# Advocating and Conceptualising Sense of School Belonging for Children and Young People with Down's Syndrome: The Views and Perspectives of Parents

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## Summary

This thesis comprises of three sections: a literature review, an empirical chapter, and a critically reflective account. The literature review uses both a systematic and narrative approach to understand the literature base in relation to children and young people with Down's syndrome, as well as the theoretical models of sense of belonging and sense of school belonging. A review was also undertaken to explore what contributes to sense of belonging for children and young people with special educational needs.

The second section is an empirical chapter, which presents a qualitative study exploring how parents with children with Down's syndrome conceptualise and advocate sense of school belonging. In total, nine parents were interviewed using semi-structured interviews which were analysed using a reflexive thematic analysis (Braun & Clarke, 2022). The findings and discussion have been included, as well as implications for practice.

The final chapter comprises of a critically reflexive account which reflects on the key steps and decisions made throughout this project. This includes selecting the research topic, the research design, other interesting findings and how the project will be disseminated.

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## **Glossary of Terms**

| Acronym | Term                                     |
|---------|--|
| ASD     | Autism Spectrum Disorder                 |
| BERA    | British Educational Research Association |
| BPS     | British Psychological Society            |
| CoHRE   | Code of Human Research Ethics            |
| CYP     | Children and Young People                |
| DECP    | Division of Education and Child          |
|         | Psychology                               |
| DfE     | Department for Education                 |
| DS      | Down's Syndrome                          |
| EHCP    | Education, health and care plan          |
| EHCNA   | Education, health and care needs         |
|         | assessment                               |
| EP      | Educational Psychologist                 |
| GDPR    | General Data Protection Regulation       |
| HCPC    | Health and Care Professions Council      |
| MLD     | Moderate learning difficulties           |
| RQ      | Research question                        |
| RTA     | Reflexive thematic analysis              |
| SEAL    | Social and Emotional Aspects of Learning |
| SEMH    | Social, emotional, and mental health     |
| SOB     | Sense of belonging                       |
| SOSB    | Sense of school belonging                |
| TA      | Teaching Assistant                       |
| TEP     | Trainee Educational Psychologist         |
| VoC     | Voice of the child                       |
| YP      | Young Person                             |

## **Chapter One: Literature Review**

#### 1.1 Introduction

This literature review explores the sense of belonging of children and young people (CYP) with Down's Syndrome (DS). The review is structured into four sections. The first section explores disability as a concept through comparisons of social and medical models. These definitions are provided at the beginning of this review to give some context, as both medical and social models are used by researchers. The definition and prevalence of DS is outlined within this section. Literature related to schooling within a historical context is also explored. This highlights how many CYP with DS are living within the UK and attending a range of education settings.

In the second section, relevant legislation is outlined. This includes the Equality Act (2010), the Children and Families Act (2014), the Down Syndrome Act (2022) and the Abortion Act (1967). The relevance and application of the legislation to CYP with DS is examined.

The third section explores a range of theoretical models which define 'sense of belonging' (SOB). This includes: Maslow's Hierarchy of Needs (Maslow, 1943), Attachment Theory (Bowlby, 1969), and the Belongingness Hypothesis (Baumeister & Leary, 1995). SOB is also explored in a school context, through highlighting theories of 'school belonging' and 'sense of school belonging' (Goodenow & Grady, 1993). The key differences between 'inclusion' and 'SOB' are also considered. Inclusive school practices are a focus within UK legislation. It is important to highlight how promoting inclusive practices differ from promoting SOB within a school context.

The final section is a literature review which considers articles that explore the SOB of CYP with SEN within educational settings. From initial scoping searches and in-depth systematic searches, there is limited literature which explores the SOB of CYP with DS. Therefore, the search was widened to consider CYP with SEN. A narrative synthesis was conducted, where themes were created by the author to explore what the facilitators and barriers are to school belonging for CYP with SEN. Relevant DS literature was also discussed, which did not fit the criteria of the systematic literature review. The role of EPs in promoting school belonging for CYP with DS and SEN is also considered. By conducting this review, the author was able to explore any gaps within the literature and consider future research.

## 1.2 Disability

It has been suggested that 16% of the global population has a disability (WHO, 2023). In 2022, UNICEF produced a document highlighting key facts about children with disabilities. As of 2021, there were 240 million CYP living with a disability, with psychosocial difficulties being the most common (UNICEF, 2021). However, this figure has varied due to poor quality data and differing definitions of disability (Mont, 2007). It has also been difficult to apply this data to children due to variance in child development and cultural differences (Gottlieb et al., 2009). It is often believed that low to middle income countries have a higher prevalence of disability due to poverty, lacking healthcare services and poor nutrition (UNICEF, 2013). However, high income countries have better medical care and more positive attitudes to disability, which may contribute to higher rates of disability being identified (UNICEF, 2013).

There are circumstances where CYP with disabilities may be frequently moving, such as refugees, internally displaced children, migrants, and returnees (UNICEF, 2022). There is currently a lack of evidence exploring the drivers of migration for CYP with disabilities and their families, as well as the discrimination they may face (UNICEF, 2022).

Statistics and data in relation to disabilities varies across countries and nations. This is related to differing definitions and perceptions of disabilities. Some countries are more aligned in using narrow, medical definitions, which are based on impairments (Mont, 2019). Many questionnaires only allow for binary (yes/no) responses, rather than providing qualitative contextual information (Mont, 2019).

As of the 2022-2023 financial year, it was estimated that 16.1 million people in the UK had a disability (Department for Work and Pensions, 2023). It was further highlighted that 11% of children in the UK had a disability (Department for Work and Pensions, 2023).

Historically, disability has been defined in several ways. The Equality Act (2010) defines disability as having a "physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities". This definition holds a relatively low threshold. 'Long-term' is defined as a year or more and 'substantial' is defined as 'more than minor or trivial' (Equality Act, 2010). This definition covers individuals with long term health conditions (including diabetes, asthma, epilepsy, and cancer) and sensory impairments (including conditions which affect sight or hearing). CYP who have a disability do not necessarily have SEN. However, there is a large overlap between CYP with a disability and

individuals with SEN. If a child with a disability requires special educational provision, they are also covered by the SEN definition (Equality Act 2010).

The definition of disability has changed throughout history, due to perceptions of prejudice (Haegele & Hodge, 2016). Two prominent models of disability are often referred to within literature which are the medical model and the social model.

## 1.2.1 Medical Model of Disability

The medical model was developed when scientists and doctors replaced religious leaders as cognitive authority (Humpage, 2007). The medical model believes that it is the responsibility of medical professionals to define illnesses and cure them (Brittain, 2004). Under this model, disability is viewed as the impairment of bodily functions, including the mind, which is caused by a disease, health condition or injury (Forhan, 2009). Like ill-health, disability needs to be cured for individuals to successfully live an independent life and function alongside others in society (Haegele & Hodge, 2016). Treatment may include rehabilitation programmes, supported living environments, residential schools or segregated special educational classrooms (Palmer & Harley, 2012).

Negative attitudes which CYP with disabilities face stem from ableism. This is the underlying values a person holds which leads to discrimination and stigma, leading to the exclusion of CYP with disabilities (UNICEF, 2022). Due to ableist mindsets, CYP with disabilities are perceived as needing to be 'fixed' (UNICEF, 2022). For systemic behaviour and social change to occur, it requires advocacy, time, investment, and integrated communication (UNICEF, 2020). Charities such as UNICEF have argued that it is crucial that the attitudes, beliefs, contexts, and challenges faced by target populations are considered in order to appropriately respond to stigma and discrimination (UNICEF, 2020).

The medical model of disability has been critiqued for several reasons. This includes a heavy reliance on medical professionals diagnosing and labelling individuals which then in turn leads to the access of services (Humpage, 2007). Moreover, the medical model categorises individuals based on their bodily functions, without taking the person's view into account. This can lead people to believe that they have limited options and autonomy over their lives (Humpage, 2007).

## 1.2.2 Social Model of Disability

The social model contrasts with the medical model. The social model of disability has been referred to within literature for several years. However, it is not universally accepted due to debates surrounding the language used within the model (Barney, 2012). The social model suggests that society imposes disabilities on individuals with impairments (Bingham et al., 2013). Under this model, disability and impairment are separate concepts. An impairment refers to an individual's body, suggesting they have a malfunction or restriction with a limb (Goodley, 2001). Whereas a disability is where an individual with an impairment is disadvantaged due to society not making amendments for them to access the community (Goodley, 2001). It is crucial to distinguish between these terms, as the social model suggests that barriers are created by society rather than an individual's physical or bodily functions. According to this model, solutions should focus on implementing political and societal changes, rather than attempting to alter the individual (Bingham et al., 2013). However, by separating impairment from disability, the social model fails to fully account for the lived experiences of individuals with disabilities (Humpage, 2007).

## 1.2.3 Down's Syndrome

DS is a genetic condition caused by the presence or partial presence of an extra copy of chromosome 21. DS is the most common genetic intellectual disability. As of 2021, the prevalence of DS was 29.7 per 10,000 total births in England (NHS Digital, 2024). There are three types of DS: trisomy 21, translocation and mosaicism (Perkins, 2017). The most common type of DS is trisomy 21, which accounts for 95% of cases (Perkins, 2017). Genetic testing is needed to determine which type of DS an individual has. There are a range of characteristics and conditions associated with DS, including short stature, visual impairments, hearing problems, congenital heart defects, low muscle tone, increased risk of Alzheimer's and thyroid disease (Antonarakis et al., 2020; Perkins, 2017).

Although DS is caused by a random error in cell division, risk factors have been identified. One risk factor is increased maternal age at conception. This has been highlighted in studies across the world, including England, Australia, and Slovenia. However, with increased prenatal screening, there has been a slight decrease in the prevalence of DS births amongst older mothers (Collins et al., 2008; Morris & Alberman, 2009; Tul et al., 2007). Environmental factors, such as the use of folic acid supplementation, tobacco or the oral contraceptive pill have been shown to increase the prevalence of DS (Antonarakis et al.,

2020). However, these findings have their limitations due to difficulties in identifying the exact dosage and timing of each factor (Coppedè, 2016).

DS is typically associated with mild to moderate learning difficulties, however this varies between individuals. Individuals with DS can show delays in areas of development which are unequal (De Graaf et al., 2014). Processing of visual information, non-verbal social functioning and receptive language are relative areas of strength for individuals with DS (De Graaf et al., 2014; Laws et al., 2000). However, relative weaknesses include expressive language, memory, and gross motor skills (De Graaf et al., 2014; Laws et al., 2000).

Despite there being a common cognitive profile for CYP and adults with DS, studies have indicated that there can be variability. Onnivello et al., (2022) explored the cognitive profiles of CYP with DS, whilst considering verbal and non-verbal intelligence. Their findings highlighted three different groups within their sample. This included one group, who had the lowest scores (higher non-verbal intelligence vs verbal), another with intermediate scores (higher verbal intelligence vs non-verbal) and the highest scores (equal verbal intelligence vs non-verbal). These findings suggest that there can be variability in the cognitive profiles of CYP with DS, highlighting that educational support may need to be more tailored and specific (Onnivello et al., 2022).

Some studies have suggested that CYP with DS show relative skills in social functioning (Fidler et al., 2008). It could be suggested that some CYP 'overuse' their social skills to compensate for other functioning domains (Fidler et al., 2008). In terms of independence skills, a study highlighted that from their questionnaire, 60% of participants (322 CYP with DS, aged 16-19 years old) had mastered some the skills needed for independent functioning (Van Gameren-Oosterom et al., 2013). This included upkeeping adequate standards of hygiene and being able to prepare breakfast (Van Gameren-Oosterom et al., 2013). However, less than 10% of participants had achieved skills such as being able to pay in a shop or basic cooking skills (Van Gameren-Oosterom et al., 2013), thus highlighting a variability in independence skills.

## 1.2.4 Down's Syndrome and Schooling

It is estimated that there are approximately 7000 to 8000 school-aged children with DS in the UK (De Graaf et al., 2021). Within the last 30 to 40 years, there has been a significant increase in CYP with DS attending mainstream schools (Van Herwegen et al., 2018). The inclusion of CYP with SEN within mainstream settings has been a topic of significant debate

since the 1960's due to the influence of comprehensive schooling and the civil rights movement (Lambert & Fredrickson, 2015). There was a positive shift in this movement due to policy changes dating back to the 1980s, which encouraged the education of pupils with learning difficulties alongside their mainstream peers. This included the introduction of the Warnock Report (DES, 1978), which led to the Education Act in 1981 and 1993 (DES, 1981; DES, 1993). Prior to inclusion legislation being implemented, children with DS were seen as 'ineducable' and were either at home or attended respite centres run by health authorities (Buckley, 2000). With the introduction of the Warnock Report (DES, 1978), children with DS were beginning to be educated, however this was typically within specialist settings (Buckley, 2000).

By the early 1990's, the amount of CYP with DS being educated within mainstream settings had increased (Cuckle, 1999). Research has suggested that CYP with DS achieve higher learning outcomes if they are educated within mainstream settings (De Graaf et al., 2013). Early longitudinal studies suggested that in 1983, 4% of CYP with DS attended mainstream education settings (Cuckle, 1997). This figure increased to 38% by 1996 (Cuckle, 1997). A recent survey conducted in 2018 suggested that this figure is approximately 58% (Van Herwegen et al., 2018). With more recent legislation, such as the SEND Code of Practice (2014), parents now have increased choice over where their child with SEND is educated, including the right to request a SEN school. Research highlights that the majority of CYP with DS complete their primary education within mainstream settings, however approximately 20-25% of CYP transition to a mainstream secondary school (Lightfoot & Bond, 2013).

CYP with DS typically require support within education settings in order to access learning opportunities. This is often from internal school staff, such as Teaching Assistants (TAs), or from external agencies, such as Occupational Therapists, Speech and Language Therapists and other health agencies (Kendall, 2019). It has been suggested that around 82% of CYP with DS receive individual support from a TA (Van Herwegen et al., 2018). However, it was not clear what the extent of the support entails. Studies exploring the general role of the TA found that duties often included delivering educational interventions and providing behavioural support (Radford et al., 2015; Wren, 2017). Although support from TAs have been shown to be beneficial, there are associated risks. This includes lack of teaching from a qualified teacher and reduced social opportunities due to personalised learning experiences (Faragher et al., 2020).

## 1.3 Relevant Legislation

There is a range of policy, legislation and law which supports and protects CYP with DS. This includes Article 24 (Education) of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). As well as the Sustainable Development Goal (Education; SDG 4) of the United Nations 2030 Agenda for Sustainable Development (United Nations, 2015). These policies allow individuals with SEN (including CYP with DS) to have rights which are related to providing an accessible and inclusive education. Further legislation has been developed to support CYP with SEN (including CYP with DS), this includes the Equality Act (2010), the Children and Families Act (2014), the Down Syndrome Act (2022) and the Abortion Act (1967).

#### 1.3.1 The Equality Act (2010)

The Equality Act (2010) outlines nine protected characteristics which should not be discriminated against. This includes individuals who have a disability, those who think they have a disability and individuals who are connected to someone with a disability. According to the Act, a person has a disability if they have a physical or mental impairment which causes long-term effects on their ability to conduct day-to-day activities. The Act ensures that bodies and service providers make reasonable adjustments to ensure that individuals with a disability are not disadvantaged in comparison to those who are non-disabled.

Schools and colleges are also legally obliged to follow the Equality Act (2010). This means that they cannot discriminate against CYP based on their disability, regarding exclusions, admissions and how they provide services (Parkin et al., 2013). Reasonable adjustments must be made for pupils who have a disability, including children with DS.

Other guidance, such as 'Public Sector Equality Duty' provides advice for public authorities about how they must comply to certain equality considerations within their functions (Government Equalities Office, 2023).

## 1.3.2 Children and Families Act (2014)

In England, the law surrounding SEND does not relate to specific disabilities, instead it considers how learning and development is impacted by SEN (Parkin et al., 2013). The most relevant legislation related to SEN is the Children and Families Act (2014). Under the Act,

state-funded schools have a legal obligation to support CYP with SEN as best as they can within their setting.

Under this Act, the SEND Code of Practice (2014) has been created to provide guidance to schools about their legal duties. This relates to Section 3 of the Children and Families Act. The guidance is relevant to Local Authorities, governing bodies of schools (including SEN schools), further education settings, colleges, pupil referral units, early years providers and health trusts and boards.

The SEND Code of Practice (2014) has been revised since 2001. This is reflected from the changes which were introduced by the Children and Families Act (2014). The new Code of Practice now covers CYP who are 0-25 years old with disabilities and SEN. Previous guidance primarily focused on CYP who were within early years or compulsory school age, which covered ages 0-19 years old. There is now a strong focus on CYP and their families being involved in decisions related to their education. Guidance is provided on how services can plan and commission jointly to ensure co-operation between health, social care, and education. Under the Code of Practice (2014), guidance is provided for schools to follow a graduated response to identify need and support CYP with SEN. CYP with more complex needs can be referred for a co-ordinated assessment, known as an Education, Health and Care Plan (EHCP). There is now a stronger emphasis on supporting CYP with SEN to succeed in education and make a successful transition to adulthood.

As outlined in the SEND Code of Practice (2014; Section 8), anyone working with CYP with a disability or SEN must consider preparation for adulthood. This must begin when working with CYP who are 14 years old (Year 9) or older, but ideally these discussions should start earlier (DfE, 2014). The Preparing for Adulthood (PfA) framework sets out how professionals in education help CYP plan for adult life and achieve the best outcomes in four areas: Employment, Independent Living, Relationships and Community, and Health and Wellbeing (DfE, 2014). LAs must ensure that CYP with SEN (including DS) have the support they need, such as advocacy, to ensure that they are involved in any planning or decision-making processes about their future (Down's Syndrome Association, 2025).

#### 1.3.3 The Down Syndrome Act (2022)

The Down Syndrome Act (2022) received Royal Assent in April 2022 and was introduced as a Private Members Bill. The Act ensures that there are provisions in place to support

individuals with DS. The Act aims to improve access to services provided by health, social care, education, and local authority services, to support individuals with DS to exercise their relevant functions (Parkin et al., 2023). It has been reported that individuals with DS and their families often struggle to access services such as social care, speech and language therapy and support in schools (Parkin et al., 2023). This Act outlines what support is available for families and what they are entitled to receive. This guidance is statutory; therefore, Local Authorities and relevant services are legally required to adhere to it.

## **1.3.4 The Abortion Act (1967)**

The Abortion Act (1967) is a key piece of legislation to be aware of, especially when considering CYP with DS. The Act legalised abortion in the UK (excluding Northern Ireland) under specific conditions (Abortion Act, 1967). In 1990, the general gestation limit for an abortion was reduced from 28 weeks to 24 weeks. A woman is permitted to have an abortion if "there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped" (Abortion Act, 1967). This criterion relates to disabilities such as DS, meaning the law allows for the termination of pregnancy at any stage, if there is a risk that a child is to be born with DS. Prenatal screening for DS is common in a lot of countries (Choi et al., 2012). Data from 2013 highlighted that in the UK, out of 1886 cases were identified as having DS, 925 underwent an abortion (Morris & Springett, 2014). Despite positive movements for CYP with DS from other legislation, the Abortion Act (1967) is framed by the medical model. It suggests that DS is a disability that must be avoided, rather than considering on societal changes to support CYP with DS. It is argued that the Act overlooks the lived experiences of CYP with DS and the positive contributions they bring (Ijezie et al., 2023).

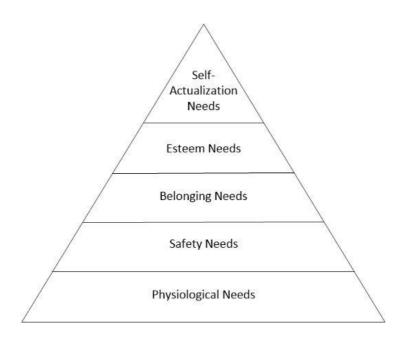
#### 1.4 Theoretical Theories of Belongingness

SOB can be defined as an innate want to feel accepted, included and supported in a social environment (Baumeister & Leary, 1995). There are a range of theories which suggest that SOB is a fundamental need (Baumeister & Leary 1995; Bowlby 1969; Maslow 1943). Although theories differ slightly, they all suggest that once 'belonging' is satisfied, positive social, emotional, and behavioural outcomes can be achieved (Prince & Hadwin, 2013). If 'belonging' is not achieved, it can lead to poor emotional and mental health, maladjustment, and negative feelings (Baumeister & Leary 1995; Bowlby 1969; Maslow 1943). Theories of belonging which are commonly cited in literature have been outlined below.

## 1.4.1 Maslow's Hierarchy of Needs

Maslow (1943) proposed that an individual needs to meet a hierarchy of needs before they can achieve 'self-actualisation'. According to Maslow (1943), an individual cannot progress through the hierarchy of needs without meeting a previous need. In total there are five needs a human strives to fulfil. This includes 'physiological needs', 'safety needs', 'love and belonging', 'self-esteem' and 'self-actualisation'. As highlighted within this hierarchy, belonging is considered as a basic human need. To meet an individual's 'belonging' needs, they must fulfil the prior levels of the hierarchy (Figure 1).

Figure 1
Maslow's Hierarchy of Needs



The first stage is physiological needs, which includes having access to food, water, shelter, clothing, and sleep. Once this has been met, an individual is then able to work towards fulfilling their 'safety and security needs'. This includes having access to employment, health, family, and social security. For children, this includes parental consistency, predictability, and fairness (Maslow, 1943). Once these two stages have been fulfilled, 'love and belonging' needs can become a focus. At this stage, individuals will strive for affectionate relationships with friends and family and will want to develop a sense of connectedness (Maslow, 1943).

## 1.4.2 Attachment Theory

Bowlby's (1969) evolutionary theory suggests that infants are born into the world with the biological predisposition to form attachments to survive. The maternal deprivation hypothesis suggests that if an infant experiences a disrupted attachment with their primary caregiver (typically their mother), this can lead to negative outcomes such as emotional, social, and cognitive difficulties (Bowlby, 1969). It is believed that children create an 'internal working model' based on their relationship with their primary caregiver. This is a framework which allows children to understand themselves and others whilst creating expectations of what social relationships may look like (Bowlby, 1969).

Recent studies have supported the notion that early attachments can be influential on later relationships. For example, McElwain et al., (2011) looked at the association between mothers' mental states during play and their child's friendship quality. Mothers were assessed whilst playing with their 24-month-old child whilst discussing their mental state. It was found that positive infant-mother attachments were positively correlated with infants' friendship interactions at 54 months old.

Positive attachments have also been shown to be associated with academic success and reduced externalising behaviours (García-Rodríguez et al., 2022). Bergin and Bergin (2009) found that secure attachments with both parents and teachers is associated with higher grades and standardised test scores compared to children who have insecure attachments. Moreover, secure attachments are also associated with higher social competence, emotional regulation, and willingness to take on challenges (Bergin & Bergin, 2009).

## 1.4.3 The Belongingness Hypothesis

There is only one theory which directly addresses SOB. The belongingness hypothesis suggests that individuals have an innate human drive to form strong and ongoing interpersonal relationships (Baumeister & Leary, 1995). Belongingness to another person or group has been associated with strong emotional and academic outcomes. The belongingness hypothesis highlights that two criteria need to be fulfilled to create strong relationships. This includes the need for frequent and pleasant interactions with other people (Baumeister & Leary, 1995). Secondly, these interactions must occur in a stable environment, where there is a reciprocal concern for each other's welfare. To belong, an individual must believe that the other person cares about their well-being and likes (or loves) them (Baumeister & Leary, 1995). This must

be mutual and reciprocated. The theory poses that ongoing, strong relationships with the same partners and groups are more satisfying than frequently changing partners. It is suggested that a lack of belonging can lead to negative outcomes.

This theory differs from ideas suggested by Bowlby (1969) or Freud (1964), where a main attachment figure typically is a mother or primary caregiver. The belongingness hypothesis suggests that a relationship does not need to be created with a particular individual and a loss of a relationship can be replaced with someone new to an extent. If a new relationship is created, this may take time with the gradual accumulation of intimacy and shared experiences (Sternberg, 1986).

The belongingness hypothesis differs from theories of social contact. Belongingness cannot be satisfied through interactions with strangers or with an unlikable individual (Baumeister & Leary, 1995). The need to belong suggests that positive, stable relationships are desired, however interactions with strangers may be the first steps in creating a long-term bond (Baumeister & Leary, 1995). This may be through practicing social skills or learning how to attract partners.

## 1.4.4 Sense of School Belonging

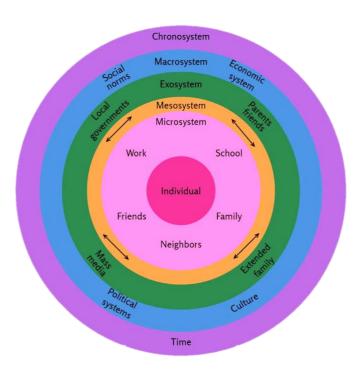
Many psychological theorists have defined SOB; however, many do not consider how definitions can be applied to an educational context. Early researchers acknowledged school environments. This includes Dewey (1938) who highlighted the importance of supportive classroom environments, Vygotsky (1962) who recognised a link between cognitive functioning and social environments, and Erikson (1968) who acknowledged social identification through educational settings.

More recent theorists have defined SOB within a school context. For example, Willms (2000) defined school belonging as an attachment to a school which includes feeling valued and accepted by peers within the school community. It is most consistently defined by Goodenow and Grady (1993) who suggest that school belonging is 'the extent to which students feel personally accepted, respected, included, and supported by others in the school environment'. This definition emphasises that school belonging has multiple features, and considers the socio-ecological contexts of peers, pupils, and teaching staff within the school environment, which is known as the microsystem (Figure 2; Bronfenbrenner, 2005; Slaten et

al., 2016). It also considers the schools culture and interactions with parents (mesosystem) and the links across these systems, which is known as the exosystem (Allen et al., 2018). Broader policies, cultural values and norms also feeds into school belonging (macrosystem), as well as the wider temporal aspects (chronosystem; Allen et al., 2018). School belonging contains three aspects. This includes, (1) an individual's relationships and experiences within school, (2) student-teacher relationships and (3) how an individual feels about school (Slaten et al., 2016).

Figure 2

Bronfenbrenner's Ecological Systems Theory



Further definitions include Allen and Kern (2017) who stated that SOSB includes feeling supported, cared for, and emotionally connected with others. Whereas authors such as Libbey (2004) suggest that SOSB is when someone has an enthusiasm and enjoyment towards school and is proud to be a part of it.

The idea of belonging is complex and multi-faceted (Cartmell & Bond, 2015). Literature reviews have been undertaken to understand the main elements which make up school belonging. It was found that although definitions of school belonging varied, consistent attributions did emerge (St-Amand et al., 2017). This included:

- Positive emotions, including intimacy, worthiness, and attachment
- Relationships with peers and teachers which are supportive and trusting
- A willingness to participate if an individual was experiencing a strong SOSB
- Harmonisation was often referred to within definitions, such as an individual aligning with situations and other people, if they feel they belong

School belonging has also been associated with a range of terms. This includes:

- School connectedness (Jose et al., 2012).
- School attachment (Hallinan, 2008).
- School bonding (Abbott et al., 1998).
- School identification (Wang & Eccles, 2012).

## 1.4.5 Inclusion vs Sense of Belonging

It is important to consider how SOB differs from other terminology such as inclusion or affiliation

Inclusion is defined as "a transformative process that ensures full participation and access to quality learning opportunities for all children, young people and adults, respecting and valuing diversity, and eliminating forms of discrimination in and through education" (UNESCO, 2019). Further definitions of inclusion include ensuring that all pupils are given appropriate support within their education setting to participate in all learning opportunities (Faragher et al., 2020).

Terms such as 'affiliation' differ from SOB. Although affiliation might mean than you are associated or connected to another being or group, it is not necessarily based on a reciprocal relationship (Slaten et al., 2016). A key element to belongingness is having an indepth social connection where there is a reciprocal concern for one another's wellbeing (Baumeister & Leary, 1995; Slaten et al., 2016).

#### 1.4.6 Sense of Belonging in a School Context

There is limited research which explores SOB within school settings, however this is an area which is slowly growing due to UK policy progressing towards a more child-centred and inclusive education system (HM Government, 2014; Ofsted & CQC, 2016). It is important

to consider what impact can be created if SOSB is prioritised for CYP with DS. Much research has highlighted positive developments in academic achievement, social development, behaviour, and emotional regulation when school SOB is met for CYP with SEN (Prince & Hadwin, 2013).

SOSB has been associated with relevant policies and outcomes. Within the Social and Emotional Aspects of Learning (SEAL), school belonginess was highlighted as a key outcome (Department for Children, Schools and Families, 2008). Frederickson et al., (2007) highlighted that school belonging should be considered as part of inclusion, where schools should focus on community and SOB. Moreover, due to school SOB being associated with positive outcomes which are in line with Ofsted (2019) recommendations (focusing on social relationships with peers, academic achievement, and self-esteem), it highlights that school belonging is an important area to explore.

## 1.5 Literature Review

#### 1.5.1 Aim of the Review

The aim of this literature review is to identify the gaps in the current literature base and gain a further understanding into the facilitators and barriers of SOB. There are currently limited findings exploring the SOSB of CYP with SEN, specifically CYP with DS. A range of studies have explored whether CYP with DS are accepted and included within education, but as of yet, the understanding of SOB for this group has not been considered within the literature base.

Earlier findings suggest that CYP with DS are no less popular than their mainstream peers (Laws et al., 1996). This differs from past studies which suggest that CYP with DS are isolated in mainstream settings (Sinson & Wetherick, 1981; Weiner et al., 1990). Moreover, studies have revealed that CYP with DS experience average levels of acceptance from their peers and there is no association between behaviour problems and peer acceptance (Laws et al., 1996). This association was evident for mainstream peers, suggesting that children may show some level of compassion for their peers with DS (Laws et al., 1996). Further findings have found that children with DS are at risk of becoming socially isolated. Research suggests that CYP with DS are less likely to be chosen to sit with at lunch, invited over to a friend's house or be nominated as someone's 'best friend' (Laws et al., 1996). Data has highlighted that students with DS have less contact with other pupils during lessons, activities such as

drawing or crafts, and during free play (Scheepstra et al., 1999). However, these findings must be considered with caution, given that there has since been advances in inclusion and SEN legislation.

Research suggests that CYP with DS face many barriers which affect their friendships and interactions with mainstream peers. This includes low task persistence (Ruskin et al., 1994), language difficulties (Guralnick et al., 2006), behavioural problems (Cuskelly & Dadds, 1992) and difficulties with understanding other people's behaviours, feelings, and intentions (Wishart, 2007).

Many studies explore the social position and popularity of students with DS, rather than exploring their school SOB. It has been suggested that measures of popularity do not necessarily reflect on a child's deeper connection to their school or the pupils in their class (Hall & McGregor, 2000). Therefore, this literature review aims to specifically explore SOB.

This literature review aims to explore what the facilitators and barriers to SOB for CYP with SEN are. It will seek to answer the following question:

What factors influence the SOB of CYP with SEN?

## 1.5.2 Search Strategy

For this review, empirical studies and literature were sourced through several search strategies. The author conducted an initial scoping search to become familiar with relevant literature, develop a search strategy and explore potential synonyms for search terms. For this project, the researcher has chosen to conduct a systematic literature review (SLR) as the primary research method. Prior to embarking on the literature review, the researcher was interested in exploring literature which was related to SOSB and CYP with DS. From preliminary scoping searches, the researcher struggled to find relevant literature. This indicated a potential gap within the current literature base.

Due to encountered difficulties, it was felt that a SLR seemed appropriate. A SLR is used to identify, collect, and critically analyse available research studies through systematic steps (Pati & Lorusso, 2018). By using this approach, it allows the researcher to be updated on the current research base related to a topic, as well as suggesting areas for further examination (Kitchenham et al., 2009). Prior to a SLR being undertaken, an early search of the literature can be helpful to determine whether the topic is too broad or whether it needs to

be narrowed (Carrera-Rivera et al., 2022). By using this approach, it allowed the researcher to systematically document and understand the existing research on SOB in SEN populations in a general sense, due to more extensive literature existing here. By using a broader exploration of SOB, it helped the researcher to understand the themes, trends, and findings, which may have implications for CYP with DS. Furthermore, by using a SLR, it allowed the researcher to highlight the absence of DS specific studies, which further reinforces the need for future research to address this gap.

Following the scoping search, a systematic search was conducted. Several databases were used to explore relevant papers (e.g., ERIC, EBSCO, PsycINFO and EThOS). Search engines were also used (e.g., Google Scholar) and relevant charity websites which hold a research database (e.g., Down's syndrome Education International). A range of databases were used due to this research project overlapping with broad topic areas, such as social science and educational psychology.

As well as using a SLR, the researcher also decided to incorporate a narrative review component within the literature search. There have been many examples of researchers using a hybrid approach, by using both aspects of narrative and SLR methodologies (Turnbull et al., 2023). By using this complementary approach, it allowed the researcher to include the limited DS specific literature, which is available, but may not fit in with the strict inclusion criteria used with SLR. By using both types of reviews, it ensured that the researcher had a comprehensive understanding of the broader context, whilst also considering the underrepresented perspective of CYP with DS and their families, in relation to SOSB.

## 1.5.2.1 Search Terms

Key words were developed through scoping searches of the literature. The literature search was conducted between July 2023 and March 2025. Table 1 highlights the main concepts which were explored within the literature search as well as any relevant synonyms. Quotation marks were used to explore exact phrases and asterisks were used to explore a word with multiple endings. For example, "learning difficult\*\*" would search for "difficulty" and "difficulties".

Citation chaining was also used within the review. This allowed the researcher to find relevant studies which were cited within other papers, which were missed within the systematic search.

