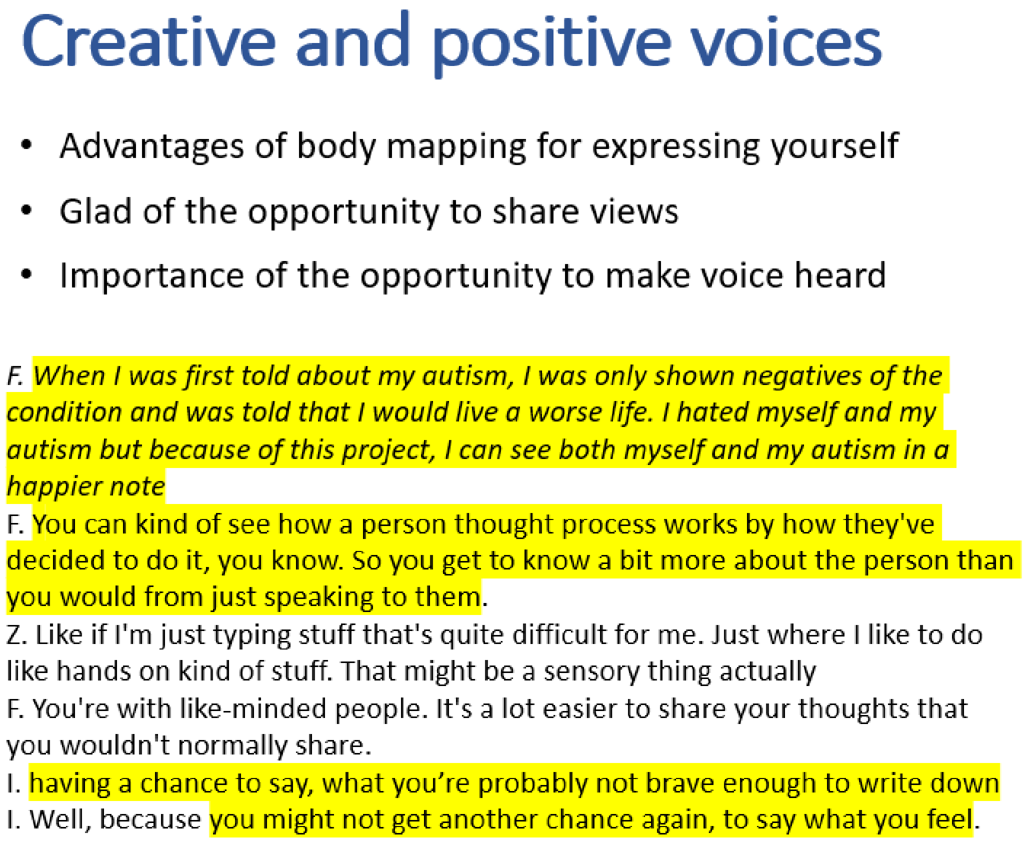
How do you think we could improve the lesson?	
More information	19
More about feelings of autistic people	6
Hearing from more perspectives	3
More specific examples of how to help	8
More videos	5
Include information/views of autistic boys	12
Have an autistic person come to school to deliver the lesson	11
By repeating the lesson yearly/every once in a while	2
It doesn't need improving	36
Improve wording of true or false`	10
More interactive	8
More fun/snappier video	3
Add views of non-autistic people 'To know that there could be autistic people in lessons' 'To learn about different neurodivergents' 'Make it less about them being different and more about them being the same/ 'Teach less stereotypically' 'We are all still autistic' 'Make people more comfortable being autistic'	

‘Not using the term aspergers because that is a harmful term for autism, high functioning and low functioning because it’s a spectrum no one is the same’

‘By having a vote if it can have a cure or medicine to stop it.’

‘By not doing it the way you are because its making people be mean. Don’t ask me to write another thing again.’

Appendix K Reflexive Thematic Analysis Coding Examples



Creative and positive voices

- Advantages of body mapping for expressing yourself
- Glad of the opportunity to share views
- Importance of the opportunity to make voice heard

F. When I was first told about my autism, I was only shown negatives of the condition and was told that I would live a worse life. I hated myself and my autism but because of this project, I can see both myself and my autism in a happier note

F. You can kind of see how a person thought process works by how they've decided to do it, you know. So you get to know a bit more about the person than you would from just speaking to them.

Z. Like if I'm just typing stuff that's quite difficult for me. Just where I like to do like hands on kind of stuff. That might be a sensory thing actually

F. You're with like-minded people. It's a lot easier to share your thoughts that you wouldn't normally share.

I. having a chance to say, what you’re probably not brave enough to write down

I. Well, because you might not get another chance again, to say what you feel.

Positive outcomes of participatory design

- Skills developed as a result of participation
- Wanting to get it right
- Positive outcomes of participatory design
- Pride in resources we created
- Developing knowledge and understanding of autism
- Unusual to focus on positives

I. More people now know what it is and what it feels like, so we changed the world
Z. A little part of a big picture
F. When I was first told about my autism, I was only shown negatives of the condition and was told that I would live a worse life. I hated myself and my autism but because of this project, I can see both myself and my autism in a happier note
Z. I think it's helped with my confidence
Z. That it's still important that I look after myself and how I feel
A. I got to meet the other people that was in it and like, I made major friends with them.
F. I think it sort of helped me learn more about myself as well as help the project as a whole
Z. I'm really happy with what we created
Z. And just to, like, to be a part of something that I know can help even more people is just a really lovely to do.
A. I'm not sure I ever knew that girls could be autistic.
Z. Being around other people who like, autistic people has been really helpful for me to gain a better understanding of myself almost.
Z. Although I might be different to a lot of other people, I still matter.
Z. It helps you understand yourself