Exploring the experiences of inclusion for children and young people with Down's Syndrome, in mainstream education, using the Mosaic Approach.

#### Shaunna McLean

Submitted in Requirement for the Doctorate in Educational Psychology (EdPsyD)

School of Education and Lifelong Learning

University of East Anglia

May 2025

Amended September 2025

This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and that use of any information derived therefrom must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution.

#### Overview

The present thesis is divided into three chapters: a thematic narrative literature review, the empirical paper, and the reflective chapter.

The thematic narrative literature review explores the concept of inclusion, as well as the facilitators and barriers to this in relation to children and young people with special educational needs and disabilities (SEND) more generally, as well as those with Down's Syndrome. Participatory research methods are also reviewed, as well as the methodology that has been previously used when conducting research with individuals with Down's Syndrome. Finally, the literature relating to the Mosaic Approach is reviewed.

The empirical paper encapsulates the present research study. The research is introduced and rationalised in the context of the literature, before the methodology and findings of the study are presented. The implications of these findings are discussed in relation to future research and the profession of educational psychology, alongside the limitations of the research.

The reflective chapter provides an overview of the researcher's experiences of conducting the research, justifications for the methodological approaches as well as the relevance of the study to the national context.

Finally, the appendices contain documents relevant to and used within the research such as consent forms and advertisements.

## **Acknowledgements**

A massive thank you to all of my participants who brought this research to life. I am so thankful for your willingness to engage in this research, and for your honesty and openness when speaking with me. To their parents, thank you for taking an interest in my study and for empowering your children to have their voices heard. Thank you to all the schools and school staff who were so accommodating of my study and gave up their time to help facilitate my school visits.

Thank you to my research supervisor, Dr Andréa Honess for your guidance, patience and pragmatism that helped shape this research, and for persevering with me through an incredibly long ethics process. To my placement supervisors, Dr Becky Farrer and Dr Becca Miller, thank you for your encouragement and understanding and for your reassurance that I would make it through thesis writing.

Thank you to my family and friends for your unconditional support and patience over the past three years and throughout the process of getting to this point in my training.

To Will, thank you for always being my biggest cheerleader. Your unwavering support and belief in me has given me so much encouragement and strength throughout this whole journey.

### **Access Condition and Agreement**

Each deposit in UEA Digital Repository is protected by copyright and other intellectual property rights, and duplication or sale of all or part of any of the Data Collections is not permitted, except that material may be duplicated by you for your research use or for educational purposes in electronic or print form. You must obtain permission from the copyright holder, usually the author, for any other use. Exceptions only apply where a deposit may be explicitly provided under a stated licence, such as a Creative Commons licence or Open Government licence.

Electronic or print copies may not be offered, whether for sale or otherwise to anyone, unless explicitly stated under a Creative Commons or Open Government license. Unauthorised reproduction, editing or reformatting for resale purposes is explicitly prohibited (except where approved by the copyright holder themselves) and UEA reserves the right to take immediate 'take down' action on behalf of the copyright and/or rights holder if this Access condition of the UEA Digital Repository is breached. Any material in this database has been supplied on the understanding that it is copyright material and that no quotation from the material may be published without proper acknowledgement.

# Contents

Overview	2
Acknowledgements	3
Chapter One: Literature Review	6
Introduction	6
Positionality	6
Narrative thematic literature review	7
Research questions for the literature review	7
Theoretical framework	8
Search strategy	12
Inclusion criteria	12
Inclusion: A history and definition	13
History of inclusion	13
A definition of inclusion	15
Factors influencing inclusion	18
The ontology and epistemology of inclusion	23
Down's Syndrome	24
What is Down's Syndrome?	24
Down's Syndrome and the law	25
Inclusion of children and young people with Down's Syndrome	26
Voices of children and young people with SEND in research	31
The use of participatory methods	31
Gaining views of individuals with Down's Syndrome	35
Mosaic Approach	36
Chapter Two: Empirical Paper	38
Abstract	38
Introduction	38
Background and rationale	39
Local and national Priorities	41
Methodology	43
Participant recruitment and characteristics	43
Ontology and epistemology	45
Quality of the research	46

Ethical considerations	52
Data collection	53
Data analysis	54
Results	57
Discussion	67
Chapter Three: Reflective Chapter	78
References	89
Appendices	101

## **Chapter One: Literature Review**

### Introduction

This chapter will explore and critically review the literature surrounding inclusion more generally, as well as the educational experiences of children and young people with SEND. This literature will begin with an introduction to inclusion, looking at how the English education system has included children and young people with SEND across the past century, as well as how inclusion has been defined within research. Inclusive practices, and barriers and facilitators to these will also be discussed in relation to children and young people more generally, as well as those with Down's Syndrome. Finally, the review will examine the participatory research methods used in research to capture the views of children and young people with SEND, including those with Down's Syndrome, as well as specifically exploring the Mosaic Approach. This literature review will also explore the implications for educational psychologists' practice, and the relevance of the research within the English education system.

## **Positionality**

The researcher's interest in the topic of the study developed from personal and professional experience of supporting individuals with Down's Syndrome to be included within specialist settings. This sparked a motivation to explore and understand the experiences of those with Down's Syndrome in mainstream provision. Through this work, parents have voiced that they felt their children and young people with Down's Syndrome were often a forgotten group in comparison to neurodiverse children and young people, with there often being a lack of training and support for school staff working with children and young people with Down's Syndrome. This provided further motivation for the study, with the hope that the research would raise the profile of Down's Syndrome and provide an opportunity for the voices of children and young people with Down's Syndrome to be heard.

This previous experience with children and young people with Down's Syndrome allowed the researcher to come into this research with an understanding of the range of needs commonly associated with children and young people with Down's Syndrome. Therefore, before the research had even begun, there was a subtle understanding that each participant would experience inclusion in a unique way. As

such, it was important that inclusion was understood from each participant's individual perspective, which aligned most with a social constructionist epistemology.

During the literature review, it became apparent that the voices of children and young people are scarce within the current literature. This strengthened the researcher's commitment to ensuring the voices of children and young people were heard throughout the research. However, the researcher was acutely aware of the range of communication needs that are present for individuals with Down's Syndrome. Therefore, an adaptable methodology was necessary to ensure accessibility for all participants, which also allowed for in depth data collection. The Mosaic Approach met this criteria, whilst aligning with a social constructionist epistemology, and also allowed for the utilisation of consultation and observation skills that the researcher had developed in their dual role as a trainee educational psychologist.

#### Narrative thematic literature review

A narrative thematic approach was utilised for the literature review. Given the scope of the research questions, and their qualitative nature, a narrative review was felt to be more appropriate than a systematic review (Pare & Kitsiou, 2017). Inclusion as a concept is very subjective in nature, with no two people likely to draw the same conclusions on a definition of inclusion or have the same inclusive experiences, which thus aligns with the more subjective style of a narrative review (Sukhera, 2022). In addition, given the relative lack of literature relating to certain areas of the review, namely research relating to educational experiences of individuals with Down's Syndrome, a narrative review would still allow conclusions to be drawn (Sarkar & Bhatia, 2021). Although a chronological narrative review may have been appropriate given the changes in inclusion that have occurred over time, a thematic narrative review was chosen due to the consistency of themes arising within the literature despite the changes in inclusion that have occurred over time.

## Research questions for the literature review

What are the experiences of inclusion for children and young people with SEND within mainstream education?

What are the experiences of inclusion for children and young people with Down's Syndrome within mainstream education?

What participatory methods are used to gather the voices of children and young people with SEND within research?

How has the Mosaic Approach been used so far within research?

#### **Theoretical framework**

The present research will consider social cognitive theory (Bandura, 1986) and self-determination theory (Ryan & Deci, 2000) as a basis for reviewing the literature. These theories emphasise the psychological needs as well as environmental factors and practices necessary for children and young people to achieve in school and thus experience a sense of inclusion (Bandura, 1986; Ryan & Deci, 2000). As such, these theories serve as a useful framework through which inclusion can be understood and interpreted. Given the historical marginalisation of individuals with SEND, it is important that research with this group aims to challenge social injustice and understand the perspectives of these individuals through representing their voice (Parris et al., 2019). One of the ways this can be achieved is through participatory research with marginalised groups, as we can only seek to promote social justice once we have an appreciation for the experiences of these individuals (Jackson et al., 2024). As such, the literature will be considered through a social justice lens to understand how promoting inclusion and using participatory methods can contribute to achieving social justice.

## Self-determination theory

Self-determination can be defined, psychologically, as an individual's sense of control over their life, and their ability to make informed choices and decisions (Ryan & Deci, 2000). Research has shown that in the context of education, a strong sense of self-determination can lead to increased persistence to engage with tasks and more positive task performance (O'Brien, 2018). Ryan and Deci (2000) propose that in order to achieve a true sense of self-determination, three psychological needs must be fulfilled: autonomy, competence and relatedness. Autonomy refers to an individual's sense of control and freedom over their choices and actions (Guay 2022; Wehmeyer & Shogren, 2020). Individuals who experience autonomy, do not necessarily experience a high level of independence, but instead experience a sense of free will (Strnadova, 2020). In education, pupils who perceive they have choice over their learning become more enthusiastic and involved with academic tasks

(O'Brien, 2018). In relation to individuals with SEND, a historical emphasis on the medical model of disability has meant these individuals have been viewed with little to no capacity for autonomy and have thus had reduced opportunities to experience control in relation to making decisions about their own life (Strnadova, 2020; Wehmeyer & Shogren, 2020). Despite the shift away from a medical model-oriented view of SEND, viewing children and young people with SEND as lacking autonomy still occurs, particularly when school staff demonstrate little awareness of their pupils' strengths and areas for development (Schunk & DiBenedetto, 2020).

Competence can be seen as an individual's sense of achievement within environments. A high level of competence motivates individuals to engage in and work towards tasks that are slightly beyond their capabilities, thus sustaining their feelings of success and achievement (Wehmeyer & Shogren, 2020; Guay 2022). Again, the levels of competence for individuals with SEND, perceived by society, are typically low, which can lead to pupils with SEND being engaged in tasks that are not challenging enough (Strnadova, 2020). This ultimately leads to reduced opportunities to learn in challenging ways, which will not result in an increased sense of competence (Wehmeyer & Shogren, 2020).

The final psychological need that must be fulfilled in order to achieve self-determination is relatedness. Relatedness can be conceptualised as experiencing emotional connection with others, ultimately leading to a sense of belonging within an environment (Guay 2022; Wehmeyer & Shogren, 2020). Within schools, a sense of relatedness can be created through peer relationships, as well as the pupil-teacher relationship (O'Brien, 2018). Unfortunately, research has shown that it is typical for individuals with SEND to experience lower levels of relatedness, as a result of smaller social networks, reduced opportunities for community participation and a high number of barriers to social engagement (Strnadova, 2020; Fisher et al., 2019). Societal attitudes, which typically deem individuals with SEND to be socially incompetent, also place limitations on social opportunities for individuals with SEND and ultimately increase experiences of social isolation (Fisher et al., 2019).

These three needs can all be easily fostered within a school environment and equally cannot develop unless an individual is within a supportive environment (Guay, 2022). Differentiation of instruction, awareness of a pupils' strengths and

needs, a focus on tasks that provide pupils with a sense of achievement, and opportunities to form social connections will all fulfil a pupils' set of psychological needs and therefore increase their motivation to engage with education (Guay, 2022; Kupers et al., 2024; Fisher et al., 2019). These practices all form the basis of inclusion, as described in the SEND Code of Practice (2015), and as such by focusing on enhancing self-determination, schools can create inclusive environments for individuals with SEND (Strnadova, 2020). It is important to consider that when these psychological needs are not satisfied, this is likely to lead to disengagement with education and give rise to difficulties educating individuals with SEND (Guay, 2022).

## Social Cognitive Theory

Social cognitive theory states that human behaviour and learning occurs through interactions between personal, behavioural and environmental factors (Bandura, 1986). Personal factors include knowledge, motivation and self-efficacy; environmental factors include home, school and classroom environments; and behaviours include teaching strategies, inclusive practices and task engagement (An & Meaney, 2015). Interaction between these factors can be conceptualised as: an individual observing the environment in which they are in, as well as the behaviours that are occurring within that environment, and in combination with their own thoughts and internal processes, an individual will learn and behave accordingly (Burney, 2008). One's own personal factors are heavily influenced by the environment and previous experiences. For example, it is not uncommon for individuals with SEND to display reduced self-efficacy, due to low levels of belief in their abilities from adults supporting them, as well as the wider society (Schunk & DiBenedetto, 2020). As a result, for individuals with SEND academic behaviours, such as effort and motivation, are likely to suffer (Schunk & DiBenedetto, 2020).

Within the education context, a pupils' learning is not only impacted by their own personal factors, but also by their teachers' personal factors and the wider interaction of these. Teachers' beliefs about a pupil's abilities will in turn affect that pupils own personal factors. For example, research has shown that if a teacher believes that a pupil's academic skills will be lower due to their disability, that pupil will then experience lower self-efficacy and typically lower motivation to engage with

academic tasks (Schunk & DiBenedetto, 2020). On the contrary, teachers who have a good understanding of their pupils' strengths and areas of development are more likely to make reasonable adjustments to the learning environment to help facilitate pupil engagement (An & Meaney, 2015).

#### Social Justice

Disadvantaged groups within society, including those with SEND, often experience discrimination and exclusion which unfairly prevent them from accessing opportunities, including education (Nesterova, 2023). Social justice can be seen as an imperative to challenge these unjust experiences and is defined by the United Nations as an underlying principle whereby nations can coexist peacefully and prosperously, and is achieved through equity, access, participation, rights and diversity (Nesterova, 2023). Social justice is often viewed through a focus on removing barriers for one specific group, with the hope that through removing these barriers everyone will be able to function equally within society (Riddell, 2009). For example, in the medical model context of disability, where disability is defined by particular traits and characteristics, individuals with SEND were educated away from their peers. In this context, society may view social justice as being in part achieved by allowing individuals with SEND to access the mainstream education system (Artiles et al., 2006). However, achieving social justice needs to go beyond the removal of barriers.

In contrast to the medical model of disability, others have viewed disability as related to the cultural, social and political context in which an individual experiences a difference (Riddell, 2009). In this context, social justice needs to go beyond the individual and the equal distribution of opportunities and resources (Nesterova, 2023). Within this framing of disability, it is argued that there are more systemic levels of discourse and prejudice within society and politics which need to be challenged if we are truly able to achieve social justice for marginalised groups (Artiles et al, 2006). To challenge this societal level of social injustice, disadvantaged groups need to be heard and understood, and relationships must be built between institutions and all societal groups, so that hierarchies of privilege can be deconstructed (Nesterova, 2023).

Within a social justice orientation, education and schools, themselves have an important role to play in empowering and achieving social justice for pupils with SEND (Artiles et al, 2006; Polat, 2011). School staff can work towards social justice by collaborating with external services to ensure support is readily available (Pantic & Florian, 2015). In addition, educational support should be accessible and readily available, rather than being provided in response to an identified need, thus ensuring that all pupils experience an appropriate education regardless of whether or not they are classified as having SEND (Pantic & Florian, 2015).

## Search strategy

A literature search was conducted by the researcher between October 2023 and September 2024, with continuous revisits as the research developed. The databases utilised for this search included: the University of East Anglia (UEA) online library and Google Scholar. The search terms used were primarily taken from the title of this research including 'Down's Syndrome', 'inclusion', '(mainstream) education' and 'SEND', and were used in varying combinations.

#### Inclusion Criteria

There is a depth and richness of literature relating to the inclusion of children and young people with SEND. In order to contain the vastness of the literature, it was decided that research published from 2015 onwards would be included within the review. The researcher felt that this time frame would be appropriate as, at the time of submission of this thesis, the research would be ten years old. In addition, 2015 is also the year in which the most recent SEND Code of Practice came into effect, thus meaning that the research included would reflect the current context of SEND within the education system. Additionally, this meant the literature would also be most relevant to the participants taking part in the study. The educational experiences for children and young people with Down's Syndrome have changed dramatically over the years. As such, it was felt that if older literature were to be included, the experiences of the participants in study would not be comparable to the conceptualisations of inclusion prior to 2015. The research included within the literature review was also limited to studies that took place within the English education system, again to reflect the national and local context and to ensure relevance to the present study.

For literature relating to Down's Syndrome, the same criteria related to date of publication was initially used, but this was then extended to include research published from 2000 onwards. This was due to the limited amount of research exploring the educational experiences of children and young people with Down's Syndrome. It was felt that without including earlier research articles, the scope of this section of the literature review would be limited. This rationale was also relevant to why research from other countries was included within this section of the literature review. Interestingly, certain countries tend to produce more research with children and young people with Down's Syndrome. One rationale for this is the implications of abortion laws within specific countries. Those countries with stricter abortion laws, such as Ireland and Middle Eastern countries tend to produce more research which is likely due to higher numbers of individuals with Down's Syndrome residing in these countries.

## **Inclusion: A History and Definition**

In this section of the literature review, a historical context to the concept of inclusion will be given, before critically exploring how inclusion is defined within the literature.

## **History of inclusion**

The inclusion of children and young people with SEND, within the education system has been an ever-developing process. In the early 20th century, educating children and young people with SEND was influenced by a medical model of disability, whereby children and young people were often defined by the disability and either segregated into specialist education settings, or not educated at all (Lindsay et al., 2020). In 1973, the notion of inclusive education was first mentioned by the Warnock Committee, which paved the way for the 1981 Education Act. This act stated that children and young people with SEND should be educated in mainstream schools unless it was deemed inappropriate or impractical for a child's needs. Special educational provision was seen to be a core component for mainstream provision, and not a separate entity, and children and young people were issued Statements of SEND to ensure this additional provision was provided (Department of Education and Science, 1981). This was the first instance of children and young people with SEND being offered mainstream schooling, however, many saw this as an expectation for these children to integrate into mainstream schools rather than

education adapt to include them (Lindsay et al., 2020). Despite the progress towards inclusion, variability in how support was implemented across local authorities was reported, amongst other concerns (Sales & Vincent, 2018; Tysoe, Vincent & Boulton, 2021). In attempt to mitigate these difficulties, the Children and Families Act (2014) was introduced which gave way to the SEND Code of Practice (2015) and the introduction of Education Health and Care Plans (Lindsay et al., 2020).

One of the most recent government initiatives related to inclusion, is the inclusion in practice initiative, aimed at gathering evidence of best practice in relation to inclusion within schools, to ensure inclusive experiences for children and young people (Inclusion in Practice, 2025). The aims of this initiative aligns with those of the present study, which would further extend the scope of the initiative by gaining an understanding of inclusive practices from the perspective of children and young people. So far, the Inclusion in Practice initiative has identified several key practices that schools across England are implementing to ensure an inclusive environment for pupils. These include strong relationships with pupils, families and the local authority; evidence-based teaching and interventions; and viewing inclusion from a whole-school, systemic perspective to ensure consistency and benefits for all pupils (Inclusion in Practice, 2025). So far, the initiative provides a good insight into the different practices being implemented in school, but further phases will explore how these practices are being implemented to aid understanding of how inclusion is being facilitated (Inclusion in Practice, 2025).

Since the 1993 Education Act, governments have published three SEND Codes of Practice to support schools and local authorities with the implementation of SEND legislation, in 1994, 2001 and 2015. Despite regularly updated governmental guidance, a consistent definition of inclusion has still yet to be determined, often leading to, once again, variability in practice when supporting children and young people with SEND (Kendall, 2019a). One reason that has been given for this lack of agreement within the literature and practice may be that inclusion is particular to the person and their own personal experiences within a learning environment, whether it be a child or young person, a parent or a member of school staff (Dimitrellou et al., 2020). As a result, inclusion can be thought of as a dynamic process, and thus it must be adapted to suit the individual needs of children and young people rather than something that can just be applied as a blanket policy (Florian & Spratt, 2013).

Despite the common difficulty in defining inclusion, several research studies have proposed a tiered system as a lens through which to view inclusion.

#### A definition of inclusion

Inclusion at the most basic level relates to placement (Selisko et al., 2024; Nilhom, 2021). Inclusion as a means of placement is often seen as children and young people with SEND being placed in mainstream rather than special schools, as seen in the 1973 Warnock Report (Department of Education and Science, 1978). If placement is equivalent to inclusion, then by placing a child or young person with SEND within a mainstream setting, social justice can be achieved as the individualistic barriers to an equal education are removed (Artiles et al., 2006). But placement can also refer to where a child is being educated within a school. Often, within mainstream schools, the placement of pupils can range from being educated within a classroom with their year group, or with peers who are at a similar stage of development, or being educated completely independently (Webster & Blatchford, 2019). Social cognitive theory states that a high proportion of our learning is achieved through the observation and interactions with others that occur in a typical classroom environment (Bandura, 1986). But for some children and young people with SEND, their education within mainstream settings is isolated, and a high percentage of their learning takes place outside of the classroom, independent of peers and with the sole support of a teaching assistant. (Webster & Blatchford, 2019; McKinlay et al., 2022). It is argued that this practice thus significantly reduces the environmental factors available for a pupil to interact with and is likely to lead to them missing out on valuable learning opportunities (Malik, 2021). For those pupils with SEND who are being educated within a mainstream classroom, in order for learning via observation within the environment to be successful, individuals must see similarities between themselves and the peers they are observing (Schunk & DiBenedetto, 2020). Within the literature it has been argued that for some pupils with SEND, the academic and social differences between themselves and their peers may be made more salient within a mainstream classroom, and as well as the impact on their learning, their opportunities to connect with others and build that sense of relatedness required for motivation will also be limited (Fisher et al., 2019). Therefore, it is clear that, for some children and young people with SEND, attending a mainstream school will not facilitate inclusion, as although barriers to accessing

mainstream education have been removed, their participation is not guaranteed to be meaningful (Artiles et al., 2006).

Within the four-tier model, at the next stage, inclusion has been defined as meeting all needs of children and young people with SEND, including social and academic needs (Selisko et al., 2024; Nilholm, 2021). At this level, children and young people with SEND are not just present in their educational setting, they are actively participating, both academically and socially (Benstead, 2019). Given the social nature of learning, increased social inclusion, both within and outside the classroom, is likely to lead to increased academic achievement (Bandura, 1986; Benstead, 2019). In order to facilitate meaningful participation, teachers require an understanding and awareness about their pupils' needs which needs to translate into appropriate adjustments (An & Meaney, 2015). Teachers must be flexible in their approaches to teaching and remove any barriers to participation (Florian & Spratt, 2013). The academic and social engagement which children and young people with SEND should be experiencing at this level of inclusion, will provide them with a sense of belonging and competence (Ryan & Deci, 2000). Which, in line with the self-determination theory, would increase their motivation to achieve within school (Benstead, 2019; Ryan & Deci, 2000; Dunleavy & Sorte, 2022). However, it has been suggested that differentiation solely for children and young people with SEND can further serve to stigmatise and discriminate against those pupils, by exacerbating and making salient their differences (Florian & Spratt, 2013). Inclusion at this level still focuses on the individual and does not consider the changes that need to occur in the wider context and culture in order to achieve social justice for children and young people with SEND (Riddell, 2009).

The third level of inclusion starts to consider cultural practices from a wider systemic level, whereby inclusion can be conceptualised as meeting the academic and social needs of all pupils within the school (Selisko et al., 2024; Nilholm, 2021). By focusing on the needs of all pupils, schools can ensure that children and young people with SEND are not further isolated by increasing the salience of their needs (Florian & Spratt, 2013). Equally, all pupils experience inclusion and social justice as, at this level, a child or young person does not require a diagnosis of SEND in order to receive additional support (Polat, 2011; Pantic & Florian; 2015). All children and young people are benefitting from the wider environmental and behavioural factors

that facilitate inclusion and learning and thus develop a motivation to succeed through a shared sense of relatedness and competence (Bandura, 1986; Ryan & Deci, 2000). This conceptualisation of inclusion has similarities with the Universal Design for Learning (UDL) approach which has gained popularity in America. The UDL approach recognises the barriers within the education system and advocates for the removal of these to ensure equal participation for all pupils (Basham et al., 2020; Phelan et al., 2025). UDL recognises the individual differences across children and young people and encourages school staff to be flexible with their teaching methods, curriculum and assessments and use evidence-based approaches to meet the needs of all pupils (Anastasiou et al., 2025; Morton & Pilgrim, 2023). UDL encourages consistent use of multiple means of representation, action and expression, and engagement, with the assumption that this will remove any potential barriers to engagement (Anastasiou et al., 2025; Basham et al., 2020). As such, UDL starts to consider the underpinning systemic practices that influence inclusion for all pupils.

The fourth and final level of inclusion described in the literature, relates to the creation of inclusive communities and a culture of inclusion within schools (Nilholm 2021; Selisko et al., 2024). By focusing on the environment as a whole, the focus is centred on the factors that influence how children and young people access the world, rather than the child themselves and their diagnosis (Marks Woolfson, 2024). This considers the systemic changes that are necessary to bring about inclusion, so that by addressing these overarching processes a sense of social justice is achieved for all children and young people (Nesterova, 2023). Schools must ensure the environment is adapted and appropriate adjustments are in place to meet the needs of all pupils, rather than trying to accommodate pupils with SEND within a fixed environment (Bandura, 1986; Benstead, 2019). As a result, a culture of inclusion would ensure that there are no barriers that impact on any pupils' ability to succeed socially and academically. This can be considered as a holistic view of inclusion as it emphasises the need for inclusion to occur across all different levels of the schooling system, in order for it to be seen as effective (Rapp & Corraal-Granados, 2024).

By combining the above themes of inclusion, inclusion in this study will henceforth refer to the presence and participation of all pupils in both academic and social aspects of school, within a learning environment that is adapted to meet their needs.

## **Factors Influencing Inclusion**

This section of the literature review examines inclusive practices within schools, for children and young people with SEND, and the barriers and facilitators to these practices. Whilst the lack of consensus regarding a definition of inclusion can make it difficult to implement (Dimitrellou et al., 2020), several other factors have also been identified to both positively and negatively affect inclusive practices.

#### Attitudes of Staff

Within the literature, attitudes of school staff towards inclusion and children and young people with SEND arises as a theme that has a massive influence on the implementation of inclusion within schools.