**Table 1**Search Concepts and Synonyms

|               | Concept 1               | Concept 2          | Concept 3              |
|---------------|-------------------------|--------------------|------------------------|
| Key Concepts  | "Down's syndrome"       | "Sense of          | "School"               |
|               |                         | belonging"         |                        |
|               |                         |                    |                        |
| Synonyms /    | "Down syndrome"         | "Belonging"        | "Education"            |
| Relevant      |                         |                    |                        |
| Terms /       | "Trisomy 21"            | "Sense of school   | "Mainstream education" |
| Abbreviations |                         | belonging"         |                        |
|               |                         |                    |                        |
|               | "Special educational    | "School belonging" | "Mainstream setting"   |
|               | needs"                  |                    |                        |
|               | "Special educational    | "School            | "SEN school"           |
|               | needs and disabilities" | connectedness"     |                        |
|               | "SEN"                   | "School bonding"   | "Special educational   |
|               |                         |                    | needs school"          |
|               | "SEND"                  | "School            | "Special educational   |
|               |                         | attachment"        | needs setting"         |
|               | Moderate learning       |                    |                        |
|               | difficult**"            |                    |                        |
|               | "MLD"                   |                    |                        |
|               | Learning difficult**"   |                    |                        |

# 1.5.2.2 Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were developed (Table 2) to find relevant research articles and to reduce potential selection bias.

 Table 2

 Inclusion and Exclusion Criteria

| Study Item       | Inclusion Criteria                   | Exclusion Criteria            |
|------------------|--------------------------------------|-------------------------------|
| Type of research | Original/primary research papers     | Secondary papers such as      |
|                  | (including doctoral theses). Must    | presentations, review         |
|                  | have access to the full article      | articles, literature reviews, |
|                  |                                      | books, and conference         |
|                  |                                      | presentations                 |
| Date             | 1995 – 2025                          | Papers published prior to     |
|                  |                                      | 1995                          |
| Language         | Published in English                 | Papers not published in       |
|                  |                                      | English                       |
| Country          | Studies from any country             | N/A                           |
| Context          | Primary or secondary mainstream or   | Non-educational settings      |
|                  | special needs schools (or            |                               |
|                  | international equivalent)            |                               |
| Participants     | Can include CYP, parents, SENCos,    | N/A                           |
|                  | teachers and other relevant school   |                               |
|                  | staff                                |                               |
| Methodology      | Can use qualitative or quantitative  | N/A                           |
|                  | methods                              |                               |
| Area of interest | Investigation primarily focusing on  | Studies which are not         |
|                  | children with DS or SEN's experience | directly exploring SOB /      |
|                  | of SOB                               | SOSB. Studies which have      |
|                  |                                      | SOB / SOSB as a theme         |
|                  |                                      | within their findings (not    |
|                  |                                      | main research focus).         |

From the researchers scoping searches, there was limited research exploring DS and SOB. Therefore, within the literature search CYP with a range of SEN were included to gain a more in-depth insight into SOSB.

In this literature search, peer reviewed articles and grey literature, such as doctoral theses were included. From scoping searches, there were limited peer reviewed articles related to SOB and SEN, therefore widening the search to grey literature allowed for further relevant evidence.

Searches were set to include papers which were published between 1995-2025. This range was chosen to account for Baumeister and Leary's (1995) theories of SOB. Studies published prior to this were excluded.

This review initially aimed to explore literature which was relevant to an English educational context. Due to limited English papers being published, international studies were also included so a range of studies could be explored. Inclusive practices and policies are now widely used across many countries.

Literature exploring mainstream or SEN primary and secondary school (or international equivalent) pupils views were included in the search. This allowed the author to capture a range of experiences across age ranges. Participants could be CYP, parents or school staff.

The criteria were applied to the titles and abstracts. If the criteria was met within the abstract, the full paper was screened. Abstracts which did not meet the criteria were discarded (see Appendix A).

Computer programmes and software were used to explore and store the relevant literature. Zotero was used to store and annotate texts. Microsoft Excel was used to organise the literature which were included in the review.

To ensure that the literature review contained papers of a high quality, the researcher also considered Gough's (2007) 'weight of evidence' (WOE) model to assess each studies methodological quality (A), appropriateness (B), and relevance to the research question (C). Each element was evaluated as either 'high', 'medium' or 'low'.

In order to assess the methodological quality (A) of each study, various scoring criteria were used. Due to both quantitative and qualitative studies being included within the literature review, two different criteria were used. For quantitative studies, these were scored using guidance from the American Psychological Association (2006). For qualitative studies, guidance was drawn on from Spencer et al., (2003) and Henwood and Pidgeon (1992). See Appendix B for further details regarding scoring.

To rate the methodological appropriateness (B) of each study, the following criteria was considered (Bond et al., 2011; Gough, 2007):

- The study must have a clearly defined participant sample. In this case, this
  would include CYP with DS or other SEN, their parents, SENCos, teachers or
  other relevant school staff.
- II. A clear and robust study design, including a strong alignment between the aims of the research, data collection and data analysis.
- III. Relevant outcome measures or frameworks to be well described to ensure that SOB or SOSB is meaningfully explored.

As highlighted by Lovell (2021), if all three criteria were met this would score 2 points, two criteria would score 1 point and zero or one criteria were met would score 0 points.

To ensure that the studies were methodologically relevant (C), the following criteria was considered:

- I. Studies must explore SOB or SOSB for children with DS or other special educational needs, in primary, secondary, mainstream, or specialist school contexts (or international equivalents).
- II. Only studies where SOB/SOSB and/or barriers and facilitators to belonging formed a primary research focus.

As highlighted by Lovell (2021), if both criteria were met this would score 2 points, 1 criterion would score 1 point and zero criteria were met would score 0 points.

Each study was awarded either low (0 points), medium (1 point) or high (3 points) scores. Only studies which scored medium or high scores across all three categories were included within the literature review. Final scores can be found in Appendix B.

## 1.5.3 Study Selection

## 1.5.3.1 Study Characteristics

In total, 15 studies were included in the literature review (see Appendix C for an overview of included studies). The studies were conducted between 2011-2023, with 10 being published in scientific journals and five being doctoral theses. Eight studies were conducted in England, two were conducted in Ireland (Culliane, 2020; Rose & Shevlin, 2016) and the remaining were conducted in Italy (Nepi et al., 2013), Israel (Kopelman-Rubin et al., 2020), Wales (Hebron, 2018), Portugal (Freire et al., 2024) and New Zealand (Alesech & Nayar,

2020). Four studies employed a mixed-methods approach, five used quantitative and six used qualitative methods.

## 1.5.3.2 Participants

Sample sizes ranged from three participants up to 1440 participants. Some studies compared children with SEN with their mainstream peers. Therefore, the population of children with SEN recruited to participate was smaller. Dimitrellou and Hurry (2019) recruited the largest amount of children with SEN, with 282 children participating. The type of SEN explored in each study varied. This included children with specific learning difficulties, SEMH needs, MLD, ASD and persistent literacy difficulties. Children were specified by having SEN through parent or teacher identification, or having a statement of SEN. Some studies only recruited participants with a specific diagnosis, whereas others explored SEN more generally.

All studies directly worked with CYP with SEN, except for Lovell (2021) who explored the views of teachers and teaching assistants, Gallagher Deeks (2023) who worked with CYP and staff, and Alesech and Nayer (2020) who worked with CYP, staff and parents.

## 1.5.3.3 Type of Schools

All of the studies included in this review were either conducted in mainstream or SEN primary or secondary schools.

## 1.5.3.4 Measures

Studies employed a range of measures to explore SOB. This included the Psychological Sense of School Membership Scale (Goodenow, 1993) which was used in five studies (Culliane, 2020; Gallagher Deeks, 2023; Hebron, 2018; Kopelman-Rubin, 2020; Porter & Ingram, 2021). The Belonging Scale (Fredrickson et al., 2007) was used in two other studies (Finnegan, 2022; Nepi et al., 2013). The Comfort subscale from the Classroom Peer Context Questionnaire (Boor-Klip et al., 2016) was used in one study (Freire et al., 2024). Dimitrellou and Hurry (2019) developed their own scale to measure SOB. This was due to the authors wanting to measure two aspects of belonging: measuring students' social relations and student's belongingness to school as an institution (Dimitrellou & Hurry, 2019).

Studies which used qualitative methods measured SOB through semi-structured interviews, qualitative questionnaires and using approaches such as video voice. This was to obtain participants views and experiences of what belonging means, as well as exploring what supports and hinders students school belonging (Alesech & Nayer, 2020; Lovell, 2021; Miles et al., 2019; Rose & Shevlin, 2016; Smedley, 2011; Ware, 2020).

#### 1.5.4 Results

Studies were explored using a narrative synthesis (Lucas et al., 2007). A narrative synthesis is an approach where an author reviews relevant qualitative or quantitative literature (Lucas et al., 2007; Popay et al., 2006). Within this synthesis, the similarities and differences in measures and variables are explored to inform the authors conclusions (Lucas et al., 2007; Popay et al., 2006). Within this review, the author created seven themes to explore what the facilitators and barriers of SOB are for CYP with SEN. The seven themes were then broken down into sub-themes (see Appendix D).

#### <u>1.5.4.1 SEN</u>

Out of the 15 included studies, seven comparatively explored SOB between groups with and without SEN.

Culliane (2020) explored CYP's SOB through the Psychological Sense of School Membership Scale (Goodenow, 1993) and found that pupils with SEN had lower levels of belonging compared to their mainstream peers. This was a significant difference and was shown to have a medium to large effect size (Culliane, 2020). This finding was further supported through qualitative methods, where both the SEN group and non-SEN group shared similar positive school experiences, however the SEN group reported distinct negative experiences which impacted their school belonging (Culliane, 2020).

Similar findings were found by Finnegan (2022). It was found that children with SEN experienced lower levels of school belonging compared to their non-SEN peers. A significant difference was found between belonging scores when using a Mann-Whitney U test.

Other studies found differences in levels of belonging depending on the type of SEN. Nepi et al., (2013) categorised students with SEN into three groups. SEN-a (students with a statement of disability), SEN-b (students with suspected learning difficulties) and SEN-c

(students who were judged to have a socio-cultural/economic disadvantage). Overall, non-SEN students were shown to be more accepted and less rejected in comparison to SEN peers (Nepi et al., 2013). When looking at the categories of SEN, the SEN-a group had the lowest levels of belonging in comparison to the SEN-b and SEN-c groups (Nepi et al., 2013).

Dimitrellou and Hurry (2019) also found differences in levels of belonging between SEN groups. Like previous research, it was found that pupils with SEN scored significantly lower on belonging scales in comparison to pupils without SEN. Pupils with SEN should not be considered a homogenous group, as pupils with behavioural difficulties were found to have a lower SOB compared to pupils with learning difficulties (Dimitrellou & Hurry, 2019).

Hebron (2018) used a longitudinal design to measure school connectedness across four time points, from the end of primary school into the beginning of secondary school. Participants included pupils with ASC and pupils with no additional needs (Hebron, 2018). It was found that students with ASC reported positive levels of school connectedness, however their scores were lower than typically developing peers (Hebron, 2018). Similar findings were found by Gallagher Deeks (2023) who looked at CYP with SEN who attended mainstream settings and Special Resource Bases (SRBs). It was found that students who attended the SRBs reported good levels of school belonging which was above the threshold of concern (Gallagher Deeks, 2023). Freire et al., (2024) found that levels of belonging between SEN and non-SEN pupils did not differ. These studies highlight that although pupils with SEN may score lower on questionnaires of SOB in comparison to typically developing peers, they may still be experiencing good levels of belonging.

The discussed literature highlights that although CYP with SEN typically show lower levels of SOB in school settings, this can vary depending on the type of SEN. Therefore, all of the studies considered in this review should be interpreted with caution, due to exploring the SOB of CYP with SEN but not DS specifically. There is a possibility that CYP with DS may show differing levels of school belonging.

Although it is insightful to explore how SOB differs between SEN and non-SEN populations, it could be endorsing an essentialist view of SEN. Grouping students into SEN and non-SEN groups is typical practice within schools, as it is a way for provision and resources to be allocated appropriately (Algraigray & Boyle, 2017). By grouping children, there is a possibility that a medical model of disability is being promoted. It may suggest that a group of children have deficits, rather than considering environmental factors which may cause difficulties.

## 1.5.4.2 Staff

## 1.5.4.2.1 Relationships with Teachers and TA's

From reviewing the literature, both quantitative and qualitative studies have highlighted the importance of staff relationships on student's SOB. Dimitrellou and Hurry (2019) found that the SOB of pupils with SEN was positively correlated with all measures of social relations. This included their social relations with their teachers, which was found to have a medium effect size and explained nearly 23% of variance in scores (Dimitrellou & Hurry, 2019). There was also a positive correlation between perceived SOB and relationships with TA's, which was a medium correlation explaining 13% of the variance in scores (Dimitrellou & Hurry, 2019). These results highlight that relationships with teachers have the strongest correlation with perceived SOB. Similar findings were found by Finnegan (2022), highlighting a moderate positive relationship between teacher warmth and TA warmth. Although results from both studies were significant, several factors were not addressed which could influence the results. This includes not controlling for how long a child knew their teacher or TA for.

Qualitative findings have supported that relationships with staff influence student's SOB. Culliane (2020) found that both SEN and non-SEN pupils described examples of when they felt connected to their schools was when they had positive and caring relationships with their teachers. This allowed students to feel supported, affirmed and valued. Students reported that they felt greater school belonging when their teachers were sensitive about their needs, nurtured them and believed in them, even when students were not high achievers (Culliane, 2020). Due to Culliane's (2020) study being conducted within one primary school, there are risks that results cannot be generalisable. However, similar findings were found when exploring teachers and TA's opinions on SOB and students with SEN (Lovell, 2021). Findings highlighted that participants felt that to build school belonging, a child needs to feel valued and wanted. Participants felt that this is built through staff showing empathy, celebrating a child's strengths, and listening to their views (Lovell, 2021). Some participants highlighted the importance of staff offering unconditional support (Lovell, 2021). Similar findings have been found by Porter and Ingram (2021), who briefly mentioned that female students with ASC found that teachers giving them praise, asking about their day, or showing an interest in their life helped to build their SOB.

In one study, it highlighted that some pupils with SEN valued their relationships with staff higher than their peers (Ware, 2020). Relationships with staff were highlighted as being

of "central importance" to their school experience (Ware, 2020). Suggesting how positive staff relationships can be crucial for some pupils SOB.

Like Lovell's (2021) study, Gallagher Deeks (2023) considered the perspectives of staff who work in SRBs. Staff shared that teacher-student relationships were important for promoting SOB; however, complexities were raised such as balancing a professional relationship with students, whilst sharing elements of their personal identity (Gallagher Deeks, 2023).

Studies have also suggested that relationships with staff can negatively influence student's SOB. Culliane (2020) found that students reported lower SOB when they had conflictual relationships with staff, where students felt that teachers had low academic expectations of them and felt staff overly disciplined them. Similar findings have been found when interviewing school staff. Lovell (2021) found that teachers and TA's felt that perceptions of some teaching staff could act as a barrier to school belonging, especially if a child is made to feel disliked or unwanted.

#### 1.5.4.2.2 Communication

Some studies highlighted the importance of staff communication and building pupil's SOB. Smedley (2011) interviewed three pupils with persistent literacy difficulties about what factors contribute and hinder school belonging. All three participants expressed a desire to talk or relate to their teaching staff (Smedley, 2011). Pupil's highlighted that they liked certain adults in their school because they talked to them, which suggested the member of staff accepted them and positively affirmed the pupil (Smedley, 2011). Participants felt that having good communication with staff was beneficial for emotional and learning support (Smedley, 2011).

Positive communication acting as a facilitator to school belonging has been highlighted in other studies. For example, Finnegan (2022) found that one participant expressed that she would like it if her class teacher spoke to her more as she enjoyed informal conversations. It was further shared that a participant felt it would be beneficial for teachers to have conversations with SEN pupils regarding the difficulty of their work (Finnegan, 2022). For this participant, it was important for them to have depth to their relationship with their classroom adults to feel supported and understood (Finnegan, 2022).

Further support is highlighted in Culliane's (2020) study. Their findings suggested that pupils felt that their belonging was enhanced when they perceived that teaching staff took an interest in them as individuals, not just as learners (Culliane, 2020). This was successful when teachers have the confidence to engage with pupils as individuals, and help to support their social, emotional, and academic skills (Culliane, 2020).

Some studies have suggested that school staff's communication can negatively impact students' SOB. For example, Smedley (2011) found that one participant shared that they felt that they did not belong when they were "in trouble" and being "told off", highlighting the importance of student-teacher relationships. Moreover, another participant shared that their relationship with their teacher was characterised by negative discourse and punitive interactions (Smedley, 2011). This led the participant to believe that their teacher did not like them and shared that they did not like their teachers "shouting" communication style (Smedley, 2011). All participants shared that it was important for them to be heard, and this is met through having an empathetic and listening teacher (Smedley, 2011).

#### 1.5.4.2.3 Attitudes

One study considered the attitudes and knowledge of teaching staff and how this impacted CYP's SOB. Alesech and Nayer (2020) interviewed CYP with SEN, parents, teachers and other professionals about acceptance and school belonging. It was highlighted that it was important that teachers have knowledge of how to teach children with learning, social and behaviour needs, as well as understanding the child's specific disability (Alesch & Nayer, 2020). One mother noted that due to the teacher not adapting or differentiating the work, her daughter did not want to come into school (Alesch & Nayer, 2020). The following school year, her daughter had a teacher who adapted the work, leading her daughter to "adore" school (Alesch & Nayer, 2020). Although it must be noted that this was one parents perspective, it highlights how lack of differentiation can potentially significantly impact a child's SOB.

## 1.5.4.3 Peers

## 1.5.4.3.1 Peer Support and Friendships

The importance of peer support and friendships being related to SOB for CYP with SEN was highlighted in both qualitative and quantitative studies. Dimitrellou and Hurry's (2019) study found a positive correlation between perceived peer relations and SOSB,

accounting for 7% of variance. Although a positive correlation was found, it must be acknowledged that the correlation was small and other factors such as staff relationships were shown to be stronger (Dimitrellou & Hurry, 2019).

Qualitative studies support the link between school SOB and friendships for CYP with SEN. Culliane (2020) found that friendship and peer support were central to participants SOB and connectedness to their school. Participants highlighted that being included and accepted by their peers helped them successfully transition to secondary school (Culliane, 2020). Group activities such as PE, practical subjects and projects were highlighted as a factor that increases SOSB (Culliane, 2020). As a result of these findings, the author suggested that schools could enhance SOSB for SEN pupils through school trips and group activities to help build connection, cohesiveness, and acceptance amongst students (Culliane, 2020). Similar findings were found by Lovell (2021). When interviewing teachers and TA's, it was felt that receiving acceptance from peers and having supportive friendships could impact a child's SOSB (Lovell, 2021).

Results from Smedley's (2011) study highlighted that peer-peer relationships emerged as a powerful theme for all participants they interviewed. All three participants felt that peer group relationships were important, and it was felt that it correlated with their SOB and feelings of sadness (Smedley, 2011). One participant recalled their feelings of not belonging in school were resolved when they began to build friendships in their class (Smedley, 2011). A clear connection was made by participants that building relationships was related to their happiness and wellbeing (Smedley, 2020).

Participants within Miles et al, (2019) study highlighted that reciprocal friendships were largely related to their overall happiness in school. It was felt that having 'true friends' allowed participants to feel comfortable and understood, which is an important prerequisite for belonging (Miles et al, 2019). Some participants expressed the value of having one key friend as opposed to a group of friends (Miles et al., 2019). Friendships were seen as a social security, which enabled participants to feel confident in large secondary school settings (Miles et al., 2019).

Gallagher Deeks (2023) interviewed staff who worked in SRBs, and they felt that meaningful friendships supported CYPs SOB. It was noted that staff should be aware that the YP were creating meaningful friendships rather than adhering to neurotypical social norms (Gallagher Deeks, 2023). One staff member noted that some of the YP within the SRB were "really social" and "really empathetic", however other children would sit by themselves

consistently at lunch time (Gallagher Deeks, 2023). The member of staff reflected on the idea that the child might want to be by themselves and the neurotypical idea of fostering friendships may be forced upon them (Gallagher Deeks, 2023). This study highlighted the importance of staff supporting CYP to develop meaningful friendships at school, in order to help promote their SOB. It is crucial for staff to acknowledge a pupil's individual needs and how they might want to form friendships in a different way.

Due to many of the studies within this review mainly focusing on mainstream settings, it could be argued that there could be differences in how CYP with SEN view friendships, dependent on the setting they attend. Ware (2020) interviewed pupils with SEN who attended a range of settings (including mainstream and specialist provision). There was a significant difference between how the YP navigated their peer relationships. The pupils who attended mainstream settings described their friendships to be very important to them and their belonging at school (Ware, 2020). Whereas a pupil who attended specialist provisions spoke about friendships, but placed less importance on them (Ware, 2020). Two pupils who attended a specialist provision and a mainstream faith school rarely spoke affectionately about friends, and viewed them as more transactional. Instead, adults formed the majority of affectionate interactions (Ware, 2020). This highlights that there can be variability in how CYP with SEN view friendships and their importance in relation to SOB. There is a possibility that this could be related to the type of setting they attend, however due to a small sample size it is difficult to confidently come to this conclusion.

### 1.5.4.3.2 Exclusion and Bullying

Many studies highlighted that social interaction problems and friendship difficulties can be a barrier of SOB for CYP with SEN (Culliane, 2020). It is suggested that CYP with SEN and SEMH needs may feel isolated and rejected by their peers which can negatively impact their self-esteem and SOB (Lovell, 2021).

Participants within Smedley's (2011) study highlighted the link between belongingness and poor relationships with other children in the classroom. It was suggested that there was a risk of participants being in a 'feedback loop', which is where CYP may experience social rejection and as a result they socially withdraw and no longer want to seek social relationships (Smedley, 2011).

Similar findings were found by Miles et al., (2019). Participants felt that they were not personally involved in any social groups, and this negatively impacted their SOB (Miles et al.,

2019). Managing group situations was highlighted by participants as a challenging aspect of school, where they often felt on the 'outside' and not being valued or acknowledged (Miles et al., 2019). Porter and Ingram (2021) found that participants reported feeling "threatened by older pupils" and feeling that they cannot be "open and themselves". Many participants referred to having to hide their identity about being different (Porter & Ingram, 2021). It must be considered that Miles et al., (2019) and Porter and Ingram (2021) specifically interviewed girls with an ASD diagnosis, therefore social interaction difficulties can be typical within an ASD profile. There is a risk that these results may not be generalisable to other SEN populations.

### 1.5.4.3.3 Peer Communication

Several studies referred to peer communication being an important factor related to SOB. Participants within Smedley's (2011) study highlighted that friends can offer emotional support and having someone to talk to was important. Participants recalled times where they felt that they did not belong due to lack of communication and feeling ignored by peers (Smedley, 2011). Two participants highlighted the importance of peer communication, with one highlighting that it is important for friends to explicitly tell each other that they are liked, and another participant felt that communication signified that they were liked by their peers (Smedley, 2011).

Miles et al., (2019) referred to peer communication within their study. Participants highlighted occasions where they felt they could not join in with their peers' conversations, due to not being able to relate to their peers as they had differing interests (Miles et al., 2019). Other participants referenced situations where they did not feel listened to or felt that their contribution to conversations were not valued (Miles et al., 2019). Some participants felt that they were often underestimated and treated as a younger child due to their SEN diagnosis (Miles et al., 2019).

### 1.5.4.4 School Environment

## 1.5.4.4.1 Academic Support

Some studies explored the impact of academic support. Participants in Culliane's (2020) study highlighted that when they experienced academic progress and support, it positively enhanced their SOSB. It was recalled that academic support could be shown in numerous ways, such as working in their lunch break, the teacher providing extra assistance,

and staying after school to do work (Culliane, 2020). Some participants shared that they felt that their teacher's academic support transformed their views on learning, leading them to achieve better grades and develop a love for certain subjects (Culliane, 2020). Similar findings were found in Finnegan's (2022) study. Participants reported that receiving academic support from a TA was a positive experience, explaining that they felt "happy" and "good" as a result (Finngean, 2022).

Rose and Shevlin (2017) found similar findings when interviewing CYP with SEN. Many participants felt that access to additional adult support, such as a TA, was essential for their learning and participation in the classroom (Rose & Shevlin, 2017).

It has been suggested that academic difficulties can negatively impact student's connectedness to their school (Culliane, 2020). Some participants shared that they struggled with some subjects which led them to question whether school was sustainable for them (Culliane, 2020). Lack of academic progress led participants to feel disheartened and upset (Culliane, 2020). In other studies, participants have expressed that they feel academic support can be overwhelming (Finnegan, 2022). One participant described their TA as "filling my brain up so quickly", which can be confusing and stressful (Finnegan, 2022). These findings suggest that although academic support can be important in building school belonging, it is crucial that school staff are tailoring support to ensure that it is appropriately pitched. Without this consideration, there is a risk that academic support can have the opposite effect, leading children to become overwhelmed.

## 1.5.4.4.2 Exclusion from the Classroom

It was highlighted in several studies that CYP with SEN often spend time away from the classroom for differentiated learning opportunities. Participants within Culliane's (2020) study highlighted that being separated from the rest of the class limited their opportunities to socialise and led to bullying. One participant expressed that they were initially excited to join a new school, but they were then disappointed when they found out they were placed in a 'special class', where they felt that peers made fun of them (Culliane, 2020).

Similar findings were found by Alesech and Nayer (2020), where one YP reported that his sense of acceptance and belonging at school increased when he was included in classroom activities alongside his peers.

Lovell (2021) interviewed teachers and TA's. Participants expressed that being excluded from the main classroom could damage CYP's belonging due to feeling isolated from the class (Lovell, 2021). From reflections, teachers and TAs expressed that teaching children outside of the classroom could make a child feel separate which could limit their opportunities to build friendships and positive relationships with their class teacher (Lovell, 2021). This in turn could be negatively impacting CYP's SOB. Participants expressed the difficulty in finding a balance between ensuring a child gets necessary interventions and support, as well as providing opportunities to be present in the main classroom (Lovell, 2021).

In a study conducted by Finnegan (2022) participants expressed that learning away from the classroom was a positive experience. All participants spoke about receiving support from a TA outside of the classroom for lessons or interventions (Finnegan, 2022). For some participants, learning away from the classroom offered some respite for them. For example, one participant expressed that they find it helpful being away from the classroom when they are angry and it helps them calm down (Finnegan, 2022). Another expressed that they enjoy being away from the classroom as it is quieter (Finnegan, 2022).

Similar findings were highlighted by Rose and Shevlin (2017). When interviewing pupils with a range of SEN, it was found that being educated away from the main classroom was favoured by most (Rose & Shevlin, 2017). Some students highlighted that it allows them access to extra help which enables them to keep up with their peers academically (Rose & Shevlin, 2017).

Despite other research suggesting that excluding children with SEN from the classroom might be detrimental to their SOB, other research suggests that it can be beneficial for children with SEMH and sensory needs.

# 1.5.4.4.3 School Ethos

Dimitrellou and Hurry (2019) found that there was a strong correlation between the perceived inclusive school ethos (as reported by pupils with SEN) and SOSB. This suggests that the higher the positive perceptions are about a school's ethos, the higher a pupil's SOB is (Dimitrellou & Hurry, 2019). Although this study highlights that an inclusive school ethos can be positive for CYP's SOB, these findings are correlational, meaning it does not account for other potential variables. Moreover, given the quantitative nature of this study, these findings do not provide insight into what fosters an inclusive school ethos from a pupil's perspective.

Gallagher Deeks (2023) found that school wide policies not only affect how the school staff work, but also impacts the CYP (Gallagher Deeks, 2023). One participant shared that they felt that their school policies were created with neurotypical children in mind, not SEND (Gallagher Deeks, 2023). This then led to CYP with SEN receiving sanctions for not adhering to uniform or behaviour policies (Gallagher Deeks, 2023). It would be interesting to explore whether CYP with SEN also feel that wider school systems, such as policies affect their SOB.

#### 1.5.4.4.4 Rewards and Punishments

One study explored the impact of rewards and punishments on CYP's SOB. In Smedley's (2011) study, two participants viewed their teachers as the provider of rewards, and these were only given to children who were 'good'. When participants were asked what would help them feel they belong, the participants described extrinsic rewards which only certain students can attain (Smedley, 2011). Rewards included, showing other staff your work, being chosen for jobs, going up a level on a chart and showing the class your skills (Smedley, 2011). Participants highlighted that they enjoyed the acknowledgement from their teachers which contributed to their self-esteem and social standing within the classroom (Smedley, 2011).

Participants also expressed that sanctions are sometimes used by teachers. One participant expressed that their teacher shouted, however other participants highlighted that sanctions included removal of equipment such as laptops and banning children from playing football (Smedley, 2011). One participant expressed that this negatively impacts their opportunities to develop their social skills, which jeopardises their friendships and social position (Smedley, 2011).

## 1.5.4.5 Activities

### 1.5.4.5.1 Extracurricular Activities

Both quantitative and qualitative studies have explored the relationship between participating in extracurricular activities and SOSB. Finnegan (2022) found a strong positive relationship between belonging scores and attending extracurricular activities. There was also a significant difference between number of extracurricular activities attended by pupils with and without SEN. Children with SEN were shown to attend less extracurricular clubs.

Porter and Ingram (2021) found that many participants voted that extracurricular activities help them feel a part of the school, and this was the highest rated factor. This included participating in sports teams or school events (Porter & Ingram. 2021).

Similar findings were found in qualitative studies. Culliane (2020) found that students reported a higher SOB and connection to their school when they participate in extracurricular activities such as sporting clubs or school musicals. It was found that the majority of non-SEN pupils reported that they attended a diverse range of extracurricular clubs, but this was not the case for pupils with SEN.

Alesch and Nayer (2020) interviewed both CYP and their parents. It was highlighted that excluding a child from school activities is a violation of their human rights (Alesch & Nayer, 2020). One parent shared that they were asked to keep their child at home during activities such as a Christmas concert or a cross country event, leading to the parent and their child feeling isolated, rejected, and not accepted by the school (Alesch & Nayer, 2020), highlighting that exclusion from school activities not only negatively impacts a child's SOB, but also their parents'.

### 1.5.4.5.2 Leisure Activities

Similar findings were found when exploring CYP's preferred leisure activities within school. Within Smedley's (2011) study, all three participants highlighted the importance of football being a leisure activity at school. From conversations, participants associated playing football with access to friendship groups, peer relationships and creating a SOB in school. Participants described that their best day at school would involve football, and their worst would be the absence of football (Smedley, 2011). Some participants highlighted that they would occasionally miss out on football, due to having to catch up on work, which leads to missing out on opportunities to develop social skills and navigate conflict resolution (Smedley, 2011). In this study, playing football was highly valued by participants. It should be considered that this study included three boys within the same class. There is a possibility that football is a large part of their school culture which could explain why it was rated with high importance. It would be interesting to explore if similar findings would be found with differing leisure activities.

## 1.5.4.6 Background and Identity

# 1.5.4.6.1 Personal Identity

Gallagher Deeks (2023) found that a YPs identity and understanding of their diagnosis can affect their SOB. Through interviewing staff who work in SRBs, it was highlighted that systemic structures around YP with SEN and how they have contributed to a "problem" narrative has become embedded within their identity (Gallagher Deeks, 2023). This has led staff to promote inclusion for these pupils and create an environment which is not there to "fix" or "mould" the YP, but instead ensure adaptations are in place (Gallagher Deeks, 2023). This study highlights that it is crucial for staff to be aware of how they can promote SOB for CYP with SEN. It must be highlighted that the views of CYP were not qualitatively explored in this study, so it must be noted that their views could differ.

# 1.5.4.6.2 Family

Two studies acknowledged the importance of family for CYPs SOB. From a staff perspective, it was highlighted that CYP having a loving and supportive home environment can act as a protective factor in supporting equal opportunities (Gallagher Deeks, 2023). It was also acknowledged that parents own beliefs and understanding of SEND can further reinforce a "problem narrative" for CYP (Gallagher Deeks, 2023). It was acknowledged by staff that there is an imbalance of power dynamics within the system and parents often have to fight for their child to get the correct support, and this can sometimes affect how parents interact with school staff (Gallagher Deeks, 2023).

From a pupil perspective, Ware (2020) highlighted that family support is crucial for CYPs belonging. Some CYP reflected on the idea that their families supported them in a functional sense, such as helping with school-work and day-to-day life (Ware, 2020). Whereas other participants shared that their family and how they were looked after by them had a significant impact on their wellbeing, by making them feel "amazing" (Ware, 2020).

Both studies highlight the importance of family, from both the perspectives of staff and CYP. It suggests that there is a range of parental responsibility, from acting as important advocates for CYP, providing functional support and emotional containment.

### 1.5.4.7 SOB as a Mediator

Only one study within this review explored SOB acting as a mediator between psychosocial difficulties and emotional regulation. Kopelman-Rubin et al., (2020) found that the more pupils with SEN could regulate their emotions, the lower their psychosocial difficulties were. This was significantly mediated by student's school SOB (Kopelman-Rubin et al., 2020). Moreover, the more students could regulate their emotions, the higher their SOB was, which positively impacted psychosocial problems (Kopelman-Rubin et al., 2020). These findings highlight the importance of schools prioritising CYP with SEN and their SOSB to promote positive outcomes for them. It must be considered that self-report measures were used within this study. Although this can be insightful, there is a potential risk of social desirability bias. Participants may be hesitant to share if they experience psychosocial or emotional regulation difficulties.

## 1.6 Parents, DS and Belonging

The literature review reveals a noticeable gap in research directly addressing parental perspectives on SOSB and DS. Nonetheless, some studies have examined the views of parents of CYP with DS, where the concept of belonging surfaced as a theme rather than the central focus. Although these studies were not included in the literature review, they hold significance and deserve attention.

A study conducted by Lyons et al., (2016) explored the views of parents who have children with DS, specifically in relation to their child's participation in everyday life, as well as the associated facilitators and barriers. This study included seven parents who have children with DS, who were aged between 5 and 12-years old. Through interviews, parents reported that their child's participation in activities helped to develop skills which enhanced their well-being and SOB (Lyons et al., 2016). The barriers and facilitators which influenced participation were attitudes and views of others, child factors, logistical issues, and modifications to the environment (Lyons et al., 2016).

Lalvani (2013) explored the views of mothers who had children with DS, specifically their views on their education. In total, 19 mothers with children aged between six months old, to six years old participated in semi-structured interviews. It was found that when mothers spoke about educational programmes, there was a focus on acceptance and group membership (Lalvani, 2013). When discussing inclusive environments, mothers expressed beliefs about where their children would 'belong' (Lalvani, 2013). As part of this belonging,

mothers expressed a want for unconditional acceptance from teachers and similar level peers (Lalvani, 2013).