Research has identified an incongruency between school staff's appreciation for inclusion and their ability, as well as their belief in this ability, to implement inclusion (Florian & Spratt, 2013). Teachers are often left responsible for facilitating inclusion in their classrooms, without much support from senior leadership which often leaves them feeling disempowered, and as a result they view inclusion more negatively than senior management. (Dimitrellou et al., 2020). Warnes et al. (2022), who surveyed 66 teachers regarding their views about concerns around inclusive education found that teachers felt as though teaching children with SEND made their jobs more stressful and they felt they were not able to provide high quality teaching to this particular group of children. In addition to teaching staff feeling pressure to implement inclusion, Smith and Broomhead (2019) found that the majority of the 15 Special Educational Needs Co-ordinators (SENCOs) interviewed often felt positioned as experts in SEND but felt powerless to implement change unless there was a whole school approach towards inclusion, which was guite often not the case. It is clear that school staff across many different roles experience feelings of incompetence in relation to implementing inclusion. A lack of competence is likely to reduce motivation to engage in inclusive practices, which thus reduces experiences of inclusion for children and young people with SEND (Ryan & Deci, 2000). One way of mitigating these feelings is to implement training on inclusion, which has been found to increase teachers' knowledge and self-efficacy towards inclusion (Marks Woolfson, 2024). However, a lack of training regarding inclusive practices is often cited by teachers within the literature (Dimitrellou et al., 2020).

As identified in the literature, mainstream school staff often experience low selfefficacy in relation to their ability to teach and differentiate for pupils with SEND. One way to increase their self-efficacy, is by encouraging collaboration with staff from specialist settings. Collaboration between mainstream and special schools can take many forms, including training, collaborative planning and co-teaching classes or particular lessons (Al-Natour et al., (2015). The aim of collaboration is to recognise that staff from mainstream and SEND schools each have their own expertise and working together and learning from each other can increase confidence, professional development and inclusive practices which would in turn allow pupils to achieve their potential (Al-Natour et al., 2015). Many benefits of collaboration have been identified for school staff, including improved attitudes towards students with learning disabilities, development of skills and knowledge as well as a shared workload (Al-Natour et al., 2015; Paires & Mandal, 2023), which in turn address some of the identified barriers to inclusion. Collaboration itself unsurprisingly does not come without barriers, which include: a lack of cooperation between school staff, power imbalances and a lack of time allocated to collaborating (Al-Natour et al., 2015). However, given the benefits for school staff, pupils and inclusion more generally, schools should endeavour to ensure that collaboration becomes an ongoing and a mandatory part of inclusive provision, and that time is offered not only to collaboration but to the development of relationships between teachers to ensure effective collaboration.

Staff attitudes around inclusion and SEND can have a pronounced effect on their interactions with children and young people with SEND. The teacher-pupil relationship has many psychological benefits for children and young people. Not only does it enhance their sense of relatedness and belonging to their school environment, it also enhances their feelings of competence by knowing that teachers believe in their capabilities (Guay, 2022; Schunk & DiBenedetto, 2020). Some limited research has found that staff who hold more negative views about the academic abilities of children and young people with SEND are less likely to engage in differentiating work which reduces opportunities for pupils to develop competence and a sense of self-efficacy (Schunk & DiBenedetto, 2020). For example, the small sample of parents in Dunleavy and Sorte's (2022) study which looked at parents' experience of inclusion for their children with SEND in mainstream schools reported

that school staff often spoke about their children in a discriminatory and negative way both in relation to their externalising needs, as well as the support necessary for their children. This was echoed by the 37 students with a range of SEND in Dimitrellou and Male (2022). In particular students with SEMH needs felt as though they were labelled, and their needs were not fully understood and supported by their teachers. Those pupils also reported negative relationships with their teachers. Interestingly, those pupils with moderate learning difficulties who participated in this study, typically reported positive relationships with their teachers, thus suggesting that a child or young person's diagnosis can be a moderating factor in teacher-pupil relationships. On the whole, these negative attitudes are likely to reduce a child's sense of belonging within a school and thus reduce their motivation to engage in learning (Ryan & Deci, 2000).

Relationships between staff, parents and children and young people

In addition to effects on children and young people with SEND, another theme arising from the literature is that parents and carers are also affected by the attitudes of school staff, with an overall effect on effective communication and collaboration. The importance of collaborating with parents has been identified as a key factor in facilitating inclusion (Kendall, 2019a) and is a key requirement in the SEND Code of Practice (2015). However, despite the legal obligations of schools and parents to work closely with one another, this does not always translate into practice. In McKinlay et al.'s, (2022) study, it was found that parents of children with Autism felt that their concerns and queries were not always heard by school staff, and as a result negatively impacted their views of inclusion. They felt school staff were not being tolerant of them, let alone their children. Dunleavy and Sorte's found similar findings in their (2022) study, as parents felt that they were at the lower end of an uneven power dynamic between themselves and school staff. In addition, they were often made to feel as though they were overreacting in relation to their child's needs. Interestingly, the majority of parents in both of these studies had a child with Autism, which may provide an explanation for these findings as literature has suggested that attitudes can be more negative towards children and young people who have a nonvisible disability (Tuersley-Dixon & Frederickson, 2016), and thus these findings cannot be seen as representative for all parents of children and young people with SEND. However, the finding that poor relationships between parents and school staff can lead to poor mental health for parents (Dunleavy & Sorte, 2022; McKinlay et al., 2022) is a concerning theme arising in the literature. Adding to the pressures that parents experience, they often felt that it was their job to advocate for their child in order to mitigate some of the negativity they were experiencing from school staff and teach staff and other pupils about what their child's SEND means for them (Dunleavy & Sorte, 2022).

## Assessment and Accessing the Curriculum

As previously stated, within the literature there is a commonly occurring theme that teachers often find it hard to meet the needs of children and young people with SEND within their classrooms (Warnes et al., 2022). In line with this, Webster and Blatchford (2019) found that teaching is often more effective when the needs and attainment of the class group are similar. To mitigate these difficulties and to support teachers in meeting the needs of learners with SEND, it is common for children and young people with SEND to be supported by teaching assistants within the classroom (Webster & Blatchford, 2019). There is a body of literature that has examined the role of teaching assistants in supporting the inclusion of CYP with SEND. It has been found that teaching assistants are often responsible for differentiating the work set by teachers but tend to be more focused on completing the work than by encouraging a child to learn and as a result, may overcompensate for a child, thus reducing a child's autonomy in relation to their learning (e.g. Webster & Blatchford, 2019). In addition, by solely being supported by teaching assistants, which often occurs outside of the classroom, pupils with SEND often become isolated from their teachers and peers (Webster & Blatchford, 2019), and they are thus unlikely to benefit from any vicarious learning that is achieved through working alongside peers and teachers (Bandura, 1986). In McKinlay et al.'s (2022) study, parents of children with autism wanted more provision for the child than just the support of a teaching assistant, as they felt this singled out their child further and thus did not provide them with the same opportunities as their peers.

The national curriculum, at present, is very much assessment driven, with pupils' levels of achievement on national assessments being taken to be an indicator of a schools' success (Williams-Brown & Hodkinson, 2021). Although there are various different assessments that young people can undertake, for example, GCSEs, BTEC

and NVQ assessments, the range is somewhat limited and leaves little room for adjustments to be made (Maher et al., 2021). As a result, the national assessments may not be developmentally appropriate for children and young people with SEND and therefore may not truly reflect the progress they have made within school (Kendall, 2019a). For instance, Maher et al., (2021) found that in PE, children and young people with SEND are expected to conform to typical ideas about how bodies should function and thus were unable to access assessments in the same way as mainstream peers. It is important that children and young people are provided with a sense of achievement within school in order to enhance their self-efficacy and feelings of inclusion and belonging within school (Benstead, 2019). The assessment driven national curriculum continues to reinforce the notions of privilege and inequality, by ascribing notions of success to those pupils who perform better in examinations (Bhopal & Shain, 2014). Thus, further marginalising and contributing to social injustice for children and young people who cannot access assessments (Douglas et al., 2016). It is important that schools strike a balance between not excluding children and young people with SEND from assessments, because they are not seen as capable, but also ensuring that what is assessed is relevant for those individuals with SEND (Douglas et al., 2016). For children and young people with SEND, it may be more appropriate to focus on the progress they are making rather than the grades they are achieving, but not all teachers have the power to change assessment processes (Maher et al., 2021). In addition, unless children and young people feel competent in their learning, a feeling that is usually validated by assessment results or feedback from teachers, they are unlikely to feel motivated to engage in their learning (Ryan & Deci, 2000). Furthermore, the national curriculum also places limitations on the autonomy of teachers, as it is so prescriptive in both content and delivery that teachers have limited control over how their lessons are structured, and how they are able to differentiate content for learners (Warnes et al., 2022). As such, this is likely to reduce their motivation and belief in their ability to differentiate work (Ryan & Deci, 2000; Bandura, 1986).

#### The Influence of Peers

As stated within the social cognitive theory, the social element of learning plays a big role in skill acquisition (Bandura, 1986) and within the literature a number of researchers have focussed on the role of peer interactions in relation to children and

young people with SEND's learning. As a result, children and young people with SEND need to be appropriately included with peers in order to develop their social skills, reduce isolation and increase their sense of belonging within the environment (Fisher et al., 2019). The social aspect of school has also been identified as one of the main motivators for parents to choose to send their child to a mainstream school (Marks Woolfson, 2024). However, Shaw (2017) argues that pupils with SEND are more likely to feel included with peers at a similar developmental age as they feel more comfortable interacting with them. This is likely related to the fact that individuals need to perceive a similarity between themselves and individuals that they are observing in order to facilitate feelings of competence and self-efficacy in relation to social interactions (Schunk & DiBenedetto, 2020). Further research identifies that difficulties building and navigating social relationships often occur for children and young people with SEND, often due to an imbalance of power within those relationships (Benstead, 2019). In addition, parents themselves feel that their children are often excluded from socialising with neurotypical peers, and this exclusion is often influenced by stigmatising attitudes towards disability passed on through generations (McKinlay et al., 2022). But equally, without being socially included, children and young people with SEND would not have the opportunity to practice and develop their social skills and social competence (Benstead, 2019).

### The ontology and epistemology of inclusion

How we view and define inclusion also depends on the ontological and epistemological view we take on teaching and learning. Within the literature, teaching and learning is often viewed through three different paradigms. A behaviourist paradigm states that children and young people learn by direct instruction, with teachers talking students through learning on a step-by-step process (Al-Shammari et al., 2019). The success of this type of learning is measured by a pupil's correct response to a question, with no opportunity for the student to define how the learning relates to their own world (Boghossian, 2006).

The next paradigm through which teaching and learning can be thought about is cognitivism. Learning then becomes meaningful when pupils relate it back to prior acquired knowledge (Malik, 2021). Individual and external factors are constantly interacting to give meaning to learning (Selisko et al., 2024). Cognitive theories of

learning emphasise the need for students to use cognitive processes such as storing, retrieval and processing to support classroom learning (Malik, 2021; Al-Shammari et al., 2019). As a result, students have an active role to play in their learning (Al-Shammari et al., 2019).

Finally, teaching and learning can also be viewed from a constructivist perspective. Constructivism emphasises the crucial role students have to play in constructing their own knowledge and deciding what has meaning for them (Boghossian, 2006). Learning should be hands-on, practical and be related to real-life experiences (Al-Shammari et al., 2019). Within this model, teachers are simply facilitators and students are given the opportunity to structure their own learning (Al-Shammari et al., 2019; Boghossian, 2006).

## **Down's Syndrome**

This section of the literature provides a medical and legal context to Down's Syndrome, and what that means for individuals with Down's Syndrome living in the UK.

## What is Down's Syndrome

Down's Syndrome, or as it is alternatively known Trisomy 21, occurs as a result of individuals being born with an extra copy of the 21st chromosome. This extra chromosome affects the way individuals' brains and bodies develop. As a result, individuals with Down's Syndrome have learning difficulties alongside an increased risk of heart conditions, early development of dementia, hearing loss, hypermobility (National Health Service, 2023), amongst other physical and sensory difficulties. Despite the associated and increased likelihood of health problems, individuals with Down's Syndrome are generally able to live high quality lives. Individuals with Down's Syndrome each have their own personalities and interests, and they should be supported to achieve their goals and full potential (Down's Syndrome Association, 2021a).

At present, there is approximately 47,000 people with Down's Syndrome living in the UK. Individuals with Down's Syndrome are able to live healthy and fulfilling lives, with a high proportion of individuals living into their 50s and 60s (Down's Syndrome

Association, 2021a). Data recorded by the NHS in 2021 demonstrates that the number of children born with Down's Syndrome was one in every 854, per 10,000 live births, which is a slight increase compared to one in every 873 in 2020 (National Health Service, 2024a; National Health Service, 2022).

## Down's Syndrome and the law

Law in the United Kingdom has various applications to individuals with Down's Syndrome and their families. Even before babies with Down's Syndrome are born, they are affected by UK legislation. During pregnancy, all women are offered the opportunity to have their unborn child tested to see if they have Down's Syndrome (Down's Syndrome Association, 2021b). Women are offered an initial test which determines the likelihood that their unborn child has Down's Syndrome, and then they may be offered a further test to provide confirmation. If a woman receives confirmation that her unborn child has Down's Syndrome, then she can either choose to proceed with or terminate her pregnancy (National Health Service, 2024(b)). According to the Abortion Act (1967), which was the first act to legalise abortion, there are three reasons as to which a unborn child can legally be aborted after the typical 24-week limit. One of these reasons is the risk that a child would be born with physical or mental abnormalities that would leave them handicapped (Abortion Act, 1967). It is under this reason, that unborn children with Down's Syndrome can legally be aborted up until birth (Down's Syndrome Association, 2021b). The application of this law to individuals with Down's Syndrome, and to the wider population of individuals with disabilities, has raised questions about society's perception of the value of the lives of those with Down's Syndromes, and it has been argued that if society does not truly value their lives, then will true social justice ever be achievable for this population (Riddell, 2009).

The associated health needs or learning difficulties that are often present in individuals with Down's Syndrome, mean that those with Down's Syndrome are classed as having SEND. As a result, children and young people with Down's Syndrome should be educated according to the SEND Code of Practice (2015). Furthermore, individuals with Down's Syndrome are also protected by the Equality Act (2010). due to the fact that Down's Syndrome can be classed as a disability. Therefore, individuals with Down's Syndrome cannot be discriminated against in

regard to education, employment and access to public services, amongst other services. In line with this, the Down's Syndrome Act (2022) was conceptualised to enhance the quality of life for individuals with Down's Syndrome and improve access to external services and agencies, including health, education and social care, across the lifespan. In July 2022, the government put out a call for evidence, in which individuals with Down's Syndrome, their families, and organisational representatives could contribute to the development of the statutory guidance related to the act (Down's Syndrome Association, 2022).

## Inclusion of children and young people with Down's Syndrome

As with the research relating to the inclusion of children and young people with SEND more generally, several themes are present in the literature relating to inclusion of children and young people with Down's Syndrome.

### Specialist settings versus mainstream

Parents of children with Down's Syndrome often face a dilemma of whether or not to send their child to a mainstream school, with many parents perceiving there to be more benefits for academic and social progress within mainstreams schools (Mullan et al., 2018). Often many pupils with Down's Syndrome complete their primary education within a mainstream school and then transfer to a special school for secondary education (Laws & Millard, 2001; Mullan et al., 2018). Regardless of educational placement, individuals with Down's Syndrome have the ability to learn if provided with an appropriate curriculum and opportunities (Hargreaves et al., 2021). In addition, students with SEND are most often educated outside of the classroom in mainstream school, and even when they are educated within the classroom this does not guarantee their participation and engagement (Engevik et al., 2018). For example, in Kanzaki et al.'s (2023) case study of a seven-year-old child with Down's Syndrome in Japan, they found that their participant's education, in comparison to their peers' education, could be conceptualised at three different levels: Same place and same task; same place and different task; different place and different task.

Although attainment and subject specific achievement are typically not measured in the same way within mainstream and specialist schools, Turner and Alborz (2010), found that pupils with Down's Syndrome attending mainstream schools showed higher levels of achievement, particularly within grammar and numeracy, than those at a specialist school. This difference is likely related to the individual differences of pupils who attend mainstream versus special schools, with Hargreaves et al. (2021) finding that pupils with Down's Syndrome who attended specialist settings were more likely to have increased communication difficulties, sensory processing d difficulties and externalising behaviours.

## Curriculum and learning opportunities

A common theme within the literature, is that children and young people with Down's Syndrome are usually taught academic subjects, such as Maths and English, outside of the classroom, whilst accessing the classroom for more practical subjects (Engevik et al., 2018; Hargreaves et al., 2021). This approach is consistent with common areas of difficulty for children and young people with Down's Syndrome (Engevik et al., 2018). There is also a trend for pupils with Down's Syndrome to participate in creative and physical activities, both in terms of academic subjects and extracurricular opportunities (Hargreaves et al., 2021; Carbone et al., 2023; Engevik et al., 2018). In Engevik et al.'s (2018) study, 39 teachers of children with Down's Syndrome identified that when education does take place outside the classroom for pupils with Down's Syndrome, it is done so to prioritise learning over inclusion within the classroom, without participation. Thus, providing pupils with Down's Syndrome with a sense of competence and achievement (Ryan and Deci, 2000).

#### Teacher's self-efficacy

Researchers in the area have found that one of the main barriers to supporting children and young people with Down's Syndrome is a lack of training for school staff, with teachers often having to find information out on their own rather than receiving specific training regarding Down's Syndrome (Laws & Millward, 2001; Bills & Mills, 2020; Van Herwegen et al., 2019). Only 11% of teachers in Van Herwegen et al.'s (2019) study reporting receiving any training relating to specific SEND, including Down's Syndrome. In Boundy et al.'s (2023) one third of TAs and half of teachers had attended Down's Syndrome related training. This often results in teachers having limited specific knowledge relating to Down's Syndrome, and a lack of understanding of the unique learning profiles of pupils with Down's Syndrome (Van Herwegen et al., 2019). Training relating to specific disabilities has been found to improve attitudes towards individuals with that disability (Carbone et al., 2023). In

addition, prior knowledge and interactions with individuals with Down's Syndrome increased teacher's positivity about teaching a pupil with Down's Syndrome in Bills and Mills (2020) study.

Differentiation is another theme that arises in relation to perceived barriers to inclusion and often results in more negative attitudes. Teachers in Johnson's (2006) study felt that the national curriculum was not appropriate for pupils with Down's Syndrome, which thus demonstrates the need for differentiation. Because of the varied learning profile of pupils with Down's Syndrome, differentiation and inclusion is particular to each individual child (Kanzaki et al., 2023; Takriti et al., 2018). In addition, differentiation becomes harder within secondary schools (Mullan et al., 2018). Teachers in both Boundy et al.'s (2023) and Engevik et al.'s (2018) study felt that, although they had a good understanding of the strengths and needs of their pupils with Down's Syndrome, they did not feel as though they had enough time to appropriately differentiate the curriculum.

These barriers to supporting pupils with Down's Syndrome often leads to negative attitudes about the child with Down's Syndrome and the teachers' own potential to teach them (Takriti et al., 2018). Often, school staff focus too much on a child's SEND, rather than their actual ability, which increases feelings of pressure related to differentiation (Laws & Millward, 2001; Takriti et al., 2018). It is clear from self-determination theory that one's own belief in one's ability to teach will have an impact on teachers' feelings of competence (Ryan & Deci, 2000). In addition, feelings of pressure and frustration may lead to more negative attitudes towards pupils with Down's Syndrome, and as a result have a negative effect on pupils' performance (Takriti et al., 2018).

## The role of teaching assistants

Students with Down's Syndrome may be educated in or outside the classroom, typically with some form of adult support (Hargreaves et al., 2021). Teachers rely heavily on support staff to assist pupils with Down's Syndrome, and the more support staff available, the more positive teacher's attitudes are to educating pupils with Down's Syndrome (Bills & Mills, 2020). The role of teaching assistants can be easily misconstrued by parents as well as school staff. For instance, in Hargreaves et al.'s (2021) study, parents of children with Down's Syndrome in mainstream schools felt

teachers held responsibility for their child's teaching and learning, whilst parents of children attending special schools believed teaching assistants held primary responsibility. In Boundy et al.'s (2023) study, teachers and teaching assistants respectively believed that they held responsibility for the teaching and learning of pupils with Down's Syndrome. Interestingly, parents also felt that teaching assistants were responsible for their child's learning (Boundy et al., 2023). It is clear that this disparity in perceived responsibility causes confusion, which has the potential to negatively impact the academic experiences of children and young people with Down's Syndrome, due to an overreliance on the support of teaching assistants (Webster & Blatchford, 2019). Planning lessons, including differentiating and adapting the work, should be the responsibility of the teacher to ensure that pupils are accessing an appropriate curriculum (Hargreaves et al., 2021).

#### Parental Role

Parents of children and young people with Down's Syndrome, and other SEND, often have to take a more active role in their child's life, and for a more prolonged period of time than for children without SEND (Laws & Millward, 2001). This may be a practical role, such as arranging hospital appointments or teaching their child sign language, or it may be more of an advocacy role, where they are required to educate school staff, and others, about their child's needs (Laws & Millward, 2001; Van Herwegen et al., 2019). Advocacy may also be in the form of ensuring their child has appropriate support in place within school (Van Herwegen et al., 2018). A high proportion of parents in Van Herwegen et al.'s (2018) study felt their children with Down's Syndrome were not having their needs met due to inappropriate support and inadequately trained staff, and as a result felt dissatisfied with school and felt compelled to increase their involvement with school.

## Peer Relationships

The opportunities for peer relationships is one of the commonly reported reasons for parents choosing to send their child with SEND to a mainstream school (Johnson, 2006; Gannon & McGilloway, 2009). However, this does not equal social acceptance and feelings of belongingness to their school community (Tuersley-Dixon & Frederickson, 2016; Mullan et al., 2018). Social inclusion also involves levels of peer acceptance, social competence and loneliness (Tuersley-Dixon & Frederickson,

2016). Individuals with Down's Syndrome typically have increased prosocial behaviours (Moss et al., 2016), but are still vulnerable to the increased mental health difficulties often experienced by children and young people with SEND due to peer rejection (Gannon & McGilloway, 2009).

In addition to being included in the classroom, children with Down's Syndrome must also be included within social times and extracurricular activities in order to develop social skills and friendships (Hargreaves et al., 2021). Support staff also have a role to play in supporting pupils with Down's Syndrome to access these social opportunities (Hargreaves et al., 2021). Including pupils with Down's Syndrome socially has a positive impact on the attitudes of other pupils within the school (Tuersley-Dixon & Frederickson, 2016). Peer attitudes have a massive impact on social inclusion of children and young people with SEND, and there is typically reduced knowledge and understanding about SEND amongst mainstream peers (Gannon & McGilloway, 2009). Their relationships with non-SEND peers are typically characterised by peers supporting and guiding them, whilst their relationships with adults are stronger. (Tuersley-Dixon & Frederickson, 2016). Previous interactions with individuals with SEND can increase positive attitudes amongst mainstream peers towards SEND, however this was not the case in Gannon and McGilloway's (2009) study specifically related to Down's Syndrome, where previous contact with an individual with Down's Syndrome resulted in no change in attitudes.

Interestingly, those children and young people with more visible disabilities, such as those with Down's Syndrome, may experience greater levels of social acceptance, than those with more hidden disabilities, for example Autism. This is likely due to the perceived need that they need support and a more obvious explanation for their difficulties (Tuersley-Dixon & Frederickson, 2016).

In Mullan et al.'s (2018) study, parents often felt that their child was not fully included in social activities. This can be exacerbated as children progress through the schooling system, when children and young people with Down's Syndrome can continue to be more reliant on their parents for opportunities for social activity, whilst peers of a similar age are socialising with increased independence (Gannon & McGilloway, 2009). This is likely related to mainstream peers' social skills developing

at a quicker pace in comparison to the social skills of children and young people with Down's Syndrome (Johnson, 2006).

## Voices of children and young people with SEND in research

This section of the literature review will focus on how participatory methods have been used to gather the views of children and young people with SEND more generally, before focusing specifically on both gaining the views of individuals with Down's Syndrome, and the Mosaic Approach as a methodology.

## The use of participatory methods

The importance of gaining the views of children and young people is being more commonly stressed in both national and global legislation. Within England, the SEND Code of Practice (2015), states that children and young people should be involved in decisions relating to their education and other external support (Daw, 2024). Article 12 of the UN Convention on the Rights of the Child (1989) states that children and young people have the right to express their opinions on matters and decisions that involve them, and that adults should respect and honour their views (Sharma 2021; Sime 2008). Typically, society has found it difficult to honour this legislation for children and young people with SEND (Jurkowski, 2008). The voices of children and young people often go unheard, both within research and their day to day lives, mostly due to unsuitable methods of gaining their opinions, particularly for those young people who are non-verbal or have communication difficulties (Dimitrellou & Male, 2020). Further barriers to gathering the views of children and young people with SEND also include professionals' reluctance to include children and young people; inaccessible meetings and children and young people's lack of awareness that they should and are able to give their views (Sharma, 2021; Bloom et al., 2020a). These barriers and the difficulties that arise when trying to capture the views of children and young people with SEND, often stem from the viewpoint that these individuals need protecting and are not capable forming their own decisions (Sime, 2008; Hill et al., 2016). Often, both in research and everyday life, adults and other professionals are seen to be the voice of these children and young people and tend to speak on their behalf (Horgan, 2017; Bloom et al., 2020a). This ascribes to the medical model of disability, where children and young people are blamed for their difficulties participating, rather than the barriers placed on them by society

(Jurkowski, 2008). In order to move away from the medical model, children and young people's views must be respected so that society can understand how they experience the world, which only they are able to describe (Horgan, 2017). There are a whole host of benefits to listening to children and young people and giving them a voice. It supports the development of their confidence, motivation and autonomy and allows them to feel as though they are a part of society (Bloom et al., 2020a; Sharma, 2021).

When supporting children and young people to participate in research, they must be involved in methods that do more than just gain their opinions (Sharma, 2021). In doing this, researchers can ensure that research is conducted with children and young people, not done to them (Benstead et al., 2023; Sime 2008). Participatory methods are a popular way of ensuring children and young people are more involved in the research process at different levels, as children and young people as participants can be involved in research by designing projects, collecting data and analysing the data (Horgan, 2017; Daw 2024). Horgan et al. (2017) argues that it is not the methods that make the research participatory, but the co-production of knowledge between the researcher and the participants. As such, participatory methods require researchers to give more power and autonomy to the participants within the research process to allow participants to authentically direct the research (Benstead et al., 2023).

Within the literature there are several participatory research methods, other than the Mosaic Approach which will be discussed in due course, which are frequently used to gather the views of children and young people with SEND. Two approaches discussed in this literature review are photovoice and emotion-based rating techniques due to their emerging use within the literature and their emphasis on alternative forms of communication, in addition to verbal methods.