A recent study was conducted within Iceland, which did explore parents who have children with DS and their views on their child's SOB (Westin et al., 2022). Although this is a highly relevant study, it was excluded from the literature review due to it involving children in pre-school settings and the researcher was also unable to obtain the full text. Results highlighted that parent's believed that their children felt a SOB to their class (Westin et al., 2022). Despite this result, it was felt by parents that their children with DS would not be able to express this view themselves, due to difficulties with communication (Westin et al., 2022).

Many studies have explored the views of parents who have children with DS, specifically topics related to inclusion (Kasari et al., 1999), their opinions on having a child with DS (Skotko et al., 2012), educational provision (Van Herwegen et al., 2018) and perceptions of their child's identity (Deakin & Jahoda, 2020). Further studies have directly explored parental views of their child's SOB; however, this has typically been associated with mainstream, preschool aged children (Johansson et al., 2024; Karlsudd, 2022).

Previous research has gathered insights from parents of children with DS. While many studies concentrate on areas such as their child's daily participation, educational experiences, or perceptions of identity, SOB has been noted as an important factor for some parents. However, it often appears as a theme within the research rather than being the primary subject of exploration.

### 1.7 Role of the EP

The role of the EP has developed and evolved over time. It has been suggested that the EP role falls under the following five functions: assessment, intervention, consultation, training, and research (Scottish Executive, 2002). These five functions are typically delivered across three levels, which is the individual level, the whole school level or at a Local Authority level (Boyle & Lauchlan, 2009). Since the introduction of the SEND Code of Practice (2014), EPs are required to provide a psychological assessment, along with other professionals as part of the EHCP process. The SEND Code of Practice (2014) further highlights that EPs work across the four broad areas of need. This includes, 'language and communication', 'learning and cognition', 'social, emotional and mental health' and 'physical and sensory' (SEND Code of Practice, 2014).

The current study is highly relevant to EP practice. As highlighted within the SEND Code of Practice (2014), organisations and settings must support CYP with SEN and disabilities and provide equitable learning experiences. It is a large part of the EP role to support inclusive practice within schools (DECP, 2022). As highlighted by the DECP (2022), "psychologists can use research findings to support the development of educationalists as reflective practitioners who promote a SOB and full participation for all students in their school". Research has highlighted that a SOB is a crucial element of inclusion (Frederickson et al., 2007), which is highly relevant to CYP with DS. By understanding what contributes to SOB for CYP with DS, EPs are able to make evidence-based recommendations to schools to support them in fostering inclusive practices.

As highlighted by Boyle and Lauchlan's (2009) research, EPs typically work across three levels, which is relevant to the current study. At an individual level, school belonging has been shown to be associated with emotional wellbeing (Arslan, 2018). Research has highlighted when SOSB is met for CYP with SEN, there are positive developments in social development, behaviour, and emotional regulation (Prince & Hadwin, 2013). For children with DS, who may experience challenges related to peer acceptance and social inclusion (Wishart, 2007), it is crucial that EPs are able to understand the factors which contribute to their SOB. Moreover, EPs are beginning to be more involved in whole-school systemic working (Boyle & MacKay, 2007), specifically in relation to pupil wellbeing. A study exploring what contributes to SOB for CYP with DS can help to highlight systemic barriers and facilitators to inclusion. This will allow EPs to help schools to create an environment that embraces connection, acceptance and a positive school ethos which not only supports CYP with DS, but the whole school community.

Research has highlighted that there are positive associations between SOB and academic outcomes for CYP with SEN (Prince & Hadwin, 2013). CYP with DS can face barriers to learning such as expressive language difficulties and memory skills (De Graaf et al., 2014). A strong SOB can help to mitigate these barriers by enhancing motivation and engagement (Neel & Fuligni, 2013). By exploring SOB and CYP with DS, it can help EPs to identify factors which hinder or enhance belonging, which allows them to develop approaches to support educational outcomes. This is a crucial role for EPs, especially as they contribute to the develop of EHCP's for CYP with SEN (SEND Code of Practice, 2014). It is essential to consider how SOB can be promoted for CYP with DS through outcomes and suggested provision.

In terms of EP practice, findings could potentially influence educational practice, guide targeted provision, and promote policies that enhance the educational experiences of CYP with DS. By focusing on SOB, it will allow EPs to support schools in fostering inclusive environments where CYP feel valued and connected to their school community, which will have a positive impact on the emotional-wellbeing and learning needs of CYP with DS.

### 1.8 Summary and Future Directions

Research has highlighted that CYP with DS attend a range of education settings (Van Herwegen et al., 2018). Yet there is limited research exploring the school belonging of CYP with DS.

The SLR highlights that CYP with SEN are experiencing lower school belonging in comparison to their non-SEN peers. Findings have suggested that levels can vary depending on the type of SEN (Dimitrellou & Hurry, 2019). It must be noted that researchers such as Gallagher Deeks (2023) and Hebron (2018), suggested that although levels of belonging might be lower for SEN pupils in comparison to typically developing peers, CYP with SEN are still meeting good levels of belonging.

Many papers highlighted the facilitators and barriers of school belonging which are experienced by CYP with SEN. Themes included relationships with staff, friendships, activities, and school environment. Many of the themes were seen to act as both facilitators and barriers to school belonging. For example, relationships with staff were seen to be positive and negative, depending on the participant (Culliane 2020; Lovell, 2021).

By conducting a SLR looking at factors which contribute to SOB for CYP with SEN, it allowed the researcher to understand the themes, findings, and trends within the topic. Although the literature was insightful, it also highlighted the absence of DS specific studies. The generalisability of these findings must be considered with caution. The studies included CYP with SEN, which included specific diagnoses such as Autism (Porter & Ingram, 2021) and persistent literacy difficulties (Smedley, 2011), whereas others did not specify. Diagnoses can come with particular cognitive or social profiles, such as social communication difficulties which are associated with autism. Thus, further reinforcing risks associated with generalising these findings. DS presents with unique developmental, social, and educational experiences that warrant focused exploration (De Graaf et al., 2014; Laws et al., 2000). Moreover, the studies included within the literature review did not consider the differences between visible

and non-visible disabilities. Researchers such as Ysasi et al., (2018) have highlighted that the visibility of a condition can lead to stigmatisation. DS is considered as a visible disability, and typically includes features such as the downward slant of the eye lids medially, ear anomalies, epicanthal folds and a flat face (Kava et al. 2004). As the studies included within the SLR included non-visible disabilities or disabilities which were not disclosed (except for Dimitrellou & Hurry, 2019), it must be recognised that there is a possibility that findings could differ when looking at a DS population.

Within the SLR, most of the studies focused on interviewing CYP with SEN. This is important as it allows researchers to explore their views directly. Some studies did consider the views of parents (Alesech & Nayer, 2020) and staff (Gallagher Deeks, 2023), which allowed a different perspective to what contributes to SOB. From the researcher's understanding, no studies solely focused on parental views. Since parents often observe and influence their child's social experiences, their perspectives can add depth to understanding how belonging is fostered or hindered. Parents play a crucial role in shaping their child's experiences of belonging through advocacy, school engagement, and home support (Krueger et al., 2019). Their insights can provide valuable information about the barriers and facilitators to belonging that children with DS face. Parents often navigate education systems, advocate for inclusion, and address challenges related to support services (Krueger et al., 2019). Their experiences can highlight systemic issues that may not be fully captured through interviews with children or school staff alone. Future research should prioritise the exploration of SOSB for CYP with DS, as this remains an under-researched area. Given their pivotal role as educational advocates, parents' perspectives are also invaluable, as highlighted in previous studies.

## **Chapter Two: Empirical Paper**

### 2.1 Abstract

There is currently a lack of research exploring what contributes to the SOSB for CYP with DS from a parental perspective. This study explores how parents of children with DS advocate and conceptualise SOSB, as well as exploring its significance in school selection and the factors which influence it. In total, nine parents participated, and semi-structured interviews were used. Data was analysed using a reflexive thematic analysis to answer four research questions. Parents conceptualised SOSB as being related to their children having equitable experiences, feeling known and valued, and being familiar with the school environment. Some parents discussed the idea that the concept of SOSB is complex and individualised, meaning individual differences must be considered. For most parents, SOSB was an important factor when selecting a school for their child with DS. For some parents, SOSB was deemed as central importance, whereas for other parents it was a more implicit factor. Other factors were raised which affected school choice, such as staff attitudes as well as parents own worry and anxiety. Most parents shared that they considered a range of schools for their child with DS. The current study also explored the factors that parents believe influence their child's SOSB. Facilitators included relationships and social interactions (with staff and peers), inclusive classroom adaptations, school ethos, extracurricular activities, the role of the parent and the child's own attributes and skills. Whereas barriers included lack of classroom adaptations, inaccessibility to extracurricular activities, difficulties with parental involvement and lack of understanding and support for individual needs. These findings have implications for CYP with DS, their parents, school staff and EPs. These findings have also been discussed in relation to the preparing for adulthood framework. Limitations and future considerations have also been raised.

## 2.2 Background and Rationale

### 2.2.1 Down's Syndrome in a National Context

Down's syndrome (DS) is a genetic condition caused by the presence or partial presence of an extra copy of chromosome 21. It is the most common genetic intellectual disability. DS is typically associated with mild to moderate learning difficulties. Despite there being a common cognitive profile for CYP and adults with DS, studies have indicated that

there can be variability; highlighting that educational support may need to consider individual differences (Onnivello et al., 2022).

The terms 'Down syndrome' and 'Down's syndrome' are used interchangeably within research. As highlighted by many charities, it is important that person first terminology is used when addressing or discussing someone with Down's syndrome. For example, saying 'a person or child with Down's syndrome' rather than 'a Down's syndrome person or child' (Down's Syndrome Association, 2021). Within this project, the term 'Down's syndrome' will be used.

Data has not yet been published regarding how many CYP with DS have an EHCP or are supported at a SEN support level. Research has suggested that CYP with DS require support within education settings to access learning opportunities (Kendall, 2019). Approximately 82% of CYP with DS receive individual support from a Teaching Assistant (Van Herwegen et al., 2018). Due to the development of inclusion policy, there has been a significant increase in CYP with DS attending mainstream schools within the last 30 to 40 years (Van Herwegen et al., 2018). This includes the Salamanca Statement (1994), which highlighted that schools must employ an inclusive orientation and provide an effective education for all CYP, including those with SEN. The majority of CYP with DS complete their primary education within mainstream settings, however approximately 20-25% of CYP transition to a mainstream secondary school (Lightfoot & Bond, 2013). Remaining students complete their education in SEN settings, where a statutory plan is required to gain a place.

Following the introduction of the Down Syndrome Act (2022), there is now an aim to raise awareness and understanding of DS. This includes collecting data through the School Census regarding where children with DS are being educated (DfE, 2024). The government has recognised that there is currently no data available which highlights how many children with DS are being educated in the UK, the types of schools they are attending and the location of schools (UK Parliament, 2023). A 'call for evidence' was launched by the Department for Health and Social Care in October 2022 to inform the development of the Down Syndrome Act. The guidance is not yet available for public consultation.

### 2.2.2 Sense of Belonging

Sense of belonging (SOB) can be defined as an innate want to feel accepted, included and supported in a social environment (Baumeister & Leary, 1995). There are differing theories which define SOB, including the Belongingness Hypothesis, Maslow's Hierarchy of

Needs and Attachment Theory (Baumeister & Leary 1995; Bowlby, 1969; Maslow 1943). Although definitions vary, they all suggest that SOB is a fundamental need which can lead to positive social, emotional, and behavioural outcomes (Prince & Hadwin, 2013).

Sense of school belonging (SOSB) is defined by Goodenow and Grady (1993), who suggest that SOSB is 'the extent to which students feel personally accepted, respected, included, and supported by others in the school environment'. SOSB contains three aspects: (1) an individual's relationships and experiences within school, (2) student-teacher relationships and (3) how an individual feels about school (Slaten et al., 2016).

Recent research has suggested that SOSB encompasses a wide range of factors, and is multifaceted and complex in nature (Shaw, 2019). Shaw (2019) interviewed 46 secondary aged pupils, who attended two different schools within England. Participants completed the Psychological Sense of Belonging Scale (Goodenow, 1993), and participated in semi-structured interviews. It was found that some students related SOSB to their relationships with peers and staff, whereas others reflected on participation in school life. For a few students, the academic aspects of learning contributed to SOSB (Shaw, 2019). It was concluded that the pupils' definitions of SOSB encompassed a wide range of factors, which highlights that school belonging can be subjective, complex, and multi-faceted (Shaw, 2019).

There is limited research which explores SOSB, however this is an area which is growing due to UK policy progressing towards a more child-centred and inclusive education system (HM Government, 2014; Ofsted & CQC, 2016). At a basic level, inclusion is educating CYP with SEN alongside their mainstream peers (Frederickson, 2008). Further definitions highlight that inclusion is an ongoing process which encompasses the wellbeing of students (Barton, 2005). An important factor of inclusion is to promote a SOB amongst the school community to ensure successful learning and well-being is met (Warnock, 2005). Parents consider high-quality, inclusive education as their child experiencing a SOB to their class and school (Satherley & Norwich, 2022).

# 2.2.3 Parental Advocacy

Legislation has highlighted the importance of collecting parental views. Under Section 19 of the Children and Families Act (2014), LA's must have regard to the views, feelings and wishes of CYP with SEN and their parents. Although there is a strong focus on the CYP themselves, it highlights the importance of parents participating in decision making to meet positive outcomes for their children (DfE, 2014). For the definition of 'parent' see Appendix E.

Parents of children with DS frequently act as advocates (Krueger et al., 2019). Parental advocacy can be defined as "a form of support, encouragement and continuous help needed by this group [children with SEN] to live their daily lives fully" (Yatim & Ali, 2022). Research has suggested that parents can be deemed as "natural advocates" for their children, due to their investment and commitments to their child's emotional and physical wellbeing (McCammon et al., 2001). Early research has highlighted that there is a pronounced need for parents of children with SEN to advocate on their behalf, in comparison to typically developing children (Mlawer, 1993). The most common environments where advocacy occurs is within healthcare systems and schools, with the goal of promoting acceptance, equality, and inclusiveness for their children (Krueger et al., 2019).

As highlighted in the Lamb Inquiry (2009), many parents of children with SEN lack confidence in SEN systems, including schools. As a result, it is crucial that the relationship between parents and schools are at the heart of an effective SEN system. It has been shown that effective communication between parents and professionals is important for children and can impact their progress (Ofsted, 2006).

For CYP with DS, their parents typically advocate for suitable school placements. Since the Education Reform Act (1988), parental choice has been a strong focus within the political discourse of school reform. Under Section 33 and 39 of the Children and Families Act (2014), a parent has the right to request a particular school for their child within an EHCP, this can include mainstream and SEN schools. For CYP without a statutory plan, their parents still make decisions regarding school placements. Parents are asked to state their preferred schools. These preferences will then influence which school a child is assigned to (GOV.UK, 2023). If there is a space at a parent's chosen school, the child will be offered a place (Allen et al., 2014). However, if the school is oversubscribed, other criteria are used. Parental choice remains an important factor throughout this process (Allen et al., 2014).

Some studies have explored what factors influence school placement decisions for parents of children with SEN. This includes questioning how the school would meet their child's needs (Bagley et al., 2001), positive staff attitudes (Kendall et al., 2019), independent living programmes, smaller classes, and teacher qualifications (Jenkinson, 1998). Further factors also include what provision is available locally, the child's individual needs and parent's social backgrounds (Nuske et al., 2019). Many studies have suggested that choosing a school for CYP with SEN can be an overwhelming and isolating experience (Hutcheson, 2018). Some

authors highlighted that some parents face conflict and confusion when choosing a school for their child with SEN (Grieve, 2012; Podvey et al., 2010).

In terms of research, when parents of children with SEN are interviewed, this can be known as proxy-reporting. Proxy-reporting is where a view or response is given by someone, such as a parent or caregiver about a sample of interest (Santoro et al., 2022). Proxy-reporting can be used for several reasons. When considering CYP with intellectual disabilities, there can be challenges with communication and cognitive understanding, especially when discussing complex topics or phenomena (Santoro et al., 2022). Proxy-reporting methods have been used widely when exploring topics related to DS, specifically parental views (Becker & Dusing, 2010). However, other studies have explored the views of CYP and adults with DS directly, in relation to topics such as their appearance and health related quality of life (Graves et al., 2016; Skotko et al., 2011). Proxy-reporting can be insightful, as it can allow an alternative perspective if an individual cannot self-report (Webb et al., 2014) and provides a holistic view of an individual or population (Becker & Dusing, 2010).

There are some considerations when looking at proxy-reporting methods. Some research studies have suggested that an individual's own experiences and biases may affect how they proxy-report. Ijezie et al., (2023) highlighted discrepancies between parental views and the views of individuals with DS, with parents reporting more negative perceptions. Lightfoot and Bond (2013) explored the primary to secondary school transition for CYP with DS. A key element of their study was gaining the voice of the child (VoC) directly. This study interviewed CYP with DS, as well as their parents and relevant support staff (Lightfoot & Bond, 2013). Although the CYP with DS were able to share their views through reasonable adjustments, it was noted by all participants that there were difficulties eliciting VoC. Parents shared that their children's views might give a generalised overview rather than considering nuanced aspects, such as saying that they dislike something, but this refers to one discrete element and not being indicative of their overall view (Lightfoot & Bond, 2013). Therefore, parents believed that asking their children's views was important, but this should be considered alongside observation and considering their child's mood and behaviours (Lightfoot & Bond, 2013).

Although parental and child views can differ, both are valid and meaningful perspectives. A study explored mothers' perceptions of their child's identity and their awareness of having DS (Deakin & Jahoda, 2020). Some mothers referred to their children being unaware of differences between themselves and peers, such as differential treatment (Deakin & Jahoda, 2020). One mother shared that her daughter had won a sack race at sports

day, due to running the race and deciding not to use the sack. The mother shared some embarrassment about this, whereas her daughter was pleased that she had won the race and appeared unaware that she had "cheated" (Deakin & Jahoda, 2020). This highlights that both a parent and child can view the same event with two differing emotions. This suggests that both children and parental views are important and meaningful. However, by speaking to parents, it allows for a more nuanced perspective whilst considering the wider contextual factors.

## 2.2.4 The Current Research Context

Research has highlighted which factors act as barriers and facilitators to SOB for CYP with SEN, particularly in areas such as autism, literacy difficulties, and SEMH needs. Studies often show that CYP with SEN experience lower SOB levels than their typically developing peers (Finnegan, 2022), though some still report good levels of belonging (Gallagher Deeks, 2023).

Most studies prioritise children's voices but also include perspectives from teaching assistants, teachers, and parents (Alesech & Nayer, 2020; Gallagher Deeks, 2023; Lovell, 2021). Influencing factors include school relationships, friendships, exclusion, bullying, adult communication, school ethos, and extracurricular opportunities (Alesech & Nayer, 2020; Gallagher Deeks, 2023; Lovell, 2021).

However, limited research specifically explores the SOB of CYP with DS. Barriers such as low task persistence (Ruskin et al., 1994), language challenges (Guralnick et al., 2006), and behavioural issues (Cuskelly & Dadds, 1992) can impact their peer relationships. Much research instead focuses on social positioning, which may not capture deeper school connections (Hall & McGregor, 2000).

Parental studies often address the inclusion of CYP with DS rather than SOB. For example, Lyons et al. (2016) noted that participation in activities improves wellbeing and SOB, while Lalvani (2013) emphasised teacher acceptance and peer similarity is key for inclusion. Broader studies examine inclusion (Kasari et al., 1999), parenting experiences (Skotko et al., 2012), educational provision (Van Herwegen et al., 2018), and identity perceptions (Deakin & Jahoda, 2020). SOB-specific research tends to focus on mainstream, preschool-aged children (Johansson et al., 2024; Karlsudd, 2022).

As highlighted by the literature review, future research should focus on the SOSB for CYP with DS, a topic that remains underexplored. Parents, as key educational advocates, offer valuable perspectives that are crucial in understanding SOSB for their children. Following inclusion legislation, such as the Salamanca Statement (1994), CYP with DS are increasingly attending a diverse range of schools. A key aspect of successful inclusion is fostering a SOB within the school community, which plays a vital role in promoting learning outcomes and well-being (Warnock, 2005). Research suggests that parents often define high-quality, inclusive education as their child experiencing a strong SOB within their class and school environment (Satherley & Norwich, 2022).

The SEND Code of Practice (2014) highlights the importance of considering parents' views, wishes, and feelings in educational decision-making. Parents of CYP with DS frequently act as educational advocates, making critical choices about where their child is educated (Krueger et al., 2019). Factors such as school culture and the school's ability to foster a SOB are often central to these decisions (Cantu et al., 2021).

While the concepts of belonging and school belonging are widely recognised, they are complex and multifaceted (Cartmell & Bond, 2015). Although common themes exist within definitions, there is considerable variability (St-Amand et al., 2017). Much of the existing literature has explored a range of SEN, including autism, persistent literacy difficulties, and SEMH needs (Alesech & Nayer, 2020; Gallagher Deeks, 2023; Lovell, 2021). These studies provide valuable insights into which factors contribute to the SOB experienced by CYP with SEN. However, DS is often associated with a distinctive cognitive and social profile, limiting the generalisability of this literature to CYP with DS.

Understanding school belonging is particularly crucial for the well-being and development of CYP with DS. Yet, this area remains underexplored, especially from the perspective of parents, who play a pivotal role in advocating for their children's educational needs and making school placement decisions. This study, therefore, seeks to examine how parents conceptualise, value, and contribute to their children's SOSB. While the focus highlights parental advocacy, it also complements the voices of children, offering a more holistic understanding of their experiences.

### 2.2.5 Rationale and Research Aims

This study aims to explore parental perspectives on the SOSB for their children with DS. While extensive research has identified factors which influence the SOB for CYP with

SEN, there appears to be a gap in studies specifically examining SOSB for CYP with DS from a parental viewpoint. This research seeks to address that gap by investigating how parents perceive SOSB, whether they consider it a meaningful concept, and what factors contribute to it from a holistic perspective. Given that parents play a crucial role as educational advocates for CYP with DS, their insights are essential for fostering school inclusion and shaping supportive educational environments.

By emphasising parental perspectives, this research aims to foster a collaborative systems approach. Insights from parents can expand professionals' understanding of the holistic factors that contribute to SOSB for CYP with DS. The findings are expected to inform professional practice and provide a deeper insight into how best to support parents and CYP with DS in educational settings.

### 2.2.6 Research Questions

The central research question in the current study is:

How do parents of children with Down's syndrome perceive and value their child's sense of school belonging?

The overarching question is addressed through the following sub-questions.

For parents with children with Down's syndrome:

- 1. How do parents conceptualise sense of school belonging for their child?
- 2. How important was school belonging to parents when choosing their child's school placement?
- 3. What do parents see as the key factors that support their child's sense of school belonging?
- 4. What do parents see as the key barriers to their child's sense of school belonging?

# 2.3 Methodology

The researcher has outlined the current studies aims and rationale. Within this section, the ontological and epistemological positioning of the research, data collection, data analysis and ethical considerations will be discussed.

## 2.3.1 Research Paradigm / Epistemological Position

Philosophical positions consist of ontology and epistemology. Ontology refers to the nature of reality (Flew, 1984). This includes how we view the world and "what kind of world we are investigating, with the nature of existence, with the structure of reality as such" (Crotty, 2003; Denzin & Lincoln, 2008). Ontological assumptions can be viewed on a continuum, ranging from 'realist' to 'relativist' (Willig, 2008). A realist ontology holds the view that the world is made up of structures that have cause and effect relationships with each other (Willig, 2008). Whereas a relativist assumption suggests that the world is made up of a diverse range of interpretations which are not orderly (Willig, 2008).

Epistemological assumptions explore human knowledge, how it is derived and its reliability and validity (Flew, 1984; Hathcote et al., 2019). Epistemology considers "a way of understanding and explaining how we know what we know" (Crotty, 2003). Epistemological assumptions are typically adopted within qualitative psychology (Madill et al., 2000). Epistemology can range from objectivism to subjectivism. Objectivism suggests that truth is within an object and is not influenced by human subjectivity or contextual factors (Crotty, 1998). Whereas subjectivism views knowledge through a social lens, which is influenced by factors such as language, race, ethnicity, social class, and gender (Denzin & Lincoln, 2005).

A researcher must also consider their methodology. This refers to how knowledge about the world is gained or collected (Denzin & Lincoln, 2008). A researcher's methodology is embedded within the ontological and epistemological stances which is guiding their research (Hennik et al., 2020).

A research paradigm is the model or framework which a researcher uses to organise their reality, observations and understanding (Babbie, 2007). A paradigm considers a researchers epistemological, ontological, and methodological stance (Denzin & Lincoln, 2008; Kuhn, 1970).

The researcher will be adopting a social constructivist paradigm for this project. Social constructivism emphasises how an individual constructs their own reality through their cognitions (Lincoln & Guba, 1985; Schwandt, 1997). It also considers the importance of social context and culture to understand society and constructed knowledge (Derry, 1999). Social constructivism considers a relativist ontology and a subjectivist epistemology; and methodologically it is typically associated with qualitative research (Plano Clark & Ivankova, 2016; Tashakkori et al., 2021). Many theories are associated with social constructivism, such

as the work of Bruner and Vygotsky, as well as Bandura's social cognitive theory (Schunk, 2012). Social constructivism can influence how we view reality, knowledge, and learning (Table 3).

 Table 3

 Social Constructivism: Reality, Knowledge, and Learning

| Areas which are affected by social | Definition   |  |  |
|------------------------------------|--|--|--|
| constructivism                     |  |  |  |
| Reality                            | Reality is constructed through human activity which cannot be discovered prior to social invention (Kim, 2001; Kukla, 2000).   |  |  |
| Knowledge                          | Knowledge is the product of humans which is constructed through cultural and social means (Ernest, 1998). Interactions and the |  |  |
| Learning                           | environment create meaning (Kim, 2001).  Learning occurs through social activities which is not a passive process (Kim, 2001). |  |  |

It must be noted that social constructivism and social constructionism are similar concepts but also have distinct differences. Both concepts share unifying themes where knowledge is constructed (Neimeyer, 1987). However, a key difference is that social constructivism focuses on how individuals construct knowledge through language, interpersonal interactions, and engagement with culture (Neimeyer, 1987). Whereas social constructionism focuses on the collective process of understanding the world (Neimeyer, 1987). Although some researchers use the terms interchangeably (Charmaz, 2006), within this project, social constructivism and social constructionism will be considered as distinct concepts.

The goal of adopting this paradigm is to collect rich and diverse qualitative data, whilst ensuring the unique perspectives of participants are shared (Burr, 1995). By exploring individuals' subjective experiences and interpretations, it will allow the researcher to understand the phenomena of SOSB and DS from a parental perspective (Creswell, 2002).

### 2.3.2 Participants

Once ethical approval had been agreed (Appendix F), participants were recruited via purposive sampling. This involves the researcher purposefully choosing participants who have

characteristics which are in line with the study aims (Hennink et al., 2020). By using this approach, it allowed the researcher to recruit participants who are 'information-rich' and have a good understanding of the study issues (Patton, 2002). Purposive sampling is also a flexible approach, which can evolve and change as the study progresses (Hennink et al., 2020). The study population was deductively defined during the design cycle, and this is then inductively refined during data collection (Hennink et al., 2020).

The participants had to meet the following criteria to participate:

- Must be a biological parent of a child with Down's syndrome.
- Their child must be aged between five to 16 years old.
- Their child must currently be in full-time education in England.
- Their child must be attending either a mainstream or special needs school (either primary or secondary level).

Within this piece of research, the researcher aimed to recruit parents who are natural (biological) parents to children who have DS. Initially, the researcher wanted to include parents who also had 'parental responsibility'; however, this includes children in care. The researcher wanted to ensure that the relationship between SOSB and DS was being explored. It is felt that if a child is in care, this could potentially influence their SOSB (Chimange & Bond, 2020).

The researcher chose to interview parents of children with DS because the SEND Code of Practice (2014) highlights that it is crucial for parents' views, wishes and feelings to be considered. Parents of CYP with DS frequently act as educational advocates and must decide where their child is educated therefore it is essential for their views to be gained (Krueger et al., 2019).

The researcher chose to interview parents who have school-aged children who attend both mainstream and special needs schools. This is because within the last 30 to 40 years, children and young people with DS have been educated in a range of settings (Van Herwegen et al., 2018). An important factor of inclusion is to promote a SOB amongst the school community to ensure successful learning and well-being is met (Warnock, 2005).

Participants were recruited through a range of means. This included the researcher contacting DS charities and asking them to distribute the recruitment flyer. Charities such as the Down's Syndrome Association shared the recruitment flyer via their website. The researcher also utilised social media, by sharing their recruitment flyer on Facebook and

LinkedIn. The researcher gained permission from admins to join DS support groups on Facebook to recruit participants. Recruitment occurred between September 2024 and January 2025, and participants were interviewed during this period.

Participants expressed interest by emailing the researcher directly. An information sheet and consent form were provided via email to potential participants (Appendix G). Once consent forms were completed electronically and returned via email, an interview was organised at a time which was convenient for the participant. In total nine people returned their consent forms and completed a semi-structured interview. The interviews explored how parents conceptualise and advocate SOSB for their child with DS. Reminder emails were sent to participants who had initially expressed interest but did not return consent forms, however there were no responses.

A summary of the participant information can be found in Table 4. Pseudonyms were used for the purpose of confidentiality.

**Table 4**Participant Information

| Participant | Mother  | Childs | Does    | School    | Type of    | Has their  |
|-------------|---------|--------|---------|-----------|------------|------------|
| pseudonym   | or      | Age    | their   |           | school     | child      |
|             | Father? |        | child   |           |            | previously |
|             |         |        | have an |           |            | attended a |
|             |         |        | EHCP?   |           |            | mainstream |
|             |         |        |         |           |            | school?    |
| Charlotte   | Mother  | 9      | Yes     | Primary   | Specialist | No         |
|             |         |        |         |           | provision  |            |
| Amelia      | Mother  | 12     | Yes     | Secondary | Specialist | Yes        |
|             |         |        |         |           | provision  |            |
| Natalie     | Mother  | 15     | Yes     | Secondary | Mainstream | N/A        |
| Olivia      | Mother  | 6      | Yes     | Primary   | Mainstream | N/A        |
| Lydia       | Mother  | 11     | Yes     | Primary   | Mainstream | N/A        |
| Victoria    | Mother  | 11     | Yes     | Secondary | Specialist | No         |
|             |         |        |         |           | provision  |            |
| Daniel      | Father  | 8      | Yes     | Primary   | Mainstream | N/A        |
| Lucy        | Mother  | 8      | Yes     | Primary   | Mainstream | N/A        |
| Jessica     | Mother  | 7      | Yes     | Primary   | Mainstream | N/A        |

### 2.3.3 Data Collection

Data was collected for this project through online semi-structured interviews. The interviews explored how parents of children with DS advocate and conceptualise SOSB for their child. Qualitative research methods are used to provide an in-depth understanding of a particular topic from the perspective of the study population and the context that they live in (Hennink et al., 2020). Data collection for this study consisted of one phase. Participants were recruited to participate in individual semi-structured interviews which lasted between 45 minutes to one hour. These interviews were conducted on Microsoft Teams to allow flexibility for participants.

### 2.3.4 Rationale for Semi-Structured Interviews

The aim of this study is to explore individuals' subjective experiences and interpretations, by exploring the phenomena of SOSB and DS from a parental perspective (Creswell, 2002). This is in line with the researcher's social constructivist viewpoint. Semi-structured interviews are deemed as an appropriate method of data collection when the researcher's goal is to understand the unique perspective of a participant, rather than collecting a generalised consensus about a phenomenon (McGrath et al., 2019).

A benefit of using semi-structured interviews is that it allows for structure, whilst also giving the researcher and participant some autonomy over topics which arise from the interview (Adeoye-Olatunde & Olenik, 2021). Further advantages include the interviewer being able to further clarify questions and having the ability to follow up on thoughts and feelings behind the participants responses which is not possible with other methods (Alamri, 2019).

The researcher is also aware that there are disadvantages associated with qualitative interview methods. This includes their time-consuming nature, such as the time taken to create the interview schedule, record and collect data, transcribe, and analyse (Bryman, 2012). Moreover, there can be difficulties with scheduling an appropriate time to conduct the interview (Alamri, 2019). Despite some of the potential disadvantages associated with semi-structured interviews, the researcher felt that this would still be the most appropriate approach given the aims, questions, and epistemological positioning of the current research.

### 2.3.5 Construction of Semi-Structured Interviews

Individual semi-structured interviews were conducted with each participant. The interviews aimed to gain parent's views on how they conceptualise and advocate SOSB for their child with DS. The interviews were used to explore how parents define 'sense of school belonging', whether SOSB was an important consideration in school choice and what they think contributes to their child's SOSB.

Semi-structured interviews are usually organised using a topic guide, which comprises of 3-5 broad topics (Knott et al., 2022). Questions are generated within each topic to help guide the discussion between the researcher and the participant (Knott et al., 2022). Each topic is based on concepts which the researcher has identified, through close study of the literature base or using small pilot studies (Gerson & Damaske, 2020). Within the current study, the interview schedule was used to guide and structure the discussions with participants, but also allowed flexibility. Typically, interview guides start with an open-ended question, which is relevant to the research topic, but is broad, to help the participant ease into the interview (Knott et al., 2022). Following this, the interview may move towards topics which are more directly associated to the overarching research questions, where the participant is encouraged to provide more concrete details and examples (Knott et al., 2022).

The interview schedule allows for the researcher to cover the broad areas that they would like to explore, however a strength of this approach is that this does not need to be rigid. For example, a participant may discuss a topic which the researcher intended on exploring later. However, by using semi-structured interviews, it means the researcher can follow the lead of the participant (Knott et al., 2022). The researcher designed their interview schedule to prompt discussions around SOSB for their children who have DS. Please see Appendix H for the researchers interview schedule.

Interviews were conducted online. It has been suggested that interviews should take place in environments which are private and provide a safe place for participants to openly share information (Doody & Noonan, 2013). In this case, this would be the participants home.

#### 2.3.6 Procedure

Participants were initially informed about the study topic through the recruitment flyer. Participants then expressed interest by emailing the researcher directly.

An information sheet was provided to participants who expressed an interest. This outlined:

- What the study is about
- Who the researcher is and their contact details
- Costs and benefits associated with participating (e.g., time taken to complete the interview and any associated risks)
- Information about the participants right to withdraw
- Information regarding ethical approval
- Information about data protection
- Next steps regarding participation

At the beginning of each interview, the researcher introduced themselves and highlighted the broad aims of the research. The researcher then re-reminded the participants about what was outlined in the information sheet, including their right to withdraw. Participants were made aware that they were able to take a break if needed. Before the interview begun, participants were allowed to ask any questions.

Participants were asked to turn off their camera during the interview as the researcher only wanted to record audio. Microsoft Teams was used to record and transcribe the interviews automatically. The researcher then thoroughly checked and amended the transcripts if it was necessary. Participants were asked to not share identifiable information, such as names of people or places within the interview. However, if a participant accidentally did share confidential information, the researcher redacted this from the transcript.

The interview began by collecting relevant background information, this included confirming that the participant had a child with DS, and they were their biological parent. Further collected data included, their child's age, the type of school they attend and whether their child has an EHCP.

The next section of the interview focused on how participants conceptualised SOSB for their child. This included exploring their views on what SOSB means to their child and reviewing published definitions. Through the researcher's literature review, Goodenow and Grady's (1993) SOSB definition was frequently used within research. Therefore, this definition was referred to within the current research. Other explored topics included reflecting on SOSB and school choice, and what factors influence SOSB.

Once the interview ended, participants were thanked for their participation. Each participant was sent a debrief sheet (Appendix I) following the interview which outlined the purpose of the study, the researchers' details, their right to withdraw, timelines for reviewing their transcripts and the contact details for the Down's Syndrome Association if they had further questions.

In total, three participants asked to review their transcripts following their interviews. These were given to the participants within four weeks of their interview.

## 2.3.7 Ethical Approval

This study gained ethical approval from the University of East Anglia's Ethics Committee. The application was completed in line with the BPS Code of Human Research Ethics (2021), BPS Code of Ethics and Conduct (2021), BERA (2018) and the HCPC standards (2023). The following were also considered: 'Informed consent and right to withdraw'; 'confidentiality, anonymity, and data protection'; and 'risk, distress, and debriefing'.

# 2.3.7.1 Informed Consent / Right to Withdraw

Information and consent forms were sent to participants who expressed interest in the study. Once participants had read the information sheet, informed consent was gained by participants electronically signing a consent form which stated that they agreed to participate and to have their interviews audio recorded (BERA 8, 9; BPS CoHRE 4).

Due to semi-structured interviews being individual conversations, participants were able to withdraw up until the data was analysed. Participants also have the right to withdraw from a study without any adverse consequences (BERA 31; BPS CoHRE 4.1). Participants were made aware of their right to withdraw before and after the study. The researcher was aware that some participants might not have felt comfortable withdrawing from the study during the interview. Therefore, the researcher was aware of any signs or non-verbal cues which could have indicated that the participant was feeling uncomfortable.

# 2.3.7.2 Confidentiality, Anonymity, and Data Protection

All data collected within this study has been handled in line with the Data Protection Act (2018) and GDPR. All audio recordings of the interviews were stored on the University of

East Anglia's OneDrive system, which is in line with the University's Data Storage policy. All recordings were deleted once they were transcribed. The data was stored on a password protected laptop in an encrypted password protected file.

In line with GDPR guidance, all data used within the data analysis was anonymous and non-identifiable information was collected. Participants were made aware of how their data is being used and stored, which will be in line with GDPR guidelines.

# 2.3.7.3 Risk, Distress and Debriefing

The researcher was aware that parents discussing their child's SOSB could be an emotive topic. The researcher took multiple steps to minimise harm. The participants were made aware about what the study entailed and the topics which would be discussed. The researcher also reminded participants that they did not have to answer any questions they did not wish to. The researcher also offered breaks throughout the interview if that was needed.

Participants were emailed a debrief sheet at the end of the interview for their records, which made them aware of the study aims and thanked them for their participation. The researcher provided their name, email, and supervisor's contact details. Contact details to the Down's Syndrome Association was also provided, who have a hotline where any question related to DS can be asked.

### 2.3.8 Rationale for Thematic Analysis / Data Analysis

For the current project, the researcher used a reflexive thematic analysis (RTA) to analyse the interview data (Braun & Clarke, 2006). Thematic analysis is commonly employed across social and health sciences, when working with qualitative data (Braun & Clarke, 2022). It should be considered that thematic analysis is not a singular method, and there are now many ways to approach and use it (Braun & Clarke, 2022). When thematic analysis was first developed by Braun and Clarke in 2006, a specific approach was not defined. Since then, the authors have recognised that thematic analysis can have multiple orientations, practices, and concepts (Braun & Clarke, 2022).

When thematic analysis was first introduced, it was an approach which was "rarely acknowledged" by academics (Braun & Clarke, 2022). Now thematic analysis is widely used in literature and research. RTA is now used by Braun and Clarke (2022) and was employed

within this study. The term 'RTA' is also used by a range of researchers (Langdridge & Hagger-Johnson, 2004). Within a RTA, the researcher takes an active role in the knowledge production (Braun & Clarke, 2019). Stages such as coding are used by the researcher to help represent their interpretations and patterns of meaning across the dataset (Byrne, 2022). A RTA helps to reflect the researcher's interpretation of the dataset, theoretical assumptions of the analysis and the analytical skills of the researcher (Braun & Clarke, 2019).

The aim of the current study was to explore individuals' subjective experiences and interpretations, by using a social constructivist lens. An advantage with using a RTA is that it is theoretically flexible, meaning it can be used with a variety of research questions and theoretical frameworks (Braun & Clarke, 2021). RTA is highly compatible with a social constructivist approach, as it allowed the researcher to focus on the subjective experiences of participants, whilst also considering the exploration of social contexts (Braun & Clarke, 2022).

In terms of dataset size, Braun and Clarke (2022) highlighted that there is no clear answer to how big a researcher's dataset should be. Due to the complexity of influencing factors, as well as considering the idea that data saturation and statistical models can be problematic (Braun & Clarke, 2019). Instead, researchers are encouraged to reflect on how rich their data is, and whether this aligns with the study aims and requirements (Braun & Clarke, 2022).

For this project, the researcher was guided by the six-step template, which was initially developed by Braun and Clarke (2006). This included familiarising yourself with the dataset, coding data through a systematic and rigorous approach, followed by generating themes, reviewing themes, refining themes, and then writing up findings (Braun & Clarke, 2006; 2022).

Braun and Clarke's (2006; 2022) six-step process is outlined in Table 5. Whilst the six phases provide researchers with guidance about how to complete a RTA, it is not a linear process (Braun & Clarke, 2022). RTA should be considered as a "progressive but recursive" process (Braun & Clarke, 2022, p.36). Therefore, during data analysis, a researcher may move back and forth between the six-stages.

Table 5
Six Stages of a RTA (Braun & Clarke, 2022)

|    | Phase of      | Outline of Stage                          | Researcher Action              |
|----|---------------|---|--------------------------------|
|    | Analysis      |   |                                |
| 1. | Familiarising | This is where the researcher becomes      | The researcher familiarised    |
|    | yourself with | deeply familiar with the data, through    | themselves with the data       |
|    | the dataset   | the process of immersion. This involves,  | through transcribing the data  |
|    |               | reading and re-reading transcripts, and   | and re-listening to interview  |
|    |               | writing notes which highlight the         | recordings. The researcher     |
|    |               | researchers' insights. This is related to | also created familiarisation   |
|    |               | each data item and data set.              | doodles to further immerse     |
|    |               |   | themselves in the data         |
|    |               |   | (Appendix J).                  |
| 2. | Coding        | This is where the researcher              | The researcher generated       |
|    |               | systematically works through the          | codes through systematically   |
|    |               | dataset. The researcher then identifies   | working through the nine       |
|    |               | significant and meaningful segments of    | transcripts. Information which |
|    |               | the dataset which is relevant to the      | appeared relevant to the       |
|    |               | research question. Analytically           | research questions were        |
|    |               | meaningful descriptions are made,         | coded using the 'comment       |
|    |               | which are known as codes. The codes       | feature' on Microsoft Word.    |
|    |               | are specific, which are aimed to capture  | This allowed the researcher to |
|    |               | single meaning.                           | highlight relevant text and    |
|    |               |   | write codes alongside the      |
|    |               | With RTA, coding can occur across         | , , , , ,                      |
|    |               | different levels. This can range from     |                                |
|    |               | explicit to implicit. This stage is not   | •                              |
|    |               | about summarising data, it is about the   | ·                              |
|    |               | researcher's analytical take. The         | summarising the data but       |
|    |               | researcher then collates their code       | reflecting on their analytical |
|    |               | labels and assigns segments of data for   | take.                          |
| _  |               | each code.                                |                                |
| 3. | Generating    | This is where the researcher finds        |                                |
|    | initial       | shared patterns amongst the datasets.     | from Microsoft Word to         |
|    | themes        | The researcher then compiles a group      | Microsoft Excel by using the   |
|    |               | of codes which share similar concepts,    | Word Macro function            |

which aims to answer the research question. This is an active process, where themes are developed based on the research questions, the dataset and the researcher's own knowledge. Codes capture more specific meaning, whereas themes are broader.

(Appendix L). Each participant was given their own Excel tab the codes could be organised by participant, and by research question. Cluster codes were created on a new Excel tab so broad patterns and initial themes could be created. Codes were provisionally placed under theme headings and could be freely moved due to the flexibility of using Excel (Appendix M). Mind maps were also created by hand to initial themes review the (Appendix N).

Developing and reviewing themes

This is where the researcher checks the initial themes and ensures they make sense in relation to the coded extracts and full dataset. It is crucial to consider whether the themes highlight important patterns in relation to the research question. During this stage, some themes may be merged, split into new themes, or discarded. At this stage it is important for the researcher to consider the relationship between themes, knowledge which exists and the wider context of the research.

This is where the researcher ensures their themes are well defined. At this stage, a brief synopsis is written for each theme. If redefining of themes is still occurring, this suggests more

development is needed.

Themes were re-checked and refined by reviewing the code cluster groups and the entire data set.

Theme names were finalised at this stage and descriptions were written for each one. Thematic maps were also created.

 Refining, defining, and naming themes

## 6. Writing up

This is where the researcher aims to tell The findings of this study were the reader a coherent story about the dataset and how it answers the research question. This includes an introduction, method, and conclusion section.

written up by considering data extracts (direct quotes from transcripts) and using analytical narrative. Α selection of data extracts were to encompass used themes and represent the participants narratives.

The researcher decided to undertake a separate RTA for each research question. This was for several reasons. The researcher felt that their four research questions were exploring different elements of a phenomena (SOSB). This approach ensured that concepts remained clearly defined rather than being merged into a broader, generalised interpretation. Additionally, analysing the questions individually allowed for the development of more nuanced and refined themes, offering a deeper exploration of each participant's experiences.

Although considered, other methods such as Interpretive Phenomenological Analysis (IPA) were not used. IPA has many strengths, such as using clear procedures and being able to focus on individuals lived experiences (Braun & Clarke, 2013). However, there were some limitations which led the researcher to choose RTA instead. For example, the final sample consisted of nine participants. Using RTA allowed the researcher to identify and analyse themes across the dataset, giving a rich and broad understanding of parental perspectives (Braun & Clarke, 2013). IPA is better suited to smaller samples; however, Parker (2005) suggests it can lack sophistication and substance due to this. Furthermore, RTA allows a reflexive approach, whilst also acknowledging how the researchers' interpretations and social constructs shape the analysis (Braun & Clarke, 2022). This is in line with the researcher's dual role of being a researcher and a TEP, as well as considering their epistemological positioning of social constructivism. IPA also considers participants lived experiences, but limits opportunities for the researcher to consider wider social contexts (Braun & Clarke, 2022). Although RTA and IPA have many similarities, such as coding and the development of themes, it was felt that RTA was best suited to the current project.

# 2.3.9 Research Quality and Researcher Reflexivity

When completing research, it is essential that attention is paid to ensuring rigour. The researcher took multiple steps to ensure the RTA was completed to a high standard. Firstly, the researcher closely followed the steps and guidance from Braun and Clarke's (2022) book, 'Thematic Analysis, a Practical Guide'. Furthermore, guidance was followed from Braun and Clarke's (2006) '15-point checklist of criteria for good thematic analysis' (Table 6).

**Table 6**15-point Checklist of Criteria for Good Thematic Analysis: (Braun & Clarke, 2006)

| Step of RTA   | tep of RTA Criteria |                              | Researchers Assessment                  |  |
|---------------|---------------------|------------------------------|---|--|
|               |                     |                              |   |  |
| Transcription | 1                   | The data has been            | The transcripts were carefully read     |  |
|               |                     | transcribed to an            | through by the researcher and checked   |  |
|               |                     | appropriate level of detail, | against the interview recordings to     |  |
|               |                     | and the transcripts have     | ensure they were accurate. Three of     |  |
|               |                     | been checked against the     | the transcripts were reviewed by the    |  |
|               |                     | tapes for 'accuracy'.        | participants.                           |  |
| Coding        | 2                   | Each data item has been      | Each transcript was reviewed            |  |
|               |                     | given equal attention in the | individually and was read multiple      |  |
|               |                     | coding process.              | times. Familiarisation doodles were     |  |
|               |                     |                              | developed for each transcript to allow  |  |
|               |                     |                              | the researcher to become immersed in    |  |
|               |                     |                              | each transcript before considering      |  |
|               |                     |                              | codes.                                  |  |
|               | 3                   | Themes have not been         | Codes were transferred from Word to     |  |
|               |                     | generated from a few vivid   | Excel to then develop themes. When      |  |
|               |                     | examples (an anecdotal       | creating cluster codes, the researcher  |  |
|               |                     | approach) but, instead, the  | ensured that each cluster had a         |  |
|               |                     | coding process has been      | sufficient number of examples before    |  |
|               |                     | thorough, inclusive, and     | being considered as a theme. For        |  |
|               |                     | comprehensive.               | example, if one cluster group only      |  |
|               |                     |                              | consisted of information from one       |  |
|               |                     |                              | participant, this was not considered as |  |
|               |                     |                              | a theme.                                |  |

4 All relevant extracts for each theme have been collated.

Relevant codes and themes were collated on Microsoft Excel.

5 Themes have been checked against each other and back to the original data set. Each theme was checked against other themes, as well as the original transcript.

6 Themes are internally coherent, consistent, and distinctive.

Themes were thoroughly checked to ensure they were consistent and distinct. This was also done through mind maps and thematic mapping to see if any similarities arose between themes.

### **Analysis**

Data has been analysed rather than just paraphrased or described. Data was analysed, cluster codes were created which led to themes. These were reviewed and amended throughout the analysis process.

8 Analysis and data match each other – the extracts illustrate the analytic claims.

Themes have been organised by research question and have been accompanied by direct quotes from the data.

9 Analysis tells a convincing and well-organised story about the data and topic. Themes have been organised by research question and have been accompanied by direct quotes from the data.

10 A good balance between analytic narrative and illustrative extracts is provided. Themes have been organised by research question and have been accompanied by direct quotes from the data.

Overall

11 Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-

over-lightly.

Sufficient time was given to each stage of the TA, including time to develop familiarisation doodles, transcribe data and develop codes and themes.

Written report

- 12 The assumptions about the thematic analysis are clearly explicated.
- 13 There is a good fit between what you claim you do, and what you show you have done i.e., described method and reported analysis are consistent.
- 14 The language and concepts used in the report are consistent with the epistemological position of the analysis.
- 15 The researcher is positioned as active in the research process; themes do not just 'emerge'.

The researcher has outlined their understanding of thematic analysis within the methods section.

The described method is consistent with what was written up in the researchers' findings.

The described epistemological position is consistent with what was written up in the researchers' analysis.

Data was analysed, cluster codes were created which led to themes. These were reviewed and amended throughout the analysis process.

In terms of reflexivity, it has been highlighted by Braun and Clarke (2022) the importance of the researcher reflecting on the relationship between analytic practices, such as theoretical underpinnings of the research, and using thematic analysis reflexively, deliberatively, and knowingly. Throughout the research process, the researcher kept reflexive diary entries. A reflective or reflexive journal entry is a way of documenting thoughts, reflections and meaning making during the data analysis period (Braun & Clarke, 2022). There is no set way to complete a reflexive journal, such as what content to include and how frequently to write, however it should be used to reflect and record initial thoughts you may be having in relation to the data (Braun & Clarke, 2022).

## 2.4 Findings and Discussion

An RTA was used to analyse the data to answer each research question. Within this section, the key themes from the RTA will be presented alongside relevant quotations from the interview transcripts. The overarching research question for this project is 'how do parents of children with DS perceive and value their child's sense of school belonging?'. This was

answered using four sub questions. Individual RTAs were conducted to answer each research question.

This section will present findings in relation to each of the research questions. The findings will be explored in an integrated format, drawing together participants' voices, interpretative analysis and connections to existing research as recommended for RTA (Braun & Clarke, 2022). By discussing each RQ in relation to existing literature, it offers a deeper understanding of each theme and its relevance to EP practice. It must be noted that although relevant studies will be referred to within this section, this is only a selection, and additional data exists beyond what is presented within these findings. For a thematic map of the overall themes and subthemes, see Figure 3.

Figure 3

Overall Findings

## How do parents of children with Down's syndrome perceive and value their child's sense of school belonging?

How important was school belonging What do parents see as the key What do parents see as the key How do parents conceptualise sense to parents when choosing their factors that support their child's barriers to their child's sense of of school belonging for their child? child's school placement? sense of school belonging? school belonging? The role of belonging in school choice **Relationships and social connections** Lack of classroom adaptations • Exclusion from the classroom • Belonging as the foundation of school choice •Relationships with peers Having equitable experiences Teacher attitudes, experience and ethos • Belonging as an implicit consideration · EHCP not being followed •Relationships with adults More than academics Feeling known, valued and understood • Having understanding and acceptance from Worry and anxiety related to school choice Inclusive adaptations and adjustments Access and inclusion to extracurricular activities others Being valued and recognised Being familiar with the school environment **Navigating school options** School ethos and attitudes Parental involvement Lack of understanding and support for individual It's complex and individualised Staff attitudes **Extracurricular activities** needs The role of the parent Advocacy and support •Communication and partnership with the school

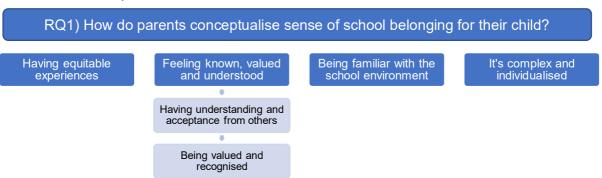
Child's personal skills and attributes

## 2.4.1 RQ1: How do parents conceptualise sense of school belonging for their child?

This RQ aims to explore how parents of children with DS actively define and construct SOSB based on their experiences. The below thematic map (Figure 4) highlights the themes and sub-themes for RQ1.

Figure 4

RQ1 Thematic Map



For RQ1, four themes were established through the RTA. For one theme, 'feeling known, valued and understood', two further sub-themes were established. The following section will individually discuss each theme and sub-theme in relation to RQ1. It must be highlighted that although each theme is discussed separately, the themes are interconnected.

#### Theme 1: Having equitable experiences

Theme 1, 'having equitable experiences' highlighted how parents felt that having the right support in place at school enables their child with DS to progress and achieve. Several participants referred to the idea that their child may need adaptations in the classroom and further support to achieve equal outcomes as other children in their class. Despite this additional support, their child has the right to be at their school alongside their peers.

Amelia: "Adaptations being made so that they get an equitable experience".

**Natalie:** "...with the understanding that they will need more support and help probably than other children".

**Natalie:** "In terms of feeling like they're a part of the school and, you know, have a right to be there as much as any other child. But it's with the understanding that their support and their education within that will be probably quite different".

**Lucy:** "...but I suppose part of that is having the right support in place".

This highlights that for some parents, providing the specific support their child needs to access learning, reach their full potential, and experience similar outcomes to their peers is an important element of school belonging.

Other participants referred to their child being actively included in their school and feeling the same way as their peers. This should be an active effort made by school, rather than it being an additional thought.

**Natalie:** "I think it means...just being the same as all the other pupils at the school. Being included and accepted in the same way...as much as is possible".

**Lydia:** "I'm really kind of pro inclusion. So, I feel like however that could be done...max inclusion to the max really, rather than just being an afterthought. But as far as possible I think it means that they should feel the same as any other child going to school".

These quotes highlight parents' beliefs that their child having access to the same opportunities as their peers plays a crucial role in fostering a SOSB. A review of the literature reveals that, while commonly used definitions do not directly address equitable experiences, the concept of inclusion is frequently highlighted (Goodenow & Grady, 1993; Shaw, 2019). Inclusion refers to the practice of educating CYP with SEN alongside their mainstream peers (Frederickson, 2007). However, this definition overlooks the necessary adaptations required to ensure that CYP with SEN can be successfully and meaningfully integrated into such environments. Goodenow and Grady's (1993) definition does not directly touch on equitable experiences, but their definition implies the importance of inclusion, which can be related to equitable classroom experiences. Shaw (2019) also included inclusion within their definition; however, this focused more on social inclusion rather than academic inclusion. Earlier authors, such as Dewey (1938), highlighted the significance of supportive classroom environments, which aligns with the perspective of the current study, that CYP with DS need appropriate support to experience an equitable education.

#### Theme 2: Feeling known, valued, and understood

This overarching theme highlights how SOSB encompasses being known by staff and children at school and being treated as a valued member of the school community. It is also important that the needs of children with DS are understood by others.

## <u>Subtheme 1: Having understanding and acceptance from others</u>

This sub-theme emphasises the importance of both teachers and peers knowing, understanding, and valuing children with DS, which contributes to their SOSB.

Many participants referred to people in their class supporting and accepting their child, as well as being included into the wider school.

**Lucy:** "If I go back to when she started school, what I wanted for her was to feel accepted and included and part of the school...part of her class, but part of the wider school".

Jessica: "It means that it's a place that she feels part of a place, that she's welcome"
... "A place that she's kind of warmly greeted and included in".

From discussions with parents, it was felt that a SOSB meant that their child felt welcomed and included in the school setting. For Lucy, this was a hope for them before their child started school.

Other participants reflected on the importance of being personally accepted for their sons SOSB. They highlighted that she felt that her son knew he was accepted at school due to his excitement.

**Victoria:** "I think personally accepted. I think he would feel that because he gets excited, he enjoys the experience because they accommodate his needs a lot. Being a special school, that's their main thing is you know how to create an environment which is conducive to learning".

Another participant raised the idea that respect from peers and teachers was a crucial element of SOSB. Olivia felt that although her son was only six years old, she felt that he would be able to understand whether he was respected in school or not.

**Olivia:** "I suppose he's only little, but I think that is important. And I think even at the age of six, you can recognise how well respected you are by your peers or by your teachers".

Several definitions of SOSB refer to the idea of acceptance, such as Goodenow and Grady (1993). They reference acceptance and respect, which suggests that children need to feel understood and valued to belong to their school. This is also similar to Willms' (2000) definition which highlights that attachment to a school requires a child to feel valued and accepted by their peers.

Baumeister and Leary's (1995) work does not explicitly discuss acceptance; however, their definition emphasises the necessity of strong, meaningful, and consistent interpersonal bonds for fostering belonging. These bonds must be frequent and positive, suggesting that acceptance and respect are inherent aspects of this definition.

Lalvani's (2013) study, which involved interviews with 19 mothers of children with DS, supports these ideas. The mothers expressed a desire for their children to feel a SOB to their educational settings, emphasising the importance of unconditional acceptance from both teachers and peers. These findings, alongside the current results, highlight the critical role of acceptance and understanding as integral components of school belonging for CYP with DS.

#### Subtheme 2: Being valued and recognised

The second subtheme highlighted the importance of children with DS being valued members of their school. This subtheme emphasises the need for children with DS to be appreciated, celebrated, and treated as equally important as others.

Amelia shared that it was important that SOSB meant that their child was liked and enjoyed by people at school, and this was important for their child's self-esteem.

**Amelia:** "I think just sort of being liked and I know it may sound a bizarre one, but just sort of like being enjoyed as a part of their experience, so that they're sort of taking that away for their self-esteem as well".

This finding is in line with previous research which has investigated the positive implications associated with SOSB. This includes Prince and Hadwin's (2013) study, which found that when SOSB is met, it can lead to positive developments in social aspects, behaviour, academic achievement, and emotional regulation for CYP with SEN. This

highlights that for CYP with DS, their self-esteem could be increased because of SOSB being met.

Both Amelia and Olivia referred to their child being recognised in school, just like any other child would. It was also highlighted that their child should be celebrated for their achievements.

**Amelia:** "I feel that it is about having a voice within the school, being sort of recognised and celebrated as much as other people within the school".

Olivia: "I think a feeling that he's valued as much as every other pupil and that he wants to attend and that he's seen in his own right".

The idea of being valued and celebrated mirrors several definitions of SOSB. This includes Willms (2000), who suggested belonging included feeling valued by the school community. This is similar to Allen and Kern (2017) who also explicitly stated that school belonging included being valued by those in their school. Other definitions, such as Shaw's (2019), reflected on the idea that school belonging included what other people do to make them feel they belong. Although this does not state the idea of being valued, it could be interpreted that by receiving recognition from other people, it means they are valued.

#### Theme 3: Being familiar with the school environment

The theme 'being familiar with the school environment' highlights how parents feel that their child being aware with the school's setting, routines, and layout is an important element of SOSB.

Victoria discussed that for her son, it is important for his SOSB to want to go to school and feel excited about the prospect of going. When discussing school during the half-term, Victoria felt that her son understood the idea that he would be returning to school soon.

**Victoria:** "I think it kind of overlaps with being happy, kind of feeling like they want to go to school or they know the school name".

**Victoria:** "Cognitively he's about four years old in his mind. So, for him it's very simple in terms of like...this morning, I'll give you an example...because we've been on half term,

we're saying, oh, we've got school next week, you know? But obviously today he didn't and he was really excited about going to school because he's recently moved there".

Natalie, Victoria, and Daniel touched on the idea that SOSB was related to the regularity related to attending school, including being familiar with the name of the school, staff, and peers, as well as understanding that it's a location their children regularly attend.

**Natalie:** "I think if you're talking about a sense of belonging...the familiar faces and familiar routines that come with sort of having a consistency of members of staff. It's not to be underestimated".

**Victoria:** "He knows the school name, he can name his teacher, he can name other students in his class".

**Daniel:** "So it's very basic. It's an understanding that it's a location where she goes every day" ... "It's more like the place, the people and the regularity".

When reviewing current literature which explores SOSB definitions, it is suggested that being familiar with the school environment does contribute. Many definitions focus on the relationships pupils have in the school as well as the idea of feeling connected and comfortable at school. Research has suggested that factors such as being proud of being a part of your school, as well as also having an enthusiasm and enjoyment towards school are part of SOSB (Libbey, 2004).

Other definitions such as Baumeister and Leary (1995) focus more on interpersonal relationships. They perceive that for belonging to be met, consistent and positive interactions are needed (Baumeister & Leary, 1995). Although their definition is about belonging in a general sense, and does not discuss the idea of familiar environments, it could be argued that by having consistent relationships with adults at school, this could build up a child's familiarity to the school environment.

Interestingly, none of the participants placed a strong emphasis on specific relationships when defining SOSB. Instead, their focus was about how their child is treated within the school environment, particularly being valued, and accepted. While many theories and definitions of belonging highlight the importance of reciprocal, strong, and ongoing relationships (Baumeister & Leary, 1995; Shaw, 2019), this theme did not emerge in the current research. One possible explanation is that much of the existing literature centres on

the views of CYP (Shaw, 2019), whereas the present study reflects the perspectives of parents. This suggests that current models of belonging may need to be broadened to include the viewpoints of parents or school staff. Additionally, it may have been an assumption from parents that positive relationships are within an inclusive, accepting, and respectful culture.

## Theme 4: It's complex and individualised

This theme acknowledges that SOSB is not a one-size-fits-all concept, and that it may need to be adapted for different children, considering their unique needs and experiences.

Some participants reflected on the idea that SOSB may be an abstract concept for their child with DS and they may struggle to define it themselves. Instead, parents understood that they may view SOSB differently to how their child might perceive it.

**Daniel:** "This is slightly too theoretical, and I don't think...yeah, there are lots of elements of it...personally accepted, yes, but I don't think she...our child with Down's syndrome would necessarily conceptualise that".

**Daniel:** "So that's kind of...that is where I would use it, but not in like in any way with when we interact with REDACTED NAME".

**Lucy:** "It's a difficult one to answer because I don't really know. Like if I asked her that, she wouldn't understand that question [to define SOSB]. So, I can only answer it from my point of view I suppose really...what I would want for her".

Previous research has also acknowledged that parents may hold different views to their children. For example, Ijezie et al., (2023) found that when they interviewed parents who have children with DS, their views differed to their children, with parents typically holding more negative perceptions. In this case, several parents referred to their child potentially not being able to understand the concept of SOSB or the idea that popular definitions would be too theoretical. Therefore, it must be highlighted that if CYP with DS were asked to define SOSB, their understanding of the question and answer may differ to their parents' responses.

Jessica discussed that standard definitions, such as ones by Goodenow and Grady (1993) may not apply to all children, and wider factors could be involved which affect elements of SOSB, such as their behaviour. It was further shared that concepts such as SOSB might want to be considered as a spectrum, rather than a set concept.

**Jessica:** "I think that's really important" ... "It's not going to be universal probably for all kids in some senses. It's obviously a massive worry as a parent of a kid with a disability that she's not going to be respected and...I think generally she is respected, but I wonder if this is sort of slightly less...I think it gets difficult when behaviour gets difficult" ... "It's a bit of a spectrum perhaps".

This mirrors research which highlights that belonging can be multi-faceted and complex (Cartmell & Bond, 2015). It could be suggested that the idea of SOSB is a social construct, which encompasses a range of factors, which can be subjective depending on who you ask (Shaw, 2019).

Although SOSB and inclusion are two differing concepts, they share some commonalities. Researchers such as Barton (2005) suggests that inclusion is an ongoing process which encompasses the wellbeing of students. Although this does not refer to SOSB directly, it is interesting to note that inclusion can be seen as an ongoing concept, which is in line with the idea that the current findings suggest that SOSB could be seen as a spectrum, which can change depending on the context the child is in.

# 2.4.2 RQ2: How important was school belonging to parents when choosing their child's school placement?

This RQ draws on parent's own constructed views of SOSB, and whether this influenced how they selected a school for their child. The below thematic map (Figure 5) highlights the themes and sub-themes for Question 2.

Figure 5

RQ2 Thematic Map



For RQ2, four themes were established through the RTA. For one theme, 'the role of belonging in school choice', three further sub-themes were established. The following section will individually discuss each theme and sub-theme in relation to RQ2. It must be noted that although each theme is discussed separately, each theme is interconnected.

## Theme 1: The role of belonging in school choice

This theme captures the idea that SOSB was a consideration for parents when selecting schools for their child. For some, this was a bigger consideration than others. Some parents considered factors beyond academic achievement.

## Subtheme 1: Belonging as the foundation of school choice

This subtheme highlights that parent's prioritised their child's SOSB when making school placement decisions. For some parents, SOSB was an important factor, and it was felt that once that was established other aspects will follow.

When asked if participants felt that SOSB was an important factor when considering their child's school placement, many parents agreed.

Charlotte: "Yeah. I thought about what she'd be like".

Amelia: "It's just a big fat yes to both".

Natalie: "It was something that I was quite conscious about as a new parent".

Lucy: "Yes, I'd say yes, yeah".

As highlighted by Lydia, SOSB was a central element when considering a school placement for their child. They reflected that if school belonging wasn't considered as being important, this could lead to negative implications such as schools not wanting to collaborate with families or being considered as a hinderance.

Lydia: "I think 100% that was what was going on. I wanted more than anything for her to be made feel welcome because if we haven't even got that initial feeling of being wanted, then there was no point. It was no starter for me because there's no point going to school where they don't want you because it's just not going to work, they're not going to want to collaborate with you or provide the best for the child. They're just going to be seen as a nuisance or a hindrance or a drain on the budget from day one".

For Amelia, they were also in agreement that SOSB was an important factor in school choice. Both Amelia and Lydia reflected on the implications associated with SOSB for their child with DS. They highlighted that if school belonging is met, then positive outcomes will follow, and everything else is considered secondary.

**Amelia:** "Friendships and that sense of belonging probably was the most important thing because everything else then follows, if it's kind of, if you're happy and if you look forward to going somewhere every day, then the rest is easier, isn't it?"

**Lydia:** "My most essential criteria going through all the schools was that she was wanted and that they were willing to provide her with the right support, which was a one to one. And then after that, everything was kind of secondary".

Natalie considered how they could ensure that their child's SOSB was met before they started school. This was through the family being a part of the local community, such as toddler groups, so relationships could be formed with other families. It was considered important for her daughter to establish her own identity, rather than being defined solely by her diagnosis of DS.

**Natalie:** "Ensuring that she was included in things like the village toddler group and local sort of play activities so that other families would get to know us so and then sure enough

when they went to primary school there were a lot of children there who already knew REDACTED NAME" ... "Therefore, it wasn't a surprise, you know, this child's acting a bit differently, or you know, we're not familiar with that behaviour. I personally tried to eliminate a lot of that by making it so that she was just herself and not this child with Down's syndrome".

Jessica also considered SOSB to be an important element when considering a school placement for her child. They raised the idea that it was also important for themselves as a parent to feel connected to the school, and this will further promote SOSB for their child.

**Jessica:** "Although it's a big mainstream primary it does have a really strong sense of community and I guess partly through me feeling connected to it...you know that will drip feed to my kids and bolster their own sense of connection".

As discussed previously, there is a lack of research exploring parental views and school choice, especially when considering CYP with DS. However, studies which have explored parental views and school choice more generally have found similar findings. Studies such as Cantu et al., (2021) found that although parents acknowledged academic reputation as an important factor in school choice, school culture and SOSB were also a crucial element. By ensuring a school promotes a SOB, it allows parents and students to feel more respected and appreciated (Cantu et al., 2021).

Researchers such as Satherley and Norwich (2021) explored the views of English parent's and their decisions about SEN school placements. One of the top three factors which were considered by parents when selecting a school was inclusive education (Satherley & Norwich, 2021). Although this does not refer to SOSB directly, the authors noted that parents felt that high-quality inclusive education meant that their child experienced SOB to their class and school, as well as social acceptance by peers (Satherley & Norwich, 2021).