When conducting participatory research with children and young people with SEND, there is a particular trend to utilise a mixed methods approach that involves visual methods, alongside the more typical interviews. This is likely reflective of the difficulties in communication experienced by a lot of individuals with SEND, and a visual aspect to research ensures participants have alternative methods through which to express themselves. (Mannion et al., 2024). With children and young

people with SEND, their communication difficulties may not only affect their ability to express themselves, but it may also impact how they interpret language and as such research methods should be adjusted based on cognitive needs as well as communicative (Geiger, 2023; Bloom et al., 2020b; Mannion et al., 2024). For example, participants in Geiger's (2023) study appeared to have a wider definition of the concept of 'friend', often describing school staff as friends, as well as peers. Children and young people with communication difficulties may also find it hard to answer more abstract questions, or questions that require them to be more insightful about their experiences (Geiger, 2023). In line with this, participants in Jackson et al.'s (2014) study found that participants found it easier to answer direct questions such as 'what do you like about yourself?' rather than being ask to 'describe themselves'. This thus demonstrates the limitations of using the traditional, predominantly interview based, research methods with children and young people with SEND (Benstead et al., 2023).

Photovoice is one of the more commonly utilised visual-based research methods. In this approach, participants are encouraged to document their perspective via photography and then engage in critical discussions regarding their photographs to allow the researcher to gain further insights into the participants' worlds (Jurkowski, 2008). Participant-led photography in research provides a sense of autonomy when participants are given freedom to choose what they are taking pictures of (Benstead et al., 2023). Jurkowski (2008) and Mannion et al. (2024) both used the photovoice technique with individuals with SEND, adults in the former study and children and young people in the latter. In both studies, participants engaged in the full photovoice procedure as well as additionally participatory aspects, such as co-analysis of arising themes with the researchers (Jurkowski, 2008; Mannion et al., 2024). This highlights the need for some level of expressive language ability in order to engage fully in the photovoice methodology (Jurkowski, 2008).

Bloom et al. (2020) and Pirker et al. (2023) both used emotions rating based techniques as a way of understanding children and young people's opinions based on their emotional reactions. Participants in both students were provided with visual representations of emotions and were then asked to assign these emotions to photographs related to their education. This method utilises children and young people's emotional responses to understand their opinion of their school

experiences, rather than relying on verbal communication (Bloom et al., 2020b). Participants in Pirker et al.'s (2023) study appeared to have better communication skills than those in Bloom et al.'s (2020b) study, as they were able to engage in semi-structured interviews to give more context about their emotional ratings. Without this further element, it would be difficult to understand participants reasoning behind their selection of emotions (Bloom et al., 2020b).

## Gaining views of individuals with Down's Syndrome

Although the prior part of this literature review has focused specifically on children and young people with SEND, this particular section will focus on research that has been conducted with both adults and young people with Down's Syndrome. This is due to the limited research that has directly gathered the views of children and young people with Down's Syndrome. Interviews have typically been used when gathering the views of older individuals with Down's Syndrome, to explore concepts such as quality of life, well-being and identity (Groves et al., 2017; Jackson et al., 2014; Takataya et al., 2022; Scott et al., 2014; Jevne et al., 2022). The use of the interview approach with an older population, suggests that they have more developed communication skills (Takataya et al., 2022). The tendency for interviews to exclude some members of the Down's Syndrome community was highlighted in Scott et al.'s (2014) study whereby participants were required to be able to communicate effectively or have mild speech difficulties. This is likely due to the problems discussed earlier, with individuals with Down's Syndrome struggling to answer more abstract, open-ended questions (Geiger, 2023). Geiger (2023) mitigated these difficulties slightly by allowing participants to choose from a set of topics to discuss, as well as using photography to reduce the verbal demand. In addition, Deakin et al. (2017) used a card sorting methodology to explore participants' self-perceptions and awareness of Down's Syndrome.

Interestingly, in Jackson et al.'s (2014) study, not all participants identified themselves as having a disability, let alone Down's Syndrome. Equally, in Groves et al.'s (2017), participants showed a minimal understanding of what their diagnosis of Down's Syndrome meant for them. Additionally, in Deakin et al.'s (2017) study, children with Down's Syndrome often identified themselves amongst pictures of mainstream peers rather than those with Down's Syndrome. This is interesting as

both sets of participants in these studies were adults, and a lack of awareness around their own diagnoses raises questions around autonomy and the level of competence ascribed to these individuals by supporting adults. It also raises ethical dilemmas for researchers as well around how much information should researchers be divulging about Down's Syndrome.

## **Mosaic Approach**

The Mosaic Approach was conceptualised by Clark and Moss (2001), to be initially used with the early years population to explore their spaces in which to play. They view children and young people as co-constructors of knowledge, and as such the Mosaic approach is a participatory research method (Clark, 2017). The Mosaic Approach has two phases: researchers and participants gathering information collectively and using this information for discussion and interpretation to facilitate change (Botsoglou et al., 2019). In addition Clark and Moss postulate that the Mosaic Approach builds a framework for listening which is made up of the following principles: multi-method, reflexive, participatory, adaptable, focused on children's lived experiences, embedded into practice (Clark, 2017). As such, researchers need to ensure that they do not devalue anyone's participation and include all data, whether or not children have participated in the intended way, as an increased understanding of participants' experiences are likely to come when researchers are least expecting it (Blaisdell, 2012).

Within their own studies, Clark and Moss have used the Mosaic Approach with children with a range of communication differences, including those with additional needs, pre-verbal children, and refugees (Clark, 2017). The use of the approach with children in the early years has continued within research (Akyol & Erkan, 2018; Botsoglou et al., 2019; Huser, 2009, Polyzou et al., 2023). In addition, although the Mosaic Approach is not a commonly used methodology within published research, the topics and participant groups for which the approach has been used to explore have diversified, for example with Kok and Yang (2022) using it to explore anti-bias education and Azunre and Sowrirajan (2020) using it to facilitate neighbourhood planning. Through participating in studies using the Mosaic Approach, children and young people have been supported to give their views on how to improve their school and their experiences of play (Botsoglou et al., 2019; Huser, 2009).

Clark and Moss (2001) initially proposed the following tools to be used in the Mosaic Approach: observations, child led interviews, children's photography and book making, child-led tours, map making and interviews. However, the flexibility of the Mosaic Approach means that researchers can select and adapt the tools to meet the needs of their participants (Baird, 2013; Blaisdell, 2012). The benefits of using photography in research have been discussed previously in this literature, however, specifically related to the Mosaic Approach, Baird (2013) found that children's identification of important places identified through photography, matched what was observed and communicated in interviews. Within the Mosaic Approach, photographs do not necessarily have to be used as data themselves, as it can be the discussions and explanations that arise through taking the pictures or using them as prompts that can be most enlightening (Baird, 2013). Objective observations allow researchers to embed themselves within the daily lives of participants and gather naturalistic information about them (Blaisdell, 2012; Rouvali & Riga, 2018). Again, observations can serve as prompts for discussion as well as aid with interpreting participants' views (Baird, 2013; Rouvali & Riga, 2018). Tours provide participants with the opportunity to guide researchers from their perspective (Rouvali & Riga, 2018; Baird, 2013). By combining all these methods, researchers achieve a deeper understanding as well as richer data (Huser, 2009; Rouvali & Riga, 2018). A mixed method approach also creates a more fun and interesting experience for participants (Akyol & Erkan, 2018).

# Summary

The literature demonstrates that the perspectives on what constitutes inclusion are broad, varying from simply placing children and young people with SEND in mainstream schools, to a more systemic approach that benefits all pupils. One reason for these variations, is likely due to the influence of an individual's circumstances on the implementation of inclusion, and as such, inclusion must be considered in the context of the individual, as well as the whole school environment. Despite the variation in definition of inclusion, several consistent themes were identified from the literature review, that acted as both barriers and facilitators to inclusion, for children and young people with SEND more generally and those with Down's Syndrome. These included: the roles of school staff, parents and peers; teachers' self-efficacy and attitudes, as well as the national curriculum. The majority

of these themes arose from research conducted with parents of children and young people with SEND or school staff, and as such an understanding of inclusion from the perspective of children and young people with SEND, and those with Down's Syndrome, was inherently lacking.

Participatory research methods are being more frequently used within the literature, with a recognition that research should be conducted with children and young people, not done to them, as well as a global emphasis on the importance of ensuring their voices are heard and incorporated into decision making. Despite this, there is still a heavy influence on the use of methods which rely on strong verbal communication abilities, which is not conducive to gathering the views of all children and young people. The Mosaic Approach is a participatory approach which utilises a multitude of methods to mitigate the need for strong verbal communication abilities. The use of this approach within the literature is still emerging and further exploration around the appropriateness of this approach with children and young people with SEND is needed. In addition, despite the trend for conducting research with children and young people with SEND, limited research has been conducted which gathers the views of children and young people with Down's Syndrome, in relation to their education. Within the limited research that has been conducted with this population, there has still be a strong emphasis on verbally-demanding data collection methods, which does not take into consideration the varying communication needs of this participant group.

The present study will aim to fill the identified gaps in literature by exploring the experiences of inclusion for children and young people themselves, focusing solely on the experiences of children and young people with Down's Syndrome. The study will also move away from a traditional approach of using verbally demanding interview based techniques to gather views, instead using the multi-method Mosaic Approach. The appropriateness of this technique, for the gathering the views of children and young people with Down's Syndrome, will also be explored to further add to the evidence base for the Mosaic Approach, potentially increasing the range of methodological approaches for gathering the views of those with communication difficulties.

# **Chapter Two: Empirical Paper**

#### **Abstract**

Although there are many barriers and facilitators to implementing inclusion, the experience of inclusion is dependent on one's own circumstances and inclusion is thus not a one size fits all concept. Despite this, literature relating to the inclusion of children and young people with SEND has been dominated by the views of parents and school staff. In addition, the voices of individuals with Down's Syndrome are rarely heard in research. As such, the current study aims to give children and young people with Down's Syndrome a platform to share and explore their experiences of inclusion. Seven participants, aged nine to fifteen, took part in the study using a Mosaic Approach methodology, utilising photographs, semi-structured interviews and observations as data collection tools. Data was analysed using Braun and Clarke's (2022) reflexive thematic analysis to reveal themes, relating to participation, relationships, adjustments to the school day and Down's Syndrome awareness. Overall, the data suggested that participants were academically and socially included within school, to a degree that allowed them to experience feelings of relatedness and success. In addition, an autoethnographic approach was used to examine whether the Mosaic Approach was an accessible and flexible tool for supporting children and young people with Down's Syndrome to express their experiences and enabling these experiences to be understood. The findings of the study are discussed in relation to the existing literature, with consideration of the implications for the practice of educational psychologists.

### Introduction

Down's Syndrome occurs as a result of individuals being born with an extra copy of the 21<sup>st</sup> chromosome. As a result, individuals with Down's Syndrome have a range of learning difficulties alongside an increased risk of heart conditions, early development of dementia, hearing loss, hypermobility (National Health Service, 2023). Despite these areas of need, individuals with Down's Syndrome are able to live fulfilling lives and achieve their own individual potential (Down's Syndrome Association, 2021). All individuals with Down's Syndrome are classed as having special educational needs and disabilities, and as a result they have a right to inclusive, mainstream education, if appropriate, as outlined in the SEND Code of

Practice (2015). Despite this collective right, the actual experiences of children and young people, with Down's Syndrome, in relation to their inclusion within education varies dramatically. This study will aim to provide an opportunity to represent the voices of children and young people with Down's syndrome as well as investigate their experiences of inclusion in mainstream education settings.

# **Background and Rationale**

Achieving both a right to education and inclusion for children and young people with SEND has been a long journey (Lindsay et al., 2020). Prior to the late 1900s, children and young people with SEND were typically segregated from their mainstream peers or not allowed to attend school at all (Frederickson & Cline, 2015). This outlook on education for those with SEND continued until the introduction of the 1981 Education Act, at which point education within mainstream schools was encouraged for children and young people with SEND and statements of SEND were issued to support with alternative provision. In the forty years since this act, there has been three SEND Codes of Practice to support with the implementation of inclusion, with the most recent in 2015 introducing Education, Health and Care Plans to detail the support needed for children and young people with SEND (Department for Education & Department of Health, 2015). Despite this, confusion still exists around how to define inclusion, and what inclusion should look like for children and young people with SEND (Kendall, 2019a). Within the literature, inclusion is described using a tiered approach from placement of children and young people with SEND in mainstream schools to all children and young people, regardless of type of school, being included in all aspects of school life including academic, social and extracurricular activities (Nilholm, 2021; Selisko et al., 2024). Inclusion at the highest level can be described as education for all children being adapted as necessary, to allow all children to achieve their potential and remove any barriers to accessing opportunities in order to facilitate inclusion (Williams-Brown & Hodkinson, 2021; Kendall, 2019a). This final tier of inclusion considers the wider environmental and societal influences on inclusion, and how there needs to be systemic change to remove barriers to achieve inclusion and a sense of social justice for all children and young people (Nesterova, 2023).

Considering the theoretical underpinnings of inclusion can aid how we view the concept. Inclusion can be understood through the lens of self-determination theory for example, inclusion should seek to provide individuals with a sense of autonomy, competence and relatedness (Ryan & Deci, 2000). Through fulfilling these three psychological needs, schools can promote motivation and engagement with academic tasks (O'Brien, 2018). In addition, promoting inclusion in this way respects children and young people's sense of agency and their capabilities, qualities that society has not always associated with children and young people with SEND (Strnadova, 2020).

The influence of the environment on inclusion can also be understood through the social cognitive theory. This theory would suggest that learning occurs through a pupil's presence and participation in the classroom environment (Benstead, 2019). Therefore, when implementing inclusion for children and young people with SEND, schools must consider how the classroom environments, as well as teachers' own beliefs and practices, can influence a pupils' knowledge and motivation (Bandura 1986; An & Meaney, 2015).

Finally, the difficulties defining and implementing inclusion may be related to how inclusion is influenced by own's own personal experiences. Inclusion can be viewed through a social constructionist lens, as the influence of one's own circumstances, such as learning needs and the school context, will affect how inclusion is constructed by individuals which in turn impacts implementation (Dimitrellou et al., 2020). As such, it is important to explore children and young people's own experiences of inclusion, rather than relying on the views of those around them.

Despite inclusion being specifically related to an individual's own contextual experiences (Dimitrellou et al., 2020), research has identified several barriers and facilitators commonly associated with successful inclusion of children and young people with SEND. Attitudes of school staff towards inclusion and children and young people with SEND, as well as relationships between school staff and parents/carers can act as both barriers and facilitators depending on the positivity of attitudes and relationships (Kendall, 2019a; Dunleavy & Sorte, 2022; Florian & Spratt, 2013; Warnes et al., 2022). Similarly, opportunities for interactions and relationships with peers acts as both a barrier and facilitator to inclusion, depending on whether

children and young people with SEND experience success in these interactions (Fisher et al., 2019; Benstead, 2019). The pressures of the national curriculum, and the influence this has on opportunities for differentiation and subsequently the negative implications on children and young people's mental health is another frequently reported barrier to implementing inclusion (Williams-Brown & Hodkinson, 2021; Kendall, 2019a). Research looking specifically at inclusion of children and young people with Down's Syndrome has identified similar barriers and facilitators, including peer relationships and attitudes, teacher's self-efficacy, differentiation of the curriculum and use of support staff (Engevik et al., 2018; Van Herwegen et al., 2019; Boundy et al., 2023; Tuersley-Dixon & Frederickson, 2016).

Within the literature surrounding individuals with Down's Syndrome and their experiences of education, there is limited research that directly captures the voices of children and young people with Down's Syndrome. The majority of the research instead focuses on parents and professionals' perspectives. As children and young people with SEND are historically a marginalised population, it is important that they are giving the autonomy to express their views and participate in research meaningfully (Jurkowski, 2008; Bloom et al., 2020a; Sharma, 2021). Methodological approaches such as Photovoice and the Mosaic Approach are commonly used within research to capture the views of children and young people with communication difficulties, as the visual tools provide an alternative method of communication (Mannion et al., 2024). Within the limited literature that has gathered the voice of individuals with Down's Syndrome, the use of verbal methods, such as interviews, has been prominent for example, Groves et al. (2017), Jackson et al. (2014) and Geiger (2023), all used interviews as their main form of data collection. Given the varied communication abilities of individuals with Down's Syndrome (Geiger, 2023), an emphasis on verbal communication is not always appropriate and as such, alternative methods of expressing views should be explored, which can be provided by tools such as the Mosaic Approach.

#### **Local and National Priorities**

In 2022, the Down's Syndrome Act was passed in parliament, with the aim of increasing access to health, education and care services in order to improve the quality-of-life for individuals with Down's Syndrome and their families. At present, the

statutory guidance relating to the Down's Syndrome Act (2022) is being formed with guidance from individuals with Down's Syndrome, their families and relevant professionals. The introduction of this Act demonstrates a national commitment to improving the lives of individuals with Down's Syndrome. As a result, it is extremely important that research gathering the views of individuals with Down's Syndrome continues to allow their voices to be heard within society and to ensure that national priorities stay up to date and relevant for this group of individuals.

In addition, in 2025, the government announced the Inclusion in Practice initiative, which aims to improve mainstream education for children and young people with SEND. Two of the areas of this initiative that are of particular relevance to the present study are 'inclusive classroom practice and culture' and 'additional support in mainstream schools'. Again, this commitment to the education of children and young people with SEND, highlights the importance of the contribution of research in this area.

Within the researcher's training placement local authority, there is focus on creating more support for children and young people with Down's Syndrome, through the creation of a pathway, SENCo support meetings and parent groups. During the creation of the pathway with parent groups, parents have voiced that they often feel that Down's Syndrome is a forgotten group compared to children and young people with neurodevelopmental disorders. As a result, they feel that there is a lack of awareness of the strengths and needs of individuals with Down's Syndrome, which aligns with the literature which has identified a lack of training for school staff regarding Down's Syndrome (Bills & Mills, 2020). The present research aims to help to promote the voices of children and young people with Down's syndrome, and also to help to direct the support that is offered within schools to promote the inclusion of children and young people with Down's Syndrome.

#### **Research Questions**

The proposed study will aim to answer the following research questions:

- 1) What are children and young people with Down's Syndrome's experiences of inclusion within mainstream education?
- 2) Is the Mosaic Approach a useful tool for gathering the views of children and young people with Down's Syndrome?

# Methodology

# **Participant Recruitment and Characteristics**

Recruitment took place via a convenience sampling approach. The researcher sent an advertisement flyer (see appendix: A) to local Down's Syndrome parent support groups, initially in the East of England, before expanding nationally. To support the national recruitment strategy, the study was also advertised via the Down's Syndrome Association both on their website and via closed social media support groups. Parents/carers were asked to express their interest in their child participating in the study via Microsoft Forms. After which, the researcher contacted them to provide further information about the study and to seek formal consent.

Seven participants, aged between nine and fifteen, were recruited for the study. All participants had Down's Syndrome and attended a mainstream primary (n = three) or secondary (n = four) school. Two of the participants attended the same primary school. Three of the participants were male, and four were female. A short description of each participant is provided below, to provide context regarding their educational circumstances. For confidentiality purposes, all participants were asked to think of a different name they would like to be referred to by within the research write up. The researcher encouraged participants to think of a favourite character from a book or a tv show to help illustrate the concept of a pseudonym and help contain participants' decisions. Participants were encouraged to think of their own pseudonyms to encourage a sense of autonomy and ownership over the data they were contributing to the study. This further increased the participatory nature of the study. All participants conceptualised their own pseudonyms apart from Pizzaboy, who was unable to communicate an alternative name. During the researcher's time with Pizzaboy, he frequently communicated that pizza was his favourite food, and as such the researcher incorporated this into his pseudonym.

# Participant Characteristics

Superbatman (F) was in year 10 of a mainstream all-girls, faith, secondary school, in an urban area.

Ariana Grande (F) was in year 10 of a mainstream secondary school, in an urban area.

Pizzaboy (M) was in year 7 of a mainstream all-through school, in a large urban area.

Jojo (M) was in year 10 of a mainstream secondary school, in an urban area.

Matilda (F) was in year 5 of a mainstream primary school, in a suburban area.

Dogman (M) was in year 6 of a mainstream primary school, in a large urban area. Bluey (F) was in year 5 at the same school.

There are no guidelines as to what constitutes an adequate sample size when using the Mosaic Approach, from Clark and Moss who conceptualised the Mosaic Approach (Clark, 2017). Within the limited published literature where researchers have utilised the Mosaic Approach, sample sizes vary, ranging from ten to 29 children and young people as participants (Huser, 2009; Botsoglou, 2019). This range is to be expected given the adaptability of the approach and the different participant groups with which it has been used. The majority of the studies where a larger sample size has been used, focus on the views and experiences of young child as collective population. However, within the present study, the wider population from which participants were sampled, children and young people with Down's Syndrome in mainstream education, is considerably smaller, and as such it is appropriate for the sample size to be smaller.

In terms of sample size in relation to the quality, power and saturation of the research, there are several reasons that justify why a smaller sample size was considered appropriate for this study. As previously mentioned, the small sample size is reflective of a smaller population group. Smaller populations often mean that saturation will be achieved sooner as it limits the amount of data that could be gathered and eligible participants prior to the research even commencing (Malterud et al., 2016). The specificity of the participants also means that the experiences discussed in the research were likely to be specific and thus less data would be required to gain an understanding of those experiences (Malterud et al., 2016; Mason, 2010). Finally, the use of three methods of data collection also meant that saturation was likely to be achieved quicker due to the variety and quantity of data gathered from each method (Mason, 2010).

### **Research Design**

# **Ontology and Epistemology**

The present study will take a relativist ontology alongside a social constructionist epistemology. A relativist ontology states that reality is the product of human interaction and our actions and as such, there are multiple realities (Braun & Clarke, 2022). In research, meaning can be made of these realities through the researcher-participant interactions (Kivunja & Kuyini, 2017). Research conducted in line with a relativist ontology will aim to understand the research phenomenon from the participants' perspectives because reality is subjective (Scotland, 2012). A social constructionist epistemology states that knowledge is socially constructed, and language helps to bring realities to life (Braun & Clarke, 2022). The language individuals use is influenced by wider historical and cultural factors, as well as the social interactions between individuals (Burr, 2015).

A relativist and social constructionist approach is appropriate for the topic of this research study as there is no agreed universal definition of inclusion. Individuals construct their own conceptualisation of inclusion through the language they use and their own experiences of inclusion (Dimitrellou et al., 2020). As such, inclusion is subjective to each and every individual, thus meaning that multiple realities of inclusion exist. In addition, the concept of and the language used to describe and define inclusion has shifted depending on the historical and cultural context (Lindsay et al., 2020). Within relativism and social constructionism, realities and knowledge are influenced by the wider context (Scotland, 2012; Burr, 2015). As such, the participants' experiences of inclusion within this study can only be understood within the current cultural climate relating to inclusion.

The Mosaic Approach is an appropriate methodology to use in the context of relativism and social constructionism. The Mosaic Approach views children and young people as co-constructors of knowledge which is the premise of a relativist approach (Blaisdell, 2012; Braun & Clarke, 2022). The Mosaic Approach was designed to allow researchers to gain an understanding of the meaning children and young people attribute to their world (Blaisdell, 2012). The use of multiple tools will afford multiple opportunities for participants to construct meaning and share their experiences, especially with the photography element of the approach (Baird, 2013).

Observations will also allow the researcher to immerse themselves in and make sense of the participants' experiences (Rouvali & Riga, 2018). By utilising the Mosaic Approach the researcher will facilitate an understanding of participants experiences of inclusion (Rouvali & Riga, 2018).

In the context of the present study, the researcher will aim to co-construct individual meanings of inclusion with participants by understanding their experiences. This will be achieved by participants constructing their experiences of inclusion through the language they use (Braun & Clarke, 2022). Through a relativist and social constructionist lens, inclusion is viewed as a subjective phenomenon. Therefore, the research will focus on participants' experiences and the meanings that these experiences give way to rather than conceptualising a definition of inclusion, as the definition would not be generalisable due to participants own contextual factors and the current national context of inclusion (Scotland, 2012; Burr, 2015).

### Quality of the Research

Research conducted underneath a social constructionist paradigm, and qualitative research more generally, does not typically fit into the scientific parameters of reliability, validity and generalisability (Scotland, 2012). In quantitative research, or research conducted under a positivist paradigm, reliability is typically measured by replication of results, the degree to which different researchers would achieve the same results (Kivunja & Kuyini, 2017). However, due to the individuality of people's experiences and realities, participants in qualitative research would not ascribe meaning to their experiences in the same way, and researchers would not interpret this meaning in the same way (Scotland, 2012). In addition, generalisability is unlikely to occur as participants' realities are located within their own personal contexts, and unlikely to be applicable beyond these contexts (Scotland, 2012). As a result, researchers have proposed different parameters by which validity and quality of qualitative and social constructionist research should be assessed. The quality of the current research study is discussed in relation to Yardley's (2011) principles of quality.

#### Table 1

Yardley's (2011) principles of quality

Principle	Description (Yardley,	In relation to the current
	2011).	research study
Sensitivity to context	The research is related	Due to the nature of
	back to existing and	inclusion as a
	relevant psychological	phenomenon and by
	theory to enhance	considering the research
	understanding of	through a social
	participant's experiences.	constructionist lens,
	In addition, participants'	inclusion can only be
	sociocultural context is	understood in the context
	considered at every stage	of one's own sociocultural
	of the research. This	experiences. As such,
	includes:	these were made salient
	- Awareness of how	throughout the research
	sociocultural	process and held in mind
	context will impact	whilst analysing the data.
	engagement and	Social cognitive theory
	participation in the	and self-determination
	study and ethical	theory were used to help
	implications of this.	understand inclusion in
	- Awareness of how	the context of the present
	sociocultural	research study.
	context will	
	influence how	The researcher's own
	participants will	reflections in the
	respond to	autoethnographic part of
	questions.	the study are considered
	Awareness of how the	in relation to theory and
	researcher's own	the wider sociopolitical
	sociocultural context may	context of research with
	influence analysis and	children and young
	interpretation of the data	people.

	and steps should be		
	taken	to minimise this.	
Commitment and rigour	The re	esearcher	Completing the literature
	demonstrates that they		review prior to data
	have l	peen careful and	collection allowed the
	thorough at each stage of		researcher to familiarise
	the research process.		themselves with the
	Again, commitment and		phenomenon of inclusion
	rigour can be demonstrated at each		to help structure the
			exploration of participant's
	stage	of the research	experiences.
	proces	ss:	Furthermore, by engaging
	-	Engage deeply	with the literature
		with the topic and	surrounding Down's
		participants in	Syndrome, the researcher
		order to provide a	was able to understand
		sense of purpose	the strengths and areas of
		and commitment to	difficulty often
		the research.	experienced by
	-	Researchers must	individuals with Down's
		demonstrate high	Syndrome and use this
		quality	information to support
		implementation of	participants to engage in
		their research	the study.
		methods, to ensure	The range of research
		comprehensive	methods used allowed for
		data collection.	a broad range of data to
	-	Engaging in an in-	be collected that painted
		depth data analysis	a rich picture of
		to fully interpret	participants' experiences.
		and understand	
		participants'	The research kept
		experiences.	reflective diaries, which

were reflexive in nature. to understand the usefulness of the Mosaic Approach as a methodological tool. Coherence and Coherence refers to the The theoretical consistency of the underpinnings of social

transparency

research study as a whole. Researchers need to demonstrate a golden thread running through their research in terms of the theoretical and methodological underpinnings. This will help to justify the methodology used in the study and show how appropriate it is for answering the research question.