This highlights that although previous studies have explored parental school choice in a general sense, similar findings were found in the current study when interviewing parents who have children with DS. Although parents in the current study chose both mainstream and SEN settings for their children, SOB was considered as an important factor in school choice, despite the chosen type of setting.

#### Subtheme 2: Belonging as an implicit consideration

This subtheme highlights that some parents valued belonging, but it wasn't always a central factor in their school choice.

Olivia: "Although maybe I didn't perceive it [school belonging] as such when we were doing that, but yes, definitely we looked around mainstream and special schools because at the time we weren't really sure what level of learning needs he had, or you know what would be suitable".

**Victoria:** "That [school belonging] was definitely one part...I think it was also about...how they would meet his kind of needs? How do they change the curriculum? But I think, yeah, belonging, I mean it's always promoted".

**Daniel:** "I would probably say yes and no. So, we didn't when we went, we didn't kind of set out to say, OK, this is a school where she personally would belong, but it was definitely part, I would say".

For these participants, it appears that school belonging was an important factor in school choice in hindsight, however at the time, this was not an explicit factor.

Previous research has found that parents consider SOSB when selecting school placements for their child (Cantu et al., 2021; Satherley & Norwich, 2021). However, in the current research, some parents acknowledged that SOSB was an important factor, but, it was not central in their decision. Instead, parents considered inclusion more generally, such as questioning how the school would meet their child's needs. This is in line with previous research, which found that parents valued the school atmosphere, the schools caring approach to pupils and the size of the classroom (Satherley & Norwich, 2021). Similarly, Bagley et al., (2001) found that parents who chose SEN secondary schools for their children valued how the school would meet their child's needs. The current research study suggests that SOSB is an important factor in school choice, amongst other considerations.

## Subtheme 3: More than academics

This subtheme highlights that when considering school placements for their children with DS, parents prioritised life skills, independence, and overall well-being over academic outcomes.

Some parents discussed the idea of choosing between a specialist provision or mainstream placement for their child. For these parents, the development of independence and life skills were important factors in choosing their child's school placement.

**Charlotte:** "She's gonna learn more life skills in a SEND school because they're more equipped" ... "And in the mainstream, she wouldn't learn those life skills because it is all academic. So that's what made my mind up in the end".

**Amelia:** "But it's part of the reason for me that I chose a SEN placement for secondary as I wanted to work towards her reducing her dependence on the adults in the situation, and actually sort of being in the position where everything is set up so that she has the best possible chance of independence".

Difficulties between choosing mainstream or SEN school options for parents of children with SEN have been cited within research (De Graaf et al., 2013). Early literature found that there were differences in what parents valued depending on what school they chose for their child (Jenkinson, 1998). It was found that parents who chose a SEN school for their child had a preference for independent living programmes, smaller classes and better teacher qualifications (Jenkinson, 1998). Whereas parents who chose mainstream options for their children with SEN valued academic support and choosing a school where their other children attended (Jenkinson, 1998). The idea of promoting independence and life skills was also highlighted in the current study. It must be noted that although elements of Jenkinson's (1998) findings align with the current study, due to being conducted in the late 1990's in Australia, it does not reflect the current legislative context and guidance which is promoted in the UK. Since the SEND Code of Practice (2014), there has been a shift in educational practices and promotion of inclusive attitudes towards CYP with SEND, regardless of whether they are educated within a mainstream or SEN setting.

Amelia and Victoria reflected on the idea that although it was important to encourage academic success, for these parent's it was not an important element when considering their children's school placement. Instead, factors such as the school celebrating other strengths or forming strong relationships was more significant.

**Amelia:** "I never put a limitation on her ability to achieve academically, however, that was not...it kind of wasn't even on the list" ... "You could see that they [the school] celebrated way more than academic achievement and they still do".

**Victoria:** "How we would feel part of that community definitely was a factor...because it isn't obviously with special needs children...the academics is small compared to all the other kind of elements of school life. It features probably, it does feature, but it's not a big feature. I would say sense of school belonging and curriculum and just if they're going to make those relationships. I think that's more of a priority, I would say, than the academic part".

Other participants shared that it was important for their child to enjoy the experience of going to school and felt that they were part of a group.

**Victoria:** "It was really important that he enjoyed and he felt good about going to school and he felt like he enjoyed the experience and felt part of a little group".

Lucy shared that they also considered their child's sensory needs and reflected their experience of looking around potential schools. It was highlighted that although the school and staff appeared to be welcoming, the sensory environment might have been a barrier for their child.

**Lucy:** "She has, like, some sensory issues. It was very noisy. Just the acoustics and everything. I just thought it's [prospective school] nice. But I don't think it's right".

This finding mirrors what has been found in previous literature. For example, Kendall (2019) who interviewed parents who have children with DS found that when considering school placements for their child, positive staff attitudes were considered important by all participants. This highlights that parents consider a range of factors when making decisions about school choice, rather than just considering academic outcomes.

#### Theme 2: Worry and anxiety related to school choice

This theme reflects the idea that many parents experienced significant stress and anxiety when deciding on the right school for their child.

Both Charlotte and Amelia spoke about the stress associated with deciding whether to send their child to a mainstream or SEN setting. They reflected on the benefits of both options, but felt they had to do what was best for their child's individual needs.

**Charlotte:** "I didn't really sleep for three months 'cause. I was like, what do I do? Do I send her? 'Cause I wanted the social side, but then I had to look at the academic".

Amelia: "It was a real internal debate as to whether I sent her to mainstream or SEN...I think there are great strengths with both and it's sort of ultimately it had to come down to what was available locally that was going to be the best option for her".

Other participants also highlighted the worry they experience when faced with making decisions about their child's school placement.

**Jessica:** "I mean, worrying about it [school choice]... would have probably been more how it manifested at that point".

Lydia highlighted that even after the decision was made about their child's school placement, they still experienced concern about how their child would be perceived at their new school.

**Lydia:** "It was all a little bit oh, you know, is this going to be the right thing? And how will people and parents and children react? This child coming into this environment, you know, will she have friends? Will they bully her? Will they make fun of her? And as we progress through the years, is that going to be more difficult?".

Parent's feeling overwhelmed by school choice has been echoed in previous research. For example, Hutcheson (2018) discussed that parents of children with SEN have different experiences of choosing a school placement in comparison to parents who have children who are typically developing. Hutcheson (2018) highlighted that navigating school options for CYP with SEN can be overwhelming and isolating for parents. It was further noted that LAs need to consider how different professionals can support parents in choosing a suitable school placement for CYP with SEN (Hutcheson, 2018). Similar findings were discussed by Grieve (2012), who found that parents reported feelings of conflict and confusion when deciding which provision would be best for their child with SEN. Similar feelings were recorded by Podvey et al., (2010) when parents of CYP with SEN were asked to reflect on their experiences of navigating the transition from pre-school to primary school. As highlighted by the current research, further support is needed for parents when selecting schools for their children with DS.

#### Theme 3: Navigating school options

This theme highlights that some parents explored a range of schools and provisions to find the best fit for their child's needs while balancing practical and personal considerations. Whereas others felt their local school would be the best option for their child.

Many parents visited a range of schools to help them make the decision about their child's school placement, as highlighted by Charlotte.

Charlotte: "I did go and look at two mainstreams and the SEN school".

Daniel also considered a range of school options for their child, including the school where their child attended nursery at the time. It was important that their daughter would be welcomed and accepted by staff. However, it was felt that the catchment school was not aligned with this view, which led the parent to consider different school options.

**Daniel:** "We just said, let's look at all the schools and there were some schools which we said that no, that's a waste of time because the leadership clearly is not like...she wouldn't be welcomed".

**Daniel:** "One part of that tribunal was whether she would be accepted and one of my kind of main arguments for why we rejected her catchment school was that she wasn't" ... "Although she had a very nice support lady in the nursery, we knew that the teachers wouldn't fully accept her".

Amelia considered local school options for their daughter. Although it was highlighted that the local school provided good provision for children with SEN, this would involve their child being removed from the classroom in order to gain support, which is not what the parent wanted.

**Amelia:** "It was just what's available to us locally was a very large mainstream school that had excellent provision. However, the provision would all be dependent essentially on her being removed from lessons or having one to one support in the lesson to achieve it".

Like Amelia, Lucy also considered the local catchment school for their child. Despite this being a popular option for the children in the immediate area, this parent instantly felt that their child would not belong if they were to attend there.

Lucy: "I went to see a few different schools and the area where we lived there is quite a few to choose from really, and I went to what seems to be the main one that, you know everybody's children seem to go to within our immediate area. I went there first and I immediately just didn't like it" ... "I didn't get a sense that she would belong. I didn't sense that she belonged or that they wanted her straight away and the more time we spent there, the more clear that became".

Both Natalie and Jessica highlighted that their local schools were their first options for their children, and there would have to be a significant reason for them to attend elsewhere.

**Natalie:** "I mean, the primary school, we're very lucky. We live in quite a small village, and we live very close to the primary school" ... "It would have had to have been a very good reason for her not to go there".

**Jessica:** "It's a bit of a fake question for us because that is our local school and we were adamant that, you know, unless there was a significant and obvious reason why she shouldn't go there, that's where she's going".

These findings are in line with current legislation. With the introduction of the Warnock Report (DES, 1978), children with SEN and DS were beginning to be educated, however earlier studies suggests that this would typically be in specialist settings (Buckley, 2000). However, in more recent years, CYP with DS are being educated in a range of different settings. Some studies have suggested that the majority of CYP with DS complete their primary education within mainstream schools, then approximately 20-25% of CYP with DS transition to a mainstream secondary school (Lightfoot & Bond, 2013). More recent findings share a similar message. Hargreaves et al., (2021) found that from conducting a survey with 569 parents of children with DS, 65% of pupils were educated in mainstream schools, however this was more common in primary (80%) than secondary (37%). Under Section 33 and 39 of the Children and Families Act (2014), a parent has a right to request a particular school for a child if they have an EHCP, including mainstream or SEN settings. Most participants reflected on the idea that they explored a range of schools for their child, including mainstream and SEN options, rather than having a set idea of where they would like their child to go.

Some parents shared that they ideally wanted their child to go to their local school, and there would have to be a good reason not to send them there. This is similar to Nuske et

al's (2019) findings, who found that school choice was dependent on the type of provision available, the child's individual needs and parent's own social backgrounds.

#### Theme 4: Staff attitudes

This theme encompasses the idea that parents considered staff's attitudes, ethos, and responses in determining whether their child would feel welcomed and included, and this played a part in school choice.

Most participants reflected on how they were made to feel by the SENCo and staff when they visited the school that they ended up choosing for their child. Amelia shared that they knew it was the right school due to how they were shown around, as well as staff's positive attitudes towards other students with DS.

**Amelia:** "The reason that I knew it was the right place was because of the way I was being shown around" ... "They were talking about another student that had been through the school that had Down's syndrome and what he had achieved and just their sense of pride".

Both Natalie and Olivia shared that they appreciated when staff would not only talk positively about children with SEN, but also consider how they would specifically support their child with DS.

**Natalie:** "One of the reasons we chose the school that we did was because when we originally went to see the SENCo...the way that she was talking to us about her expectations and sort of plan for my daughter to be in school...were very much in line with what we wanted for her as well".

**Olivia:** "The way in which the SENCo, or the headteacher, would approach when you talk about your child's needs, or how they might include them, or you know how they might consider their education and their social needs as well".

**Olivia:** "I think every child is so individual, so in a way, what they talk about possibly doing, it's good that they have ideas. But I think it's more of a sense of how they respond to your child individually and what they feel could be put in place or you know, so it's having that adaptability from their perspective as well".

Several participants shared that they took their child along with them to visit schools, and this helped parents to see how their child was perceived by staff.

**Lydia:** "I found along the way when I went to different schools in deciding which school I'd like my child to go to I had different kind of reactions when people met my child and it was really...you could tell straight off sometimes or it would come out when you've spoken to people".

**Daniel:** "The last time we went to see a school she came with us as well" ... "she would be running around and go and see places" ... "It's always a test when we take her to places, how much she's accepted. So that is a big thing".

Lucy: "Yeah, the lady that we met with, who was the SENCo at the school. She was very nice to me and she was quite willing to chat and answer my questions. And but...I took my child along with me to every school meeting because it was a year before she was due to start school, so I was being well prepared" ... "And she [the SENCo] made it feel like my child was a nuisance".

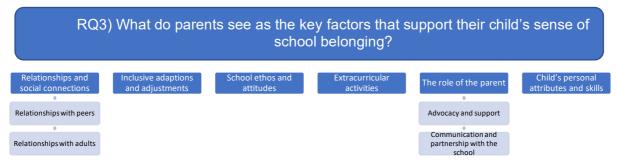
Staff attitudes affecting parental school choice has been previously cited in literature. This includes Kendall's (2019) findings, who found that parents who have children with DS considered positive staff attitudes to be an important factor when choosing a school for their child. Moreover, Satherley and Norwich (2021) found that the school's atmosphere and their caring approach to pupils were considered within the top three influencing factors for parents when choosing a school for their child. Considering previous literature and the current findings, staff attitudes can significantly impact parental school choice.

# 2.4.3 RQ3: What do parents see as the key factors that support their child's sense of school belonging?

This RQ explores participant's subjective views about facilitators of SOSB, which have been shaped by their own experiences. The below thematic map (Figure 6) highlights the themes and sub-themes for Question 3.

Figure 6

RQ3 Thematic Map



For RQ3, six themes were established through the RTA. For one theme, 'relationships and social connections', two further sub-themes were established. For another theme, 'the role of the parent', two sub-themes were also established. The following section will individually discuss each theme and sub-theme in relation to RQ3. It must be highlighted that although each theme is discussed separately, each theme is interconnected.

### Theme 1: Relationships and social connections

This theme highlights the importance of relationships, including peers, staff, and wider adults in school, and how they all play a part in promoting SOSB.

#### Subtheme 1: Relationships with peers

This sub-theme highlights the importance of peer interactions, such as having a buddy system, maintaining friendships, and being recognised as part of the wider school community. These connections help foster a SOSB and social inclusion.

Some participants felt that their children having peers was a contributing factor to their SOSB, as highlighted by Amelia.

**Amelia:** "The thing that's really key and that can sort of help carry you through 'cause if you know that you've got that sort of good peer support that's really vital".

Similar views were shared by Lydia. They reflected on the fact that their child also had a diagnosis of autism, as well as having DS. They highlighted that although their daughter

might not be as social as other children with DS, they still view peer interactions to be an important element of SOSB.

Lydia: "She definitely loves interacting, but she'll only like to interact with some people, but she does...she seems less fussed than maybe a typical T21 profile without being autistic" ... "I think it still is important to her and I think she's got recognition and awareness and that's certainly with special friends. She certainly seems to be a lot more...interacting with them and you know, even giving them a hug or something like that. So, she definitely has those kind of connections".

This is in line with findings from Ware (2020), who found that CYP with SEN who attended mainstream settings spoke about friendships being a part of their SOSB, however placed less importance on this in comparison to other factors. Moreover, findings from Gallagher Deeks (2023) raised the idea that some CYP with SEN develop friendships in their own way, which may not fit the stereotypical norm, however these friendships are still valuable. This is in line with Lydia's quote, highlighting that their daughter may be "less fussed" about interacting in comparison to other CYP with DS, however she has an awareness that she has special friends and connections.

Both Amelia and Natalie reflected on the idea that it is important for their child to have peers who are similar to them in some way. Amelia shared that their child attended a mainstream primary school but transitioned to a SEN secondary school. Although it was felt that she had some peers at primary, it became apparent at the secondary transition day that she had different interactions with peers who were similar to her.

Amelia: "She didn't necessarily have her peers there [at primary school]. She had some friends...there are people that we're still in touch with" ... "It was interesting when she had her transition day...and her TA went with her, and the TA said that she, just for that one day, was with a bunch of kids that we didn't know. She saw her interact in a completely different way that she had never observed within a mainstream environment".

Natalie also shared that their daughter had a friendship group at their mainstream school which comprised of children who also had additional needs.

**Natalie:** "There's definitely a peer group, that peer group that she spends more time with now. Now they're getting closer to GCSEs. But they have a range of additional needs and they've almost got their own little cohort within the year group. So, I guess the differences

have become a bit more obvious, but it's been kind of natural progression instead of going straight in, right, you're in that group, you're in that group, you're in that group."

This finding is consistent with previous research which has interviewed CYP with SEN directly. Culliane (2020) found that friendships and peer support was crucial to CYP's SOSB, specifically being included and accepted by their peer group. Similar findings were found by Smedley (2011) who interviewed CYP. As the current research focused on the views of parents rather than CYP directly, it is also important to consider findings which used proxy reporting methods. Lovell (2021) interviewed TA's who supported CYP with SEMH needs and found that they viewed having supportive and accepting friendships was crucial for CYP's SOB, which is consistent with the current study.

Some parents referred to their children being friends with similar peers, and how this was essential for their SOSB. This is in line with Miles et al's (2019) study, who found that CYP with SEN valued reciprocal, true friendships, with an emphasis on smaller meaningful friendships rather than being a part of larger groups. Lalvani (2013) interviewed parents who have children with DS, and they expressed that belonging included having unconditional acceptance from similar level peers.

Several participants referred to the importance of making wider connections with other children in the school and how this was beneficial for their child's SOSB.

Charlotte shared that their daughter who is in Year 5 was given opportunities to play with some of the children in Reception. This parent felt that this has been an enjoyable experience for their daughter due to the other children being excited to see her and this has increased her SOSB.

Charlotte: "Yeah, 'cause, I think it helps her feel special because I think it's reception. They mix them with...even though she is in Year 5" ... "She seems to enjoy being included in that and yeah, she'll definitely feel she actually belongs with them. Apparently, they all come over and there's about three little ones who gather around saying REDACTED NAME, REDACTED NAME".

Natalie shared that there have been opportunities for her daughter to gain academic support from the sixth formers in the school. This has led her to create a bond with them, leading to her to consider them as her friends.

**Natalie:** "For maths, getting some of the sixth formers to actually come and help the students that needed a bit of extra help. Again, you know, I think that that really helps. So, she would list them as friends, even though as an adult you kind of know...well actually they're not really. But that's how she would define it".

Olivia reflected on similar experiences, where their son was paired with a Year 6 pupil through a buddy system. This led their son to become a known member of the school where other children would know his name and say hello to him.

**Olivia:** "Last year he was in reception, they had a sort of buddy system with the Year 6 pupils, and he had an adorable buddy, but it meant that everyone in Year 6 got to know him as being a bit of a character".

The positive impacts associated with CYP with DS having opportunities to integrate with a wide range of children in their school has been raised in similar research. Culliane (2020) highlighted that CYP with SEN being a part of group projects or practical activities increases SOSB. By being a part of these activities, it can help to build connection, acceptance, and cohesiveness amongst students (Culliane, 2020).

### Subtheme 2: Relationships with adults

This sub-theme emphasises the role of teachers and school staff in supporting belonging. Consistent staff to build positive, trusting relationships with children with DS is crucial for emotional support and social integration.

Many participants shared that their child valued the relationships they have with adults in the school and would consider these to be friendships.

**Amelia:** "I think this is maybe where I see a difference between my daughter that has Down's syndrome and maybe her peers in that for her, the relationships with the adults have always felt more important to her than the relationships with her peers".

**Amelia:** "If there was some kind of event, if there was a school disco or something, you'd get the gaggle of friends and then REDACTED NAME would be seeking out the adults in that scenario for her sort of reassurance".

**Natalie:** "I'm very confident that if you asked her, she would say yes, she feels like she belongs there and it's a positive thing for her. And I think the staff really do have a lot to do with that, because if you say, oh, who are your friends at school or you know if you write down your friends she would list some staff, some support staff and some of her particular favourite staff members".

The idea that parent's perceived that their child with DS value their relationship with adults over peers has also been supported by previous research. Ware (2020) found that when interviewing CYP with SEN, some pupils rated their relationships with staff to be higher than their peers. Relationships with staff were highlighted as being of 'central importance' and was considered crucial for SOSB (Ware, 2020). Similar has been shown by both Amelia and Natalie, highlighting that their child sees their relationships with staff as important, and would consider them as being their friend.

Some participants shared that they thought that their child being known by adults in the school increased their SOSB, especially if they knew their name.

**Charlotte:** "They know the name of every child in that school. I don't know how, but they'll be walking down the corridor and they're like, hi. Hi. And saying their name".

**Natalie:** "The fact that the teachers all know her...she's like a minor celebrity in the school, you know and everybody knows her".

**Olivia:** "I mean, the whole school knows him by him, for good or for bad, but they all, say hi to him and wave at him, but it's really lovely actually".

Numerous authors have supported the notion that being known by staff is crucial for SOSB. This includes Smedley (2011) and Finnegan (2022), who found that pupils enjoyed when adults in school would talk to them, which led to them feeling accepted and affirmed. Similarly, Culliane (2020) highlighted that SOSB was increased when pupils found that staff took an interest in them as individual's and not just learners. This has been highlighted in the current study, that parents shared their children enjoy when staff make the effort to learn their name or say hello, outside of the classroom context.

Many participants spoke about the consistency of staff and how this has positively impacted their child's SOSB, particularly TA's.

**Natalie:** "I think if you're talking about a sense of belonging...the familiar faces and familiar routines that come with sort of having a consistency of members of staff. It's not to be underestimated".

**Olivia:** "But they've [TA's] made a massive difference to his learning as well as to his enjoyment being there".

**Lucy:** "But I think having those two ladies [1:1 TA's] and that consistency really did make her feel like she belonged at school. And she developed such a good, strong relationships with both of them. Yeah, that was all really good".

**Jessica:** "All credit to her and her TAs, I think they really deserve a mention because they are amazing and sort of supporting her to access the learning and navigate the social side. They, you know, you can tell they really deeply care for her".

The idea of staff being of central importance to SOSB has been mirrored by several authors. This has included Lovell's (2020) findings, highlighting that TA's felt that for SOSB to be built, staff need to make CYP feel valued and wanted.

Quantitative studies have highlighted similar findings. This includes relationships with teachers and TAs to be positively correlated with feelings of SOSB (Dimitrellou & Hurry, 2019; Finnegan, 2022). In both studies, relationships with teachers had stronger correlations than TA relationships. This is interesting to reflect on, as in the current study, all participants spoke in detail about the relationship and support their child receives from a TA. Minimal accounts were shared about strong relationships with teachers. Much of the literature exploring staff relationships and CYP with SEN's SOSB has mainly focused on teacher relationships (Culliane, 2020; Porter & Ingram, 2021). However, it must be noted that studies such as those by Dimitrellou and Hurry, (2019) and Finnegan (2022) did not control for factors such as how long the child had known their TA or teacher for, which may have impacted their findings. Research has highlighted that approximately 82% of CYP with DS have individual TA support (Van Herwegen et al., 2018), and a similar message was conveyed in the current study. Therefore, for CYP with DS, consistent TA relationships may be deemed more important for their SOSB in comparison to teachers, due to receiving a high level of TA support. Many participants shared that their child had received support from the same TA for several years.

Both Olivia and Victoria shared that wider members of staff also positively impacted their child's SOSB, including the school caretaker, receptionist, and transport support.

**Olivia:** "Like the caretaker waving to him in the morning and knowing his name and kind of walking him in and things like that, you know, sometimes it's those little things that make the biggest difference to his day-to-day life at school".

**Olivia:** "For example, that, you know, the lady at the reception desk at the front or the caretaker and the way that they know his name and chat to him like any other member".

**Victoria:** "The transport people who come with attachments and stuff like that, they have quite a role as well because obviously they travel with your child a lot and yeah, they basically have a role as well because they pick up your child and they drop them off".

This highlights that it is not just relationships with teacher's which increase SOSB for CYP with DS, but TA relationships and non-teaching staff are also deemed as crucial.

#### Theme 2: Inclusive adaptations and adjustments

This theme highlights the structural and practical adjustments that are needed to ensure children with DS are included in the classroom. It focuses on maintaining participation, spending time in the class, and integrating children while making necessary adaptations to ensure they can keep up with their peers.

Participants highlighted the importance of work being adapted and being able to academically keep up with their peers as an important element of SOSB. This also includes physically being within the classroom for the majority of the teaching content and receiving extra support when needed.

**Charlotte:** "That the work is adapted to her level and that she's feeling that she can keep up with the work".

**Daniel:** "Like one element within the class is that she is...the school tries to include her like even just physically as part of the class. So that is key".

**Daniel:** "Because she has her own assistant teacher, who obviously takes her out to certain sessions. So, she goes in and out. She sometimes goes to other kind of...a lower class, one year below and she has her own practise. And then sometimes joins the other main school".

**Jessica:** "I mean generally she does really well. And I would say on those times, she's probably in the class 80% of the time and she's kind of doing remarkably well and is kind of an age appropriate [level]".

The idea of adapted and accessible learning in the classroom being important for SOSB has been cited in literature. Alesech and Nayer (2020) found that acceptance and belonging was increased for CYP with SEN when they were included in classroom activities alongside their peers. Further findings found that academic support from teachers transformed CYP's views on their learning, which led them to achieve better grades, develop a love for a subject and feel happier, which is essential for SOSB (Culliane, 2020; Finnegan, 2022).

Many participants referred to teachers making non-academic adaptions for their child, and these have led to positive consequences for their learning and emotional wellbeing.

**Natalie:** "The school have been very good, and they acknowledge that in certain areas she does need more personal support, you know, in terms of nurture and caring and self-care and things like that. She still needs that".

Olivia: "I suppose I think they talked with us about how they want him to be part of the class and part of the classroom, learning as much as possible, but equally recognising that he has, you know, he might need sensory breaks or he has physical needs or he needs, you know, he doesn't eat very well. So, they're more than happy for him to be having his snack during phonics lessons or, you know, things like that, just being adaptable to his needs".

**Lydia:** "[The school are] very aware of her individual kind of sensory needs and how they have grown in trying to work around that kind of constraints, as it were, in trying to put her well-being first, you know in as much things as they can do".

**Jessica:** "She has less of an expectation for her to be on the carpet. I think she finds personal space difficult, so she's more likely to...you know, annoy people if she's on the carpet. So, they're good at relaxing and letting her sit at her table and have, like, fidget toys".

The current study has highlighted that it is important that teachers are aware of the individual differences of CYP with DS and make adaptations accordingly, which is essential for the development of their SOSB. This is similar to research by Alesech and Nayer (2020), who highlighted that it was deemed as important for teachers to have knowledge on how to

teach CYP with social and behaviour needs, as well as being aware of their specific disability in order to promote acceptance and belonging. This highlights the need for both academic and personal adaptations for CYP with DS.

### Theme 3: School ethos and attitudes

This theme explores the overall atmosphere of the school and the attitudes of staff. It highlights how a positive, inclusive ethos and supportive attitudes contribute to a child's SOSB.

Some participants felt that having a school ethos where their child is celebrated within school is crucial for their SOSB. This has led to their children feeling valued.

**Amelia:** "She's felt an amazing sense of belonging all the way through primary, and she really felt a big part of the school. And I think they have done a superb job in absolutely celebrating her in all of her glory and everything that she could bring".

Olivia: "A lot of it comes from the whole school ethos about inclusion and how to celebrate differences" ... "Even you know the attempts that he made with phonics or when he tries to look at books and sound out words or sounds, he got a certificate for that one week and he, you know, was called up in front of the whole assembly class. So, he was so proud. They said they celebrate his achievements in front of the whole school and they make him feel really valued".

The importance of celebrating pupils has been highlighted in previous research. Smedley (2011) found that rewards increased CYP with SEN's SOSB, such as being chosen for a certain job, showing the class your skills, or going up a level on a chart. It was found that children enjoyed the encouragement from teachers, which contributed to their self-esteem and social standing in the classroom (Smedley, 2011). Although similar findings were found in the current study, it was felt that participants reflected on the celebration of CYP with DS at a whole school level, not just at a classroom level. Therefore, this is an important distinction to reflect on when considering how to promote SOSB for CYP with DS.

Most participants touched on the idea that a positive and accepting school ethos plays a role in increasing their child's SOSB. Some participants believed that this needed to be initiated by Senior Leadership and then effectively communicated to other members of staff.

Olivia: "I think a lot of it comes from, you know, the people at the top, the headteacher and the SENCo having that ethos and spreading it throughout the staff members and throughout the school as well".

**Natalie:** "They can still have that ethos and I think, yeah, we talked about it initially. You know the attitudes of the school and the social, yeah, the sort of social environment where it's you know everyone treats everyone else the same regardless of how different they might seem".

**Natalie:** "I think probably that I think the way that the school treats her on a daily basis, so that's the school community as a whole. I think that is the most important thing because it's one thing of saying one thing at home but for then, if she were to go into school and experience something very different, then that that wouldn't really hold up. So, I think I think perhaps the way that the school community includes and responds to her is probably more important".

Quantitative findings from the literature base are in line with the current study. Dimitrellou and Hurry (2019) found a strong correlation between perceived inclusive school ethos and SOSB for CYP with SEN. Although this is in line with the current study's findings, due to the quantitative nature of Dimitrellou and Hurry's (2019) study, it did not specify what contributes to an inclusive school ethos. In the current study, it was discussed that a positive school ethos includes the social environment, where everyone is treated the same and staff positively respond to you. This ethos should be created by people "at the top" such as the Headteacher and SENCo and spread throughout the rest of the school.

#### Theme 4: Extracurricular activities

This theme highlights the social and emotional advantages of extracurricular involvement. It focuses on how activities like choir and sports day help build connections, boost self-esteem, and provide opportunities for recognition, all of which contribute to a child's SOSB.

Jessica shared that they initially signed their daughter up to attend the choir club so she could stay out of the cold in wintertime. However, this experience then evolved into something that she enjoyed and looked forward to, which increased her SOSB. It also felt important to this parent that their daughter was able to showcase their abilities to other teachers and parents.

Jessica: "The autumn term of Year 2 was the school choir for Key Stage 1. And I had really low expectations, to be honest. And in part I signed her up because it's the winter term. It's really cold. She struggles to be outside. Sometimes, at least it's one that's inside, it's structure and you know, that's also helpful to have structure rather than free flow, which because the playground can be a bit unruly and a bit hard" ... "She did brilliantly. She learnt all the songs she performed in the winter...sort of concert and I think that's part, you know, that's an important part of belonging to being part of the school performing" ... "But for me it is really kind of important being part of something and being seen by other parents and other teachers from around the school who don't necessarily know you".

Lydia shared that their daughter joined a football club, and although aspects of it were difficult, there were many associated positives, such as being able to interact with other children in the school, which increased SOSB.

**Lydia:** "So last year she did do an after-school football club...the 1:1 stayed behind after school for that hour after school for her to do football club" ... "That was the first time in the school that she'd actually done something out of school with the other children. And although she still kind of struggled to a point, you know, to the level of what they were playing" ... "She was able to kind of have that interaction. So, I think that was really beneficial. And I wish that there was other clubs that they could have done".

Natalie also shared the benefits of extracurricular clubs on SOSB. They shared that although their daughter is not currently enrolled in a club, there has always been opportunities to join and is encouraged by the school.

**Natalie:** "She's always had the opportunity to join extracurricular groups and things, and she's done a few of them that have interested her" ... "She's never been excluded from any of those and they positively encourage all of the students to take part in something, whether it's a sport activity or a music activity".

The importance of inclusion in extracurricular activities for promoting SOSB has been widely cited in literature. This includes quantitative studies which have shown a strong correlation between SOSB and attending extracurricular activities (Finnegan, 2022). Porter and Ingram (2021) found that CYP with SEN felt that participation in extracurricular clubs helped them to feel part of the school and rated it as the most important factor in promoting SOSB. Similar findings were also outlined by Culliane (2020). This highlights that SOSB for

CYP with DS should not just be promoted at a classroom or learning level, instead it is important to consider how CYP can be included in wider aspects of school life.

## Theme 5: The role of the parent

This theme focuses on the pivotal role parents play in supporting their child's SOSB, through advocacy, active involvement, and building a collaborative relationship with the school.

## Subtheme 1: Advocacy and support

This sub-theme highlights the role of parents as advocates for their child's social and educational needs. It includes supporting friendships, raising awareness of DS, and seeking specialist support to ensure their child's needs are met.

Lydia shared that advocacy is a large part of her role as a parent of a child with DS. They reflected on the idea that they have had to develop their confidence when communicating with school and professionals in order to ensure the correct support is in place for their child.

**Lydia:** "I think also another thing is the parent and being able to advocate. Because I do think you have to. I'm quite a quiet person, but since I've had REDACTED NAME, I've had to be really quite bullish" ... "Because I can't sit back and be quiet because it affects my child and I've realised when you have a child with a disability, things don't come to you. You have to make them happen".

Jessica discussed the idea that although their daughter has established good friendships and is invited to parties or play dates, she still requires parental support. Jessica shared that they feel that this support is higher than what they provide for their other children.

**Jessica:** "But I have to, I guess, make more effort and work harder on behalf of my eldest daughter [in comparison to their other children without DS] to those things, which is sort of a discredit to her in many senses because she has formed many independent friendships and does get asked to people's houses and to parties" ... "Obviously relationships are more tricky, but we have play dates and broadly they're successful and we go to other people's houses, it's not just here. I guess one of the difficulties is that I've got to be there and supervise".

Amelia shared that there is often an innate drive to fight for support for their child with DS, and it can come as a surprise when school or professionals are onboard with suggestions.

**Amelia:** "There's often a sense of...shock if you go into a meeting and you ask for something and somebody says yes, I agree. Let's go for it. Then you're kind of like, oh, hang on a minute...I was ready for the battle".

Jessica shared that through parental advocation, spreading information on DS and getting professional support has been crucial for their child's SOSB.

**Jessica:** "With my encouragement they do an assembly on world Down's syndrome day" ... "I bought a load of world Down's syndrome day badges last year and quite a lot of the teachers and TAs are still wearing them on their lanyards, which is, you know, it sounds like a real sort of nothing, but actually I find that quite a nice touch, to be honest".

**Jessica:** "There is not a local DS education specialist. So, we've found someone privately that we fund. The school were initially a bit kind of funny about it...what was the implications time wise? How many staff are going to be required for the feedback, but...I think they've just found it really helpful".