Transparency ensures that enough details are given about the methodological and analytical procedures, to convey a transparent picture of the study to the reader. Researchers should be reflexive and consider how their own personal decisions have

justice and social constructionism illustrate the importance of providing participants with the autonomy and opportunity to voice their own experiences. The Mosaic Approach was a suitable methodology to use to afford participants multiple ways to convey their experiences in order to facilitate an understanding of inclusion.

The use of an autoethnographic approach aligns with a social constructionist paradigm, to understand the usefulness of the Mosaic Approach within this particular research context.

affected the research process and the data.

A clear description of methodology and data analysis has been provided. Although the Mosaic Approach is a flexible methodology, justification for the choice of particular methods has been provided.

# Impact and importance

Ensuring validity of research helps to ensure that the research will have an impact. Impact can be practical and have a benefit for practitioners or the wider community. Alternatively, it may be more theoretical and support to further understanding of a phenomenon or change the way society considers a topic. This may also lead to more practical implications.

The ultimate goal of the present research study is to further understand the experiences of inclusion from the perspective of children and young people with Down's Syndrome. Although inclusion is viewed from an individualistic perspective, the research may further enhance the wider understanding of inclusion. The research may also shift the sociocultural perspective on whether or not children with Down's Syndrome, and wider SEND, should be educated within mainstream or specialist settings. There may be some practical implications for

educational professionals in the form of suggestions for best practice.

Although, within this study, the appropriateness of the Mosaic Approach as a methodological tool can only be understood in relation to context of this research, linking the research's experiences to wider theory will support further use of the approach.

### **Ethical Considerations**

The present study was approved by the UEA School of Education and Lifelong Learning Ethics Committee (see appendix: F). In addition, given the researcher's dual role as a trainee educational psychologist, the study was also conducted in line with Health and Care Professions Council (HCPC) Standards of Conduct, Performance and Ethics (2024), the HCPC Standards of Proficiency (2023) and the British Psychological Society (BPS) Code of Conduct and Ethics (2021).

Upon expression of interest, consent forms and participant information sheets were sent to parents/carers as well as child friendly versions for the children and young people, in order to gain informed consent (HCPC (2024) 1.4, 2.3) (see appendices: B and C). Upon receipt of these forms, the researcher then met with parents, via Microsoft Teams, to gain further information about the child or young person, their school, and any reasonable adjustments they might have required to participate in the study, such as communication aids (HCPC (2024) 2.4). The researcher then made contact with the headteacher of the schools to seek permission to undertake

the research visits within the school environment. Given the mixed methods approach that was used for the methodology, different ethical considerations were required for each stage of the visit.

#### Observations

Consent was sought from the class teacher who was delivering the lesson in which the researcher observed (HCPC (2024) 1.4) (see appendix: D). In addition, information sheets were sent to schools for them to distribute to other parents to inform them of the observation. The researcher also developed a script which was used to inform pupils about the purpose of the observation (HCPC (2024) 2.4), if they had any questions on the day. The researcher did not record any information about staff or other pupils when carrying out the observations, in order to reduce the risk of harm to other individuals within the observation (HCPC (2024) 5.1, 6.1, 6.2).

# Participant-led Photography

Participants were instructed not to photograph staff or students within the school, as their consent had not been provided. In the event this did occur, photographs were cropped or blurred to remove other individuals, again to maintain privacy and confidentiality of other individuals (HCPC (2024) 5.1, 6.1, 6.2).

#### Interviews

Participants were offered the opportunity to have a familiar adult present during the interview and offered the chance to stop or pause the interview at any point (HCPC (2024) 1.3).

Data collection, handling and storage was carried out in accordance with the Data Protection Act (2018), General Data Protection Regulation (GDPR) and University of East Anglia (UEA) Research Data Management Policy (2019). Personal and identifiable information was stored on UEA OneDrive, on a password protected laptop. Participants were asked to come up with their own pseudonyms to anonymise themselves. Audio recordings of the interviews were deleted after transcription.

In line with safeguarding procedures, any disclosures were to be reported to the Designated Safeguarding Leads within the schools, as well as the research

supervisor. Any ethical concerns were to be reported to the research supervisor and recorded on the UEA ethics system.

#### **Data Collection**

The Mosaic Approach was developed by Clark and Moss in 2001. The approach utilises a range of methodologies and views participants as co-constructors of knowledge, in order to create a shared perspective of participants' worlds and construct meaning (Clark, 2017). Methodological tools used within the Mosaic Approach include: observations, photography, interviews, map-making and tours (Blaisdell, 2012). The exact methods used are at the discretion of the researcher in order to adapt the approach to the needs of the participant and research questions (Baird, 2013). As such, the multiple methods not only allow for triangulation to enrich the data, but they also provide a range of ways in which participants can engage, removing barriers to participation (Clark, 2017). Data from these methods are then analysed together and combined to form a mosaic representative of participants experiences (Huser, 2009). It is through these mosaics that meaning is constructed and participants' experiences are brought to life (Clark, 2017).

To keep the study manageable, the researcher chose the following methods to form the Mosaic Approach: classroom observations, breaktime observations, participant-led photography and semi-structured interviews. Given the communication difficulties that can sometimes be present in individuals with Down's Syndrome, the use of semi-structured interviews with support staff was considered to increase the richness of the data, but ultimately the researcher felt that the three methods combined produced a rich data set.

Each research visit began with an informal chat between the participant and the researcher to outline the plan for the day and to gain verbal consent that participants were still happy to engage with the study. The researcher then observed the participants' first lesson of the day (see appendices: H1 and H2). Lessons observed included: Art, Physics, English, Maths and Child Development. The researcher typically observed from the side or the back of the classroom, and did not interact with the participants, pupils or staff unless approached. This was then followed by the breaktime observation. Again, the researcher did not engage with the participants or other individuals unless approached, to maintain a naturalistic observation.

Next came the participant-led photography section of the visit. Some participants had pre-identified locations that they wished to take pictures of. For those that did not, the researcher encouraged them to think of around five places within school that they enjoyed spending time. This was not a limitation, more a guidance to ensure participants weren't overwhelmed having to think of multiple locations.

The interviews took a semi-structured approach (see appendices: G1 and G2) but also included reflections from the observations and photography. Five of the participants chose to have a familiar teaching assistant in the interview with them. Several of the teaching assistants did support participants with the interview by prompting them with relevant information, but questions were always directed to the participant. Interviews lasted between 20-35 minutes, and following the interview participants were given a debrief as to what will happen next in the project (see appendix: E).

For research question two, the researcher kept a reflective diary of the research process (see appendices: I1 and I2). This diary recorded participants engagement with the tools of the Mosaic Approach, focusing on how they engaged and what facilitated them to engage with the tools. The researcher also reflected on their own use of the methodological tools and the approach, how this varied between participants, and what the researcher learnt from each use of the approach.

#### **Data Analysis**

Reflexive thematic analysis was used to analyse the data for research question one (Braun & Clarke, 2022). Data from the interviews and observations were combined and jointly analysed using thematic analysis. Reflexive thematic analysis was appropriate for this research study due to the emphasis on subjectivity, which fits with a social constructionist epistemology (Braun & Clarke, 2022). A reflexive approach to thematic analysis also ensures rigour, demonstrating a commitment to the quality and validity of the research with a qualitative context (Yardley, 2011). A step-by-step account of how the data was analysed in accordance with the six phases of Braun and Clarke's (2022) reflexive thematic analysis can be found in table: 2. Please see appendices K and L for coding and theme development.

For research question two, an autoethnographic approach was taken to analyse the data. The researcher's own reflections were used as the data, and then critically

discussed, similarly to Baird's (2013) critical reflection of the Mosaic Approach. Autoethnography seeks to understand a researcher's own experience through embedding that experience within theory and sociopolitical context (McIlveen et al., 2010). An autoethnographic approach aligns with the relativist ontology and social constructionist epistemology in that the usefulness of the Mosaic Approach as a methodological tool will be analysed and understood within the context of the researcher's own experiences and it's use with this particular group of children and young people with Down's Syndrome (McIlveen, 2008).

Table 2

Braun and Clarke's (2022) six stages of thematic analysis

Phase of thematic	December / Duction 0	A -4:
	Description (Braun & Action	
analysis	Clarke, 2022).	
Familiarising yourself with	Researchers must The interview data	
the dataset	immerse themselves in	transcribed and read
	the dataset, reading the	alongside the
	data multiple times and	observational data. Initial
	recording initial insights.	thoughts and links
		between the two types of
		data were recorded.
Coding	Parts of the data that	Codes were generated
	relate to the research	from the interview and
	question are labelled.	observational data. The
	These labels should	researcher coded the
	capture meaning related	data multiple times at
	to the research question.	both a surface and a
	As reflexive thematic	deeper level of
	analysis was used, labels	understanding.
	were both implicit and	
	explicit.	
Generating initial themes	Codes are brought	Codes from the two types
	together to construct	of data were combined
	themes. Themes	and organised into initial

	represent ideas or	themes. Themes were
	concepts that provide an	initially kept broad before
	answer to the research	being broken down into
	question. Themes should	subthemes. Naming of
	be broader than codes	the themes at this stage
	and convey a shared	was descriptive rather
	meaning.	than informative.
Developing and reviewing	Themes are reviewed	Themes were reviewed,
themes	against codes and the	deleted and combined to
	initial dataset to ensure	ensure they conveyed the
	they convey the meaning	essence of the data set in
	and patterns highlighted	a succinct way.
	within the dataset.	
	Themes are often	
	collated, discarded or	
	created during this stage.	
Refining, defining and	Themes begin to enter	The names and
naming themes	their final form and are	definitions for each theme
	named and defined.	and subthemes were
	Names should be	conceptualised. Names of
	informative and	themes transitioned from
	descriptions should	being descriptive to
	convey the purpose of the	illustrative. Descriptions
	theme in relation to the	clarified the theme and
	data.	conceptualised it in
		relation to the research
		question.
Writing up	The write up ties together	The definitions of themes
	the themes and the	were combined with
	dataset in order to answer	quotes from the data set
	the research question and	to illustrate and answer
	to convey a sense of the	the research question.
	data to the reader.	-

# Research Question One: Results - Key Themes

The following themes are in answer to research question one: What are children and young people with Down's Syndrome's experiences of inclusion within mainstream education? Data from the participants' interviews and the researcher's observations were combined when conceptualising these themes. As such, exerts from interviews and the researcher's observation notes are provided as evidence for these themes.

## Theme 1: Facilitating engagement through reasonable adjustments.

This theme describes the provision schools put in place to reduce and remove any barriers that participants may have experienced when trying to engage in school. All participants benefited from varying adjustments and adaptations to their curriculum, school day, and staff support to enable them to access a mainstream education. Not all participants were aware of and able to identify all the support that was in place for them, suggesting that adjustments are well integrated and embedded into participants' school days.

# Subtheme 1.1: Accessing alternative spaces

Five participants made use of designated areas for SEND pupils within their school. These spaces were typically one room or a group of rooms, and the naming of these spaces varied. Ariana Grande referred to hers as 'SEND' and Superbatman's was called 'learning support', which connotated the purpose of these areas within the title. Pizzaboy's, Dogman's and Bluey's spaces were referred to by the room name, with a general understanding that these rooms were primarily for pupils with identified SEND. Use of these spaces was typically structured. For Dogman, Bluey, Ariana Grande and Superbatman, these spaces were accessed for the core subjects, as well as more targeted interventions. Superbatman described that she had her "SaLT (speech and language therapy) support" in her learning support area. Pizzaboy was able to access his space as and when needed, for both academic work and as a breakout space. Pizzaboy and Ariana Grande had use of these alternative spaces at social times, with Pizzaboy opting to use this space more frequently than Ariana Grande, 'Pizzaboy navigated his way to the SEND room after

buying his snack from the canteen'. In addition to alternative rooms, for Ariana Grande and Superbatman there was 'unofficial' SEND areas within whole school areas, such as the lunch halls, which SEND pupils seemed to gravitate to, to be supported by teaching assistants. At breaktime Ariana Grande was observed to 'sit in the canteen area, next to her teaching assistant with other SEND pupils.'

These spaces were used with other pupils with SEND, allowing participants to feel a part of the SEND community and form connections with pupils with similar needs to themselves. Participants were still supported by teaching assistants within these alternative spaces but there seemed to be a shift from teaching assistants supporting participants 1:1, to a smaller group approach. For example, Dogman was observed to be "working at a table with three other pupils, with the support of one teaching assistant".

All participants who made use of SEND specific areas took pictures of them on the tours, which demonstrated that these spaces were important to them. All participants were happy to spend time in these spaces and spoke about them fondly, with Bluey preferring her alternative space to her mainstream classroom: "my favourite is SEND class".

Although Matilda did not have a designated alternative space, she did "do some work outside the classroom" and on further exploration this was primarily for targeted interventions on spellings with her teaching assistant. Jojo did not have an alternative space which he accessed and instead spent all his time in the mainstream areas of the school community.

#### Subtheme 1.2: An appropriate alternative curriculum

Five of the participants had an alternative curriculum for Maths and English. All other subjects were typically studied under a mainstream curriculum. Jojo and Matilda accessed a mainstream curriculum for all academic subjects. For Superbatman and Ariana Grande, they were completing NVQ level Maths and English qualifications instead of at GCSE level. Superbatman: "No I don't do those [maths, English and science] for GCSE". Dogman and Bluey's school implemented a bespoke English and Maths curriculum for several year five and six pupils with SEND, which they both accessed. Dogman: [do you do maths and English in SEND class?] "yeah." This curriculum was adapted to be at a slightly lower level than the typical year five and

six English and Maths curriculum. During the observation, Bluey was also 'engaging in a sight word reading activity' which is part of an intervention specifically targeted for individuals with Down's Syndrome to support with literacy and numeracy development. This intervention formed a part of her daily alternative curriculum. Pizzaboy's curriculum was adapted across all subjects, and he was, for example, observed to be 'completing a worksheet requiring him to order numbers one to twenty'. He was typically provided with differentiated work relating to the topic being covered by his mainstream class which he then completed with the support of a teaching assistant. Observations and interview data suggested that these curriculum adaptations were appropriate for these five participants and were targeted at their level in order for participants to experience success. All alternative curriculums were implemented with high levels of adult support.

### Subtheme 1.3: Making use of additional resources and equipment

All but one participant was observed to be using a whiteboard within class, on which teaching assistants wrote down content from the class whiteboard, which participants then copied off the smaller whiteboard into their books. The adults supporting Dogman also used a Dictaphone to record sentences he had produced, to support him in writing them down, *Dogman: "[what was your TA using to help you write] a recorder"*. Bluey benefited from "getting some sheets when I'm sounding out the words" which were phonics memory aids to support her in spelling out words when writing. Ariana Grande was observed to be 'provided with enlarged worksheets' to support with her visual difficulties. Participants were all comfortable using these resources and they were provided without request by school staff.

Superbatman and Matilda had access to lifts, and their wheelchairs, within their school, to support with their mobility. Their use of these was self-directed, but often adults would ask or encourage both participants to use them. For example, Matilda's class teacher 'encouraged her to use the lift to get to assembly because of the busy corridors.'

Several of the participants also had support from external services such as a "speech and language therapist" for Superbatman and an "occupational therapist" for Bluey. This support typically took place within school.

# Theme 2: Participation – Actively engaging in meaningful activities

Theme two explores the concept that the participants were active members of their school and wider communities. From the data, active participation and engagement meant that individuals were participating in activities that brought them joy, a sense of accomplishment and provided them with further opportunities to experience a sense of belonging.

# Subtheme 2.1: Members of the school community

Some participants spoke about being involved in whole school activities or activities which established their presence within the school. For example, Superbatman expressed that inclusion in sports day was particularly important for her "When we done sports day we they say people's names and they say what they won". Other activities included: assemblies, sports day and fundraising opportunities. Matilda was also observed to be 'attending a singing assembly with the rest of the school'. These activities provided participants with the same opportunities as their mainstream peers and helped to foster a sense of belonging and relatedness with the wider school community. They also provided further opportunities for social interactions with peers outside their immediate social circles.

#### Subtheme 2.2: Academic opportunities

All participants experienced the same academic opportunities as their mainstream peers, for at least a portion of their curriculum. For Pizzaboy this was typically being present in the classroom with his mainstream peers, rather than completing the same academic work, as he was observed to be 'at the back of the mainstream Maths class, completing differentiated work'. For Dogman and Bluey, they spent their afternoons in their mainstream classroom, whilst Matilda undertook the same curriculum as her year group.

For the three participants who were at the GCSE stage of their education, their options-based subjects typically fell into the categories of creative subjects and life skills. For example, Jojo was studying "Art... and I do food tech as well", whilst Superbatman was "doing drama, child development". These subjects were being studied at GCSE level, and participants were educated alongside their mainstream peers. Participants studied the same GCSE curriculum as their peers and were able to access this curriculum with just minor adjustments or support from staff. All three

participants expressed enthusiasm regarding these subjects and chose to take pictures of their corresponding classrooms on the tour.

#### Subtheme 2.3: Extracurricular involvement

All but one participant voiced that they were a member of extracurricular clubs outside of school. For most participants, these clubs formed a massive part of their everyday life, with some often-attending multiple clubs a week, such as Dogman: "Then after cricket I go to swimming on Thursdays". Clubs that participants attended typically involved sports, performing arts or creative activities, as illustrated by Ariana Grande: "Thursday, Photography I think...then Friday, trampolining". Some clubs were facilitated at school, whilst others were external, creating a wider sense of community for participants. All participants expressed that they enjoyed these clubs, and they were centred around activities that participants were interested in engaging in. Attendance at extracurricular clubs also provided participants with further opportunities to socialise with peers, both those with and without Down's Syndrome, for example Superbatman's extracurricular opportunities: "some people with Down's Syndrome go to hockey and sometimes with swimming club".

### Theme 3: School as a source of positivity and happiness

All participants spoke generally very positively about school. They all conveyed a sense of happiness within school and were pleased to attend school. All participants experienced a sense of achievement and success within school and did not speak about any academic difficulties.

# Subtheme 3.1: Satisfaction and enjoyment during school

Participants expressed an overall satisfaction with school as a whole, their lessons, the support they received from staff and the SEND areas. All participants communicated a particular enjoyment with their subjects and social times, such as *Pizzaboy: "I like lunch, maths, playground and science"*. This was also conveyed through participants choosing to photograph several of their classrooms and social spaces. Often when asked if there was anything that would make school better or anything more that staff could be doing to support them, participants responded that there was nothing, with Bluey saying: *"I think they are doing everything"*. Some participants voiced that they struggled with the busyness of school, *Superbatman:* 

"less people", and the social aspects of school, Jojo: "not being rude and not swearing", and stated that these aspects could be improved. However, these difficulties did not seem to affect their positive opinions of school.

## Subtheme 3.2: Experiencing a sense of achievement

All participants were supported to experience a sense of achievement within school. Within lessons this varied from answering questions, to sharing work with others, to just being able to access the work and feeling a sense of achievement when they completed a task correctly. For example, Bluey stated that: "I'm always only one ask questions and know all the things in Maths...and every single lesson", whilst Superbatman was observed to be 'sharing her work with another pupil who was struggling'. Staff actively encouraged participation and celebrated with participants when they answered a question correctly. Some participants spoke about achievement on tests, such as Matilda: "I'm quite a bit [good at spelling tests]", and again this was celebrated by both support staff and class teachers.

### Subtheme 3.3: Aspirations and positive outlook for the future

Most participants had an idea about what they wanted to do after school, and all had high aspirations for their life. For instance, Matilda stated: "I want to be a vet", and Ariana Grande wanted to "live in New York". It was clear that participants' aspirations had come from their own interests and ambitions, and they had been given the autonomy to develop these. For the three participants in year ten, they were all developing their ideas about their post-16 opportunities. Participants reported being supported by both parents and school staff to aid them in their decisions, as well as being actively involved in these decisions with Jojo attending his annual review: "different people came and I was here as well".

# Theme 4: A fine line between independence and adult support

This theme details the support participants received from adults, to help them manage to access school. All participants accessed support from teaching assistants to navigate their school day, both within lessons and at social times. This typically took the form of 1:1 support, although this varied in terms of times of the day and lessons. It was interesting to consider how staff support affected participants' independence.

### Subtheme 4.1: Academic support

All participants were supported by teaching assistants within the classroom typically on a 1:1 basis, although for Bluey and Dogman, they were supported by 'three members of staff, shared between eight pupils' within their SEND class. Teaching assistants' academic support involved keeping participants on task, supporting them to answer questions and scaffolding work by supporting participants to break down tasks to make them more manageable. For example, Superbatman 'attempted to read questions on a worksheet and her teaching assistant corrected her if need be'. Teaching assistants often supported participants' writing by copying things off the class whiteboard onto a smaller whiteboard. At times it felt like support from staff was coming at a detriment to participants' independence. For example, Ariana Grande's teaching assistant was often observed to be 'gluing in worksheets' or 'taking over with writing answers' for her, which at times seemed overbearing. Participants often found it difficult to specifically identify the support teaching assistants provided to them. Instead, they identified more general support, for example: Jojo: "They help me with my geography, maths, art and English" and Matilda: "She helps me with spellings."

### Subtheme 4:2 Social support

Pizzaboy, Ariana Grande and Superbatman were all supported by staff at social times. Staff often facilitated conversations both just 1:1 with the participants or with other pupils with SEND. For example, the researcher observed 'staff members talking to Pizzaboy at breaktime and trying to include him in conversations.' For all participants, their support staff helped to facilitate social interactions within the classroom as well, often encouraging participants to work with peers. At times, these interactions did become off task, for instance Ariana Grande was observed to be 'engaged in off task discussion with teaching assistant and other pupil about her nails.' These interactions were heavily scaffolded, and unlikely to take place for most participants without adult support. All participants appeared to have stronger social connections with staff than peers and often choosing and seeming more confident to have conversations with their support staff.

### Subtheme 4.3: Parental Support

Although all participants spoke about their family, and the activities they do with their family outside of school, only two participants mentioned the support they receive from their parents in relation to school. Superbatman spoke about her parents helping her with homework and exploring post-16 options, "Mum will have check like about colleges…so they know about having Down's Syndrome and learning difficulties and stuff". Ariana Grande stated that "my mum came to do an assembly" to speak about Down's Syndrome to staff and other students. Both these participants were in year 10, and as such this subtheme highlights the need for continued parental support throughout adolescence, at a time when independence is typically increasing.

### **Theme 5: Interacting with others**

Theme five explores participants' rapport with other members of their school communities. Interview and observational data demonstrated that all participants appeared to have good relationships with others and felt confident in their interactions. The nature of their interactions changed depending on who they were more comfortable with, with some interactions being more formal or purposeful rather than personal. All participants were able to engage in reciprocal interactions but again to varying degrees depending on their levels of communication and who they were interacting with.

#### Subtheme 5.1: Interactions with staff

The arrangements for support staff varied between participants, but typically participants either had one member of staff who supported them all the time, or they had several members of support staff who rotated in supporting the participant. Regardless of the arrangement, all participants had a good relationship with their support staff. When Bluey was asked if the adults in school were nice to her, she responded with "all the time". Jojo also provided the following description about his support staff: "With Sir and Miss, they always help me erm Miss always be nice and helpful with any student that are annoying." Often participants' relationships with support staff were closer than the typical staff-pupil relationship, with support staff also taking on more of a friendship role as well, for example Superbatman described herself as being "a bit cheeky and climbing on" one of her teaching assistants. Interactions with teachers were more formal, and typically involved teachers asking

participants questions in lessons, or supporting them to understand a topic. For instance, Ariana Grande's teacher frequently 'checked in with her understanding of the topic'. Often the participants were well known within the school community, and as such staff tended to greet them frequently within the corridors, with 'multiple staff and students saying hello to Pizzaboy as he walked by'.

### Subtheme 5:2: Interactions with peers

For most participants, interactions with peers without SEND occurred within the classroom. This included structured discussions about the topic, other pupils supporting the participant as well as off topic discussions. For example, Superbatman was encouraged to 'share work with other pupil who was struggling'. For Jojo, he spent his breaktime 'interacting with peers without SEND', and although he was included by these peers, he did appear to be on the edge of the social group. When asked to identify friends, most participants named friends both with and without SEND. All but one participant said that peers are generally nice to them within school, for example: Pizzaboy: "[are all the other children nice to you in school?] yeah." Jojo did state that some peers are mean to him, but he said he typically ignored them or asked adults for support in navigating conflicts. Jojo: "I think one of my friends…he always be nice to me… and XXX and his brother they are mean to me"

### Subtheme 5.3: Interactions with other pupils with SEND

All but two of the participants showed a particular preference for spending their social times with other pupils with SEND. For the older participants, Ariana Grande, Superbatman and Pizzaboy, there was a particular area within the school where pupils with SEND could spend their breaktimes and lunchtimes and be supported by adults. These SEND areas tended to be within a whole school area, such as the canteen, for example when asked what she does at break and lunchtimes, Ariana Grande stated: "I sit on the same table [with others with SEND]." For these participants, it was difficult to ascertain whether it was their choice to spend their time in these areas or if it was more adult directed, however, all participants seemed happy to spend time in these areas. For Dogman, he chose to play with his peers with SEND on the playground and identified these peers as his friends, Dogman: "I have five friends…in [SEND class]". Bluey and Matilda appeared to struggle with

peer interactions the most, both appearing on the edge of social groups at breaktime. Bluey spent most of her breaktime 'walking around the playground singing to herself, occasionally interacting with others with SEND' whilst Matilda chose to 'dance alongside others'. However, they both seemed happy and content at breaktime and they both felt they had lots of friends when asked.

# Theme 6: Knowledge and understanding of Down's Syndrome

Subtheme 6.1: Own awareness and understanding

All participants knew they had a diagnosis of Down's Syndrome but only Bluey and Superbatman were able to go into detail about what their diagnosis meant for them. Superbatman and Bluey spoke about their learning difficulties as well as associated health needs that affected them within school. For example, Bluey felt that "Down's Syndrome makes me even harder" whilst Superbatman spoke about what she communicated to others about having Down's Syndrome: "I told everyone I have one extra chromosome...I think they probably need to know that I still have a hole in my heart." It may have been that because of these health needs, they were more aware of how Down's Syndrome affected them. Whereas for other participants, their Down's Syndrome did not have an effect on their day to day lives as much. For example, when Ariana Grande asked what does having Down's Syndrome look like for her, she responded with 'I don't know'. The participants who had a more limited awareness of Down's Syndrome typically described little difference in their experience of school or their treatment from others as a result of having Down's Syndrome.

### Subtheme 6.2: Participants as a representation of Down's Syndrome

As participants were either the only person with Down's Syndrome within their school, or the only other person, they themselves acted as an ambassador for Down's Syndrome. Interestingly, this seemed more apparent for the participants in secondary schools. Through their presence they educated staff and peers about Down's Syndrome, with Superbatman also self-advocating for herself by delivering an assembly on Down's Syndrome where she was "talking about what I have and what I like to do". Ariana Grande's previous school "did odd socks day" because of her representing Down's Syndrome. Additionally, in the case of Jojo, other peers

looked out for him and ensured he was being supported by asking 'where Jojo's teaching assistant was' when the teaching assistant had not yet turned up to class.

#### **Discussion**

This section of the thesis discusses the findings of each research question in relation to theory and the literature base. The discussion of findings related to research question one will discuss and interpret participants' experiences according to each of the themes identified in the results section, to facilitate a sense of understanding of participants' experiences. For research question two, the researchers' own experiences will be discussed and contextualised in order to show their relevance to practice. Finally, the implications for wider educational psychology practice will be discussed alongside limitations and ideas for future research.

#### Research Question One: Discussion

This section of the discussion will examine the findings of research question one: What are children and young people with Down's Syndrome's experiences of inclusion within mainstream education?

Theme 1: Adjustments This theme explored the adjustments that schools had put in place to support participants to engage in lessons, and everyday school life. Additional resources and equipment were more specific to individual participants and their particular needs, but differentiation in terms of additional resources and equipment was well embedded for all pupils. This ease of differentiation may have been related to the relatively limited time and effort required from staff to implement these resources. Time and effort are two factors commonly cited by school staff as barriers to differentiation, and, as a result, inclusion (Boundy et al., 2023; Engevik et al., 2018).

The subthemes of alternative space and curriculum were more consistently experienced across participants. Participants typically had an alternative space to complete Maths and English related subjects, for which they undertook a different curriculum. This practice is common across the literature, with individuals with Down's Syndrome typically displaying difficulties with particular areas of Maths and English (Hargreaves et al., 2021) and they thus access a differentiated curriculum to

address these areas of need (Carbone et al., 2023). By providing participants with a more appropriate and differentiated curriculum for English and Maths, participants were supported to experience a sense of achievement, which may give way to feelings of competence and self-efficacy (Schunk & DiBenedetto, 2020; Wehmeyer & Shogren, 2020). These practices can contribute to an overall sense of academic inclusion for participants, demonstrating that presence within the mainstream classroom does not necessarily equate to inclusion, as outlined by Engevik et al. (2018) who highlighted that schools often used alternative spaces and curriculum to prioritise learning and academic achievement, over participation in mainstream classrooms.

The use of alternative spaces did not come at a detriment to participants' academic or social inclusion. Students were not isolated in these areas, instead learning in alternative spaces took place amongst peers of a similar academic level. As such, participants were not singled out in relation to the differentiation of their work (Florian & Spratt, 2013). Accessing alternative spaces with others provides participants with the opportunity to experience a sense of similarity with their peers. This in turn can lead to developing a sense of competence in relation to their academic abilities, as participants may view themselves as achieving in line with their peers, which could lead to an increased sense of motivation to engage in learning (Schunk & DiBenedetto, 2020).

Theme 2: Participation All participants were part of multiple communities, both within and outside of school. These were typically related to creative, performing arts and physical activities, all of which were within participants areas of interests, and typical of the experiences of the wider Down's Syndrome community (Carbone et al., 2023). These extracurricular activities may provide further structured opportunities for social skill development, to further enhance feelings of social inclusion, both in and out of school, (Gannon & McGilloway, 2009). Participants may start to develop feelings of relatedness and connection as they participate in activities with others who share the same interests (Strnadova, 2020). These types of opportunities can help to reduce social isolation for participants, which is often commonly experienced by children and young people with SEND (Fisher et al., 2019). In addition, these communities may help to develop participants levels of autonomy, as they were able

to participate without much adult support and of their own volition (Ryan & Deci, 2000).

Not only does relatedness occur through connections with others, but it also occurs as a result of feeling a sense of belonging to the school as a whole, which can be fostered through inclusion and involvement with whole school events and communities (Strnadova, 2020). Whole school opportunities may also increase participants' visibility amongst mainstream peers, which Tuersley-Dixon and Frederickson (2016) found increases acceptance within the school community, thus promoting social inclusion.

Participation within the mainstream curriculum was adapted to suit each participants' needs, but typically it was centred around participation in creative and life skills related subjects, as evidenced in the literature (Hargreaves et al., 2021; Carbone et al., 2023; Engevik et al., 2018). This emphasis on a creative and life skills-based curriculum, may be related to the fact that these subjects are easily adjusted to meet participants needs, without requiring too much differentiation. This is particularly relevant for those pupils within secondary schools where differentiation becomes harder as the curriculum content increases in complexity (Mullan et al., 2018). By not requiring too much differentiation, participants are able to complete the same work as their peers, thus contributing to feelings of competence and self-efficacy, due to a perceived similarity to peers (Florian & Spratt, 2013).

**Theme 3: Positivity** All participants spoke positively about school and conveyed enjoyment and satisfaction with their school experience. They were happy with all aspects of school, and felt they were treated nicely by staff and peers. Their connections with others supported them to develop a sense of belonging and relatedness (Ryan & Deci, 2000).

Participants were supported to experience a sense of achievement at multiple points during their school day further contributing to senses of competence and self-efficacy (Ryan & Deci, 2000; Bandura, 1986). Achievement was not limited to success on examinations but instead focused on how participants engaged with the curriculum and learning, emphasising how easily achievement can be promoted within schools (Benstead, 2019). This sense of achievement conveyed a feeling that participant's engagement in the curriculum was appropriate and provided them with enough

challenge to experience a sense of competence (Wehmeyer & Shogren, 2020; Guay, 2022). Participants aspirations for the future also conveyed a sense of autonomy over their lives. The support that they received from school staff and parents to develop these aspirations, conveyed a feeling of belief in participants' ability to achieve these aspirations (An & Meaney, 2015).

Theme 4: Independence versus adult support This theme illustrates the dual role support staff have to play in supporting pupils with Down's Syndrome within school. The first role is supporting pupils in an academic context. This support varied from being more practical, for instance, writing things down off the whiteboard, to simply reminding them to stay on task. For some participants, teaching assistants were having to support with scaffolding the work which begs the question whether tasks were appropriately differentiated enough, and who holds responsibility for that differentiation (Takriri et al., 2019; Hargreaves et al., 2021; Boundy et al., 2023). At times, the support received from teaching assistants did border on overbearing, whereby participants were not encouraged to be independent. Teaching assistants were also distractions themselves and often engaged in off-topic discussions. In this way, teaching assistants could have a negative impact on participants' learning (Webster & Blatchford, 2019).

The second role is that of a social nature, whereby staff not only scaffold conversations with other peers, but their relationship with pupils with Down's Syndrome borders on a social relationship as well as a professional one. This social role is well documented within literature, with children with SEND often finding it easier to form relationships with adults, and adults having to support pupils with Down's Syndrome to navigate social opportunities, potentially as their social skills do not increase in line with their peers (Tuersley-Dixon & Frederickson, 2016; Hargreaves et al., 2021; Johnson, 2006).

The levels of parental support for some participants were not surprising given the adversarial role parents often have to play in the lives of their children with Down's Syndrome (Van Herwegen et al., 2019). This did highlight the distinction between participants and their mainstream peers, with some participants' still needing this support, during adolescence, a time of increasing independence (Laws & Millward, 2001).

Theme 5: Interactions Theme five illustrated how the participants within this study typically had stronger relationships with staff and other SEND pupils, than mainstream peers. The gravitation towards forming relationships with other SEND pupils may be due to the disparity in social skill development, in that, although individuals with Down's Syndrome are typically prosocial, their social skills do not develop at the same rate as same-aged peers (Johnson, 2006). They may thus feel more comfortable interacting with peers at a similar social level to them, as relationships with same-aged peers may be characterised by power imbalances (Shaw, 2017; Benstead 2019).

Strong relationships with support staff are not uncommon within the literature, with relationships with adults likely to be stronger than those with peers (Tuersley-Dixon & Frederickson, 2016). Children and young people are typically more reliant on their parents to provide social activities, and this reliance may transfer to school staff within the education setting (Gannon & McGilloway, 2009). As such, support staff have a clear role to play in supporting children and young people with Down's Syndrome to access social opportunities within school (Hargreaves et al., 2021).

Overall, all participants considered themselves to have friends as well as good relationships with support staff, thus demonstrating a clear sense of relatedness which ultimately will lead them to experience belonging within school (Ryan & Deci, 2000). Despite the general lack of friendships with same-aged peers, all participants seemed to experience a sense of acceptance from the school community as well, thus contributing to their social inclusion (Tuersley-Dixon & Frederickson, 2016). Some participants were on the edge of social groups more than others, but this did not seem to impact their experiences of school.

# Theme 6: Knowledge and understanding of Down's Syndrome

Wider school knowledge around Down's Syndrome was centred around each individual participant with Down's Syndrome. Interactions with individuals with a disability can both improve teacher's attitudes towards teaching pupils with that disability, as well as positively impact peer attitudes (Bills & Mills, 2020; Gannon & McGilloway, 2009) And as such, by simply having Down's Syndrome, participants may be improving attitudes, held by staff and peers, towards individuals with Down's Syndrome in wider society.

It is not unsurprising that many participants displayed a limited awareness around Down's Syndrome and what it meant for them. This may be because they do not understand the label given to them (Jackson et al., 2014; Groves et al., 2017), or because they do not need to understand it because having Down's Syndrome does not affect their everyday lives.

#### **Research Question Two: Results and Discussion**

This section of the chapter will discuss the findings of research question two: 'is the Mosaic Approach a useful tool for gathering the views of children and young people with Down's Syndrome?'. No quantitative data was collected to answer this question, as opposed to the approach used by Akyol and Erkan (2018), who used pre and post measures to examine the change in involvement levels of an experimental group who had received a Mosaic approach-based teaching method. Instead, an autoethnographic approach was used, to discuss my own reflections, in relation to previous research and theoretical underpinnings.

One of the attractions of the Mosaic Approach as a research method, is it's flexibility in combining multiple tools to triangulate and increase the richness of the data (Schulze, 2024). When using the Mosaic Approach in the current study, I was able to combine the data to enhance my understandings of participants' experiences both during data collection and data analysis. During the interviews, I was able to use their observation notes and participants' photographs to extend and contribute to the discussions (Baird, 2013). The extra tools used in addition to an interview also provided me with additional time to build rapport with participants, which helped to ensure the interviews were relaxed to enable participants to feel comfortable enough to share their experiences. In line with triangulation, the Mosaic Approach also helped to facilitate the inclusion of a wider range of participants. Pizzaboy, for example, had the most limited communication skills out of all participants and, in the interview, primarily communicated through yes and no answers or by pointing to symbols. If an interview methodology had solely been used, then it would have been difficult to generate codes from Pizzaboy's data. As such, this study provides further evidence for the Mosaic Approach as a useful tool to gather the views of children and young people with communication difficulties (Baird, 2013).

Observations provided an opportunity for me to embed myself in the participants' typical school day. All observations were conducted prior to the interviews, and as such the researcher was able to use events they had observed as prompts in the interview (Baird, 2013; Rouvali & Riga, 2018). For instance, some participants struggled to identify what support was offered to them by staff, so I was able to remind them of support I had seen during the observation which helped participants to understand what was being asked of them.

The tours of the school that occurred whilst participants were taking their photographs provided an opportunity for more naturalistic discussions about school life, and provided additional information that may not have arisen within the interviews (Blaisdell, 2012). Additionally, they allowed me to see the school from the participant's perspective (Rouvali & Riga, 2018). The photography section provided participants with a sense of agency (Benstead et al., 2023). Participants were given the freedom to take pictures of places they felt were important to them. All participants had clear ideas about where they wanted to take pictures of within school, which further conveyed the significance of these areas to the participants.

As previously stated, the interviews with this group of participants would not have provided rich enough data, if used as the sole methodology due to difficulties with communication. Although all participants engaged well in the interviews, their answers were often not detailed and it was sometimes too difficult to explore concepts further and more deeply with them (Polyzou et al., 2023; Geiger, 2023).

Although the mosaic approach as a methodology is a participatory approach, the participatory nature of this study was limited due to ethical and time constraints. Defining participation as children and young people taking an active role in the research process (Daw, 2024), then the only part of this study that could truly be defined as participatory is the participant led tours and photography. However, there are many different conceptualisations of participatory research within the literature. For example, Horgan (2017) defined participatory methods to be more focused on the relationship between the researcher and the participants, so that a true understanding of participants' worlds was understood and represented within the research. In addition, Hill et al.'s (2016) study, described a six level approach to participation research as follows: co-option, compliance, consultation, co-operation,

co-learning and collective action. In line with this model, the present study could be seen to be at a co-learning level whereby researchers and participants were working together to conduct the research activity and share understandings.

Clark and Moss conceptualised a framework for listening which forms the core of the Mosaic Approach. This framework states that the following principles underlie the Mosaic Approach: multi-method, reflexive, participatory, adaptable, focused on children's lived experiences and embedded into practice (Clark, 2017). The multimethod nature and participatory aspects of the current study have been discussed in previous sections of this discussion. The study was reflexive in that participants were supported to share their own experiences, and I tried to embed themselves in the participants' everyday lives, whilst being mindful of the influence of my own knowledge and language (Braun & Clarke, 2022). The approaches used within the current study were easily adaptable to suit the needs of individual participants, for example using communication symbols to support Pizzaboy in answering questions during the interview. Although the methodology was not necessarily embedded into the practice of the staff working with the participants, support staff and some teachers were exposed to the methodology and hopefully saw it as an interesting experience for the participants. In addition, in my dual role as a trainee educational psychologist, the Mosaic Approach has some potential use for how educational psychologists gather the views of children and young people, especially those with communication difficulties. Children and young people have the right to have their views heard in relation to their education, as stipulated in the SEND Code of Practice (2015), and educational psychologists often are well positioned to represent these views within their reports (Smilie & Newton, 2020). Many of the tools within the Mosaic Approach could be used by educational psychologists to make the child views sections of their reports more participatory and child led. Finally, the Mosaic Approach aligned well with the epistemological approach of social constructionism. It views children and young people as experts of their own lives and aims to provide a rich understanding of participants lived experiences (Clark, 2017; Huser, 2009). As such, participants were supported to share their experiences of inclusion and these were understood within their own individual contexts.

## **Summary of findings**

Overall, participants were supported to experience feels of autonomy, competence and relatedness in multiple ways. Competence and self-efficacy was encouraged through engagement in appropriate curriculars, both with mainstream and SEND peers. Relatedness was fostered through relationships with staff and peers as well as participation in whole school activities that enabled participants to convey a sense of presence within school. This then further contributed to a wider whole-school awareness of Down's Syndrome. Autonomy was supported through community participation and development of aspirations. These practices conveyed a sense of academic and social inclusion for children and young people with Down's Syndrome. Additionally, participants themselves served as a representation of Down's Syndrome, and in doing so spread awareness of Down's Syndrome amongst the wider school community.

In addition, the Mosaic Approach is a useful and adaptable tool that can be utilised to gather the views of children and young people with Down's Syndrome. The multimethod approach afford participants multiple opportunities to share their experiences. The approach also aligned with the social constructionist and social justice lenses of the research study, by giving participants' a voice to share their experiences and positioning them as experts of their own realities.

#### Limitations and ideas for future research

As with any research study, there were several limitations to the present research, The small participant sample limited the richness of the data and also provided a very limited account of experiences in relation to inclusion. Given the difficulties with recruitment, and the sample population size of this participant group, it may be hard to recruit an increased number of participants if the research were to be conducted again. Future research could seek to gain the perspectives of family members and school staff to expand the dataset and provided alternative experiences of inclusion.

Participant's communication abilities and their ability to answer open-ended questions is likely to have affected the richness of the data collected. This could have been mitigated by the researcher's development of a range of alternative questions to ask participants if they struggled with more abstract questions. Future research could address this limitation by utilising different methodologies within the Mosaic Approach. For instance, the use of card sorting activities as utilised by Geiger (2023)

and Deakin et al., (2018) have proven to be an effect tool to use in research with children and young people with Down's Syndrome.

### Implications for the practice of educational psychologists

The present study afforded an opportunity to hear and represent the voices of children and young people in a naturalistic way, through a social constructionist lens. This meant that participants' views were represented authentically with little interpretation from the researcher, to allow for participants' experiences to be fully understood from their perspective (Braun & Clarke, 2022). Gathering the views of children and young people with SEND in relation to their education is stipulated as an essential practice within the SEND Code of Practice (2015). However, within the educational psychologist community, there has been a debate about how the voice of the child should be represented. For instance, some educational psychologists choose to paraphrase what the child has been said, whilst others believe that their voices should be recorded word for word, without putting any interpretation on the child's views (Smilie & Newton, 2020). Obviously, there are logistical reasons which may influence an educational psychologists' decision on how views should be represented. However, in order to give weight to a child or young person's experiences and promote a sense of social justice for them whilst ensuring the gathering of their views is not done solely for tokenistic purpose, the findings of this study would encourage representing children and young people's views as authentically as possible.

The use of the Mosaic Approach could further to supporting educational psychologists to help give weight to the voice of children and young people. Educational psychologists frequently utilise observations and consultations as a way of information gathering (Smilie & Newton, 2020). However, it must be considered whether other tools may be more appropriate both for those with communication difficulties and to make the process more accessible and engaging for child or young person. Due to the constraints of the educational psychologist role, the time afforded to meeting with the child or young person is often limited, especially in the case of EHCNAs. As such, children and young people may find it difficult or uncomfortable to speak in depth and honestly about their experiences to an educational psychologist they have never met before (Smilie & Newton, 2020). The use of photography and a

child-led tour in the present study provided an opportunity for more naturalistic conversation, and provided the participants with a sense of autonomy to direct the conversation and share their experiences. Therefore, the use of more interactive approaches within educational psychologists' practice, such as photography or mapmaking, that are advocated for within the mosaic approach, may help to build rapport more quickly with children and young people, allowing for more authentic sharing of experiences.

The literature review identified a gap in teacher training regarding the needs of children and young people with Down's Syndrome (Van Herwegen et al., 2019). Educational psychologists could be well placed to provide this training, to support schools in understanding the strengths and needs of those with Down's Syndrome from a social model of disability. Although educational psychologists do not necessarily have the specific knowledge about Down's Syndrome as a disability, encouraging schools to look at inclusion of children and young people with Down's Syndrome from a broader perspective, and through a social model of disability, would help school staff to increase inclusive practices for all pupils (Pantic & Florian, 2015). This increased understanding of Down's Syndrome would also help to increase the self-efficacy of school staff as well, which is frequently highlighted as a barrier to inclusion (Bills & Mills, 2020). Training would also allow staff members to support with advocation for the child or young person with Down's Syndrome. It became clear in the present research that the majority of participants were unaware of how having Down's Syndrome affected them, which would potentially leave them vulnerable to not being able to advocate for what support they needed. By increasing the knowledge and awareness amongst school staff around Down's Syndrome, they would be able to support individuals with Down's Syndrome with identifying how their needs affect them in school, thus increasing their own awareness of their strengths and areas of development (Carbone et al., 2023). The final implication of training would hopefully be improved relationships between school staff and parents. Parents have frequently voiced that they felt dissatisfied with the awareness of Down's Syndrome amongst school staff (Van Herwegen et al., 2018). As such, specific training in relation to Down's Syndrome would allow parents to feel confident in a school's ability to support their child or young person.

**Chapter Three: Reflective Chapter** 

#### Introduction

This chapter provides my reflections on the research process, methodologies, and the wider context of the research. This research was reflective in nature, in part due to the use of reflexive thematic analysis and secondly due to the use of my own reflections to provide data for research question two. This constant reflexive, reflective process ensured I was aware of how I was shaping and influencing the research through my own practice and experiences (Braun & Clarke, 2022). This reflectivity and reflexivity helped to ensure quality and validity throughout the research process (Yardley, 2011). Embedded within these reflections are the HCPC Standards of Proficiency (2023) and the BPS Standards (2023) to demonstrate how this research has supported my development as a trainee educational psychologist (see appendix: J).

## The ethical approval process

HCPC Standards of Proficiency: 2.1, 2.2, 2.3, 2.4, 2.7, 2.8, 2.9, 2.12, 2.13, 4.1, 4.4, 4.5, 5.2, 5.3, 5.5., 5.6, 6.0, 6.1, 6.2, 7.8, 7.12, 9.1, 9.2, 10.1, 10.3, 12.1, 13.7, 13.24, 13.29, 13.34, 13.59

BPS Standards: 1f, 2a, 2c, 2e, 2h, 2i

Gaining ethical approval for this research study was incredibly challenging and raised some interesting questions for educational psychologists and their practice. Conducting research with children and young people, with or without SEND, typically makes the ethical process more intensive due to their classification as a vulnerable group, and the need to ensure any potential risk of harm has been identified and mitigated (BPS 2021, 3.1, 3.3; HCPC 2024, 6.1, 6.2). The additional use of a photography methodology also needed some further considerations due to the risk of other people, who had not consented to the study, being captured within the photographs (BPS 2021, 3.3; HCPC 2024, 6.1, 6.2). I had pre-empted the ethical implications of both these factors prior to beginning the ethical process, however it was the observation methodology that gave rise to the most ethical issues.

Originally, the ethics committee required that I seek permission from the parents of all the children and young people who would be present during the breaktime and classroom observations. This would have been logistically impossible, especially for the breaktime observations, as I would have had to gain consent from hundreds of

parents. In addition, if a parent had not consented to their child being within the vicinity of the observation, it would have been extremely difficult to identify that child amongst hundreds of pupils, when conducting that observation. After further discussions with the ethics committee and reassuring them that no observational data would be gathered on any other pupils, they agreed to the observations taking place, provided I produced an information sheet that schools could distribute to parents to inform them that the observations were taking place. Additionally, I gained consent from the staff who would be teaching the lesson I was observing to ensure they were informed about my observation.

It was interesting that I did not anticipate the ethical implications of an observational approach prior to my ethics application. Interestingly, when discussing this part of my ethics application with the chair of the ethics committee, she described themselves as over-sensitive and felt that us as (trainee) educational psychologists are often under-sensitive to the wider ethical implications of research. I believe this raises questions and ethical implications for the wider practice of educational psychologists, not just in relation to research. Often educational psychologists utilise observations of children and young people as part of their information gathering. Typically, in these situations, consent is gained from parents to allow the educational psychologist to work with their child. However, the stance of the ethics committee raises the question should we be gaining consent from others in the classroom, depending on the nature of the observation. In addition, there is an ongoing debate within the profession about whether children and young people should be informed they are being observed. Some educational psychologists state that observing a child or young person without informing them is unethical, whilst others argue that if they are aware they're being observed then they will alter their behaviours, and the observation will no longer be naturalistic. Having gained informed consent for this study and, in doing so, made participants' aware they would be observed, I believe that their behaviours did not change dramatically as a result of my presence in the classroom. As such, I would argue that children and young people should always be informed they are being observed. As a profession educational psychologists need to ensure they are continuing to be ethically sensitive during their practice. The HCPC Standards of Performance, Conduct and Ethics (2024) and BPS Code of Conduct and Ethics (2021) should be made salient, and practice should be examined against these to

ensure that the profession is not becoming complacent in regard to ethics related to practice.

As previously mentioned, research with children and young people often warrants a more robust ethical review, especially when they have SEND. Although this is necessary to protect participants from harm, it can, at times, be seen to be at odds with the values underpinning participatory research. Within participatory research, children and young people are viewed as autonomous individuals, who hold the agency and capabilities to participate in research and make decisions about the degree of their participation (Horgan, 2017). Ethical procedures typically state that for children and young people, parental consent is needed alongside consent from the children and young people themselves, with parents then acting as gatekeepers to children and young people's participation (Sharma, 2021). As such, children and young people's participation can be overruled by their parents which does not value their agency in decision making processes (Sime, 2008). Respecting children and young people's autonomy, particularly those with SEND, also has implications from a social justice perspective as if we continue to diminish the value of their voice and agency, we are further contributing a sense of social injustice (Horgan, 2017).

#### National context of the research: Inclusion in Practice Initiative

HCPC Standards of Proficiency: 2.10, 2.14, 12.4, 12.29, 12.32, 12.6

BPS Standards: 7c, 7j

In 2025, the Inclusion in Practice initiative was launched by the government. This initiative is run by an advisory group who will collect evidence and provide expert evidence to the government about how to improve inclusion for children and young people with SEND in mainstream education. This initiative as a whole demonstrates the wider societal commitment to improving inclusion, and thus highlights the importance of the current research project. Six areas will be focused on by this initiative:

- Inclusive classroom practice and culture
- Partnerships with families
- Early identification of SEND
- Additional support in mainstream schools

- Workforce capability and expertise
- Enabling conditions and incentives

The present research study identified a range of good inclusive practise within schools for children and young people with Down's Syndrome, as well as highlighting the importance of relationships with families and training for staff. Evidence such as the current research study will be essential in reinforcing and evidencing what support is needed in schools not only to promote inclusion for children and young people with Down's Syndrome, but also children and young people with SEND. As such the present research could help inform and provide evidence for points one, four and five of the initiative.

One principal educational psychologist is on the committee responsible for directing this initiative. I believe this demonstrates the importance not only of educational psychologists providing evidence for this initiative, but also getting involved in research and practices that influence local and national policies. Educational psychologists are expertly positioned to influence the wider systems of Bronfenbrenner's ecological model, due to their direct work with children and young people and schools, their understanding of the SEND system, as well as their position within local authorities (Cumber & Gulliford, 2024; Schulze et al., 2019). Research skills form a large chunk of the doctoral training, however, after qualification most educational psychologists do not engage in research and local authorities rarely orchestrate research that is large-scale and wide-reaching (Topping & Lauchlan, 2013). Many educational psychologists often express frustration at the monotony of completing individual assessments for EHCPs, as well as an interest in reducing social injustice at higher levels of policy (Schulze et al., 2019; Cumber & Gulliford, 2024). Therefore, by getting involved in wider initiatives, educational psychologists can make use of research skills and have an influence on larger populations of children and young people.