The current study has highlighted that parents of children with DS play a crucial role in acting as advocates in both educational and social situations, which is essential for ensuring the correct support is in place to promote their child's SOSB. These findings are in line with definitions of parental advocacy, such as Yatim and Ali (2022) suggesting that parental advocacy can be defined as "a form of support, encouragement and continuous help needed by this group [children with SEN] to live their daily lives fully". Parents of CYP with SEN are often deemed as "natural advocates", as they are highly invested in their child's emotional and physical wellbeing (McCammon et al., 2001). Gallagher Deeks (2023) suggested that supportive home environments can act as a protective factor in supporting equal opportunities.

Further support comes from Ware (2020), who interviewed CYP with SEN. Participants reported that family support was crucial for their SOSB, as their families supported them in numerous ways, such as in a functional sense (e.g., help with schoolwork and day-to-day life) or supporting their wellbeing (Ware, 2020). Although this study supports the current projects findings, it must be noted that Ware (2020) only gained perspectives from CYP with SEN. Although the CYP with SEN could acknowledge that their families supported them, they may not have been aware of the extent of the behind the scenes work which their family implements

to ensure the correct support is in place. This idea was reflected on by many parents within the current study, highlighting that the outcome of parental advocacy is often positive, but time and effort is required.

#### Subtheme 2: Communication and partnership with the school

This sub-theme focuses on the importance of a trusting and communicative relationship between parents and the school. It emphasises the need for collaboration, shared goals, and open communication to effectively support the child's development and SOSB.

Participants shared that it has been helpful when staff are willing to take their suggestions on board and having open communication with parents. This has been essential for promoting their child's SOSB but also building positive relationships between home and school.

Amelia: "They [the school] had meetings with the parents and they sort of really listened and what was nice is that sort of...it would have been a meeting back in May or June with the head teacher with the principal and the class teacher for the new school".

Amelia: "There's a new SENCo in place...I know her own kids are neuro spicy. I know that she will bend over backwards and so if she says I'm really sorry, it's just not been possible...I also trust that she would have tried everything before she gives me a no".

**Olivia:** "I think just maybe on a sort of higher level, school have been happy to take on board suggestions that we've given".

**Lydia:** "And even when there has been questions where they're not quite sure "is this good?" or "is this bad?" or "how do we do this?"...there's been more of a conversation and negotiations between myself and school as to how can we solve this or is this a good idea? or not a good idea? So, you know, there's been lots of conversations had over the years with how we should kind of handle things or approach things and do stuff".

This is an area which lacks research, specifically when considering parents who have children with DS. As highlighted in the Lamb Inquiry (2009), many parents of children with additional needs lack confidence in SEN systems, including schools. As a result, it is crucial that the relationship between parents and schools are at the heart of an effective SEN system. It has been shown that effective communication between parents and professionals is

important for children and can impact their progress (Ofsted, 2006). The findings from the current study highlight that having good communication between parents and school is essential, and this includes having regular meetings with school, staff being open to parent's suggestions and working together collaboratively. By staff working with parents and being open to suggestions shows they demonstrate a collaborative approach, a willingness to adapt, and a commitment to meeting the needs of CYP with DS effectively. This openness fosters positive relationships, enhances trust, and supports a shared understanding between parents and staff, ultimately benefiting the child's development and SOSB.

## Theme 6: Child's personal attributes and skills

This theme focuses on the child's individual qualities, including their non-verbal and academic skills. It highlights how these traits contribute to their SOSB and how they perceive themselves within the school environment.

Both Natalie and Jessica reflected on the idea that their child's reading ability has led them to be able to be included in classroom activities and feel similar to their peers, which has been crucial for their SOSB.

**Natalie:** "We've been very fortunate in that my daughter is quite literate. Again, I've got to give my husband the credit for this...but he started sort of doing phonics and early reading with her" ... "I know that not all children with Down's syndrome are going to have that capability because of other issues that they might have, but she was able to respond to that so she could read before she started primary school" ... "So, I think that was a massive help, you know, because she did feel like she was already sort of capable and keeping up and therefore the school were able to include her from the beginning in different activities".

**Jessica:** "Kids have different abilities and we're really thankful that REDACTED NAME is a high achiever" ... "Achieving reading and at the same level as her peers and she is doing really well with her spellings and so she's, you know, up there amongst it and that I'm really mindful that that is likely to...the gaps you know the horrible cliche the gaps likely to widen".

As highlighted in previous literature, DS is typically associated with mild to moderate learning difficulties, however this can vary depending on the individual (De Graaf et al., 2014). In terms of academic abilities, the current study highlights that parents of children with DS feel that if their child has a good level of reading and spelling skills, this has helped them keep up

with the class and access similar work, which has helped their SOSB. However, some parent's acknowledged that this might not be the case for all children with DS.

A lot of participants referred to their child's non-verbal skills, especially their ability to be aware of other people's emotions. Despite some participants highlighting that their child cannot always verbalise how they feel, they can often pick up on how they are perceived by others.

**Olivia:** "I think they're [children with DS] very empathetic and they are very quick to perceive how other people view them".

**Lydia:** "Although she's not able to kind of verbalise kind of how she feels, she struggles with that...she definitely absorbs emotions and feelings, and she understands more than what she can kind of speak out herself. So, you can feel it and that she would have felt that kind of abrasiveness or not wanted, you know, and that would affect how she feels as well about herself".

**Daniel:** "Kind of very strong sense of where you might call emotional intelligence, so they [children with DS] can often interpret other people's emotions" ... "She perceives other people's reaction and applies that to herself".

Olivia: "I think like with a lot of children with Down's syndrome, my son can understand a lot better than he can communicate to others. And a lot of that is almost the sort of nonverbal things as well, that he can understand so he can really pick up on people's behaviour, their emotions, their facial expressions, all of that. So, I think the way someone approaches him makes a huge difference to his self-esteem. His, you know, behaviour towards them, his sense of inclusion and belonging as well".

In terms of non-verbal social functioning, many parents highlighted that their child is empathetic and has good emotional intelligence, despite not always being able to verbally articulate this. This is in line with research, highlighting that CYP with DS typically have good non-verbal social functioning and difficulties in expressive language skills (De Graaf et al., 2014; Laws et al., 2000). If CYP with DS can pick up on how they are perceived by others, it equips them to be able to respond to social inclusion or exclusion, and build emotional connections with others. This awareness supports their confidence and ability to engage in group activities, fostering a greater SOSB.

## 2.4.4 RQ4: What do parents see as the key barriers to their child's sense of school belonging?

This RQ explores participant's views about barriers of SOSB, which have been shaped by their own experiences. The below thematic map (Figure 7) highlights the themes and subthemes for Question 4.

Figure 7

RQ4 Thematic Map



For RQ4, four themes were established through the RTA. For one theme, 'lack of classroom adaptions', three further sub-themes were established. The following section will individually discuss each theme and sub-theme in relation to RQ4. It must be noted that although each theme is discussed separately, each theme is interconnected.

#### Theme 1: Lack of classroom adaptations

This theme suggests that some children with DS face significant barriers to participation in school, affecting their SOSB. These barriers stem from a lack of classroom adaptations, exclusion from learning opportunities, and limited efforts to foster independence. Teacher attitudes and missed opportunities for creative, flexible approaches further reinforce these challenges, making it harder for children to engage meaningfully in their education and school community.

### Subtheme 1: Exclusion and limited differentiation

Parents shared that limited adaptations and a lack of reasonable adjustments resulted in children being removed from the classroom or relying heavily on 1:1 support. These barriers prevent full participation in learning, reducing engagement with teachers and peers.

Lydia shared that they had difficulties in the past with their daughter being mainly supported and taught by her 1:1 TA, rather than the class teacher. Although it should be the class teacher's responsibility to support with learning, Lydia discussed how some teachers would not know vital information in relation to her daughter's level of learning.

Lydia: "One of the issues that I have had over the years... is that it has been down to the 1:1...it's her responsibility rather than the teacher. Whereas I've always felt and I've always been told, it's the teachers responsibility...which they delegate to the 1:1 who'll do support stuff. But I was feeling that my daughter was being taught by a 1:1 rather than the teacher. And it's lovely to have 1:1s but they're not qualified as teachers" ... "Some teachers wouldn't even know what she was doing or what level she was on or anything. I just thought you can't keep passing the buck and putting it on the 1:1".

Lucy shared a similar experience, where their daughter was not being supported by the class teacher and was taken out of the classroom with her 1:1 TA. They shared their frustrations that this arrangement was not communicated with them. It was felt that this exclusion from the classroom negatively impacted their daughters SOSB, due to making her look different and stand out to the other children.

Lucy: "It became clear that she wasn't really having any engagement with the class teacher themselves." ... "She was being taken out of class most of the time, which we weren't aware of for a long time. And then it became clear that she wasn't actually in the main class for most of her lessons" ... "I believe that that situation where she was out of the class for such a long period of time obviously didn't help her situation with the other children in class. But it just kind of made her stand out more as somebody who was different".

Although having access to a consistent TA was recognised as a facilitator to SOSB for CYP with DS in RQ3, it should be considered how this could also be a barrier. Research has highlighted that approximately 82% of CYP with DS have individual TA support (Van Herwegen et al., 2018), and many participants in the current study raised that their child had

their own 1:1 TA or access to a frequent TA. However, it was acknowledged by participants that TAs should be used effectively to enhance learning experiences rather than being used to "babysit" or further exclude children from the classroom. Research has suggested that TAs can be beneficial, however there can be associated risks such as lack of teaching from a qualified teacher and reduced social opportunities (Faragher et al., 2020). As highlighted in the SEND Code of Practice (2014), "teachers are responsible and accountable for the progress and development of the pupils in their class, including where pupils access support from teaching assistants or specialist staff". This highlights that teachers should be responsible for the learning experiences of CYP with DS, not TA's. TAs should be guided by teachers to compliment teaching instruction, reinforce key concepts, assist with differentiated tasks, and encourage pupil independence (DfE, 2019).

Previous research has also echoed that exclusion from the classroom can act as a barrier to SOSB. Culliane (2020) found that students with SEN reported that when they are excluded from classroom activities, this limited their opportunities to socialise and increased bullying. Lovell (2021) found similar findings, where TAs acknowledged that teaching children with SEN away from the main classroom can make children feel separate and limit opportunities to build relationships with peers and the class teacher. As highlighted by the current study, exclusion from the classroom and the dependence on 1:1 teaching opportunities can lead to CYP with DS missing out on essential learning and socialisation experiences, thus negatively impacting their SOSB.

#### Subtheme 2: Teacher attitudes

This subtheme encompasses the idea that some parents shared that a lack of differentiation, rigid teaching approaches and staff attitudes can hinder inclusion and SOSB. While creativity and adaptability could enhance participation, missed opportunities to promote independence leave children overly reliant on support, impacting self-esteem and limiting their ability to develop autonomy.

Lydia shared that a lack of differentiation from the class teacher left their daughter being unable to access the lesson content.

**Lydia:** "They have like, times when parents can come in and see what they're doing in the class" ... "And what she was given, I thought, was quite tricky" ... "She had no concept...but I thought it could have been done at a simpler level" ... "And they hadn't done

that. And I felt quite upset. I just felt she's not gaining anything from this because she's got no concept".

Amelia shared that their child's experience at school could be determined by which teacher they were allocated. They reflected on the stress associated with waiting to find out which class teacher their child would be having.

Amelia: "We've had some excellent teachers and then it's like the end of the year when you find out who the teacher is next year. Just fills you with absolute dread because everybody knows within the school who are the good teachers and who are the ones that you really don't want" ... "I'd say there's two teachers within our primary school that if I found out that we had them as a class teacher, I wouldn't quite know what to do with myself".

Lucy talked about the lack of understanding of inclusive practices from her daughter's class teacher. After raising that Makaton was not being used in the classroom, despite it being written in their daughters EHCP, it was felt that the teacher used tokenistic methods rather than imbedding inclusive practices into their day-to-day work.

**Lucy:** "She [class teacher] started to say...Oh, oh, girls, girls...And like called a small group of the girls from the class over and made them sign good morning to her [their daughter] in front of me, and these poor kids were like obviously just looking really awkward and uncomfortable. They did it. But I was like...that's not the point. Like you're really missing the point".

Teacher's attitudes towards differentiation and inclusion can negatively impact the SOSB for CYP with DS. This has been supported by literature which has explored the views of CYP with SEN and parents. A participant in Finnegan's (2022) study expressed that lack of differentiated academic support from an adult can be overwhelming and shared that their TA was "filling my brain up so quickly", leading to feelings of stress and confusion. From a parental perspective, a study noted that a lack of understanding from the teacher and limited differentiation led to a participant's daughter to not want to attend school (Alesech & Nayer, 2020). Positive teacher attitudes towards inclusion and differentiation is essential for the SOSB of CYP with DS, as this not only shows children they are a valued member of the classroom but also allows for meaningful learning and social opportunities. The current study has highlighted that teachers should be doing more than offering tokenistic methods, and instead consider how inclusive practices can be embedded within the classroom.

# Subtheme 3: EHCP not being followed

This subtheme highlighted that the failure to implement EHCP provisions due to resource limitations, staff knowledge gaps, or lack of accountability can significantly impact children's access to appropriate support, ultimately affecting their ability to thrive in school.

Olivia shared the realities that despite their son having an EHCP, they were aware that all of his support would not be financially covered.

**Olivia:** "Despite him having an EHCP, we know full well that that doesn't cover every aspect of his needs in terms of financially supporting a 1:1 for him the whole time".

Lydia and Lucy shared examples of where their children's EHCP provision was not being followed by school. This included a lack of differentiated work and not accessing wider professionals such as Speech and Language.

**Lydia:** "We did have a few tricky times with some staff that would refuse to differentiate, and then there'd be behaviour problems and then we have discussion, we'd find out that nothing had been differentiated and the teacher just said "I haven't got time to differentiate" point blank. You know, it's like, well, you know, we've got an EHCP that states this child needs this, but she'd just say, "I'm sorry, I've not got the time" and, you know, nothing was done about it".

**Lucy:** "She has had quite significant difficulties with speech and language, and I was a lot more aligned in the earlier years on using Makaton. And that was part of her EHCP, but it became quite clear that they were not consistently using Makaton with her".

**Lucy:** "She hadn't been seen for nearly a year [by SALT]. And we weren't aware of that. So as far as we knew, she was getting an enhanced service at school and found out that wasn't happening".

One of the key themes identified in this study was that parents felt their child's EHCP provision was not always being followed. From reviewing the existing literature, it was revealed that research specifically exploring the implementation of EHC provision and its relation to SOSB is currently limited. When considering the studies included within the literature review,

only five were conducted in the UK, and the remainder were conducted in countries where EHCPs are not used, however similar support may be in place. Only two of the UK studies within the review explicitly mentioned EHCPs, and this was solely in relation to their participation criteria rather than as a focus of analysis (Finnegan, 2022; Ware, 2020).

A possible explanation for the limited discussion of EHCP provision and its relation to SOSB in the literature may be due to the methodological focus of existing research. Many of the studies primarily gathered the perspectives of CYP, rather than parents or staff. It could be suggested that children potentially prioritise other aspects of their school experience over EHCP provision when discussing their SOSB. In contrast, parents may be more attuned to whether the provision outlined in an EHCP is being implemented, particularly given their role in advocating for their child's needs. This highlights a potential gap in the literature regarding parental perspectives on the implementation of EHCPs and their impact on the SOSB of CYP with DS.

As highlighted by the SEND Code of Practice (2014), "when an EHC plan is maintained for a child or young person the local authority must secure the special educational provision specified in the plan". This highlights that an EHC is a legal document and professional's must follow the support and interventions which are outlined to ensure CYP with DS access experiences which will enhance their learning, emotional wellbeing, communication, sensory and social needs.

#### Theme 2: Access and inclusion to extracurricular activities

As highlighted by RQ3, extracurricular activities play a key role in fostering a SOSB, yet access can be limited by staff preferences, logistical barriers, and financial costs. While extracurricular activities provide valuable opportunities for social engagement, the emotional and financial strain on families can create further inequalities in participation.

Difficulties with accessing extracurricular activities for children with DS was raised by several participants. Lydia shared that often their daughter has required additional adult support to access activities, however this has been met with difficulties such as lack of adults being available, financial constraints or parents being asked to support.

**Lydia:** "It was very limited access to school clubs and then you have the issues of the funding like you're having 1:1 support because that's what she has at school. So, then it's like, you know, can we get the funding for this, you know, because a lot of the times, parents are

expected to be the support, which wasn't good for her because, you know, like other children, you don't want your parents tagging along all the time".

Olivia discussed how they had enquired about after school clubs for their son, however there was no space. Olivia reflected on the idea that this may not have been entirely true.

**Olivia:** "After school clubs we sort of looked into it a bit at first and I think the initial feedback from the clubs was oh, sorry, we don't have any space. We've got a very long waiting list, but I suspect that some of that was hesitance on the fact that they would have to look into providing a lot more support for him".

Jessica shared that although their daughter enjoys after school club and experiences a good SOSB, Jessica has battled with ensuring their daughter receives the correct support. It was discussed that this has not only had a financial impact for Jessica, but also has taken a toll on their own emotional wellbeing.

Jessica: "Then this opportunity came up [to join an after-school club] and even better it was run by...it was like the side hustle of one of her class teachers" ... "But the labour and the admin and the sort of battling that has gone on to get her a place has just been soul destroying, frankly" ... "I just find...it's just so discriminatory basically and it's been a bit depressing. She has attended you know...but at vast expense to us because basically we pay double. So as far as she's concerned, I believe she's fully included and belongs. As far as I'm concerned, I've lost count of the number of emails, phone calls, meetings, forms, etc that I filled in and gone through to try and get, you know, more equity applied to the process".

A key theme that emerged in this study was that parents perceived exclusion from extracurricular clubs as a barrier to their child's SOSB. From reviewing the existing literature, it could be suggested that exclusion from extracurricular activities and its impact on SOSB for CYP with SEN has not been explored in depth. Some studies have suggested that CYP with SEN attend less extracurricular activities in comparison to non-SEN peers (Culliane, 2020; Finnegan, 2022). When interviewing parents who have children with SEN, it was found that parents perceived it to be a violation of their children's human rights if they were excluded from extracurricular activities (Alesech & Nayer, 2020). Miles et al., (2019) found similar findings, where CYP with SEN reported that they felt a low SOSB when they were not personally involved in any social groups. In contrast, a substantial body of research highlights the benefits of extracurricular participation for pupils' with SEN's SOSB (Culliane, 2020;

Finnegan, 2022; Porter & Ingram, 2021). This suggests that where access to these activities are restricted, it may act as a barrier to belonging.

One parent in this study shared that, from their child's perspective, they felt a SOSB due to having access to an afterschool club. However, the parent described the significant administrative and communicative efforts required to secure this access, which took an emotional toll. This raises the possibility that children may not always be aware of the barriers that exist, particularly if parents are working behind the scenes to facilitate their inclusion. As a result, parents may be more attuned to exclusion from clubs and other non-inclusive practices than their children. This may explain why previous literature suggested that parents and CYP with DS have differing perspectives (Ijezie et al., 2023). This finding highlights a potential disparity in perspectives and suggests that parental efforts to ensure inclusion may be an important but often invisible aspect of their child's school experience.

### Theme 3: Parental involvement

Many parents take on an advocacy role to secure the best possible support for their child, often at significant emotional and personal cost. Frequent battles with the school system, feelings of being unheard, and strained relationships with staff can impact parental wellbeing and trust in the school's commitment to inclusion.

Many parents reflected on the idea that some of the difficulties they have encountered with school has been related to lack of communication between staff and parents. Lydia shared that smaller difficulties have grown bigger due to inconsistent communication.

**Lydia:** "I think communication really has been the crux of all the problems we've had with school" ... "things have gone smoother when we've had more regular communication, so that those little things don't become big things".

Daniel and Jessica expressed feeling the need to consistently follow up with staff. Even if something is put into place, parents cannot always trust that the support will continue. Jessica reflected on the time and effort associated with communicating with staff can impact parents own emotional wellbeing.

**Daniel:** "You always have to kind of check up on the school whether it's happening, so you can't just sit back and say, OK, right, I kicked up a big fuss last time...so hopefully now they're going to like...keep that ongoing".

**Jessica:** "I guess that's my biggest...well not bugbear, but that's one. That's the thing I feel most as an injustice as a mum of a kid with additional needs in that I feel like...everything takes me so much more time and like things like communication. There's just so much more admin with our eldest daughter than there is with our others at this point, and that is really draining".

Jessica shared that difficulties with communication can impact their relationships with staff.

**Jessica:** "It's a bit awkward because I walk past him [the Headteacher] a few times a week on the gate and we say hello" ... "You know, it's a new year. I need to refresh his memory on it, but again you know it's that sort of constant feeling of, well, that's another job and I can't just walk past this person and just say hello and just mean hello because it just reminds me of another thing that I've got to do to promote".

Lucy shared a scenario where they were unsure if their daughter had meaningful friendships at school. When they approached the class teacher, they were told that their daughter did have friends, however Lucy later found out that children in their daughter's class were nice to her, but she did not have reciprocal friendships. Lucy felt that the teacher did not fully communicate this, as they did not want to hurt the parents' feelings.

**Lucy:** "They're trying to kind of make us feel better and you know, and their intentions are probably right or good. Not right, but good. But actually, that's not helpful to us because we want a genuine...! certainly do...anyway...! want a genuine picture of what is happening for my child at school".

There is a lack of research exploring this issue, as much of the existing literature has focused on children's perspectives. As a result, children may not always be aware of the communication challenges their parents experience when navigating the education system. As highlighted in the Lamb Inquiry (2009), many parents of children with SEN lack confidence in SEN systems, including schools. As a result, it is crucial that the relationship between parents and schools are at the heart of an effective SEN system. It has been shown that effective communication between parents and professionals is important for children and can impact their progress (Ofsted, 2006). Gallagher Deeks (2023) found that staff acknowledged that there is currently a power imbalance with the SEN system, where parents have to fight for support, and this can impact how parents interact with school staff.

Similarly, the SEND Code of Practice (2014) highlights the importance of strong engagement and communication with parents, emphasising that schools must work collaboratively with parents to support children with SEN. By having consistent discussions between home and staff, it can help to build confidence in the actions which are being taken by the school (DfE, 2014). Effective parental engagement with school can "strengthen the impact of SEN support by increasing parental engagement in the approaches and teaching strategies that are being used...finally, they can provide essential information on the impact of SEN support outside of school" (DfE, 2014). These findings suggest that while policy acknowledges the importance of parental communication, inconsistencies in practice continue to pose barriers. This impacts both parental trust in the system and, potentially, their child's overall school experience, which will be affecting their SOSB.

## Theme 4: Lack of understanding and support for individual needs

A lack of awareness and tailored support for children's individual needs can create significant barriers to their inclusion and SOSB. Gaps in staff knowledge, low expectations, and insufficient adaptations can prevent children from fully participating and reaching their potential.

Many participants highlighted that although there is a common cognitive and social profile which is associated with DS, there is also a level of variance.

**Olivia:** "I think the biggest thing is that, you know, there are a lot of similarities with children with Down's syndrome, but there's so many differences".

**Victoria:** "I have other friends who have children with Down's syndrome and they're all very, very different in their academic ability".

**Lydia:** "Children with Down's syndrome have got a unique learning profile and you've got...you can get specific training courses purely on their learning profile and from DSE and other places like that. So, you know, yeah, there will be generic SEN things, but there's also a certain profile within that as well that's very specific to children with Down's syndrome".

Both Daniel and Lucy shared experiences where staff underestimated the abilities of their child due to having DS, and not fully understanding their needs.

**Daniel:** "[A staff member viewed] Down's syndrome as just like...we have to maintain their existence, but don't like, don't aspire too much more. And that aspiration part was...is something we had quite an in-depth meeting with the headteacher [about]".

**Lucy:** "It's quite clear that my child was being stifled by her [TA] because she didn't understand Down's syndrome. She didn't understand my child. She didn't understand how Down's syndrome affected my child".

Natalie shared that due to the school successfully supporting their child with DS, they overgeneralised this to other children with DS, and did not consider the individual differences of the children.

**Natalie:** "And I think they [the school] almost got a bit caught out because other children with Down's syndrome started at the school after my daughter. They kind of thought, oh, we've done OK, we've got this child and she's been doing OK, so we'll be fine with this one as well and actually...one of them was OK, but another one had very, very serious additional needs".

A key theme that emerged from this study was the lack of understanding of DS and support for individual needs. Parents highlighted that, while there are some commonalities in the learning profile of children with DS, there is also considerable variation. Many parents expressed frustration that school staff sometimes fail to recognise these differences, instead making assumptions based on previous experiences with other children with DS. As a result, some parents reported that staff were surprised when their child did not conform to their expectations, which in turn affected the level of support provided. Despite there being a common cognitive profile for CYP and adults with DS, studies have indicated that there can be variability. Onnivello et al., (2022) explored the cognitive profiles of CYP with DS and found variation in verbal and non-verbal intelligence. These findings suggest that there can be variability in the cognitive profiles of CYP with DS, highlighting that educational support should consider individual differences (Onnivello et al., 2022).

Despite the significance of this issue, the literature review revealed that very few studies have explored the role of individual identity and diagnosis in shaping a child's SOSB. Only one study touched on this concept, examining how young people with autism developed a 'problem narrative' around their diagnosis, which influenced both their self-perception and the way they were treated by others (Gallagher Deeks, 2023). However, none of the reviewed studies specifically considered the experiences of children and young people with DS.

## 2.5 Summary of Findings / Conclusion

This study aimed to explore how parents of children with DS conceptualise SOSB, whether SOSB was an important element within school choice and what factors affect SOSB. From a literature search, previous studies have explored which factors act as barriers and facilitators to SOSB for CYP with SEN. However, limited studies have directly explored what contributes to the SOSB for CYP with DS, and how it is conceptualised by parents. By using Braun and Clarke's (2022) RTA, this study identified key themes in relation to four research questions.

The first RQ aimed to explore how parent's conceptualised SOSB. In total, four themes arose. Parent's highlighted that SOSB for their child was about having access to equitable experiences, so children with DS could be accepted in the same way as other children, whilst also considering reasonable adjustments. Furthermore, SOSB encompassed more than just physical inclusion, but ensuring that their child felt known, valued, and understood by peers and adults in their school. It was also recognised that being familiar with the school, such as knowing the building or members of staff also defined SOSB and led to feelings of excitement for some children. Finally, it was noted SOSB can be a complex and individualised concept, highlighting that schools must recognise and respond to the individual differences of CYP with DS.

For many parents, SOSB was a key factor when considering school placements for their children with DS and they turned down schools if they felt their child would not belong there. For some parent's, SOSB was an important but not a central element when choosing a school. For all participants, factors beyond academic considerations were important, such as developing life and independence skills, or attitudes from staff. Some parents referred to the worry and stress they faced when navigating school choice, highlighting the internal conflict about whether they were making the right decision, especially when deliberating between mainstream or SEN settings. Considering multiple schools appeared to be popular amongst participants, with the exception of a few who wanted their child to attend their local school, unless there was good reason not to send them.

Participants identified a range of factors that positively contributed to their child's SOSB. This included six main themes, such as relationships and social connections, inclusive classroom practices, school ethos and attitudes, extracurricular activities, the role of the parent

and the child's personal attributes and skills. Many parents shared that advocacy for their child and good communication with schools was essential for promoting SOSB and ensuring their child's needs were understood and met. Some participants spoke about the strengths their children possess, such as strong non-verbal skills and how this is essential for their child in understanding how they are perceived by others.

Despite parents sharing positive experiences associated with their child's SOSB, some felt that there were significant barriers. This included lack of learning adaptations, such as their child being excluded from the classroom and mainly receiving support from a 1:1 TA, teachers' attitude towards differentiation and inclusion, and EHCP provision not being consistently followed. Other challenges included difficulties accessing extracurricular activities, and staff not understanding the individual differences of CYP with DS. Many parents discussed the emotional toll which was associated with parental advocacy, where their child's SOSB fell solely on parents, rather than being embedded within school practices.

### 2.6 Implications for Practice

### 2.6.1 For children with DS

As highlighted in previous research, when SOB or SOSB is met, it can lead to many positive outcomes. This includes increased academic attainment, emotional regulation, and social opportunities (Prince & Hadwin, 2013). It is important that the voices of CYP with DS are considered in terms of how to support with greater SOSB. Although this thesis considered parental perspectives, the responses from interviews highlighted that many factors positively and negatively impact SOSB. These findings suggested that SOSB for CYP is more than academics, it encompasses having equitable experiences; feeling known, valued, and understood, and being familiar with the school environment. It was further noted that SOSB for CYP with DS can be complex and individualised, meaning it is essential that schools are aware that SOSB may be conceptualised differently depending on the child or parent, meaning individual approaches are key. It is also crucial that schools and staff are aware of how to enhance SOSB for CYP, to promote the best possible outcomes. This includes developing positive peer-peer and child-staff relationships, promoting inclusive classroom practices, having positive attitudes towards CYP with DS, access to extracurricular activities and celebrating the unique skills and attributes of CYP with DS.

#### 2.6.2 For Parents

As highlighted by the current study and previous research, parents of children with DS can face significant worry and stress when choosing a school for their child (Hutcheson, 2018). It has been highlighted that parents consider their child's SOSB when choosing a suitable school placement, as well as wider factors such as staff attitudes, and independence skills. If a child has an EHCP, parents have the choice of mainstream or SEN settings (DfE, 2014), which can contribute to further uncertainty when considering school placements. It would be beneficial for parents who have children with DS to receive more support around school choice, such as clearer information and professional guidance so informed decisions can be made.

Parents who have children with SEN are often natural advocates for their children (Krueger et al., 2019). The current study highlighted that parents of children with DS provide continuous support and advocation for their children. However, the difficulties parents face when trying to promote inclusion and SOSB for their child was raised. This includes experiences of stress and frustration due to systemic barriers and having to repeatedly fight for their child's right to inclusion. This suggests a need for systemic support for parents. This shouldn't just include advocacy training but also the development of emotional support networks, peer support and access to relevant professionals to help alleviate the emotional toll associated with advocation. On a wider level, schools and policymakers need to recognise the stress and frustration that some parents face and need to create a collaborative and proactive approach to reduce the need for constant parental advocacy.

CYP with DS often share some similarities in their cognitive and social profile (De Graaf et al., 2014). However, as highlighted within the current study, parents raised that their children should be considered as individuals, who have unique skills and traits. The recognition of parents' expertise is essential for working collaboratively. The current findings show that parents of children with DS have a unique understanding of their child's needs, including their strengths, challenges and what contributes to their SOSB. It was reported that many parents felt unheard or dismissed by school staff, leading to mistrust and frustration. It is essential that schools and professionals need to actively engage parents in decision making, rather than viewing it as a procedural requirement. This includes co-developing educational plans and strategies.

#### 2.6.3 For Schools

Children with DS are now attending a range of different educational settings, including mainstream and SEN schools (Lightfoot & Bond, 2013). The current research has highlighted that to promote inclusion and SOSB for CYP with DS, it requires more than a child attending a mainstream setting. True SOSB is where schools foster meaningful participation, friendships, and a positive ethos. It is crucial that teachers are given time to reflect on how they support CYP with DS. This includes providing a balance between inclusion in the classroom, as well as accessing additional TA support and differentiated work. School staff should not assume that SOSB will naturally occur for CYP with DS. An active effort needs to be made to ensure meaningful peer relationships are supported, inclusive practices are embedded in their classroom(s), and access to all aspects of school life are facilitated.

The findings from the current study indicate that some teachers and school staff lack understanding and training in supporting CYP with DS, in particular encouraging social inclusion and SOSB. Due to this, CYP with DS may be unintentionally excluded from the classroom and rely on TAs, rather than direct teacher engagement. It is essential that schools invest in training on developing their understanding of DS, inclusive practices and SOSB.

#### 2.6.4 For EP Practice

The current research has indicated that EPs have a role in promoting and supporting SOSB for CYP with DS across multiple levels. Within EP working, collaboration with parents is a core element of the role (Boyle & Lauchlan, 2009). This study's findings have highlighted that EPs have a role in supporting parental advocacy. This includes EPs working with parents to empower them through offering advocacy strategies and ensuring their voices are heard during decision making processes. Moreover, EPs could support parents in making choices about school placements. Although it is not the role of the EP to name specific schools, EPs can make parents aware of the importance and benefits of SOSB for CYP with DS (Prince & Hadwin, 2013). EPs can support in advocating for a broader view of school placements, beyond academic success.

At a wider level, a large part of the EP role is working with TAs, teachers, SENCos and Senior Leadership (Boyle & Lauchlan, 2009). EPs can work systemically with schools to implement interventions and approaches to enhance SOSB for CYP with DS, such as inclusive classroom practices, school-wide policies which fosters community and peer

mentoring. Further training for staff is essential, by enhancing teacher and TAs understanding of DS, inclusion and how to promote their SOSB.

## 2.6.5 Preparing for Adulthood

The current study is also relevant to frameworks such as Preparing for Adulthood (PfA), as outlined in Section 8 of the SEND Code of Practice (2014). Although the current study did not consider parents who have children in post-16 settings or beyond, PfA should be considered from when a child is 14-years old (DfE, 2014).

Education provides a crucial foundation for preparing young people for adulthood, extending beyond academics (Ofsted & Care Quality Commission, 2023). A strong SOB within an educational setting plays a vital role in this transition, as research has shown that SOB contributes to positive academic, emotional, and behavioural outcomes (Prince & Hadwin, 2013). For CYP with DS, fostering a SOB within their education setting is particularly important. This sense of connection should also extend to the various environments they engage with as they transition into adulthood, including post-16 education, work placements, day centres, and extracurricular activities.

As highlighted by the current study's findings, parents of children with DS view SOSB as more than social inclusion and academic outcomes. Many participants touched on the idea that school selection was based on long-term considerations, such as developing independence skills. Please see Appendix O to see how each theme relates to each area of PfA, and practical implications.