National context of the research: Down's Syndrome Act

HCPC Standards of Proficiency: 2.10, 2.14, 12.4, 12.29, 12.32, 12.6

BPS Standards: 7c, 7j

Similarly to the wider societal focus on inclusion, the government have also, in recent years, demonstrated a commitment to improving the lives of individuals with Down's Syndrome. The Down's Syndrome Act was announced in 2022. The aims of the act are thought to be similar to the Autism Act which was brought into fruition in 2009, whereby professionals and wider society are educated more widely about Autism, and thus Down's Syndrome (Walsh & Hall, 2012). By doing so, society can be encouraged to understand Down's Syndrome through a social model of disability, to truly remove barriers and understand Down's Syndrome in the context of society beyond the condition itself (Walsh & Hall, 2012).

The introduction of this act highlights the timeliness and importance of the present research study, and how the content of which could be used to improve the lives of children and young people with Down's Syndrome. Again, there is scope for educational psychologists to become involved in providing evidence and supporting implementation of the act to increase our engagement with wider national initiatives (Cumber & Gulliford, 2024).

#### Recruitment

HCPC Standards of Proficiency: 2.11, 2.13, 5.1, 5.2, 5.3, 5.4, 5.6, 5.8, 12.32

BPS Standards: 3d, 3f

Recruitment was another challenging aspect of the research process. My initial recruitment strategy was to advertise through local parent carer groups, but approximately only five parents expressed interest from these groups. I then applied to advertise my research through the Down's Syndrome Association, which garnered more interest in the project, demonstrating the power of the community the Down's Syndrome Association has built. However, I am aware that both these recruitment strategies likely limited my population to parents who were active members of the Down's Syndrome community. In addition, advertising solely through online methods discriminated against individuals who did not have access to the internet or social media.

When distributing my advertisement to local support groups, one Down's Syndrome support group did respond to say that they would not be distributing the flyer for my study due to the pressures, they believed, parents were under. They also felt that the

research may cause tension between parents and schools if schools did not agree to allow the study to take place. Whilst I completely respected the viewpoint of this support group, I found it interesting that this group made this decision on behalf of parents and ended up acting as an additional gatekeeper to children and young people's participation (Sharma, 2021).

## Research with children and young people

HCPC Standards of Proficiency: 2.11, 2.13, 2.5, 4.7, 5.1, 5.2, 5.3, 5.4, 5.5, 5.6, 5.7, 5.8, 11.1, 12.32, 13.2,

BPS Standards: 3a, 3b, 3d, 3f, 4h

Conducting research with children and young people was an incredibly rewarding experience and each participant reminded me why I persevered through a complex ethical process. My small participant sample allowed me to not lose sight of my participants as individuals and ensure their voices and experiences were represented meaningfully and not lost within the research. Despite the satisfaction and enjoyment of conducting research with children and young people, there were some uncertainties associated with this particular participant group that arose during the research process. For example, although I attempted to gain an understanding of each participant by meeting with their parents beforehand, up until my actual visit, I still had concerns about their ability and desire to engage. Luckily, all participants were happy to engage, and I could see our rapport developing throughout my visits. Pizzaboy was the only participant for whom I was not prepared for his communication difficulties, despite meeting with his parent beforehand, but I was able to adapt my interview strategy on the spot to enable him to engage appropriately. I also had concerns about how rich my data would be. I had prepared my interview questions to be a mix of open and closed questions, but I found that some participants struggled with the open-ended questions. During the interviews, at times I struggled to reframe the questions in an appropriate way and often resorted to asking more closed questions. However, this demonstrated the value of using the Mosaic Approach and the opportunity to triangulate three sets of data for each participant (Huser, 2009). Had I used another participatory methodology such as Photovoice, I believe the requirement on verbal communication would have been too

heavy for my participant group, and they would not have been able to engage in critical discussions about their photographs (Jurkowski, 2008).

I felt the process allowed each participant to have a voice and contributed to a wider sense of social justice for these participants. However, upon reflection, I wondered about my participants' own understanding of social justice. Especially, for the participants who displayed a limited awareness of Down's Syndrome and the associated difficulties, do they actually recognise themselves as a marginalised group? If not, do we need to respect their satisfaction with life and education or do we need to advocate on their behalf and for the wider Down's Syndrome community who are not having such positive experiences. In addition, their experiences may not always be so positive, so should they be encouraged to advocate for themselves in anticipation of difficult situations. I wonder also about the role parents have to play in reducing individual's awareness of their needs. Parents often take on an advocacy role for their children and young people with SEND, and in doing so, are parents limiting the opportunities children and young people have to advocate for themselves and develop an awareness of the history of the community to which they belong (Laws & Millward, 2001). I believe these considerations highlight the fact we can advocate on behalf of marginalised groups, but the true need for social justice must come from those groups themselves as we do not have a true understanding of their experiences (Nesterova, 2023).

In order to maintain and ensure I follow through with the social justice perspective I have spoken about throughout my research, I need to ensure I appropriately disseminate my research and not treat the participants' views as tokenistic (Parris et al., 2019; Smilie & Newton, 2020). This is relevant to my research in two ways. For one, I need to ensure that participants' experiences of school are communicated to ensure more positive educational experiences for children and young people with Down's Syndrome and wider SEND. In addition, to also communicate the usefulness of the Mosaic Approach as a tool, to increase its use to capture the voices of children and young people, particularly those with communication difficulties. Dissemination needs to go beyond the traditional publication of research within academic journals. Journals are typically only accessed by researchers and other academics, which contributes to a sense of social injustice, as findings are typically not reaching the people who need to hear them the most (Parris et al., 2019). One of the

requirements of advertising through the Down's Syndrome Association was that they be provided with a summary of results once the study is complete, which will help to disseminate the findings to the wider Down's Syndrome community.

## Choice of methodological and analytical tools for research question two

HCPC Standards of Proficiency: 2.7, 3.1, 3.2, 4.1, 4.8, 6.2, 7.15, 7.16, 10.1, 10.3, 11.3, 11.6, 12.2, 13.11, 13.15, 13.27, 13.29, 13.37, 13.54, 13.6, 13.8

BPS Standards: 9b, 9d, 9e, 9f, 9g, 10b

Research question two has been the subject of many critical discussions between myself and my supervisor. Given the limited research conducted with individuals with Down's Syndrome, and the lack of diversity of methodological approaches within that research, I felt it was important to consider the usefulness and success of the Mosaic Approach as a tool to use with this population. However, deciding how to measure the success of the approach was difficult. Within the literature, Akyol and Erkan (2018), used the Leuven Involvement Scale for Young Children to measure how involvement levels changed as a result of a Mosaic Approach based education programme. However, their participant sample was significantly bigger and homogenous, with 52 five-year-old participants overall split into a control and an experimental group. My participant sample was significantly smaller, and could not be described as a homogeneous population, given the variations in demographics and communication levels amongst the participants. As such, using a quantitative tool to measure success of the methodology would not have yielded valid and reliable results. In addition, quantitative methodological tools are typically associated with a positivist research paradigm, whereby reality is objective, and research aims to explain causality in relationships (Scotland, 2012). In addition, a positivist paradigm does not take context into consideration when attempting to explain relationships (Kivunja & Kuyini, 2017). As such, a quantitative methodology would have been at odds with the social constructionist lens through which this research has been conducted. Baird (2013) was the only other researcher who had engaged in an evaluation of the Mosaic Approach methodology. Her approach to doing so was a critical reflection, related back to previous research. In order to give my methodology more structure, I decided upon an autoethnographic approach. The autoethnographic approach also considers one's role as a practitioner as well as a

researcher, which was important given my dual role as a trainee educational psychologist and researcher (McIlveen, 2008). In addition, the approach aligns with my social constructionist paradigm with the findings based off my own experiences of the research, within the particular context of the study (McIlveen, 2008). Autoethnography aims to understand these experiences in relation to theory, practice and wider societal context (McIlveen et al., 2010). Relating experiences back to theory does not typically align with a social constructionist paradigm, as bringing in theory does not value the socially constructed nature of language and phenomena (Kivunja & Kuyini, 2017). However, engaging with theory ensures that the autoethnography is critical and allows for an interpretation of my experiences (McIlveen, 2008). The use of only one data collection tool for this research question may have led to biases in the data (Poerwandari, 2021), but to ensure validity and quality, the research was reflected on in line with Yardley's (2011) four key principles. I also ensured I was reflexive throughout the process, being critical about my own understandings and experiences to ensure I was remaining subjective to the research (Poerwandari, 2021).

## Researching an elusive concept

HCPC Standards of Proficiency: 2.14, 5.5, 5.8, 12.29, 12.3, 12.32, 12.35, 12.38, 12.39, 12.40

BPS Standards:1c, 1d

As illustrated in the literature review, inclusion is a difficult concept to define (Kendall, 2019a). This has implications for both implementation and research, as depending on the definition used, conclusions and practices regarding inclusion will vary. Considering the variability in implementation and how inclusion is shaped by one's individual experiences and circumstances (Dimitrellou et al., 2020), I wanted to keep my definition of inclusion broad. Although, from a social constructionist lens, a definition of inclusion is not entirely necessary as participants will construct their own experiences of inclusion, a definition was initially needed to help structure the research. As such, I combined the final two levels of Nilholm's (2021) and Selisko et al.'s (2024) tiered approaches to defining inclusion to conceptualise the following definition: 'the presence and participation of all pupils in both academic and social aspects of school, within a learning environment that is adapted to meet their needs'.

In doing so, I wanted to capture the meaningful, multi-faceted nature of inclusion and emphasise the influence of social and environmental factors on inclusion, in line with social cognitive theory (Bandura, 1986).

When initially developing the research study, I debated whether to use a preconceived definition of inclusion to structure my study, or to co-construct the definition with the participants. Co-construction would have been more in line with the social constructionist paradigm in which my research was conducted, whereby individuals would construct a definition using their language and contextual experiences (Dimitrellou et al., 2020; Braun & Clarke, 2022). However, I had concerns about the communication levels of the participants, and whether or not they would be able to comprehend the abstract nature of inclusion as a concept as well as understand and verbalise what inclusion meant for them. As such, I made the decision to define inclusion prior to meeting with my participants and then structure my interview questions around this definition. Reflecting back on this, I believe I made the right decision as my participants did find it difficult to answer more openended and ambiguous questions, and I thus feel that they would have struggled to define an elusive concept such as inclusion, particularly those with weaker communication skills. By structuring the interview around a definition of inclusion, I believe I was able to create a more containing approach for participants which still allowed them the flexibility to share their experiences, whilst approaching the concept of inclusion in a more indirect way. Obviously, there were several advantages and weaknesses to this decision. One benefit was that participants involvement in the project was more tailored to their abilities thus facilitating their participation. In terms of weaknesses, although I have tried to use the research to define inclusion, I am likely to be imposing my own preconceived ideas and experiences of inclusion onto the participants which may be thus subconsciously positioning myself as the expert. In addition, when conducting the interviews and interpreting the data, I may also have been understanding their experiences through my own definition of inclusion, rather than respecting their individual realities. However, by acknowledging this and being reflexive in my analysis I hope to have minimised the influence of my own contextual understandings.

Given the elusive and contextual nature of inclusion, the ontological and epistemological perspectives of relativism and social constructionism aligned well

with the research and are useful paradigms through which to view inclusion. Inclusion, through a social constructionist lens, is defined through the experiences of individuals, and the language and meaning they ascribe to the term inclusion (Braun & Clarke, 2022). By immersing myself in participants' school lives through the use of the Mosaic Approach, I was afforded a deeper understanding of their contextual experiences, and I was supported to make meaning of these alongside participants. There are ways in which the current study is not purely social constructionist, for example my use of a preconceived definition of inclusion, and the fact that participants experiences are discussed in relation to previous theory and literature in the discussion part of the empirical paper. However, I believe relating participants' experiences back to theory provides national context for their experiences and situates their experiences in the wider understanding of inclusion.

#### References

Al-Shammari, Z., Faulkner, P. & Forlin, C. (2019). Theories-based inclusive education practices. *Education Quarterly Review*, *2*(2), 408 – 414.

Akyol, T. & Erkan, S. (2018). The effect of Mosaic based Approach on involvement levels of children. *International Journal of Educational Methodology*, *4*(4), 303 – 309.

An, J. & Meaney, K. (2015). Inclusion practices in elementary physical education: a social-cognitive perspective. *International Journal of Disability, Development and Education*, 62(2), 143 – 157.

Artiles, A., Harris-Murri, N. & Rostenberg, D. (2006). Inclusion as social justice: critical notes on discourses, assumptions, and the road ahead. *Theory into Practice*, *45*(3), 260 – 268.

Azunre, G. & Sowrirajan, T. (2021). The mosaic approach as a tool to facilitate participatory planning with children: insights from Milan, Italy. *Education 3-13, 49*(5), 529 – 544.

Baird, K. (2013). Exploring a methodology with young children: reflections on using the Mosaic and Ecocultural approaches. *Australasian Journal of Early Childhood*, 38(1), 35 – 40.

Bandura, A., & National Inst of Mental Health. (1986). *Social foundations of thought and action: A social cognitive theory.* Prentice-Hall, Inc.

Benstead, H. (2019). Exploring the relationship between social inclusion and special educational needs: mainstream primary perspectives. *Supporting for Learning, 34*(1), 34 – 53.

Benstead, H., Graham, V. & Jowett, V. (2023). The power of 'research conversations' in analysing and interpreting the views and perspectives of children identified with SEND. *Journal of Research in Special Educational Needs*, *24*(4), 1035 – 1045.

Bhopal, K. & Shain, F. (2014). Educational inclusion: towards a social justice agenda?. *British Journal of Sociology of Education*, *35*(5), 645 – 649.

Bills, K. & Mills, B. (2020). Teachers' perceptions towards inclusive education programs for children with Down Syndrome. *Journal of Research in Special Educational Needs*, *20*(4), 343 – 347.

Blaisdell, C. (2012). Inclusive or exclusive participation: paradigmatic tensions in the Mosaic Approach and implications for childhood research. *Childhoods Today, 6*, 1 – 18.

Bloom, A., Critten, S., Johnson, H. & Wood, C. (2020)a. A critical review of methods for eliciting voice from children with speech, language and communication needs. *Journal of Research in Special Educational Needs*, 20(4), 308 – 320.

Bloom, A., Critten, S., Johnson, H. & Wood, C. (2020)b. Evaluating a method for eliciting children's voice about educational support with children with speech, language and communication needs. *British Journal of Special Education, 47*(2), 170 – 207.

Boghossian, P. (2006). Behaviorism, constructivism, and socratic pedagogy. *Educational Philosophy and Theory,* 38(6), 713 – 722.

Botsoglou, K., Beazidou, E., Kougioumtzidou, E. & Vlachou, M. (2019). Listening to children: using the ECERS-R and Mosaic Approach to improve learning environments: a case study. *Early Child Development and Care, 189*(4), 635 – 649.

Braun, V. & Clarke, V. (2022). *Thematic analysis: a practical guide.* Sage Publications Ltd.

British Psychological Society. (2021). *Code of ethics and conduct*. https://explore.bps.org.uk/content/report-guideline/bpsrep.2021.inf94

British Psychological Society. (2023). Standards for the accreditation of doctoral programmes in educational psychology.

https://cms.bps.org.uk/sites/default/files/2023-12/Educational%20Psychology%20Handbook%20-%20Standards%20for%20Accreditation.pdf

Boundy, L., Hargreaves, S., Baxter, R., Holton, S. & Burgoyne, K. (2023). Views of educators working with pupils with Down Syndrome on their roles and

responsibilities and factors related to successful inclusion. *Research in Development Disabilities*, *142*, 104617.

Burney, V. (2008). Applications of social cognitive theory to gifted education. *Roeper Review*, *30*(2), 130 – 139.

Burr, V. (2015). *Social constructionism* (3<sup>rd</sup> Ed.). Taylor and Francis Group.

Carbone, A., Castaldi, M. & Szpuner, G. (2023). The relationship between teachers and pupils with Down Syndrome: a qualitative study in primary schools. *Behavioral Sciences*, *13*, 274.

Clark, A. (2017). Listening to young children (3<sup>rd</sup> Ed.): a guide to understanding and using the Mosaic Approach. Jessica Kingsley Publishers.

Cumber, D. & Gulliford, A. (2024). 'If you see something that's not right, we need to challenge it.' A critical review and qualitative exploration of educational psychologists' perceptions of social justice and practice in local authority services in the West Midlands. *Educational and Child Psychology, 41*(2).

Daw, C. (2024). Participatory research (PR) working with adolescent research assistants in a specialist school. *Journal of Participatory Research Methods*, *5*(1).

Deakin, K., Moore, D. & Jahoda, A. (2018). Children and young people with Down Syndrome: their awareness of Down Syndrome and developing self-perceptions. *Journal of Applied Research in Intellectual Disabilities, 31,* 1197 – 1208.

Department for Education. (2014). *Children and Families' Act 2014*. https://www.legislation.gov.uk/ukpga/2014/6/contents

Department for Education and Department of Health. (2015). *Special Educational Needs and Disability Code of Practice: 0 to 25 years*.

https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Department of Education and Science (1978). Special Educational Needs: Report of the Committee of Enquiry into the Education of Handicapped Children and Young People (The Warnock Report). HMSO.

Department of Education and Science. (1981). *Circular 8/81. Education Act 1981*. <a href="http://www.educationengland.org.uk/documents/des/circular8-81.html">http://www.educationengland.org.uk/documents/des/circular8-81.html</a>

Dimitrellou, E., Hurry, J. & Male, D. (2020). Assessing the inclusivity of three mainstream secondary schools in England: challenges and dilemmas. *International Journal of Inclusive Education*, *24*(10), 1097 – 1113.

Dimitrellou, E. & Male, D. (2020). Understanding what makes a positive school experience for pupils with SEND: can their voices inform inclusive practice?. *Journal of Research in Special Educational Needs*, *20* (2), 87 – 96.

Douglas, G., McLinden, M., Robertson, C., Travers, J. & Smith, E. (2016). Including pupils with special educational needs and disability in national assessment: comparison of three country case studies through an inclusive assessment framework. *International Journal of Disability, Development and Education, 63*(1), 98 – 121.

Down's Syndrome Association. (2021a). *About Down's Syndrome*. <a href="https://www.downs-syndrome.org.uk/about-downs-syndrome/">https://www.downs-syndrome.org.uk/about-downs-syndrome/</a>

Down's Syndrome Association. (2021b). *Where we stand*. <a href="https://www.downs-syndrome.org.uk/about-dsa/who-we-are/where-we-stand">https://www.downs-syndrome.org.uk/about-dsa/who-we-are/where-we-stand</a>

Dunleavy, A. & Sorte, R. (2022). A thematic analysis of the family experience of British mainstream school SEND inclusion: can their voices inform best practice? *Journal of Research in Special Educational Needs*, 22(4), 332 – 342.

Engevik, L., Naess, K. & Berntsen, L. (2018). Quality of inclusion and related predictors: teachers' reports of educational provisions offered to students with Down Syndrome. *Scandinavian Journal of Educational Research*, *62*(1), 34 – 51.

Fisher, M., Athamanah, L., Sung, C. & Josol, C. (2019). Applying the self-determination theory to develop a school-to-work peer mentoring programme to promote social inclusion. *Journal of Applied Research in Intellectual Disabilities*, 33, 296 – 309.

Florian, L. & Spratt, J. (2013). Enacting inclusion: a framework for interrogating inclusive practice. *European Journal of Special Needs Education*, 28(2), 119 – 135.

Frederickson, N. & Cline, T. (2015). *Special Educational Needs, Inclusion and Diversity* (3<sup>rd</sup> Ed.). Open University Press.

Gannon, S. & McGilloway, S. (2009). Children's attitudes toward their peers with Down Syndrome in schools in rural Ireland: an exploratory study. *European Journal of Special Needs Education*, *24*(4), 455 – 463.

Geiger, S. (2023). Views of school held by children and young people with Down's Syndrome. How do we ask and what do they report?. *Educational and Child Psychology, 40*(3), 131 – 149.

Government Equalities Office. (2010). *Equality Act 2010*. <a href="https://www.legislation.gov.uk/ukpga/2010/15/contents">https://www.legislation.gov.uk/ukpga/2010/15/contents</a>

Groves, E., Rayner, K. & Muncer, S. (2017). "It's good, they're like me; the same but different." An interpretative phenomenological analysis of the identities of women with Down's Syndrome. *Journal of Applied Research in Intellectual Disabilities, 31,* 445 – 453.

Guay, F. (2022). Applying self-determination theory to education: regulations types, psychological needs, and autonomy supporting behaviours. *Canadian Journal of School Psychology*, *37*(1), 75 – 92.

Hargreaves, S., Holton, S., Baxter, R. & Burgoyne, K. (2021). Educational experiences of pupils with Down Syndrome in the UK. *Research in Developmental Disabilities*, *119*, 104115.

Health and Care Professions Council. (2023). *Standards of proficiency: practitioner psychologists*. <a href="https://www.hcpc-uk.org/standards/standards-of-proficiency/practitioner-psychologists/">https://www.hcpc-uk.org/standards/standards-of-proficiency/practitioner-psychologists/</a>

Health and Care Professions Council. (2024). *Standards of conduct, performance and ethics*. <a href="https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/">https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/</a>

Hill, V., Croydon, A., Greathead, S., Kenny, L., Yates, R. & Pellicano, E. (2016). Research methods for children with multiple needs: Developing techniques to facilitate all children and young people to have 'a voice'. *Educational and Child Psychology*, 33 (3), 26 – 43.

Horgan, D. (2017). Child participatory research methods: attempts to go 'deeper'. *Childhood*, 24(2), 245 – 259.

Huser, C. (2009). Children's voices on play in a Mosaic Approach study: children as conscious participants in a case study. *Bogazici University Journal of Education*, 26(1), 35 – 48.

Inclusion in Practice. (2025). About inclusion in practice.

https://inclusioninpractice.org.uk/about/

Jackson, C., Cavenagh, P. & Clibbens, J. (2014). Communication and self-esteem in adults with Down Syndrome. *International Journal of Language and Communication Disorders*, *49*(3), 275 – 287.

Jevne, K., Dolva, A-S. & Kollstad, M. (2022). The perspective of emerging adults with Down Syndrome – on quality of life and well-being. *Journal of Intellectual Disabilities*, 26(4), 839 - 852.

Johnson, D. (2006). Listening to the views of those involved in the inclusion of pupils with Down's Syndrome into mainstream schools. *Support for Learning, 21*(1), 24 – 29.

Jurkowski, J. (2008). Photovoice as participatory action research tool for engaging people with intellectual disabilities in research and program development. *Intellectual and Developmental Disabilities*, 46(1), 1-11.

Kanzaki, M., Kato, H. & Sato, T. (2023). A case study of transductive resolution: analysing the practice of inclusive education for a girl with Down's Syndrome at an elementary school in Japan. *Integrative Psychological and Behavioural Science*, *57*, 1256 – 1272.

Kendall, L. (2019)a. Supporting all children to reach their potential: practioner perspectives on creating an inclusive school environment. *Education 3-13, 47*(6), 678 – 691.

Kendall, L. (2019)b. Supporting children with Down Syndrome within mainstream education settings: parental reflections. *Education 3-13, 47*(2), 135 – 147.

Kivunja, C. & Kuyini, A. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of Higher Education*, *6*(5), 26 – 41.

Kok, X. & Yang, W. (2022). 'Quilting' a play-based anti-bias curriculum for very young children: the Mosaic Approach. *European Early Childhood Education Research Journal*, *30*(6), 827 – 851.

Kupers, E., de Boer, A., Bakker, A., de Jong, F. & Minnaert, A. (2024). Explaining teachers' behavioural intentions towards differentiated instruction for inclusion: using the theory of planned behaviour and the self-determination theory. *European Journal of Special Needs Education*, 39(4), 638 – 647.

Laws, G. & Millward, L. (2001). Predicting parents' satisfaction with the education of their child with Down's Syndrome. *Educational Research*, *43*(2), 209 – 226.

Lindsay, G., Wedell, K. & Dockrell, J. (2020). Warnock 40 years on: the development of special educational needs since the Warnock report and implications for the future. *Frontiers in Education, 4*, Article 164.

Maher, A., van Rossum, T. & Morley, D. (2023). Assessing the learning of pupils with special educational needs and disabilities in mainstream school physical education. *British Education Research Journal*, 49, 110 – 125.

Malik, S. (2021). Learning theory of cognitivism and its implications on students' learning. *Worldwide Journal of Multidisciplinary Research and Development.* 

Mannion, N., Fitzgerald, J. & Tynan, F. (2024). Photovoice reimagined: a guide to supporting the participation of students with intellectual disabilities in research. *International Journal of Qualitative Methods*, 23, 1 – 16.

Marks Woolfson, L. (2023). Is inclusive education for children with special educational needs and disabilities an impossible dream?. *British Journal of Educational Psychology*.

McIlveen, P. (2008). Autoethnography as a method for reflexive research and practice in vocational psychology. *Australian Journal of Career Development*, 17(2), 13 – 20.

McIlveen, P., Beccaria, G., du Preez, J. & Patton, W. (2010). Autoethnography in vocational psychology: wearing your class on your sleeve. *Journal of Career Development*, *37*(3), 599 – 615.

McKinlay, J., Wilson, C., Hendry, G. & Ballantyne, C. (2022). "It feels like sending your children into the lions' den" – a qualitative investigation into parental attitudes towards ASD inclusion, and the impact of mainstream education on their child. *Research in Developmental Disabilities, 120,* 104128.

Mullan, P., Prendeville, P. & Kinsella, W. (2018). Factors influencing the successful transition of young people with Down Syndrome. *British Journal of special education*, *45*(4), 371 – 391.