The Mental Capacity Act (2005) underpins the PfA Framework. As CYP with DS transition to adulthood, they have a right to participate in decisions which affect their lives. Under the Mental Capacity Act (2005), it is highlighted that from the age of 16, CYP should be assumed to have capacity, unless it is proven otherwise. Where possible, CYP with SEN should be included in decision making, and necessary adaptions need to support this (Down's Syndrome Association, 2025). This is relevant to the current study, as it was highlighted that many parents took on the role of advocating for their child with DS. This was to ensure that their child's needs were met, especially when they felt schools were not being responsive. However, as CYP with DS grow older, there is an expectation that supported decision-making is promoted. With guidance from professionals, parents should be encouraged to shift from being primary advocates to co-advocates, ensuring their child is empowered to take a more active role in decisions about their future. Parental advocacy should not be diminished but

instead reframed to foster independence and prepare CYP with DS for adulthood. Advocacy should support CYP with DS in gaining autonomy while remaining in line with the PfA framework (DfE, 2014) and the Mental Capacity Act (2005), ensuring that their voices are heard.

#### 2.7 Limitations and Future Considerations

Although the findings of the current study bring insights across multiple levels into how parents advocate for a SOSB on behalf of their children, it is important to consider potential limitations. A valid critique of this research is that it did not directly gain the views and perspectives of CYP with DS. Although previous research has considered the voices of CYP with DS (Graves et al., 2016; Skotko et al., 2011), it is still an area which requires further exploration, especially in relation to SOSB. Some studies have highlighted the risks associated with proxy-reporting methods (Ijezie et al., 2023). As the CYP with DS are experiencing SOSB themselves, it would have been interesting to gain their insights. Although some parents in the current study highlighted that their child might not understand the concept of SOSB and other studies have found differing perspectives between CYP with DS and their parents (Ijezie et al., 2023), this should not be generalised to all children with DS. As highlighted by previous research, many CYP with DS are capable of sharing rich and insightful views about their education and lives (Graves et al., 2016; Skotko et al., 2011).

A key consideration for future research is the direct inclusion of CYP with DS in conversations about their own experiences of SOSB. While parental perspectives provide invaluable insights, such as highlighting advocation and overcoming systemic barriers (Becker & Dusing, 2010). Some accounts from the current study highlight that parents and children may sometimes perceive SOSB in different ways. For example, one participant noted that their child with DS considered a sixth-form maths buddy to be a friend and acknowledged that this relationship might not fit a neurotypical definition of friendship. Moreover, another parent shared that they believe their child feels a strong SOSB in an afterschool club, despite the parent having to overcome significant barriers to secure their place. These examples illustrate that both child and parent perspectives are valid, even though they may differ. It is not a matter of one perspective being 'true' and the other being 'false,' but rather that they offer complementary accounts of SOSB. Future research should consider how both perspectives can interact and inform each other, where parents can bring insight around systemic challenges and advocacy, whereas CYP can bring accounts of their direct experiences within

school. This could be collected through a range of methods such as observations, adapted interviews, photo-elicitation or assisted communication tools (Lightfoot & Bond, 2013).

Another important consideration is the potential self-selection bias which may have occurred during recruitment within the current study (Robison, 2014). The researcher was interested in finding out about parent's conceptualisations, experiences, and examples of SOSB in relation to their child with DS. Participants were recruited through a range of means, including DS charities and Facebook groups. However, it could be argued that those who volunteered to participate were actively engaged in advocating for their child and felt confident in discussing their opinions and experiences in relation to SOSB. Research has suggested that a range of factors can either increase or decrease parental advocacy. This can include parent's own education and skills, financial status, time commitments and the severity of the child's condition (Smith-Young et al., 2022). These demographics were not collected in the current study; however, it is still important to consider potential self-selection bias. Therefore, the findings of the current study may not fully represent the experiences of parents who are less active in advocacy.

In terms of future research, it could be interesting to explore how parental advocacy and conceptualisations of SOSB vary by factors such as geographical location, socioeconomic background, ethnicity, or school type (mainstream vs SEN school). As discussed, advocacy can be affected by a range of factors (Smith-Young et al., 2022). This is crucial to explore, as it gives a richer intersectional understanding of how SOSB is influenced by cultural, social, and structural factors. This can lead to more tailored understanding and support, such as offering advocacy guidance and support for families from underrepresented backgrounds and school policy development which considers parental and child equity gaps.

## **Chapter Three: Reflective Account**

#### 3.1 Introduction

Research has highlighted that in more recent years, the EP profession has developed to encompass a range of roles, including research (Boyle & Lauchlan, 2013). This is also in line with the HCPC (2023) standards of proficiency (SOP 13.26, 13.27 and 13.28). Within the role of being a scientist-practitioner, reflection and reflexive practice is essential, as highlighted by the BPS (2017) practice guidelines (1.3), BPS CoHRE (2021) and HCPC (2023) standards of proficiency. Reflexivity involves critically analysing how your values and beliefs shape your methods and design, as well as how academic disciplines influence your research (Braun & Clarke, 2022).

Within this third chapter, I aim to reflect on the process of conducting the current research. This includes reflecting on my own beliefs and values and how this shaped my project. This chapter aims to compliment both Chapter 1 and 2 of this thesis. I have critically reflected on a range of stages which occurred throughout this process, such as choosing my topic, conducting a literature review, developing my methodology, data analysis and final conclusions. I have chosen to write this chapter in first person due to this being a reflective account.

# 3.2 Selection of my Research Area

My interest in supporting CYP with SEN and complex needs developed through various professional experiences. After finishing college, I worked as a Support Worker for a charity specialising in respite care for CYP and adults with diverse medical and learning needs. Alongside this, I became a 1:1 Personal Assistant (PA) to a young person with DS. These roles significantly shaped my understanding of the challenges and opportunities faced by CYP with SEN in non-educational settings (Dixon & Biehal, 2007; Pilkington et al., 2019).

I then undertook a degree in BSc Psychology, where I completed developmental and educational psychology modules. These experiences gave me an awareness of the research base surrounding CYP with SEN and introduced me to a range of theoretical perspectives, particularly in relation to education. After graduation, I became a Teaching Assistant (TA) at a specialist provision which supported CYP with ASD, alongside continuing as a PA. This allowed me to explore diverse aspects of SEN support and advocacy within educational

settings, including the importance of fostering inclusion and belonging through a range of activities (DfE, 2021).

Through observation and reflection during my job roles, I became particularly interested in the topic of parental advocacy and supporting CYP with SEN. In various cases, I observed access to extracurricular activities or opportunities, such as drama clubs, horse riding, and supported work placements which appeared to enhance the SOB and self-confidence of the CYP (Culliane, 2020; Finnegan, 2022). Moreover, I saw parents making sure that the correct support was in place for their child, such as organising visits from external professionals or ensuring EHC provision was being followed. These opportunities were often facilitated by proactive parental advocacy, which highlighted to me the impact of parental involvement (Yatim & Ali, 2022). Following these reflections, my research aims to explore the influence of parental advocacy in promoting a SOSB and positive outcomes for CYP with DS.

#### 3.3 Literature Review

I began to clarify my thesis project in Summer 2023, through conducting scoping searches and refining my research interest. At this point, I knew I wanted to explore a topic around DS and SOSB, but this remained quite broad. I was apprehensive to conduct a literature review, as I had not completed one to this scale before, and I was concerned about missing crucial pieces of research. I initially used guidance from Boland et al's (2017) book 'Doing a Systematic Review: A Student's Guide'. Although this was aimed at master's level students, it was helpful to gain an initial understanding of literature reviews.

Through my scoping searches, I struggled to find relevant literature related to DS and SOSB / SOB. Much research I came across considered views related to DS and inclusive education (Er-Rida et al., 2024), quality of life (Fucà et al., 2022) and social position (Laws et al., 1996). One study explored parental perspectives of SOSB for CYP with DS, however I could not gain access to the full article (Westin et al., 2022). Some research did speak about SOB for CYP with DS, however this was a theme which arose, rather than being a factor which was being explored in depth (Lyons et al., 2016). With limited research discussing SOSB for CYP with DS, I knew this was an area I wanted to further explore.

This led me to conduct a hybrid approach to my literature review. I initially used a systematic literature review. This allowed me to have a structured approach in exploring and organising the current literature base and any potential gaps (Snyder, 2019). Due to the lack of research exploring DS and SOSB, I felt it was best to broaden my search to SEN and SOSB

/ SOB to gain an understanding into what factors facilitate or hinder SOB. Alongside this, I also used elements of a narrative review so I could also consider the limited DS specific literature which did not fit into the SLR search criteria. There have been many examples of researchers using a hybrid approach, by using both aspects of narrative and SLR methodologies (Turnbull et al., 2023).

At the beginning of my search, I initially wanted to explore CYP who attended mainstream settings. This is because inclusion policy and guidance has led to more children with SEN being educated in mainstream settings (Van Herwegen et al., 2018). Research also further highlighted that the majority of CYP with DS were being educated in mainstream settings within their primary education (Van Herwegen et al., 2018). However, through reflections within supervision, we discussed that SOB and inclusion should be felt and promoted regardless of which type of setting a child attends. Therefore, I decided to widen my search to include CYP with SEN who attend either mainstream or SEN settings.

In terms of research exploring SOB and SEN, there appeared to be a range of literature. The majority of the included studies explored the views of CYP with SEN directly. This was a strength as it is in line with current guidance and legislation, such as the SEND Code of Practice (2014), which highlights the importance of CYP with SEN being included in decision making about their education. By using child voice directly, it allows children to reflect on their own experiences, without having the perceptions from others (Graves et al., 2016; Skotko et al., 2011). However, potential limitations must be raised. Limited research considered to ensure that CYP understood the concept of SOB, therefore there is a risk that they could have been reflecting on their feelings about school in general, rather than their deeper connection to school and the people within it (Hall & McGregor, 2000). However, by considering studies such as Lovell's (2021), who gained views from TAs, and also Alesech and Nayer (2020), who triangulated data from staff, parents and CYP, it allowed for a holistic view of what contributes to SOSB.

It is also important to consider how CYP with SEN were identified to participate within the studies. Some highlighted that a statement of SEND was needed (Nepi et al., 2013), or a diagnosis (Miles et al., 2019), whereas others used pupil or teacher self-report methods to identify SEN (Porter & Ingram, 2021). For the literature review, no inclusion or exclusion criteria was applied to how SEN needed to be identified to explore the broadness of data. However, it must be considered that some children's voices may have been excluded if they did not fit the specific studies inclusion criteria, such as needing a diagnosis to participate.

I am also aware that both medical and social models of disabilities are often employed in research exploring SEN. Although I was mainly interested in exploring what factors acts as facilitators and barriers to SOB, some researchers took a more comparative approach, looking at both SEN and non-SEN groups (Culliane, 2020). Although this was insightful, I recognise that this might be endorsing an essentialist view of SEN, which is in line with a medical model of thinking. As highlighted in Chapter 1, this is an approach which is often used in schools to ensure that resources and provision is appropriately allocated (Algraigray & Boyle, 2017). This could suggest that children are being grouped by deficits, rather than considering the environment which might be causing difficulties.

It must also be acknowledged that the literature review was conducted by one researcher. It has been suggested that using at least two researchers helps with the reliability and quality of the literature review (Snyder, 2019). Therefore, there is a risk that there was potential bias when selecting studies within my review. To reduce this, I regularly revisited the literature review, and this was reviewed by my research supervisor. There is also a possibility that I have not reviewed all of the relevant studies. I took steps to reduce this, such as using a range of search phrases, using different databases, and also using citation chaining. Therefore, this ensured a breadth and variety of literature was included, with the aim of providing an overview of the topic of SOB and CYP with SEN.

Conducting the literature review reinforced my understanding that research on DS and SOB is limited. However, exploring SEN more broadly revealed valuable findings.

## 3.4 Developing my Participant Group

I always knew that I wanted my research to focus on DS and SOSB. However, I felt that I faced a dilemma surrounding my participant group. I was unsure whether to work with CYP with DS directly or whether to interview parents.

In the early stages of planning, I was thinking of working with children with DS and exploring their ideas of school belonging. At the time, I felt it would be beneficial to work directly with the population group, as much research has suggested that exploring the views of CYP with DS' is limited (Lightfoot & Bond, 2013). However, I began to think about the feasibility of this. At first, I thought about what data collection would look like. I reflected that using a visual approach, such as a Talking Mat or symbols would be beneficial to gain pupils views, especially those with speech, language, and communication needs (Lightfoot & Bond, 2013). I also considered using drawing-based approaches, such as the ideal school or asking them

to draw what belonging means to them (Moran, 2001). However, several concerns emerged. This included that SOB / SOSB can be considered a complex and abstract phenomenon (Cartmell & Bond, 2015), and there are risks that CYP with DS may struggle to understand the concept (Westin et al., 2022), and instead may focus on what they like and dislike about school. Moreover, there is a possibility that I could be excluding CYP with DS who cannot communicate their views either through verbal or visual means. I also considered the ethical implications associated with recruiting participants who are children and had a learning difficulty (NSPCC, 2023).

I reflected on Lightfoot and Bond's (2013) study, which explored the perspectives of CYP with DS, along with parents and support staff, regarding inclusion and transition. Within the study, all participants felt that there were difficulties in obtaining the views of CYP with DS (Lightfoot & Bond, 2013). Some parents shared that on some occasions, their child may say they dislike something, but they might only be referring to one element of a situation, rather than a holistic view (Lightfoot & Bond, 2013). It was suggested that gaining the voice of CYP with DS is still crucial, however this should be triangulated with observation data and considering CYPs mood and behaviour (Lightfoot & Bond, 2013). It was highlighted that parents are then left with the task of advocating for their child with DS when working with professionals and ensuring correct provision is in place (Lightfoot & Bond, 2013).

As discussed within the literature review section of this chapter, I initially wanted to recruit participants who attended mainstream schools. This is due to the increase of CYP with DS attending mainstream settings (Van Herwegen et al., 2018). However, upon reflection with my supervisor, it was raised that this potentially risks falling into inclusion, rather than SOSB. These are concepts which have been shown to share some similarities but also distinct differences (Slaten et al., 2016). We also discussed that SOSB should be promoted in all settings which CYP with DS attend, not just mainstream settings. Therefore, I decided to explore both mainstream and SEN settings.

These reflections led me to think about potentially selecting parents who have children with DS as my participant group. Although the SEND Code of Practice (2014) highlights the importance of child voice, it also suggests that working in collaboration with parents is also crucial. I reflected on my previous roles and found that as a Support Worker, Teaching Assistant, Assistant Psychologist and now a TEP, a common theme I saw within my work was that parents were advocating for their CYP with SEN (McCammon et al., 2001). Parents were making important decisions regarding their education and care, and for some parents this is

a role they would continue as their child progresses into adulthood (Krueger et al., 2019). Therefore, I felt it was important to explore parental views further.

This decision was met with some scepticism from some peers and members of the course team, particularly as child voice is recognised as a crucial element of EP practice (Harding & Atkinson, 2009). I experienced moments of doubt, questioning whether I had chosen the right focus for my project. However, in its earlier stages, I tried to feel confident in my rationale. This was supported by previous research examining the perspectives of parents of children with DS on various topics (Deakin & Jahoda, 2020; Skotko et al., 2012; Van Herwegen et al., 2018), alongside literature highlighting the crucial role of parental advocacy in supporting CYP with SEN (Krueger et al., 2019). It was during my data collection that my confidence in the topic began to grow. Many parents expressed appreciation for the opportunity to share their experiences, which reinforced the significance of my research. Listening to the efforts these parents made to advocate for their children and ensure the right support was in place to foster a SOSB was inspiring. Their dedication to achieving equity for their child with DS was evident in actions such as organising presentations for World Down's Syndrome Day, reaching out to external professionals for additional support, and maintaining consistent communication with schools. Many participants touched on the idea that there have been "fights" or "battles" along the way, and although this did have an emotional toll on parents' wellbeing, the outcome meant their child felt that they truly belonged to a setting.

Some participants reflected on the discrepancies between their views and their child's views. This included their children not always being aware of the support and advocation their parent would be doing in the background to ensure that their SOSB was met. Another example was a parent highlighting that their child views many people as their 'friends', including staff or acquaintances at school, whereas the parent acknowledged that from their perspective, these relationships would not meet the definition of a 'friendship'. These differences have been noted in previous literature (Deakin & Jahoda, 2020). However, these accounts helped to solidify that although parent and child views may differ, they are both valid and meaningful perspectives. By interviewing parents, it allowed me to gain a holistic picture of what contributes to SOSB for CYP with DS (Becker & Dusing, 2010). The importance of parental advocation was highlighted by one of my participants: "I've realised when you have a child with a disability, things don't come to you. You have to make them happen".

I also made the decision to interview biological parents, rather than parents who have 'parental responsibility'. This was a decision I found difficult, as I felt it was important to explore all parents' views. However, from conversations in supervision, we discussed that 'parental

responsibility' could include CYP with DS who are in care. Research has suggested that being a child in care can affect your SOB (Chimange & Bond, 2020). Although this may not be the case for all children in care, I wanted to reduce any influencing factors which could impact SOSB.

## 3.5 Ontology and Epistemology

I first came across ontology and epistemology during my first year of doctoral training. At the time, I remember feeling confused and unsure of my understanding. This uncertainty led to concern, as I knew a strong understanding of these concepts would be essential for conducting doctoral research.

I discussed this in supervision, and my supervisor shared a helpful diagram which showed ontology and epistemology as a spectrum. Ontological assumptions can be viewed on a continuum, ranging from 'realist' to 'relativist' (Willig, 2008). Whereas epistemology can range from objectivism to subjectivism (Crotty, 1998). By understanding my ontology, epistemology, and methodology separately, it allowed me to understand my overall positioning. This led me to choose social constructivism which considers a relativist ontology and a subjectivist epistemology; and methodologically it is typically associated with qualitative research (Plano Clark & Ivankova, 2016; Tashakkori et al., 2021). Social constructivism emphasises how an individual constructs their own reality through their cognitions (Lincoln & Guba, 1985; Schwandt, 1997). It also considers the importance of social context and culture to understand society and constructed knowledge (Derry, 1999). This felt highly relevant to my study, as I was interested in exploring how parents who have children with DS conceptualise and advocate SOSB. By using a social constructivist lens, it allowed me to reflect on their subjective realities, whilst considering the broader social context and educational environments.

#### 3.6 Developing Research Questions

Throughout this process, I found I had to develop and re-develop my research questions. Authors such as Mayer (2008) suggested that research questions should reflect personal interest, educational relevance, theoretical grounding, and empirical testability.

Following my initial literature review, I developed the following research questions:

From the perspective of parents who have a child with Down's syndrome:

- What does 'sense of school belonging' mean for CYP with Down's syndrome?
- What facilitates school belonging for CYP with Down's syndrome?
- What are the barriers of school belonging for CYP with Down's syndrome?

I presented my initial ideas and research questions to my cohort and tutor team. Questions were raised about why I chose to interview parents, rather than CYP directly. The key piece of feedback was that it was felt that I had a good rationale for collecting parent voice rather than trying to gain child's voice through parents. This made me re-think how I was framing my questions, as I was interested in exploring parental views.

Following feedback, I re-developed my research questions and submitted this as part of a summative research proposal.

- How do parents of children with Down's syndrome conceptualise sense of school belonging?
- What are parents' experiences of advocating school belonging for their child with Down's syndrome?

Following feedback from the marker, it was felt that it was not explicitly clear what I meant by "parents' experiences of advocating school belonging for their child". It was suggested that I considered rewording the second research question, potentially considering what parents think schools do to support SOB. It was felt that this would still relate to advocation, but there is also a clearer link to EP practice.

I then had further discussions within supervision and reviewed my research questions. We discussed that a large part of parental advocation for CYP with SEN is having to choose a school placement for their child (Allen et al., 2014). Therefore, it felt important to incorporate that element within the research questions.

This led me to develop the final research questions which were highlighted in Chapter 2 of this thesis.

### 3.7 Data Collection

The structure of my project and approach to data collection has evolved throughout this process. When I originally proposed my research study, I originally wanted to conduct it in two phases. To collect rich qualitative data, focus groups and semi-structured interviews

were proposed (Gillham, 2000; Yin, 2018). It was suggested that the first phase would involve a focus group, with 6-10 participants, where parents could co-construct a joint understanding of what SOSB means for their children with DS (Cohen et al., 2017; Krueger, 2014; Shaw 2019). To organise definitions, I wanted to use concept mapping. Concept mapping is an approach which allows groups to map out their ideas about a certain topic (Trochim & McLinden, 2017). Typically, it involves six steps: preparation, generation, structuring, representation, interpretation, and utilisation (Trochim & McLinden, 2017). The purpose of the second phase was to explore how parents who have children with DS advocate SOSB through semi-structured interviews.

As highlighted by Mayer (2008), it is important that your methodology is deemed as feasible. From reflections in supervision, I wondered whether it would be realistic to recruit and conduct two phases with the timeframe I was given. Instead, I felt that I could still answer the same questions by using one phase and semi-structured interviews. Although I was disappointed to not use my original plan and use a concept mapping approach, I felt it was important to feel that my project was manageable.

I conducted individual semi-structured interviews via Microsoft Teams. This meant that interviews could take place in a private and safe space (Doody & Noonan, 2013). By conducting interviews online, it meant that the research was open to anyone in England who could access Microsoft Teams. Therefore, my results are not specific to just one LA. Unfortunately, I did not collect information regarding participants geographical location as it did not seem relevant to my research questions. However, this could be interesting to explore further in the future as some research has suggested that SEND support can be a 'postcode lottery' (Education Policy Institute, 2025).

#### 3.8 Interview Process

I used an interview schedule to guide all interviews. This was developed following guidance from Knott et al., (2022). Although an interview schedule was used, it allowed for flexibility meaning the interviewee was able to discuss topics which felt important to them. Details regarding how I developed the interview schedule can be found in Chapter 1.

It was an interesting experience conducting the interviews. My only previous experience of research was during my undergraduate degree where I used quantitative methods and in Year 1 using a questionnaire to gain qualitative data for a small-scale research project. I was initially nervous to conduct the interviews, as this was a new experience. As part

of my role as a TEP, a large part of my work is meeting and talking with parents (Boyle & Lauchlan, 2009), which reassured me.

During this study, I held a dual role as a doctoral researcher and also a TEP. It is essential that researchers plan for any difficulties which may arise because of their dual role (Geddis-Regan et al., 2022). This has also been highlighted within research and practice guidelines (BERA 19; HCPC SoP 2.12). Within the current research, I did not recruit participants from the LA I was on placement in. Instead, I advertised on social media, meaning anyone within England could have volunteered to participate. Although there was a possibility that a parent who I have worked with previously could have volunteered, this probability was low. I did not have any previous relationship (personal or professional) with any of the recruited participants.

Although I did not have a prior working relationship with the parents, I was conscious of the dual-role I held as both a TEP and a researcher. Based on my experiences working with parents in my TEP role, particularly within a consultation capacity, I was concerned that the interviews might feel like consultations rather than research-focused discussions. To address this, I carefully drew on the skills I had developed as a TEP, such as working effectively with adults, facilitating meetings, and applying my knowledge of child development (Farrell & Woods, 2015). I also utilised consultation skills, including demonstrating empathy, active listening, re-focusing conversations, and summarising key points (Nolan & Moreland, 2014). However, to maintain adherence to the interview framework, I deliberately refrained from using consultation techniques such as challenging information or formulating action plans (Farrell & Woods, 2015; Nolan & Moreland, 2014). This felt crucial, as the aim of the interviews was to understand parents' experiences and perspectives rather than to identify solutions. The use of the interview schedule helped ensure the discussions remained structured and aligned with my research objectives.

During some interviews, parents shared emotional and difficult stories, which required me to remain mindful of my role as a researcher rather than a TEP. In these moments, I relied on my active listening and empathy skills to navigate the challenges while maintaining an appropriate stance.

### 3.9 Data Analysis

I only had experience of using thematic analysis when I was in my first year of doctoral training, when conducting a small-scale research project. This was helpful as it helped me

become familiar with the basic principles of thematic analysis. However, in that instance thematic analysis was used at a much smaller scale. Therefore, I felt apprehensive using an RTA with 9 participants and interview data that was 45 minutes to an hour long.

It was useful to use Braun and Clarke's (2022) guide to help me understand the RTA process in greater depth and have access to worked examples within the textbook. Their companion website, ThematicAnalysis.net (Braun & Clarke, N.D.) was also helpful to gain access to resources related to RTA, which assisted me in managing my worries about the process.

I immersed myself in the data by transcribing and re-reading my transcripts. A helpful task I undertook was developing familiarisation doodles based on my transcript data. As I was able to recruit some of my participants earlier on in the recruitment process, therefore I had sufficient time to undertake this task. In line with Braun and Clarke's (2022) guidance, it is important to immerse yourself in the data in a way which works for you. This is especially important if you are working on the data analysis independently. By using familiarisation doodles or notes, it allows you to engage in the data and grasp concepts in a "messy and casual" way (Braun & Clarke, 2022).

From looking at previous theses, I noticed that many researchers tend to code and theme by hand. I personally preferred to use the comment function on Word, as I found it quicker and easier. From reading Braun and Clarkes (2022) guide, I noticed that the Macro function was discussed. By using this function, it meant that I could turn the comment codes into a Microsoft Excel spreadsheet, where codes could be listed alongside the transcript data (Braun & Clarke, 2022). Despite this process being computer aided, it allowed me to engage in the data and reduced the level of reading and writing which is required for handwritten methods (Braun & Clarke, 2022).

When it came to developing themes, this felt like an ongoing process. This stage worried me as I felt that I had to get it 'right' the first time. However, by following Braun and Clarke's (2022) guidance, it helped me to see the data analysis process as being iterative and recursive. Rather than trying to complete my analysis as quickly as possible, I had to remind myself that themes would develop overtime and taking a break from the analysis would be helpful. I followed Braun and Clarkes (2022) advice about embracing the subjectivity I bring as a researcher. It also helped to remain reflexive, knowing that theme development was an ongoing process which was revisited and changed throughout the process.

Initially, I felt apprehensive about the high number of themes in my research, as I had identified 18 in total. Upon reflection, I realised that this was likely due to several factors. My research is structured around four distinct sub-questions, each exploring different aspects of SOSB from the perspective of parents of children with DS. Naturally, this approach led to a variety of themes, as it was essential to address the research questions in a meaningful and comprehensive way.

Furthermore, I conducted interviews with nine participants in total, each lasting between 45 minutes to an hour. The richness of the data collected provided a diverse range of perspectives, which contributed to the substantial number of themes uncovered in my analysis.

# 3.10 Other Interesting Findings

It's important to highlight that the current study uncovered valuable insights and by using an RTA it helped to explore the shared experience amongst participants (Kelly, 2017). Braun and Clarke (2022) highlight that it is crucial that researchers are thorough during the coding and theming process, which is ongoing and changes overtime. The nature of RTA presents with a potential limitation, where some extracts from the transcripts may not have been developed into themes. This is often the case when certain experiences are unique to a single participant and are not shared by others, leading to their exclusion from the broader thematic analysis.

For example, Lucy discussed in depth about their daughter's difficulties with creating meaningful friendships and how this negatively impacted her SOSB. It was further felt that the teachers and school staff did not always understand the importance of meaningful friendships for CYP with DS.

**Lucy:** "She's never really had, like yeah, formed solid friendships. And so, she doesn't know any different. So, to her, she's quite happy with the way things are. But from my point of view, and I know her dad feels the same... She doesn't".

While some participants briefly mentioned challenges with friendships, these were not explored in as much depth as they were by Lucy. Interestingly, friendship difficulties and bullying did not emerge as a theme within this study, despite previous research highlighting its potential negative impact on the SOSB for CYP with SEN (Culliane, 2020; Lovell, 2021).

There are several possible reasons for this. Firstly, with a sample of nine parents, it could be suggested that their children may not have encountered significant friendship difficulties, which could account for the lack of emphasis on this topic. Alternatively, findings might differ with a larger sample size. Additionally, much of the existing research focuses on CYP's own perspectives, which may provide greater insight into their experiences with friendships than parental accounts.

Lucy shared that they became aware of their daughter's struggles in forming friendships after observing her interactions at a birthday party. This observation prompted Lucy to raise questions with school staff, demonstrating how parental perceptions and advocacy can play a crucial role in addressing social challenges.

Lucy: "[At parties] She was just playing on her own. None of them were really making an effort to properly include her. So that led to me questioning school even more. And saying, does she have friendships in school? And they'd say, oh, yes, yes, yes. And I'm like, right, OK. So, I'm going to tell you what I've seen at parties. So, to me, if they were genuinely friends with her in school, that wouldn't be happening at a party".

Therefore, it could be suggested that parents are not always aware of these experiences, especially if staff are not being transparent with their communication. This may suggest why this was not commented on in depth by other participants.

Although I enjoyed the process of using RTA, and having a structured approach to data analysis, I encountered difficulties when certain experiences or narratives did not fit neatly into an established theme.

# 3.11 Dissemination of Findings

To my knowledge, this is the first study to explore how parents of school-aged children with DS conceptualise and advocate for SOSB. It contributes to the existing literature, which has predominantly focused on SEN more broadly. I am committed to sharing the findings of my study. As highlighted in Chapter 2, the current study has implications for CYP with DS, their parents, schools, and EPs.

I initially plan to disseminate my findings at a service level. I hope to present the overview of my study and findings at my placement LAs Team Day. Given the prevalence of

CYP with DS, it is likely that EPs within my service will have already worked with CYP with DS and their parents, and will continue to do so in the future.

As highlighted in the participant consent form, I will be sharing my findings with the participants who took part in the study. This will be presented in a short summary and emailed to participants following submission. I will also make participants aware that they are welcome to access the full thesis once it is uploaded onto UEAs digital repository. I would also like to share my findings with charities which supported my research, such as the Down's Syndrome Association. This will ensure that the findings of the current study reach CYP with DS and their parents who did not participate.

My thesis will also be uploaded onto UEAs online digital repository, which will be open access. This means that anyone who is interested in reading the full text will be able to access this. I also hope to pursue the possibility of publishing my study in a research journal, such as 'Educational Psychology in Practice'.

#### 3.12 Conclusion

Overall, I thoroughly enjoyed the research process and contributing to an area that I am passionate about. This experience has been crucial for my own personal and professional development. This has included developing a systematic literature review and gaining a deeper understanding into ontology and epistemology, specifically social constructivism (Lincoln & Guba, 1985), and its relevance to my research. I also learnt about how to develop semi-structured interviews (Knott et al., 2022) and balancing my dual role of being a TEP and doctoral researcher during the interview process (Geddis-Regan et al., 2022). Using RTA was also an interesting and insightful experience (Braun & Clarke, 2022).

It was moving to hear about parents' experiences of advocating for their children with DS, specifically supporting their SOSB. This is often an unseen role many parents of CYP with DS take on. It was apparent that every parent wanted the best outcome for their child, whether that was ensuring they have access to more equitable experiences, having the correct support in place, organising extracurricular activities, or celebrating DS. For many parents, the role of advocation can negatively impact their own emotional wellbeing, highlighting the need for further support. However, despite these challenges, many participants touched on positive experiences for their child with DS.

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# Appendix A - Excluded Studies

| Article  | Reason(s) for Exclusion                 |
|--|---|
| Prince, E. J., & Hadwin, J. (2013). The  | Systematic literature review            |
| role of a sense of school belonging in   |   |
| understanding the effectiveness of   |   |
| inclusion of children with special   |   |
| educational needs. International Journal   |   |
| of Inclusive Education, 17(3), 238-262.  |   |
| Pesonen, H. (2016). Sense of   | Review of published studies             |
| belonging for students with intensive  |   |
| special education needs: An exploration  |   |
| of students' belonging and teachers'   |   |
| role in implementing support.  |   |
| Gur, A., & Bina, R. (2023). Facilitators   | Systematic literature review            |
| of sense of belonging among people   |   |
| with intellectual and developmental  |   |
| disabilities: A systematic review.   |   |
| Journal of Intellectual Disabilities, 27(2),   |   |
| 516-538.   |   |
| Midgen, T., Theodoratou, T., Newbury,  | Included children who were younger than |
| K., & Leonard, M. (2019). 'School for  | school age / could not access full text |
| everyone': An exploration of children  |   |
| and young people's perceptions of  |   |
| belonging. Educational and Child   |   |
| Psychology.  |   |
| Lyons, R., Brennan, S., & Carroll, C.  | Belonging emerged as a theme, was not   |
| (2016). Exploring parental perspectives  | directly explored                       |
| of participation in children with Down's   |   |
| syndrome. Child Language Teaching  |   |
| and Therapy, 32(1), 79-93.   |   |
| Mellon, S. L. (2015). A mixed methods  | Unable to gain access to full article   |
| study investigating a sense of belonging   |   |
| in young people with autism spectrum   |   |
| disorder in mainstream education   |   |
|  |   |
| [Doctoral dissertation, Queen's  |   |
| belonging. Educational and Child Psychology.  Lyons, R., Brennan, S., & Carroll, C. (2016). Exploring parental perspectives of participation in children with Down's syndrome. Child Language Teaching and Therapy, 32(1), 79-93.  Mellon, S. L. (2015). A mixed methods study investigating a sense of belonging in young people with autism spectrum | directly explored                       |

| belonging: Listening to the voices of secondary school students who have undergone managed moves. School Psychology International, 39(1), 56-73.  Svavarsdottir, E. K. (2008).  Connectedness, belonging and feelings about school among healthy and chronically ill Icelandic schoolchildren. Scandinavian Journal of Caring Sciences, 22(3), 463-471.  Zhao, W. M., Thirumal, K., Renwick, R., & DuBois, D. (2021). Belonging through sport participation for young adults with intellectual and developmental disabilities: A scoping review. Journal of Applied Research in Intellectual Disabilities, 34(2), 402-420.  Spalletta, O. (2021). Patrons of the State: Reciprocity, Belonging, and Life with Down's syndrome in Denmark [Doctoral dissertation, Brandeis University].  Raines, A. R., Francis, G. L., Fujita, M., & Macedonia, A. (2023). Belonging from the perspectives of individuals with disabilities: A scoping review. Psychology in the Schools, 60(6), 2112-2127.  Johnsen, P. N. (2024). A DisCrit analysis of experiences influencing belonging for college students with disabilities [Doctoral dissertation, University of Northern Colorado].  Barnes, R., Kelly, A. F., & Mulrooney, Included college / university aged students withdens of the students with disabilities [Doctoral dissertation, University of Northern Colorado]. | Craggs, H., & Kelly, C. (2018). School  | Focus on managed moves  |
|---|---|---|
| secondary school students who have undergone managed moves. School Psychology International, 39(1), 56-73.  Svavarsdottir, E. K. (2008). Focus was on pupils with chronic illnesses rather than SEN about school among healthy and chronically ill Icelandic schoolchildren. Scandinavian Journal of Caring Sciences, 22(3), 463-471.  Zhao, W. M., Thirumal, K., Renwick, R., & DuBois, D. (2021). Belonging through sport participation for young adults with intellectual and developmental disabilities: A scoping review. Journal of Applied Research in Intellectual Disabilities, 34(2), 402-420.  Spalletta, O. (2021). Patrons of the State: Reciprocity, Belonging, and Life with Down's syndrome in Denmark [Doctoral dissertation, Brandeis University].  Raines, A. R., Francis, G. L., Fujita, M., & Macedonia, A. (2023). Belonging from the perspectives of individuals with disabilities: A scoping review. Psychology in the Schools, 60(6), 2112-2127.  Johnsen, P. N. (2024). A DisCrit analysis of experiences influencing belonging for college students with disabilities [Doctoral dissertation, University of Northern Colorado].  Barnes, R., Kelly, A. F., & Mulrooney, Included college / university aged   |   | 5   |
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| Barnes, R., Kelly, A. F., & Mulrooney, Included college / university aged   | with Down's syndrome in Denmark [Doctoral dissertation, Brandeis University].  Raines, A. R., Francis, G. L., Fujita, M., & Macedonia, A. (2023). Belonging from the perspectives of individuals with disabilities: A scoping review. Psychology in the Schools, 60(6), 2112-2127.  Johnsen, P. N. (2024). A DisCrit analysis of experiences influencing  | education.  Scoping review  Included college / university aged          |
|   | with Down's syndrome in Denmark [Doctoral dissertation, Brandeis University].  Raines, A. R., Francis, G. L., Fujita, M., & Macedonia, A. (2023). Belonging from the perspectives of individuals with disabilities: A scoping review. Psychology in the Schools, 60(6), 2112-2127.  Johnsen, P. N. (2024). A DisCrit analysis of experiences influencing belonging for college students with  | education.  Scoping review  Included college / university aged          |
| H. M. (2021). Student belonging: The students   | with Down's syndrome in Denmark [Doctoral dissertation, Brandeis University].  Raines, A. R., Francis, G. L., Fujita, M., & Macedonia, A. (2023). Belonging from the perspectives of individuals with disabilities: A scoping review. Psychology in the Schools, 60(6), 2112-2127.  Johnsen, P. N. (2024). A DisCrit analysis of experiences influencing belonging for college students with disabilities [Doctoral dissertation,                                   | education.  Scoping review  Included college / university aged          |
|   | with Down's syndrome in Denmark [Doctoral dissertation, Brandeis University].  Raines, A. R., Francis, G. L., Fujita, M., & Macedonia, A. (2023). Belonging from the perspectives of individuals with disabilities: A scoping review. Psychology in the Schools, 60(6), 2112-2127.  Johnsen, P. N. (2024). A DisCrit analysis of experiences influencing belonging for college students with disabilities [Doctoral dissertation, University of Northern Colorado]. | education.  Scoping review  Included college / university aged students |

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Kaley, A., Donnelly, J. P., Donnelly, L., Humphrey, S., Reilly, S., Macpherson, H., ... & Power, A. (2022). Researching belonging with people with learning disabilities: Self-building active community lives in the context of personalisation. *British Journal of Learning Disabilities*, *50*(3), 307-320.