National Health Service. (2022). *NCARDRS Congenital Anomaly Official Statistics Report*, 2020. https://digital.nhs.uk/data-and-

information/publications/statistical/ncardrs-congenital-anomaly-statistics-annual-data/ncardrs-congenital-anomaly-statistics-report-2020/prevalence-t21-t18-t13

National Health Service. (2023). Down's Syndrome.

https://www.nhs.uk/conditions/downs-syndrome/

National Health Service. (2024a). *NCARDRS Congenital Anomaly Official Statistics Report, 2021*. <a href="https://digital.nhs.uk/data-and-">https://digital.nhs.uk/data-and-</a>

<u>information/publications/statistical/ncardrs-congenital-anomaly-statistics-annual-data/ncardrs-congenital-anomaly-statistics-report-2021/prevalence-of-t21-t18-t13</u>

National Health Service. (2024b). *Termination for fetal anomaly.* https://www.nhs.uk/pregnancy/support/termination-for-fetal-anomaly/

Nesterova, Y. (2023). Towards social justice and inclusion in education. In Postiglione, G., Johnstone, C. & Teter, W. (Eds.), *Handbook of education policy* (pp. 301-313). Edward Elgar Publishing.

Nilholm, C. (2021). Research about inclusive education in 2020 – how can we improve our theories in order to change practice? *European Journal of Special Needs Education*, *36*(3), 358 – 370.

O'Brien, P. (2018). Self-determination for primary school children: theory and practice. *REACH Journal of Special Needs Education in Ireland*, *31*(2), 155 – 168.

Pantic, N. & Florian, L. (2015). Developing teachers as agents of inclusion and social justice. *Education Inquiry, 6*(3), 27311.

Pare, G. & Kitsioi, S. (2018). Methods for Literature Reviews. In Lau, F. & Kuziemsky, C. (Eds.). *Handbook of eHealth evaluation: an evidence-based approach.* University of Victoria.

Parris, L., Sabnis, S., Shriberg, D., Sullivan, A. & Proctor, S. (2019). Bringing social justice principles into school psychology research. *Communique*, *48*(2), 6 – 15.

Pirker, A., Hafenscher, J. & Lindner, K-T. (2023). Investigating the self-perception of social, emotional and academic inclusion of students with and without special educational needs through photovoice. *Education Sciences*, *13*, 423.

Poerwandari, E. (2021). Minimizing bias and maximising the potential strengths of autoethnography as a narrative research. *Japanese Psychological Research*, 63(4), 310 – 323.

Polat, F. (2011). Inclusion in education: a step towards social justice. *International Journal of Educational Development*, 31, 50 – 58.

Polyzou, S., Botsoglou, K., Zygouris, N. & Stamoulis, G. (2023). Interactive books for preschool children: from traditional interactive paper books to augmented reality books: listening to children's voices through mosaic approach. *Education 3-13,* 51(6), 881 – 892.

Rapp, A. & Corral-Granados, A. (2024). Understanding inclusive education – a theoretical contribution from system theory and the constructionist perspective. *International Journal of Inclusive Education*, *28* (4), 423 – 439.

Riddell, S. (2009). Social justice, equality and inclusion in Scottish education. *Discourse: Studies in the Cultural Politics of Education*, *30*(3), 283 – 296.

Rouvali, A. & Riga, V. (2018). Redefining the importance of children's voices in personal social emotional development curriculum using the Mosaic Approach. *Education 3-13, 47*(8), 998 – 1013.

Ryan, R. & Deci, E. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68–78.

Sales, N. & Vincent, K. 2018. Strengths and limitations of the Education, Health and Care plan process from a range of professional and family perspectives. *British Journal of Special Education*, *45*(1), 61 – 80.

Sarkar, S. & Bhatia, G. (2021). Writing and appraising narrative reviews. *Journal of Clinical and Scientific Research*. *10*. 169 – 172.

Schulze, J., Winter, L., Woods, K. & Tyldsley, K. (2019). An international social justice agenda in school psychology? Exploring educational psychologists' social justice interest and practice in England. *Journal of Educational and Psychological Consultation*, 29(4), 377 – 400.

Schulze, V. (2024). Developing and using an adapted mosaic approach to explore children's foreign language learning experiences in primary school. *Research Methods in Applied Linguistics*, *3*, 100155.

Schunk, D. & DiBenedetto, M. (2020). Social cognitive theory, self-efficacy, and students with disabilities. In Martin, A., Sperling, R. & Newton, K. (Eds.). *Handbook of educational psychology and students with special needs* (pp 243-261). Routledge.

Scotland, J. (2012). Exploring the philosophical underpinnings of research: relating ontology and epistemology to the methodology and methods of the scientific, interpretive and critical research paradigms. *English Language Teaching*, *5*(9), 9 – 16.

Scott, M., Foley, K-R., Bourke, J., Leonard, H. & Girdler, S. (2014). "I have a good life": the meaning of well-being from the perspective of young adults with Down Syndrome. *Disability and Rehabilitation*, *36*(15), 1290 – 1298.

Selisko, T., Eckert, C. & Perels, F. (2024). Models of disability as distinguishing factor: a theoretical framework of inclusive education and the application to a literature review. *Cogent Education*, *11*(1), 2379681.

Sharma, P. (2021). Barriers faced when eliciting the voice of children and young people with special educational needs and disabilities for their Education, Health and Care Plans and annual reviews. *British Journal of Special Education*, 48(4), 455 – 476.

Shaw, A. (2017). Inclusion: the role of special and mainstream schools. *British Journal of Special Education*, *44*(3), 292 – 312.

Sime, D. (2008). Ethical and methodological issues in engaging young people living in poverty with participatory research methods. *Children's Geographies*, *6*(1), 63 – 78.

Smillie, I. & Newton, M. (2020). Educational psychologists' practice: obtaining and representing young people's views. *Educational Psychology in Practice*, *36*(3), 328 – 344.

Strnadova, I. (2020). The importance of self-determination and inclusion for students with intellectual disability. In Martin, A., Sperling, R. & Newton, K. (Eds.). *Handbook of educational psychology and students with special needs* (pp 75-94). Routledge.

Sukhera, J. (2022). Narrative reviews: flexible, rigorous, and practical. *Journal of Graduate Medical Education*, *14*(4), 414 – 417.

Takataya, K., Kanzaki, Y., Mizuno, E. & Sakai, I. (2022). Thoughts of young adults with Down Syndrome. *Archives of Psychiatric Nursing, 41,* 195 – 200.

Takriti, R., Atkinson, S. & Elhoweris, H. (2019). Teachers' expectations of children with Down Syndrome starting school in the United Arab Emirates or United Kingdom. *European Journal of Special Needs Education*, *34*(4) 546 – 554.

Topping, K. & Lauchlan, F. (2013). Educational psychologists as researchers. *The Australian Educational and Developmental Psychologist*, *30*(1), 74 – 83.

Tuersley-Dixon, L. & Frederickson, N. (2016). Social inclusion of children with complex needs in mainstream: does visibility and severity of disability matter?. *International Journal of Developmental Disabilities*, *62*(2), 89 – 97.

Tysoe, K., Vincent, K. & Boulton, H. (2021). Implementing the 2014 SEND reforms in England: perspectives from SENCOs. *Support for Learning*, *36*(3), 486 – 505.

UK Public General Acts. (1967). *Abortion Act 1967* https://www.legislation.gov.uk/ukpga/1967/87/contents

UK Public General Acts. (2009). *Autism Act 2009*. https://www.legislation.gov.uk/ukpga/2009/15/contents

UK Public General Acts. (2024). *Down's Syndrome Act 2022*. https://www.legislation.gov.uk/ukpga/2022/18

Van Herwegen, J., Ashworth, M. & Palikara, O. (2018). Parental views on special educational needs provision: cross-syndrome comparisons in Williams Syndrome, Down Syndrome and Autism Spectrum Disorders. *Research in Developmental Disabilities*, 80, 102 – 111.

Van Herwegen, J., Ashworth, M. & Palikara, O. (2019). Views of professionals about the educational needs of children with developmental disorders. *Research in Developmental Disabilities*, *91*, 103422.

Walsh, N. & Hall, I. (2012). The Autism strategy: implications for people with autism and for service development. *Advances in Mental Health and Intellectual Disabilities,* 6(3), 113 – 120.

Warnes, E., Done, E. & Knowler, H. (2022). Mainstream teachers' concerns about inclusive education for children with special educational needs and disability in England under pre-pandemic conditions. *Journal of Research in Special Educational Needs*, 22(1), 31 – 43.

Webster, R. & Blatchford, P. (2019). Making sense of 'teaching' 'support' and 'differentiation': the educational experiences of pupils with Education Health and Care Plans and Statements in mainstream secondary schools. *European Journal of Special Needs Education*, *34*(1), 98 – 113.

Wehmeyer, M. & Shogren, K. (2020). Self-determination and autonomous motivation. In Martin, A., Sperling, R. & Newton, K. (Eds.). *Handbook of educational psychology and students with special needs* (pp 262-291). Routledge.

Williams-Brown, Z. & Hodkinson, A. (2021). 'What is considered good for everyone may not be good for children with Special Educational Needs and Disabilities': teacher's perspectives on inclusion in England. *Education 3-13, 49*(6), 688 – 702.

Yardley, L. (2011). Demonstrating validity in qualitative research. In J. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 234-251). Sage Publications Ltd.

## **Appendices**

## Appendix A: Recruitment flyer

## **Research Opportunity!**

I am investigating the experiences of inclusion for children and young people with Down's Syndrome in mainstream education.

#### Are you?

A parent/carer of a child or young person, aged 9-16, with Down's Syndrome currently attending a mainstream primary or secondary school?

#### What will the study involve?

The study will involve me observing your child in one of their lessons and at breaktime, as well as speaking to them about their experiences of school. I will also ask them to take me on a tour of their school, as well as take pictures of places that are important to them within school.

#### Who am I?

My name is Shaunna McLean and I am a traines educational psychologist at University of East Anglia, supervised by Dr Andrea Honess (a.honess@ues.ac.uk). If you have any questions about the study, you can contact me via email: <a href="mailto:snauni-schaus">snauni-schaus</a>

#### How to take part?

If your child or young person is interested in taking part, and you are happy for them to do so, please scan the QR code or click on the link below to register your interest. I will then be in touch to provide you with more details about the study.

https://forms.affice.com/e/gkCMeZ0kV1



This study was approved by the Education and Lifelong Learning Ethics Review Committee (ethics application number: ETH2324-1483) Appendix B: Participant information sheet and consent form

Easy read Project Title: Experiences of inclusion at mainstream school: the opinions of students who have Down's Syndrome.

Project Title: An exploration of children and young people's, with Down's Syndrome, experiences of inclusion within mainstream education settings.



Hello. My name is Shaunna. I am a researcher at the University of East Anglia. I am doing a study to find out more about what children and young people with Down's Syndrome think about inclusion in their schools.

I am asking you to be in my study because you have Down's Syndrome, and you attend a mainstream school.

You can decide if you want to take part in the study or not.

This sheet tells you what I will ask you to do if you decide to take part in this study.

Please read it carefully.

If you decide you want to be in the study and then you change your mind later, that's ok.

All you need to do is tell me that you don't want to be in the study anymore.

I will take away any information you may have already given me.

You or someone who looks after you can email me shaunna.mclean@uea.ac.uk

If you have any questions you can speak to me during the study or ask someone who looks after you to email me.

## What will happen if I say that I want to be in the study?

- I will look at the activities that you do in your lesson.
- I will look at how your teacher includes you in the lesson.
- I will look at the type of work you do in the lesson.
- I will stand at the back of your classroom. I will make notes.
- I will watch the sort of games you play at breaktime.
- I will see whether you play by yourself or with other people.
- I will stand in the playground. I will make notes.
- You will take me on a tour of your school.



- You will take photos of things and places that are important to you in school.
- I will give you a tablet to take the photos.



- I will ask you questions about school. You can choose which questions you want to answer.
- We will take about the photos you have taken.
- This will take place in school, in a quiet room.

If you don't want to talk about something, that's ok. You can stop talking to me at any time.

If you say it's ok, I will record what you say with an audio recorder.

## Will anyone else know what I say in the study?

I will not tell anyone else what you say to me.

I will only tell someone else if you talk about:

- Someone hurting you
- You hurting yourself
- You hurting someone else

I might need to tell someone else about that to keep you and other people safe.

All the information that I have about you from the study will be stored in a safe place. I will look after it very carefully.

I will write a report about the study and show it to other people. I won't put your name in the report.

No one will know that you're in the study.

I may also share your information with other researchers. I will use it for teaching and research purposes. If I share it, I will take out your name.

## How long will the study take?



- The study will take half a day.
- I will watch one of your lessons, for 45 minutes to one hour.
- The tour will last for 30 minutes.
- I will ask you questions for an hour.
- It will all take place at school.

## Are there any good things about being in the study?



You won't get anything for being in my study.

You will be able to share your views about school. You can talk about good and bad things.

This will help to make things better for you in school.

It will also help make things better for other children and young people with Down's Syndrome in their schools.

## Are there any bad things about being in the study?



This study will take up some of your time during the school day.

You may also talk about some of your experiences at school which have not been good for you.

If you get upset at any point, we can stop the study. We will find a trusted adult for you to talk to.

## Will you tell me what you learnt in the study at the end?

Yes, I will if you want me to.

There is a question on the next page that asks you if you want me to tell you what I learnt in the study.

If you circle Yes, when I finish the study, I will tell you what I learnt.

I will give your parent or guardian the information about what I found out in my study once it is all finished so that they can share it with you.

## What if I am not happy with the study or the people doing the study?

If you are not happy with how I am doing the study or how I treat you, then you or someone who looks after you can:

- Tell me during the study.
- Email me shaunna.mclean@uea.ac.uk
- Contact my supervisor: andrea.honess@uea.ac.uk
- Email my Head of School Prof Yann Lebeau y.lebeau@uea.ac.uk

You can also talk to your parent/carer or someone at school, if you are unhappy with the study.

## How do I know that this study is ok to take part in?

All research I undertake is checked and approved by an Ethics Committee at the University of East Anglia before I can start it (ethics application number: ETH2324-1483).

# What if I want to know more about the information collected on me in the study?

If you want to know more about the information collected about you, you or someone who looks after you can email me shaunna.mclean@uea.ac.uk or you can email the University's Data Protection Officer (dataprotection@uea.ac.uk) who helps to protect your information.

The Information Commissioner's Office (ICO) helps to protect everyone's information.

If you are unhappy with mine or the University Data Protection Officer's responses about your information, you can speak to the ICO.

## **Further information**

This sheet was last updated on  $2^{nd}$  September 2024. I will update you if I make any changes to this sheet. This information sheet is for you to keep.

## My contact details:

Shaunna McLean

Faculty of Social Sciences School of Education and Lifelong Learning University of East Anglia Norwich Research Park Norwich NR4 7TJ United Kingdom

Email: shaunna.mclean@uea.ac.uk

## Participant Consent Form (First Copy to Researcher)

If you are happy to be in the study, please:

- write your name in the space below.
- sign your **name** at the bottom of the next page.
- put the date at the bottom of the next page.

You should only say 'yes' to being in the study if you know what it is about, and you want to be in it. If you don't want to be in the study, don't sign the form.

In saying yes to being in the study, I am saying that:

- ✓ I know what the study is about.
- $\checkmark$  I know what I will be asked to do.
- $\checkmark$  Someone has talked to me about the study.
- √ My questions have been answered.
- ✓ I know that I don't have to be in the study if I don't want to.
- $\checkmark$  I know that I can pull out of the study at any time if I don't want to do it anymore and it will not be possible to take away any information I have already given me.
- ✓ I know that I don't have to answer any questions that I don't want to answer.
- $\checkmark$  I know that the researchers won't tell anyone what I say when I talk to them unless I talk about being hurt by someone or hurting myself or someone else.

# Now I am going to ask you circle 'Yes' or 'No' to tell me what you are happy to do or not do in the study.

Are you happy for me to come to your school and watch one of your lessons and breaktime? Yes No

Are you happy to show me around your school and take pictures? Yes No

Are you happy to meet with me and talk about school? Yes No

Are you happy for me to audio record your voice? Yes No

Do you want me to tell you	I what I learnt in the study? Yes No
•••••	•••••
Signature	Date

### Participant Consent Form (Second Copy to Participant)

If you are happy to be in the study, please:

- write your name in the space below.
- sign your **name** at the bottom of the next page.
- put the date at the bottom of the next page.

You should only say 'yes' to being in the study if you know what it is about, and you want to be in it. If you don't want to be in the study, don't sign the form.

In saying yes to being in the study, I am saying that:

- ✓ I know what the study is about.
- ✓ I know what I will be asked to do.
- $\checkmark$  Someone has talked to me about the study.
- √ My questions have been answered.
- ✓ I know that I don't have to be in the study if I don't want to.
- ✓ I know that I can pull out of the study at any time if I don't want to do it anymore and it will not be possible to take away any information I have already given me.
- ✓ I know that I don't have to answer any questions that I don't want to answer.
- $\checkmark$  I know that the researchers won't tell anyone what I say when I talk to them unless I talk about being hurt by someone or hurting myself or someone else.

# Now I am going to ask you circle 'Yes' or 'No' to tell me what you are happy to do or not do in the study.

Are you happy for me to come to your school and watch one of your lessons and breaktime? Yes No

Are you happy to show me around your school and take pictures? Yes No

Are you happy to meet with me and talk about school? Yes No

Are you happy for me to audio record your voice? Yes No

Do you want me to tell you what I learnt in the study? Yes No

	• • • • • • • • • • • • • • • • • • • •
•••••	•••••
Signature	Date

#### Appendix C: Parent/carer information sheet and consent form

Faculty of Social Sciences School of Education and Lifelong Learning University of East Anglia Norwich Research Park Norwich NR4 7TJ United Kingdom

Email: shaunna.mclean@uea.ac.uk

An exploration of children and young people's, with Down's Syndrome, experiences of inclusion within mainstream education settings.

#### (1) What is this study about?

This study is looking at gaining the views of children and young people with Down's Syndrome about their experiences of school, in particular their experiences of inclusion. Very little research has been conducted which gathers the views of children and young people with Down's Syndrome in relation to their education and inclusion within school. Research that has been conducted suggests that more could be done to make schools more inclusive for children and young people with Down's Syndrome.

Your child or young person has been asked to participate in this study as they are a pupil with Down's Syndrome, aged 9-16, at a mainstream school.

This Participant Information Sheet tells you about the research study, to help you decide if you want your child or young person to take part in the study. Participation in this research study is voluntary. By giving consent for your child or young person to take part in this study you are agreeing that you:

- √ Understand what you have read.
- √ Agree for your child or young person take part in the research study as outlined below.
- ✓ Agree to the use of your child or young person's personal information as described.
- √ You have received a copy of this Participant Information Sheet to keep

#### (2) Who is running the study?

The study is being carried out by the following researcher(s): Miss Shaunna Mclean, Trainee Educational Psychologist. This will take place under the supervision of Dr Andrea Honess, Educational Psychologist, (andress.honess@uea.ac.uk)

#### (3) What will the study involve?

There will be several different parts to the study. First of all, I will spend some time at school, observing your child during one lesson and one breaktime, so I can understand how they participate in their lessons and navigate unstructured social times. I will then ask your child or young person to take me on a tour of their school. Whilst we're on the tour, I will ask them to take pictures of places in the school that are important to them. The photographs will be taken on a tablet belonging to the researcher

and they will be used as part of the data analysis.

Finally, we will have a final discussion to talk about how school is going and what their experiences of inclusion are in their school. This will take place in school and will be audio recorded. Once the interview is completed, you and your child will have the opportunity to review a transcript of your child's interview, if you wish to do so.

#### (4) How much time will the study take?

Overall, the study will take approximately half a day. Your child or young person will only be observed in one lesson and one break time. The tour and picture taking part of the study will take approximately 30 minutes. The interview part of the study will take approximately an hour. It will all take place at school.

If you request to review your child's interview transcript after your interview, you will have a week to check that the transcript matches your child's experience and provide me with any comments or feedback about the transcript.

# (5) Does my child or young person have to be in the study? Can I withdraw them from the study once they have started?

Being in this study is completely voluntary and you do not have to consent to your child or young person taking part. Your decision whether they participate will not affect your current or future relationship with the researchers or your child or young person's school.

If you decide to allow your child or young person take part in the study, you can withdraw your consent at any point, before data analysis. You can do this contacting the researcher.

#### (6) What are the consequences if I withdraw my child or young person from the study?

There are no consequences for withdrawing from the study. You are free to stop your child or young person from participating at any time. Unless you say that you want me to keep them, any recordings will be erased and the information you have provided will not be included in the study results. If you decide later to withdraw from the study the information will be removed from my records and will not be included in any results, up to the point your child or young person's data is fully anonymised.

#### (7) Are there any risks or costs associated with being in the study?

Aside from giving up time, we do not expect that there will be any costs associated with taking part in this study. It may be that you child or young person's experiences of inclusion in school have not been entirely positive. If this is the case, and discussions around inclusion cause upset to your child or young person, then they will be offered to stop the research. A trusted adult within school will also be identified for them to talk to.

Anything that is discussed within the interview will be kept confidential unless your child or young person, or anyone else is at risk of harm.

#### (8) Are there any benefits associated with being in the study?

I hope that your child or young person will find participating in the study an enjoyable experience. Currently, very little research has been carried out that directly gathers the views of children and young people with Down's Syndrome. I hope this study will provide an opportunity for your child or young person to have their voice heard and also help demonstrate the importance of listening to individuals with Down's Syndrome.

By investigating experiences of inclusion at school, it is hoped that the results can be used to help schools become more inclusive places for children and young people with Down's Syndrome and those with other special educational needs.

#### (9) What will happen to information provided and data collected during the study?

All data collected from the research project will be completely anonymous and stored securely. Only the researcher will have access to the data.

Your child or young person's personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

The information your child or young person provides will be stored securely and their identity will be kept strictly confidential, except as required by law. Study findings may be published, but they will not be identified in these publications if you decide to allow them participate in this study.

Study data may also be deposited with a repository to allow it to be made available for scholarly and educational purposes. The data will be kept for at least 10 years beyond the last date the data were accessed. The deposited data will not include your child or young person's name or any identifiable information about them.

#### (10) What if I would like further information about the study?

When you have read this information, Miss Shaunna Mclean (<a href="mailto:shaunna.mclean@uea.ac.uk">shaunna.mclean@uea.ac.uk</a>) will be available to discuss it with you further and answer any questions you may have.

#### (11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. This feedback will be in the form of one page summary. This feedback will be provided in the 2025 Autumn term. You can indicate that you wish to receive feedback about the study on the consent form below.

#### (12) What if I have a complaint or any concerns about the study?

If there is a problem please let me know. You can contact me, or my supervisor, via the University of East Anglia at the following addresses:

Miss Shaunna Mclean School of Education and Lifelong Learning University of East Anglia Norwich NR4 7TJ shaunna.mclean@uea.ac.uk

Dr Andrea Honess School of Education and Lifelong Learning University of East Anglia Norwich NR4 7TJ a.honess@uea.ac.uk

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Head of School of Education and Lifelong Learning: Professor Yann Lebeau (y.lebeau@uea.ac.uk, 01603 592757).

#### (13) How do I know that this study has been approved to take place?

To protect your child or young person's safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) (ethics application number: ETH2324-1483).

#### (14) What is the general data protection information I need to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your child or young person's data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your child or young person's personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your child or young person's data protection rights at the Information Commissioner's Office (ICO).
- If you are unhappy with how your child or young person's personal data has been used, please contact the University's Data Protection Officer at <a href="mailto:dataprotection@uea.ac.uk">dataprotection@uea.ac.uk</a> in the first instance.

#### (15) OK, I want my child or young person to take part - what do I do next?

If your child or young person is interested in taking part, and you are happy for them to do so, please sign this consent form below, confirming you have read all the information. Please then return the form to me, alongside your child or young person's, via email. I will then be in touch to arrange a time for us to meet and get started with the research.

#### (16) Further information

This information was last updated 2<sup>nd</sup> September 2024.

If there are changes to the information provided, you will be notified by the researcher. This information sheet is for you to keep.

# Parent/Carer Consent Form (First Copy to Researcher)

I,
child/young person[PRINT NAME] to participate in this
research study.
In giving my consent I state that:
- I understand the purpose of the study, what my child/young person will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep for my records, and have been able to discuss my child/young person's involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study, and I am happy with the answers.
<ul> <li>- I understand that being in this study is completely voluntary and my child/young person does not have to take part. My decision whether they take part in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future. It will also not affect my relationship with my child or young person's school.</li> <li>- I understand that I may withdraw my consent at any time if I do not wish my child/young person to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results.</li> <li>- I understand that the results of this study will be used in the way described in the information sheet.</li> </ul>
- I understand that personal information about me and my child/young person that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
I consent to:
My child/young person being observed at school Yes No My child/young person taking part in a tour of their school and taking pictures Yes No My child/young person being interviewed Yes No Audio-recording of the interview Yes No Reviewing transcripts Yes No
Would you like to receive feedback about the overall results of this study? Yes No
If you answered YES, please indicate your preferred form of feedback and contact details:
Signature
PRINT name
Date

# Parent/Carer Consent Form (Second Copy to Parent/Carer)

I,[PRINT NAME], give consent for my
child/young person
In giving my consent I state that:
- I understand the purpose of the study, what my child/young person will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I may keep for my records, and have been able to discuss my child/young person's involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study, and I am happy with the answers.
- I understand that being in this study is completely voluntary and my child/young person does not have to take part. My decision whether they take part in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future. It will also not affect my relationship with my child or young person's school I understand that I may withdraw my consent at any time if I do not wish my child/young person to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results I understand that the results of this study will be used in the way described in the information sheet.
- I understand that personal information about me and my child/young person that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
I consent to:
My child/young person being observed at school Yes No My child/young person taking part in a tour of their school and taking pictures Yes No My child/young person being interviewed Yes No Audio-recording of the interview Yes No Reviewing transcripts Yes No
Would you like to receive feedback about the overall results of this study? Yes No
If you answered YES, please indicate your preferred form of feedback and contact details:
Signature
PRINT name
Date

#### Appendix D: School staff observation consent form

Faculty of Social Sciences
School of Education and
Lifelong Learning
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

Email: shaunna.mclean@uea.ac.uk

An exploration of children and young people's, with Down's Syndrome, experiences of inclusion within mainstream education settings.

#### (1) What is this study about?

This study is looking at gaining the views of children and young people with Down's Syndrome about their experiences of school, in particular their experiences of inclusion. Very little research has been conducted which gathers the views of children and young people with Down's Syndrome in relation to their education and inclusion within school. Research that has been conducted suggests that more could be done to make schools more inclusive for children and young people with Down's Syndrome.

You have been provided with this information sheet as you currently teach/work with a child or young person with Down's Syndrome.

This Participant Information Sheet tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about. Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

- √ Understand what you have read.
- $\checkmark$  Agree to take part in the research study as outlined below.
- $\checkmark$  Agree to the use of your personal information as described.
- $\checkmark$  You have received a copy of this Participant Information Sheet to keep

#### (2) Who is running the study?

The study is being carried out by the following researcher(s): Miss Shaunna Mclean, Trainee Educational Psychologist. This will take place under the supervision of Dr Andrea Honess, Educational Psychologist and Course Director (andress.honess@uea.ac.uk).

#### (3) What will the study involve?

The study will involve the researcher coming to observe one of your lessons, in order to see how the child who has expressed interest in participating in the study participates in your lesson.

No information will be recorded about you or any of the other pupils within your class as part of the observation.

#### (4) How much of my time will the study take?

The observation will last the length of one lesson. The researcher will stand at the back of the classroom making notes during the observation.

#### (5) Do I have to be in the study? Can I withdraw from the study once I have started?

Being in this study is completely voluntary and you do not have to consent to taking part. Your decision whether they participate will not affect your current or future relationship with the researchers or your school.

If you decide to take part in the study, you can withdraw your consent at any point, before data analysis. You can do this contacting the researcher.

#### (6) What are the consequences if I withdraw from the study?

There are no consequences for withdrawing from the study. You are free to ask the researcher to leave at any time. Unless you say that you want me to keep them, any notes will be destroyed and the information you have provided will not be included in the study results. If you decide later to withdraw from the study the information will be removed from my records and will not be included in any results, up to the point your data is fully anonymised. If you wish to withdraw from the study you can contact the researcher: shaunna.mclean@uea.ac.uk.

#### (7) Are there any risks or costs associated with being in the study?

Aside from giving from having the researcher in the lesson, we do not expect that there will be any risks or costs associated with taking part in this study.

It is acknowledged that within schools, there are often varying practices of inclusion, and differences of opinion as to what constitutes inclusion. Anything that is observed within the lesson will be kept confidential unless anyone is at risk of harm.

#### (8) Are there any benefits associated with being in the study?

By investigating experiences of inclusion at school, it is hoped that the results can be used to help schools become more inclusive places for children and young people with Down's Syndrome and those with other special educational needs.

#### (9) What will happen to information provided and data collected during the study?

All information collected during the research will be completely anonymous and stored securely. Only the researcher will have access to the data.

Your personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

The information you provide will be stored securely and your identity will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be identified in these publications if you decide to participate in this study.

Study data may also be deposited with a repository to allow it to be made available for scholarly and educational purposes. The data will be kept for at least 10 years beyond the last date the data were accessed. The deposited data will not include your name or any identifiable information about you.

#### (10) What if I would like further information about the study?

When you have read this information, Miss Shaunna Mclean (<a href="mailto:shaunna.mclean@uea.ac.uk">shaunna.mclean@uea.ac.uk</a>) will be available to discuss it with you further and answer any questions you may have.

#### (11) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. This feedback will be in the form of one page summary. This feedback will be provided in the 2025 Autumn term. If you wish to receive feedback, you can indicate so on your consent form.

#### (12) What if I have a complaint or any concerns about the study?

If there is a problem please let me know. You can contact me, or my supervisor, via the University of East Anglia at the following addresses:

Miss Shaunna Mclean School of Education and Lifelong Learning University of East Anglia Norwich NR4 7TJ shaunna.mclean@uea.ac.uk

Dr Andrea Honess School of Education and Lifelong Learning University of East Anglia Norwich NR4 7TJ a.honess@uea.ac.uk

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Head of School of Education and Lifelong Learning: Professor Yann Lebeau (y.lebeau@uea.ac.uk, 01603 592757).

#### (13) How do I know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee).

#### (14) What is the general data protection information I need to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a University.

In addition to the specific information provided above about why your personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your data protection rights at the Information Commissioner's Office (ICO).

• If you are unhappy with how your personal data has been used, please contact the University's Data Protection Officer at <a href="mailto:dataprotection@uea.ac.uk">dataprotection@uea.ac.uk</a> in the first instance.

#### (15) OK, I want to take part – what do I do next?

If you are happy to have your lesson observed, please sign this consent form below, confirming you have read all the information. Please then return the form to me via email.

#### (16) Further information

This information was last updated on 2<sup>nd</sup> September 2024.

,
my lesson observed as part of the research study.
n giving my consent I state that:
- I understand the purpose of the study, what I will be asked to do, and any risks/benefits nvolved.
I have read the Participant Information Sheet, which I may keep for my records, and have been able to discuss my involvement in the study with the researchers if I wished to do so.  The researchers have answered any questions that I had about the study, and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether they take part in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future. It will also not affect your relationship with your school.
- I understand that I may withdraw my consent at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results.
I understand that the results of this study will be used in the way described in the information sheet.
- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.
consent to:
A lesson being observed by the researcher Yes No
Would you like to receive feedback about the overall results of this study? Yes No
f you answered YES, please indicate your preferred form of feedback and contact details:
Signature
PRINT name

Date.....

# Participant Consent Form (Second Copy to Participant) my lesson observed as part of the research study. In giving my consent I state that: - I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved. - I have read the Participant Information Sheet, which I may keep for my records, and have been able to discuss my involvement in the study with the researchers if I wished to do so. - The researchers have answered any questions that I had about the study, and I am happy with the answers. - I understand that being in this study is completely voluntary and I do not have to take part. My decision whether they take part in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future. It will also not affect your relationship with your school. - I understand that I may withdraw my consent at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study results. - I understand that the results of this study will be used in the way described in the information sheet. - I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law. I consent to: A lesson being observed by the researcher Yes No Would you like to receive feedback about the overall results of this study? Yes No If you answered YES, please indicate your preferred form of feedback and contact details:

If there are changes to the information provided, you will be notified by the researcher. This

Signature .....

Date.....

information sheet is for you to keep.

PRINT name.....

#### Appendix E: Study debrief

Thank you for meeting with me and discussing your experiences of school. I hope you enjoyed participating in the research. The information you provided helped me to understand how you find school and whether anything could be improved. I will now look at the information you gave me, alongside the information other children and young people have given me, to see if there is any similarities and differences regarding how pupils with Down's Syndrome experience inclusion at school. Once I have completed this, I will get back in touch with your parent or carer to provide you with feedback on the results of the research.

If you feel upset about any of the things we have discussed today, please do tell your teacher or parent and they will be able to talk things through with you. If you feel that you need to talk to somebody else, please consider the organisations below. Please note that the research team are not responsible for the actions or support offered by these services.

www.youngminds.org.uk

https://www.barnardos.org.uk/

If you have any more questions do let you parent or carer know and they can help you to get back in touch with me.

It was a pleasure to meet you, and thank you again.

#### Appendix F: Ethical approval letter

Study title: An exploration of children and young people with Down's Syndrome experiences of inclusion in mainstream education.

Application ID: ETH2425-1130 (significant amendments)

Dear Shaunna,

Your application was considered on 4th December 2024 by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee).

The decision is: approved.

You are therefore able to start your project subject to any other necessary approvals being given.

This approval will expire on 30th April 2025.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the EDU S-REC (School of Education and Lifelong

Learning Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (<a href="mailto:dataprotection@uea.ac.uk">dataprotection@uea.ac.uk</a>).

I would like to wish you every success with your project.

On behalf of the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee)

#### Appendix G: Excerpts of interview data

### Appendix G1: Superbatman interview data

R: Yeah amazing. And how does having Down's Syndrome affect your experience of school?

S: I have like just difficulties, learning difficulties, and sometimes I have a little bit of a stutter. Not all the time, just a bit. And write the answer, I'm saying to them the answers to the question. They write it down and I copy off it. Because my memory is super bad.

R: That's really good that you've got that strategy in place then. You say the answers, they write it down and you copy.

S: Yeah

R: And that works well for you?

S: Yeah

R: Are there any other little strategies you do like that?

S: I sometimes, like for life skills, I sometimes get help, someone says the letter and I press it.

R: When you're typing?

S: Yeah

R: Okay, so they help you to spell out things and things like that?

S: Yeah

R: What about in PE or more active subjects, how does having Down's Syndrome affect you then?

S: So when I was a baby, I had a hip problem and I had an operation, on this leg because this one stopped growing completely.

R: Okay

S: So when I'm at school, I can't do certain things in PE, like make sure I don't hurt myself

R: yeah and do you take lots of breaks as well?

S: yeah

R: Yeah and what about walking around school? Do you find that easy or difficult sometimes?

S: Sometimes easy to walk, I have a wheelchair in school so when I'm in pain with my hips I have my wheelchair to sit on.

#### Appendix G2: Jojo interview data

R: So is there anything else you would like staff or students to know about Down's Syndrome? Or do you think they know everything?

J: I think they erm I think they know everything

R: They know everything and is there anything else that you think people could do in school to help you?

J: Not being rude

R: Yeah not being rude

J: And not swearing

R: Mhm

J: I did it once but accidentally \*unintelligible\*

R: okay. And what about anything else that the adults could do to help you?

J: Erm Mr XXX helps me with my Art, he always, he always do his funny dance around.

# Appendix H: Excerpts of observational data

# Appendix H1: Bluey breaktime observation

Brutijno
- B cure at for meals much laker an
La liniBring off weds.
B willing around phyground his herself.  Brying song wheel friends.  Cocassionally going over to group of dilbur.  I am sen helper class but men infeliency.
Diving Dong wheel mends.
- Occassionally aging our to pour of dilbren
how sen fulle cluss but new unfaline,
Hum rather than interacting.
Sea holle chos.

Appendix H2: Matilda classroom observation

- Allend'er) to header het fiddling at Dune bine.  - The prompting her to librer.  - The held heard authory up Bries.  - The astrony which are she thinks we pure, alletention to shaper.  Les leader astrony which does question at sure
- The held hand authory up Bris.
- The asing which are sa thinks we purs,
La Sendre aston what dus question at sur
Mine.
- Po come aget he to get hand up after letting threets wone with her - 4 other people on tible.  - A and of date B learning objective for an up tabent.
- 4 other pupils on libe.
- It as de at dute B learning objecture for
To 11 1/1/1

# Appendix I: Excerpts of reflective diaries

# Appendix I1: Ariana Grande reflective diary

Participant Information	What went well?	What would I do differently next time?	What did I learn from this visit?
Year 10 female pupil in an urban secondary school.	Ariana Grande engaged well with the whole research process. The observation of a science lesson provided me with a good opportunity to see how she was supported academically. Ariana Grande was enthusiastic to take pictures of the majority of her classrooms and places in school that she accesses.	Ariana Grande seemed to struggle with open-ended questions, often resulting to yes or no answers. As a response to this, my own questioning became very closed and the data gathered from Ariana Grande's interview may not have been as rich as I would have liked. Prior to my next interview, I will think of possible ways to reframe some of the more open-ended and abstract questions. This will ensure I'm able to adapt the questions to suit the communication needs of the participant but not resort to asking closed question as a result of having to think of alternative questions on the spot.	The opportunity to spend time with Ariana Grande prior to the interview was instrumental in providing me with an understanding of her experiences. This demonstrated the importance and value of how having some prior knowledge of participants' experiences can facilitate the interview process and generate more questions that I had not previously thought of.

Appendix I2: Pizzaboy reflective diary

Participant Information	What went well?	What would I do differently next time?	What did I learn from this visit?
Year 7 male pupil in an urban all-through school.	Pizzaboy enjoyed the photography part of the visit and was supported by his teaching assistant to identify places to take pictures of.  The difficulties with Pizzaboy's communication further highlighted the benefit of using multiple methodological tools and had this not been the case, I would have had to consider how his data could have been used within the study.	Pizzaboy's communication levels were extremely limited, more so than I was prepared for. I was able to make sure of the symbols he uses within school to support him in answering some of the questions. However, it would have been useful to have had more symbols more specifically relating to the questions I was asking. I would have also adjusted the questions to make them more suitable to be answered with symbols.	Despite discussing communication levels with Pizzaboy's mum prior to my visit, I was not aware that he. Perhaps in my meeting with his mum I could have been more explicit about whether he used any particular resources to support with communication. Equally, Pizzaboy's mum may have simply been used to his communication skills, and as such not seen the need to mention them to me in our meeting.
		It may have been beneficial to include an interview with school staff as part of Pizzaboy's mosaic. However, consideration would have had to been given as to whether all participants would then need a school staff interview as part of their Mosaic to make the process and the data consistent.	If I had been more prepared with a bigger range of symbols then I do feel that the data generated from Pizzaboy's interview would have been richer.

Appendix J: HCPC Standards of Proficiency and BPS Standards

Competency Area	HCPC Standards of Proficiency	BPS Standards
Promoting Education and Development	2.14, 2.7, 2.8, 5.5, 5.8, 12.1, 12.29, 12.30, 12.32, 12.35, 12.38	1c - Demonstrate knowledge and application of pedagogic practices and their conceptual and evidential bases, taking account of normal progression and development, and the modifications necessary to support effective learning and development for children, young people and young adults with special educational needs/additional learning needs and disabilities (SEND).
		1d - Demonstrate knowledge and understanding of biological, cultural, and social influences on learning, cognitive, social-emotional functioning, mental health and developmental processes, and application of evidence-informed curriculum and instructional strategies.  1f - Evidence an
		understanding of issues relating to mental capacity and consent.
Personal and Professional Values, Ethics and Skills	2.1, 2.2, 2.3, 2.4, 2.7, 2.9, 2.12, 2.13, 4.1, 4.4., 4.5, 5.2, 5.3, 5.5, 5.6, 6.0, 6.1, 6.2, 7.8, 7.12, 9.1, 9.2, 10.1, 10.3, 13.7, 13.24, 13.29, 13.34, 13.59	2a - Demonstrate professional and ethical practice which adheres to the British Psychological Society's Code of Ethics and Conduct and the HCPC Standards of Conduct, Ethics and Performance.
		2c - Work ethically and effectively at an appropriate level of autonomy, with awareness of the limits of competence, and accepting accountability to relevant

		professional, academic and service leaders/managers.
		2e - Challenge views and actions judged potentially harmful to the child or young person.
		2h - Demonstrate an appreciation of the importance of the wellbeing of those with whom they work.
		2i - Demonstrate the ability to identify and communicate personal values and reflect honestly on the implications for their professional practice.
Equity, Diversity and Inclusion	2.11, 2.13, 5.1, 5.2, 5.3, 5.4, 5.5, 5.6, 5.7, 5.8, 12.32	3a - Demonstrate appreciation of diversity in society and the experiences and contributions of all.
		3b - Demonstrate understanding and application of equality and diversity principles and actively promote inclusion and equity in their professional practice.
		3d - Take appropriate professional action to redress power imbalances and to embed principles of anti-discriminatory and anti-oppressive practice in all professional actions.
		3f - Be aware of attitudes to impairment, disability, and neurodiversity and where relevant, redress influences which risk diminishing opportunities for all vulnerable children and young people including those with SEND and their families.

Consultation	25 47 11 1 12 2	Ab domonstrate use of
Consultation	2.5, 4.7, 11.1, 13.2	4h - demonstrate use of evidence-informed personcentred approaches to ensure that children, young people and other consultees are appropriately included within the process and are able to contribute to plans and decisions that are made for them.
Service Delivery and Organisational Change	2.10, 2.14, 12.4, 12.29, 12.32, 12.6	7c - Identify and understand policies, structures and accountability systems in a range of educational and other settings (e.g. early years, school, further education, youth justice) to ensure effective service delivery for all children.  7j - Demonstrate knowledge and understanding of the history of educational psychology and how political, social and economic factors and influences have shaped and continue to shape the development of the profession of educational psychology.
Research and Enquiry	2.7, 4.7, 6.2, 7.16, 11.2, 11.3, 11.6, 12.2, 13.11, 13.15, 13.27, 13.29, 13.37, 13.54, 13.55, 13.6, 13.8, 13.9	9a - Promote the place of enquiry and empirical research as a method that can support and inform decision-making processes for key partners such as educational settings, local authorities and other relevant organisations.  9b - Demonstrate knowledge of paradigms and methods appropriate for research in the field of educational psychology;  9d - Develop a critical understanding of research design, including the rationale for the choice of

		alternative techniques, the
		formulation of 'researchable'
		questions and appropriate
		alternative approaches to
		research.
		9e - Plan and conduct
		rigorous research i.e. identify
		research questions,
		demonstrate an
		understanding of ethical
		issues, choose and
		implement appropriate
		methods and analysis, report
		outcomes and identify
		appropriate pathways for
		dissemination, including
		publication and contribution
		to the professional
		knowledge base.
		9f - Develop critical
		understanding of the
		philosophy of research,
		including alternative
		epistemological positions to
		provide a context for theory
		construction and refinement.
		9g - Develop a critical
		appreciation and
		understanding of advanced
		methods relevant to applied
		psychological research.
		9i - Disseminate research to
		a range of audiences,
		through presentation and
		writing research reports and
		contribute to the
		professional knowledge
		base.
Transferable Skills	2.6, 3.1, 3.2, 4.1, 4.8, 5.9,	10b - Demonstrate self-
	6.4, 7.1, 7.5, 7.6, 7.8, 7.15,	awareness and work as a
	10.1, 10.3, 14.1, 14.2, 14.5	reflective practitioner.
		10f - Demonstrate effective
		interpersonal
		communication skills across
		a range of settings and
		activities (including use of
		, <u> </u>

interpreters, taking account of their strengths and limitations).
10l - Working safely: understand and demonstrate awareness of safety needs of self and others; demonstrate awareness of workplace and other safety requirements and procedures; ensure the practice environment is safe for all.

# Appendix K: Theme Development

# **Initial Round of Theme Development**

Theme	Sub-theme(s)	Code(s)
Adjustments		Alternative spaces
		Alternative curriculum
		Equipment
		Resources
		Alternative activities
		External services
Participation – Actively	School Life	Participation in whole class
engaging in meaningful		activities
activities		Participation in school
		communities
		Participation in whole school
		activities
	Academic subjects	Mainstream GCSEs – creative
	, , , , , , , , , , , , , , , , , , ,	Mainstream GCSEs – life
		skills.
	Extracurricular	Creative activities
	_,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	Physical activities
		School trips
		Same opportunities as
		others.
Presence		Presence in mainstream
Treseries		lessons
		Accessing whole school
		areas at social times
		Designated SEND area at
		social times.
Positive feelings	Satisfaction and enjoyment	Satisfaction with lessons
rositive reetings	Satisfaction and enjoyment	Satisfaction with school
		Satisfaction with staff
		support Satisfaction with SEND area
	Achievement	
	Achievement	Participation in lessons
		Achievement in tests
		Achievement through
		answering questions
		Achievement through sharing
		work
		Appirations for fire
		Aspirations for future
		Positive outlook
A dult augus suit	A o o do mr.: -	Belonging
Adult support	Academic	Scaffolding work
		Practical
		Prompting to stay on task
		Prompting to answer
		questions
		Writing

	Social	Scaffolding conversations
		Social interactions
	Parent support	Parental advocacy
		Support with homework
Independence		Independence with
maspenaenes		academic tasks
		Independence at social
		times
Interactions	Staff	Teacher interactions
mendenene	ota	Relationships with support
		staff
	Peers	Talking to peers in class
	1 0010	Mainstream peers checking
		in and supporting
		Friendships
		On the edge of social groups
		Positive interactions with
	SEND	peers Interacting with other SEND
	JLIND	Interacting with other SEND pupils
		• •
		Preference for interacting
		with those with SEND
		Social interaction with others
		with Down's Syndrome
Down's Syndrome – whole		Whole school activities
school		Staff knowledge
		Staff training
		Lack of staff and pupil
		awareness
Down's Syndrome - self	Impact	No difference having Down's
		Syndrome
		Not treated differently
		because of Down's
		Syndrome
	Own understanding	Lack of awareness around
		school awareness of Down's
		Syndrome
		Own knowledge and
		understanding of Down's
		understanding of Down's Syndrome related needs
		understanding of Down's Syndrome related needs Own knowledge of Down's
		understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome
	Representation	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation
	Representation	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome
Difficulties	Representation  Down's Syndrome related	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation
Difficulties	·	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation Self-advocacy
Difficulties	·	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation Self-advocacy Sensory
Difficulties	·	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation Self-advocacy Sensory Physical
Difficulties	·	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation Self-advocacy Sensory Physical Social
Difficulties	·	understanding of Down's Syndrome related needs Own knowledge of Down's Syndrome Self-representation Self-advocacy Sensory Physical Social Visual

Not encouraging independence

# Second round of theme development

Theme	Sub-theme(s)	Code(s)
Adjustments	Space	Alternative spaces
		Designated SEND area at
		social times.
	Curriculum	Alternative curriculum
	Resources	Equipment
		Resources
Participation – Actively	School life	Participation in whole class
engaging in meaningful		activities
activities		Participation in school
		communities
		Participation in whole school
		activities
		Presence in mainstream
		lessons
		Accessing whole school
		areas at social time
	Academic subjects	Mainstream GCSEs – creative
		Mainstream GCSEs – life
		skills.
	Extracurricular	Creative activities
	Extraodiffodiai	Physical activities
		School trips
		Same opportunities as
		others.
Positive feelings	Satisfaction and enjoyment	Satisfaction with lessons
rositive leetings	Satisfaction and enjoyment	Satisfaction with essons
		Satisfaction with staff
		support Satisfaction with SEND area
	A a lai a va a a a a b	
	Achievement	Participation in lessons
		Achievement in tests
		Achievement through
		answering questions
		Achievement through sharing
	<del></del>	work
	Future aspirations	Aspirations for future
		Positive outlook
Adult support	Academic	Not encouraging
		independence
		Independence with
		academic work
		Scaffolding work
		Practical
		Prompting to stay on task
		Prompting to answer
		questions

	Social	Not encouraging
	Social	independence
		Independence at social
		times
		Scaffolding conversations
		Social interactions
	Parental	Parental advocacy
		Support with homework
Interactions	Staff	Teacher interactions
		Relationships with support
		staff
	Peers	Talking to peers in class
		Mainstream peers checking
		in and supporting
		Friendships
		On the edge of social groups
		Positive interactions with
		peers
		Belonging
	Others with SEND	Interacting with other SEND
		pupils
		Preference for interacting
		with those with SEND
		Social interaction with others
		with Down's Syndrome
Down's Syndrome related	Impact	Whole school activities
		Staff knowledge
		Staff training
		Lack of staff and pupil
		awareness
		No difference having Down's
		Syndrome
		Not treated differently
		because of Down's
		Syndrome
	Own understanding	Lack of awareness around
	Own understanding	school awareness around
		Syndrome
		•
		Own knowledge and
		understanding of Down's
		Syndrome related needs
		Own knowledge of Down's
		Syndrome
	Representation	Self-representation
		Self-advocacy

# Final round of theme development

Theme	Sub-theme(s)	Code(s)
Facilitating engagement	Accessing alternative spaces	Alternative spaces
through reasonable		Designated SEND area at
adjustments		social times.
	An appropriate alternative curriculum	Alternative curriculum
	Making use of additional	Equipment
	resources and equipment	Resources
Participation – Actively	Members of the school	Participation in whole class
engaging in meaningful	community	activities
activities		Participation in school
		communities
		Participation in whole school
		activities
		Presence in mainstream
		lessons
		Accessing whole school
		areas at social time
	Academic opportunities	Mainstream GCSEs - creative
		Mainstream GCSEs – life
		skills.
	Extracurricular involvement	Creative activities
		Physical activities
		School trips
		Same opportunities as
		others.
School as a source of	Satisfaction and enjoyment	Satisfaction with lessons
positivity and happiness	during school	Satisfaction with school
	C	Satisfaction with staff
		support
		Satisfaction with SEND area
	Experiencing a sense of	Participation in lessons
	achievement	Achievement in tests
		Achievement through
		answering questions
		Achievement through sharing
		work
	Aspirations and positive	Aspirations for future
	outlook for the future	Positive outlook
A fine line between	Academic support	Not encouraging
independence and adult		independence
support		Independence with
• •		academic work
		Scaffolding work
		Practical
		Prompting to stay on task
		Prompting to answer
		questions

	Casialawanant	Natarana
	Social support	Not encouraging
		independence
		Independence at social
		times
		Scaffolding conversations
		Scaffolding social
		interactions
	Parental support	Parental advocacy
	• •	Support with homework
Interacting with others	Interactions with staff	Teacher interactions
S		Relationships with support
		staff
	Interactions with peers	Talking to peers in class
	intordottono with poors	Mainstream peers checking
		in and supporting
		Friendships
		On the edge of social groups
		Positive interactions with
		peers
		Belonging
	Interactions with other pupils	Interacting with other SEND
	with SEND	pupils
		Preference for interacting
		with those with SEND
		Social interaction with others
		with Down's Syndrome
Knowledge and	Own awareness and	Lack of awareness around
understanding of Down's	understanding	school awareness of Down's
Syndrome	G	Syndrome
,		Own knowledge and
		understanding of Down's
		Syndrome related needs
		Own knowledge of Down's
		Syndrome No difference beging Down's
		No difference having Down's
		Syndrome
		Not treated differently
		because of Down's
		Syndrome
	Participants as a	Self-representation
	representation of Down's	Self-advocacy
	Syndrome	Whole school activities
		Staff knowledge
		Staff training
		Lack of staff and pupil
		awareness

# Appendix L: Code Development

Raw data excerpt	Initial code(s)	Final code(s)
'TA encouraging Superbatman to share work with others in class who were struggling'	Social interaction Staff support	Scaffolding social interactions
"I also like doing assemblies, talking about what I have and what I like to do" - Superbatman	Participation Community	Participation in whole school activities Self-advocacy
"And then after cricket I go to swimming on Thursdays" - Dogman	Physical activity Extracurricular	Physical activities
'Dogman able to identify a country in Africa from the story, when asked during whole class activity'	Participation Achievement	Participation in whole class activities Participation in lessons Achievement through answering questions
"I want to be a teacher" – Jojo	Aspirations	Aspirations for future
'Other pupils checking in on Jojo about TA'	Social interaction Down's Syndrome awareness	Self-representation Mainstream peers checking in and supporting
"Make the sheets bigger" – Ariana Grande	Adjustments	Resources
'Teacher checking in with Ariana Grande's understanding'	Staff support Scaffolding	Teacher interactions Scaffolding work
"I like Maths" – Matilda	Core subjects	Satisfaction with lessons
'Matilda was interacting with others but mostly dancing alone'	Social interaction	On the edge of social groups
"My favourite is [SEND class]" – Bluey	Satisfaction	Satisfaction with SEND area Alternative space
'Bluey asking for support once finished writing her sentence'	Staff support Independence	Self-advocacy Independence with academic work Interactions with teachers
'Pizzaboy in year 11 Maths classing completing counting to 20 worksheet'	Alternative space Alternative curriculum	Alternative space Alternative curriculum"