Social care focus

# Appendix B - Gough's Weight of Evidence (2007)

#### Scoring Criteria

The following guidance has been directly taken from Bond et al., (2011) to analyse WOE A:

Criteria on which the quality of a quantitative study was judged were drawn from American Psychological Association (2006) and gave a 1-point credit for the presence of each of the following criteria:

- Use of a randomised group design
- Focus on a specific, well-defined disorder or problem
- Comparison with treatment-as-usual, placebo, or less preferably, standard control
- Use of manuals and procedures for monitoring and fidelity checks
- Sample large enough to detect effect
- Use of outcome measure(s) that have demonstrable reliability and validity (2-point weighting given for more than one measure used).

The criteria on which the quality of a qualitative study was judged were drawn from Spencer, Rithie, Lewis & Dilton (2003), and Henwood & Pidgeon (1992), and gave 1 point credit for the presence of each of the following criteria:

- Appropriateness of the research design
- Clear sampling rationale
- Well executed data collection execution
- Analysis close to the data
- Emergent theory related to the problem
- Evidence of explicit reflexivity
- Comprehensiveness of documentation
- Negative case analysis
- · Clarity and coherence of the reporting
- Evidence of researcher-participant negotiation
- Transferable conclusions
- Evidence of attention to ethical issues

# WOE Scores

| Author                | Weight of evidence | Weight of evidence | Weight of evidence |
|-----------------------|--------------------|--------------------|--------------------|
|                       | (A) -              | (B) -              | (C) -              |
|                       | Methodological     | Appropriateness    | Relevance of       |
|                       | Quality            |                    | Focus              |
| Cullinane (2020)      | Medium             | High               | High               |
| Nepi et al., (2013)   | Medium             | High               | High               |
| Lovell (2021)         | High               | High               | High               |
| Smedley (2011)        | High               | High               | High               |
| Finnegan (2022)       | High               | High               | High               |
| Dimitrellou & Hurry   | Medium             | High               | High               |
| (2019)                |                    |                    |                    |
| Miles et al., (2019)  | Medium             | High               | High               |
| Kopelman-Rubin et     | Medium             | Medium             | Medium             |
| al., (2020)           |                    |                    |                    |
| Rose & Shevlin        | High               | High               | High               |
| (2016)                |                    |                    |                    |
| Hebron (2018)         | Medium             | High               | Medium             |
| Gallagher Deeks       | High               | High               | High               |
| (2023)                |                    |                    |                    |
| Freire et al., (2024) | Medium             | High               | High               |
| Porter & Ingram       | Medium             | High               | Medium             |
| (2021)                |                    |                    |                    |
| Alesech & Nayar       | High               | High               | High               |
| (2020)                |                    |                    |                    |
| Ware (2020)           | High               | High               | High               |

Appendix C - Study Selection

Studies included in the literature review

| Study            | Study Aims and       | Sample                   | Country | Study Method /   | Key Findings                |
|------------------|----------------------|--------------------------|---------|------------------|-----------------------------|
|                  | Objectives           |                          |         | Design           |                             |
|                  |                      | SEN Type                 |         | Type of Paper    | <del>_</del>                |
| Cullinane (2020) | This study compares  | Pupils were recruited    | Ireland | Semi-structured  | Students with SEN           |
|                  | levels of belonging  | from a large, co-        |         | interviews and   | reported lower SOB          |
|                  | between students     | educational post-        |         | questionnaires – | in comparison to their      |
|                  | with SEN and         | primary school.          |         | Mixed methods    | non-SEN peers.              |
|                  | students without     |                          |         |                  |                             |
|                  | SEN. The barriers    | Phase 1 – 25 pupils      |         |                  | Distinctive barriers        |
|                  | and facilitators of  | with SEN                 |         |                  | and facilitators were       |
|                  | school belonging was |                          |         |                  | highlighted which           |
|                  | also explored.       | Phase 2 – 12             |         |                  | impacts CYPs                |
|                  |                      | students with SEN        |         |                  | connection to school.       |
|                  |                      | and 11 mainstream        |         |                  |                             |
|                  |                      | peers                    |         |                  | Five themes                 |
|                  |                      | Specific learning        |         | Peer-reviewed    | <br>emerged:                |
|                  |                      | difficulties, emotional  |         | journal article  | <ul> <li>Teacher</li> </ul> |
|                  |                      | and behavioural          |         |                  | support and                 |
|                  |                      | difficulties, borderline |         |                  | relationships               |
|                  |                      | and mild general         |         |                  |                             |

|                     |                     | learning difficulties,   |       |                  | Academic                          |
|---------------------|---------------------|--------------------------|-------|------------------|-----------------------------------|
|                     |                     | and autism spectrum      |       |                  | engagement                        |
|                     |                     | disorder                 |       |                  | and progress                      |
|                     |                     |                          |       |                  | <ul> <li>Peer support</li> </ul>  |
|                     |                     |                          |       |                  | and                               |
|                     |                     |                          |       |                  | friendships                       |
|                     |                     |                          |       |                  | <ul><li>Extra-</li></ul>          |
|                     |                     |                          |       |                  | curricular                        |
|                     |                     |                          |       |                  | activities                        |
|                     |                     |                          |       |                  | <ul> <li>Inclusion and</li> </ul> |
|                     |                     |                          |       |                  | participation                     |
| Nepi et al., (2013) | This study explores | 418 (122 SEN)            | Italy | Questionnaires – | Results suggest that              |
|                     | the social position | primary school pupils    |       | Quantitative     | CYP with SEN                      |
|                     | and inherent SOB of | aged eight to 11         |       |                  | struggle to gain a                |
|                     | primary school      | years old                |       |                  | good social position,             |
|                     | pupils.             | Students who had a       |       | Peer-reviewed    | are peripheral within             |
|                     |                     | statement of             |       | journal article  | the class, are less               |
|                     |                     | disability (cognitive or |       |                  | accepted and feel                 |
|                     |                     | sensory motor),          |       |                  | distant from their                |
|                     |                     | learning difficulties or |       |                  | school.                           |
|                     |                     | behavioural              |       |                  |                                   |
|                     |                     | difficulties             |       |                  | For non-SEN peers,                |
|                     |                     |                          |       |                  | the higher the                    |

|                |                       |                       |         |                 | proficiency, the                    |
|----------------|-----------------------|-----------------------|---------|-----------------|-------------------------------------|
|                |                       |                       |         |                 | higher the SOB to                   |
|                |                       |                       |         |                 | their school and pee                |
|                |                       |                       |         |                 | acceptance.                         |
| Lovell (2021)  | This study explores   | 15 teaching           | England | Semi-structured | Findings suggested                  |
|                | why children with     | assistants and        |         | interviews -    | that TAs and                        |
|                | SEMH needs are        | teachers working      |         | Qualitative     | teachers valued                     |
|                | less likely to        | within mainstream     |         |                 | school SOB.                         |
|                | experience SOB and    | primary schools       |         |                 |                                     |
|                | what contributes to   | Social, emotional,    |         | Doctoral thesis | Barriers of SOB were                |
|                | their SOB.            | and mental health     |         |                 | highlighted including               |
|                |                       | needs                 |         |                 | <ul> <li>Difficulties in</li> </ul> |
|                |                       |                       |         |                 | forming                             |
|                |                       |                       |         |                 | friendships                         |
|                |                       |                       |         |                 | • Exclusion from                    |
|                |                       |                       |         |                 | the classroom                       |
| Smedley (2011) | This study explored   | Three boys aged       | England | Semi-structured | There were                          |
|                | the lived experience  | eight to 10 years old |         | interviews –    | similarities in the                 |
|                | of 'belongingness' of | attending the same    |         | Qualitative     | CYPs experiences o                  |
|                | three boys with       | mainstream primary    |         |                 | belonging but there                 |
|                | persistent literacy   | school                |         |                 | were also some clea                 |
|                | difficulties who      | Persistent literacy   |         | Doctoral thesis | differences.                        |
|                |                       | difficulties          |         |                 |                                     |

|                 | attended mainstream   |                     |         |                  | Five key themes                   |
|-----------------|-----------------------|---------------------|---------|------------------|-----------------------------------|
|                 | school.               |                     |         |                  | were identified:                  |
|                 |                       |                     |         |                  | <ul> <li>Interpersonal</li> </ul> |
|                 |                       |                     |         |                  | relationships                     |
|                 |                       |                     |         |                  | <ul> <li>Teacher</li> </ul>       |
|                 |                       |                     |         |                  | practices                         |
|                 |                       |                     |         |                  | <ul> <li>Emotional</li> </ul>     |
|                 |                       |                     |         |                  | equilibrium                       |
|                 |                       |                     |         |                  | <ul> <li>Physical</li> </ul>      |
|                 |                       |                     |         |                  | illness                           |
|                 |                       |                     |         |                  | Self-exclusion                    |
| Finnegan (2022) | Explored the impact   | 49 pupils from four | England | Semi-structured  | Children with SEN                 |
|                 | of relationships with | mainstream primary  |         | interviews and   | experience lower                  |
|                 | classroom adults and  | schools. Eight      |         | questionnaires – | school belonging,                 |
|                 | teaching assistant    | reported to have    |         | Mixed methods    | attend fewer                      |
|                 | support on school     | SEN, three had      |         |                  | extracurricular                   |
|                 | belonging of children | EHCPs               |         |                  | activities, have higher           |
|                 | with SEN.             | Type of SEN not     |         | Doctoral thesis  | TA support, and have              |
|                 |                       | specified           |         |                  | weaker relationships              |
|                 |                       |                     |         |                  | with their teachers in            |
|                 |                       |                     |         |                  | comparison to non-                |
|                 |                       |                     |         |                  | SEN peers.                        |

| Dimitrellou & Hurry  | To understand the     | 1,440 (282 SEND)       | England | Questionnaires - | Findings highlighted     |
|----------------------|-----------------------|------------------------|---------|------------------|--------------------------|
| (2019)               | schooling             | pupils, in years 7-10, |         | Quantitative     | that pupils with SEN     |
|                      | experiences of pupils | from three             |         |                  | are not a                |
|                      | with SEMH             | mainstream             |         |                  | homogenous group.        |
|                      | difficulties and MLD  | secondary schools      |         |                  | Pupils with              |
|                      | by investigating      | Social, emotional,     |         | Peer-reviewed    | behavioural              |
|                      | whether they have     | and mental health      |         | journal article  | difficulties reported to |
|                      | positive SOB and      | needs and moderate     |         |                  | have lower SOB and       |
|                      | social relations.     | learning difficulties  |         |                  | social relations in      |
|                      | Whether these         |                        |         |                  | comparison to CYP        |
|                      | factors vary based on |                        |         |                  | with learning            |
|                      | school ethos.         |                        |         |                  | difficulties.            |
|                      |                       |                        |         |                  | SOB was associated       |
|                      |                       |                        |         |                  | with positive relations  |
|                      |                       |                        |         |                  | with teachers and        |
|                      |                       |                        |         |                  | school ethos.            |
| Miles et al., (2019) | To explore SOB and    | 10 students aged 10-   | England | Semi-structured  | Findings suggest that    |
|                      | social experiences of | 12 years old (all      |         | interviews -     | factors such as          |
|                      | female adolescents    | female) who attend     |         | Qualitative      | having key               |
|                      | diagnosed with ASD    | mainstream school      |         |                  | friendships and          |
|                      | who attend            | Diagnosis of autism    |         | Peer-reviewed    | perceived social         |
|                      | mainstream schools.   | spectrum disorder      |         | journal article  | competence are           |

|                   |                        |                     |        |                  | important for                          |
|-------------------|------------------------|---------------------|--------|------------------|--|
|                   |                        |                     |        |                  | developing a SOB in mainstream school. |
|                   |                        |                     |        |                  |  |
| Kopelman-Rubin et | This study explores    | 249 students in     | Israel | Questionnaires - | Findings suggest that                  |
| al., (2020)       | the relationship       | seven and eighth    |        | Quantitative     | the better the CYP                     |
|                   | between                | grade (146 boys and |        |                  | could regulate their                   |
|                   | psychosocial           | 103 girls) from 11  |        |                  | emotions, the lower                    |
|                   | difficulties and       | public schools      |        |                  | their psychosocial                     |
|                   | emotional regulation   | Specific learning   |        | Peer-reviewed    | difficulties were. This                |
|                   | amongst CYP with       | disorder            |        | journal article  | association was                        |
|                   | specific learning      |                     |        |                  | significantly mediated                 |
|                   | disorders. The role of |                     |        |                  | by a student's sense                   |
|                   | SOB was also           |                     |        |                  | of school belonging.                   |
|                   | explored.              |                     |        |                  | Moreover, the better                   |
|                   |                        |                     |        |                  | the CYP could                          |
|                   |                        |                     |        |                  | regulate their                         |
|                   |                        |                     |        |                  | emotions, the higher                   |
|                   |                        |                     |        |                  | their school                           |
|                   |                        |                     |        |                  | belonging was, which                   |
|                   |                        |                     |        |                  | is linked to fewer                     |
|                   |                        |                     |        |                  | psychosocial                           |
|                   |                        |                     |        |                  | difficulties.                          |

| Rose & Shevlin  | Using data from a      | 120 interviews (did  | Ireland | Semi-structured  | Pupils shared that     |
|-----------------|------------------------|----------------------|---------|------------------|------------------------|
| (2016)          | four-year longitudinal | not specify how      |         | interviews -     | their SOSB was         |
|                 | study, they            | many children, but   |         | Qualitative      | developed through      |
|                 | considered             | stated that children |         |                  | positive relationships |
|                 | the relationship       | met with the         |         |                  | with adults and        |
|                 | between acceptance     | interviewer twice)   |         |                  | peers, as well as the  |
|                 | and belonging as       | Type of SEN not      |         | Peer-reviewed    | extent to which pupils |
|                 | critical factors in    | specified            |         | journal article  | could define the level |
|                 | defining what it       |                      |         |                  | of support they        |
|                 | means to be included   |                      |         |                  | received.              |
|                 | in school.             |                      |         |                  |                        |
| Hebron (2018)   | A longitudinal study   | 28                   | Wales   | Questionnaires – | Pupils reported        |
|                 | was used to measure    | students with ASC    |         | Quantitative     | positive levels of     |
|                 | school                 | (23 male, 5 female)  |         |                  | school                 |
|                 | connectedness          | and a comparison     |         |                  | connectedness          |
|                 | across transition      | group of 21 students |         |                  | across transition      |
|                 | (primary to            | with no additional   |         |                  | points. However,       |
|                 | secondary)             | needs (16 male, 5    |         |                  | their scores were      |
|                 |                        | female)              |         |                  | lower than typically   |
|                 |                        | ASC                  |         | Peer-reviewed    | developing peers.      |
|                 |                        |                      |         | journal article  |                        |
| Gallagher Deeks | To understand the      | 8 CYP completed the  | England | Semi-structured  | Quantitative findings  |
| (2023)          | levels of SOB for YP   | questionnaire.       |         | interviews and   | found that there were  |
|                 |                        |                      |         |                  |                        |

| in an autism SRB             |  |  | questionnaires –   | varying levels of SOB   |
|------------------------------|--|--|--|---|
| and                          | 7 members of staff   |  | Mixed methods  | with no difference  |
| to gain an                   | completed a semi-  |  |  | between SRBs and  |
| understanding of             | structured interview.  |  |  | Mainstream.   |
| teachers'                    | ASD  |  | Doctoral thesis  | <del>_</del>  |
| perspectives on ways         |  |  |  | Qualitative findings  |
| to foster SOB for            |  |  |  | found four themes,  |
| CYP.                         |  |  |  | for factors which   |
|                              |  |  |  | enhanced or acted as  |
|                              |  |  |  | a barrier against sob,  |
|                              |  |  |  | this was equal  |
|                              |  |  |  | opportunities,  |
|                              |  |  |  | meaningful  |
|                              |  |  |  | relationships,  |
|                              |  |  |  | communication and   |
|                              |  |  |  | understanding of  |
|                              |  |  |  | autism as   |
|                              |  |  |  | well as whole-school  |
|                              |  |  |  |   |
|                              |  |  |  | policies  |
| To explore the               | 914 students (56%  | Portugal   | Questionnaires –   | policies SOB was positively   |
| To explore the relationships | 914 students (56% boys, 10% SEN).  | Portugal   | Questionnaires –<br>Quantitative   | •   |
| ·                            | ,  | Portugal   |  | SOB was positively  |
|                              | and to gain an understanding of teachers' perspectives on ways to foster SOB for | and 7 members of staff to gain an completed a semi- understanding of teachers' ASD  perspectives on ways to foster SOB for | and 7 members of staff to gain an completed a semi- understanding of teachers' ASD  perspectives on ways to foster SOB for | and 7 members of staff to gain an completed a semi- understanding of teachers' ASD Doctoral thesis perspectives on ways to foster SOB for |

|                 | structure of            |                      |             |                     | negatively (weakly)   |
|-----------------|-------------------------|----------------------|-------------|---------------------|-----------------------|
|                 | classroom social        |                      |             |                     | associated with       |
|                 | networks, peer-         |                      |             |                     | social rejection.     |
|                 | related                 |                      |             |                     |                       |
|                 | social experiences in   |                      |             |                     |                       |
|                 | the classroom and       |                      |             |                     |                       |
|                 | the sense               |                      |             |                     |                       |
|                 | of belonging of         |                      |             |                     |                       |
|                 | students with and       |                      |             |                     |                       |
|                 | without SEN.            |                      |             |                     |                       |
| Porter & Ingram | Explores barriers and   | 108 Year 8 - 9 girls | England     | Mixed methods       | Participants reported |
| (2021)          | support of SOB for      | (aged 12–14 years)   |             |                     | that they felt less   |
|                 | girls who self-identify | Not specified        |             | Peer-reviewed       | connected to school.  |
|                 | as having SEN.          |                      |             | journal article     | Relationships in      |
|                 |                         |                      |             |                     | school was deemed     |
|                 |                         |                      |             |                     | as important. SOSB    |
|                 |                         |                      |             |                     | meant feeling safe    |
|                 |                         |                      |             |                     | and being yourself,   |
|                 |                         |                      |             |                     | and not hiding your   |
|                 |                         |                      |             |                     | "quirky bits".        |
| Alesech & Nayar | Explored how            | 6 case studies       | New Zealand | Data were obtained  | Several themes        |
| (2020)          | schools promote or      | (comprising of a     |             | through interviews, | emerged as a result:  |
|                 |                         |                      |             | observations and    |                       |

|             | hinder SOSB for     | student with SEN, a               |         | written sources -         | - emphasis needs       |
|-------------|---------------------|-----------------------------------|---------|---------------------------|------------------------|
|             | pupils with SEN.    | parent and staff).  Not specified |         | Qualitative Peer-reviewed | to centre on the child |
|             |                     |                                   |         |                           |                        |
|             |                     |                                   |         | journal article           | - the legal rights of  |
|             |                     |                                   |         |                           | the child              |
|             |                     |                                   |         | - and how schools         |                        |
|             |                     |                                   |         |                           | can effectively        |
|             |                     |                                   |         |                           | cater for the          |
|             |                     |                                   |         |                           | whole child and        |
|             |                     |                                   |         |                           | support diversity.     |
| Ware (2020) | Case study approach | 6 participants, are               | England | Video voice, self-        | All participants       |
|             | was used to explore | 11+ and have an                   |         | portraiture, and life-    | shared that they had   |
|             | how CYP with SEN    | EHCP (from SEN                    |         | mapping - Qualitative     | at least some SOB to   |
|             | view themselves and | and mainstream                    |         |                           | their school.          |
|             | what contributes to | schools)                          |         |                           | Important factors      |
|             | SOB.                | Not specified                     |         | Doctoral thesis           | included positive      |
|             |                     |                                   |         |                           | relationships with     |
|             |                     |                                   |         |                           | teachers and suppor    |
|             |                     |                                   |         |                           | staff.                 |

Appendix D - Analysis Groups and Subgroups

| Number<br>of<br>Articles | Analysis Group and Subgroups        | Included Papers                                    |
|--------------------------|-------------------------------------|--|
| 7                        | SEN                                 | • Culliane (2020)                                  |
|                          |                                     | <ul> <li>Dimitrellou &amp; Hurry (2019)</li> </ul> |
|                          |                                     | • Finnegan (2022)                                  |
|                          |                                     | <ul> <li>Freire et al., (2024)</li> </ul>          |
|                          |                                     | <ul> <li>Gallagher Deeks (2023)</li> </ul>         |
|                          |                                     | <ul> <li>Hebron (2018)</li> </ul>                  |
|                          |                                     | <ul> <li>Nepi et al., (2013)</li> </ul>            |
| 9                        | Staff:                              | Alesech & Nayer (2020)                             |
|                          |                                     | <ul> <li>Culliane (2020)</li> </ul>                |
|                          | Relationship with teachers and TA's | <ul> <li>Dimitrellou &amp; Hurry (2019)</li> </ul> |
|                          |                                     | • Finnegan (2022)                                  |
|                          | Communication                       | <ul> <li>Gallagher Deeks (2023)</li> </ul>         |
|                          |                                     | <ul> <li>Lovell (2021)</li> </ul>                  |
|                          |                                     | <ul><li>Porter &amp; Ingram (2021)</li></ul>       |
|                          |                                     | <ul> <li>Smedley (2011)</li> </ul>                 |
|                          |                                     | • Ware (2020)                                      |
| 8                        | Peers:                              | • Culliane (2020)                                  |
|                          |                                     | <ul> <li>Dimitrellou &amp; Hurry (2019)</li> </ul> |
|                          | Peer support and friendships        | <ul> <li>Gallagher Deeks (2023)</li> </ul>         |
|                          |                                     | <ul> <li>Lovell (2021)</li> </ul>                  |
|                          | Bullying and exclusion              | <ul> <li>Miles et al., (2019)</li> </ul>           |
|                          |                                     | <ul><li>Porter &amp; Ingram (2021)</li></ul>       |
|                          | Communication                       | <ul> <li>Smedley (2011)</li> </ul>                 |
|                          |                                     | • Ware (2020)                                      |
| 7                        | School environment:                 | Alesech & Nayer (2020)                             |
|                          |                                     | <ul> <li>Culliane (2020)</li> </ul>                |
|                          | Academic support                    | • Dimitrellou & Hurry (2019)                       |
|                          |                                     | <ul> <li>Finnegan (2022)</li> </ul>                |
|                          | School ethos                        | • Gallagher Deeks (2023)                           |
|                          |                                     | <ul> <li>Lovell (2021)</li> </ul>                  |
|                          | Exclusion from class                | <ul> <li>Smedley (2011)</li> </ul>                 |

|   | -                          |   |                               |
|---|----------------------------|---|-------------------------------|
|   | Rewards and sanctions      |   |                               |
| 5 | Hobbies:                   | • | Alesech & Nayer (2020)        |
|   |                            | • | Culliane (2020)               |
|   | Extracurricular activities | • | Finnegan (2022)               |
|   |                            | • | Porter & Ingram (2021)        |
|   | Leisure Activities         | • | Smedley (2011)                |
| 2 | Background and Identity:   | • | Gallagher Deeks (2023)        |
|   |                            | • | Ware (2020)                   |
|   | Personal identity          |   |                               |
|   | Family                     |   |                               |
| 1 | SOB as a mediator          | • | Kopelman-Rubin et al., (2020) |

# Section 576 of the Education Act 1996 The Cl defines "parent" as: respon

- 'All natural (biological) parents, whether they are married or not;
- Any person who, although not a natural parent, has parental responsibility for a child or young person;
- Any person who, although not a natural parent, has care of a child or young person'.

# The Children Act 1989 defines "parental responsibility" as:

- 'Having parental responsibility means assuming all the rights, duties, powers, responsibilities and authority that a parent of a child has by law.
- People other than a child's natural parents can acquire parental responsibility through:
- being granted a residence order
- being appointed a guardian
- being named in an emergency protection order (although parental responsibility in such a case is limited to taking reasonable steps to safeguard or promote the child's welfare)
- · adopting a child'

# **Appendix F – Ethical Approval**

**Study title:** Advocating and Conceptualising Sense of School Belonging for Children and Young People with Down Syndrome: The Views and Perspectives of Parents.

**Application ID:** ETH2324-1440

Dear Isobel,

Your application was considered on 21st May 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 31st August 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 - Information and Consent Form



Isobel Moors
Trainee Educational Psychologist

School of Education and Lifelong Learning

University of East Anglia Norwich Research Park Norwich NR4 7TJ United Kingdom

Email: I.Moors@uea.ac.uk
Web: www.uea.ac.uk

Advocating and Conceptualising Sense of School Belonging for Children and Young People with Down Syndrome: The Views and Perspectives of Parents.

#### PARTICIPANT INFORMATION SHEET

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

You are invited to take part in a research study about how parents of children with down syndrome conceptualise and advocate sense of school belonging for their child. You have been invited to participate in this study because you are a parent of a child with down syndrome, and I am interested in hearing about your experiences. 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.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your 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: *Isobel Moors*, a Trainee Educational Psychologist, on the Doctorate in Educational Psychology (EdPsyD) in the School of Education and Lifelong Learning at University of East Anglia.

This study will take place under the supervision of Imogen Nasta Gorman (Associate Professor and Co-Programme Director for the Doctorate in Educational Psychology at UEA - *I.Gorman@uea.ac.uk*).

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

If you decide you would like to participate, this study will involve an individual online interview with the researcher (Isobel Moors).

The interview will focus on themes of 'how sense of school belonging is conceptualised' and 'how can you advocate sense of school belonging'.

The interviews will take place on Microsoft Teams at a time that is convenient for you. Interviews will be audio-recorded. All information collected will be anonymous. You will be given the option to review your transcripts following the online interview.

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

The online interview will last approximately 45 minutes to an hour. You will be given the option to review your transcripts following the online interview. If you choose to review your transcript, these will be provided within 4 weeks of the interview taking place. Reviewing your transcript should take between 30-45 minutes.

### (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 take part. Your decision whether to participate will not affect your current or future relationship with the researcher or anyone else at the University of East Anglia now or in the future.

If you decide to take part in the study, you can withdraw your consent up until the data is analysed. You can withdraw by emailing the researcher. You do not need to tell the researcher why you are withdrawing consent.

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

You are free to stop the interview 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. You may also refuse to answer any questions that you do not wish to answer during the interview. If you decide at a later time to withdraw from the study your information will be removed from our records and will not be included in any results, up to the point I have analysed and published the results, and this would include the submission of the thesis for assessment purposes.

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

Talking about your child's sense of school belonging could be a sensitive topic. However, there are unlikely to be risks from it. Aside from you giving up your time, I do not expect that there will be any other cost or risks associated with taking part in this study.

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

Your responses are likely to provide details about the experiences of parents who have children with down syndrome, particularly in relation to sense of school belonging. It may also help to identify what facilitates and what are the barriers to developing a sense of school belonging. This could inform schools and educational psychologists about how children and young people with down syndrome can feel more included in their educational settings. Parents are also important

educational advocates for their children; therefore, this study hopes to gain their important perspective.

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

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.

The information you provide will be stored securely and your identity will be kept strictly confidential, except as required by law. Study findings will be used for the purposes of my dissertation and may also be used for other scholarly and educational purposes such as research publications and in teaching, but you will not be identified if you decide to participate in this study. Where the study findings are solely used for the thesis, the data will be destroyed following the examination of the dissertation. Where the study findings will also be used for other purposes such as publications, the data will be kept for at least 10 years beyond the last date the data were used. The study findings may be deposited in a repository to allow it to facilitate its reuse. 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, Isobel Moors (<u>I.Moors@uea.ac.uk</u>) will be available to discuss it with you further and answer any questions you may have about the study.

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

You have a right to receive feedback about the overall results of this study. If you are happy to, you can email me, and I can send you a summary of the research findings once the project is complete. You will receive feedback following the end of the project (approximately August 2025).

#### (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 via the University at the following address:

Isobel Moors
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ
I.Moors@uea.ac.uk

If you would like to speak to someone else, you can contact my supervisor: Imogen Nasta Gorman
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ

#### I.Gorman@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 the 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 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, I am 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?

You need to fill in one copy of the consent form and return it to the researcher via email (I.Moors@uea.ac.uk). Please keep the letter, information sheet and copy of the consent form for your information.

#### (16) Further information

This information was last updated on 19.02.2024.

If there are changes to the information provided, you will be notified via email.

## PARTICIPANT CONSENT FORM (First Copy to Researcher)

| ,[PRINT<br>this research study.  | Γ NAME], a   | agree to   | take p   | art in  |
|--|--|--|--|---|
| n giving my consent I state that:  |  |  |  |   |
| <ul> <li>I understand the purpose of the study, what I wrisks/benefits involved.</li> <li>I have read the Participant Information Sheet, which have been able to discuss my involvement in the study to do so.</li> <li>The researcher have answered any questions that I happy with the answers.</li> <li>I understand that being in this study is completely vollipart. My decision whether to be in the study will not researcher or anyone else at the University of East An</li> <li>I understand that I may stop the interview at any time that unless I indicate otherwise any recordings will the provided will not be included in the study results. I also to answer any questions I don't wish to answer.</li> <li>I understand that the results of this study will be us information sheet.</li> <li>I understand that personal information about me that this project will be stored securely and will only be agreed to. I understand that information about me will permission, except as required by law.</li> </ul> | I may keep y with the had about untary and affect my iglia now o if I do not in be erased so underst sed in the t is collecte used for | research<br>t the st<br>I do no<br>relation<br>r in the<br>wish to<br>d and tha<br>way des | y record her if I w udy and t have to nship win future. continuo ie inform t I may i scribed the cou | s, and vished I I am take the the e, and nation refuse in the rse of have |
| consent to:  |  |  |  |   |
| Participating in an interview  | YES  |  | NO   |   |
| Audio-recording  | YES  |  | NO   |   |
| Would you like to review your transcript following the intervi   | iew?   |  |  |   |
|  | YES  |  | NO   |   |
| Would you like to receive feedback about the overall results   | of this stud   | ly?  |  |   |
|  | YES  |  | NO   |   |

| Signature  | •••••• | <br>•••••• | •      |      |
|------------|--------|------------|--------|------|
| PRINT name |        | <br>       | •••••• | •••• |
| Date       |        | <br>       |        |      |

#### Appendix H - Interview Schedule

### **Proposed Interview Schedule**

## Before the interview begins:

- My name is Izzy, and I am a Trainee Educational Psychologist studying at UEA. As part of my doctoral training, I have to complete a research project.
- This interview will be audio-recorded. I will let you know when the recording begins and ends.
- I have chosen to explore the views of parents who have children with down syndrome. In particular I will be exploring sense of school belonging.
- This interview should take around 45 minutes to an hour. Please let me know if you would like a break at any point.

Before we begin, I would like to re-highlight some key points from the information sheet:

- I will be audio-recording this interview. This recording will be deleted once I have transcribed the data. Please do not share any confidential information, such as your child's name, the school they attend or the specific location of where you live. If information is accidentally shared, this will be redacted from the transcripts. All your data will remain anonymous. The data from this interview will be kept confidential, on password encrypted devices. I will let you know once the recording has begun.
- As I only need to record audio, I will ask you to turn off your camera when I start recording the interview.
- If you do not wish to answer any of the questions, please let me know. I am happy to move onto the next question.
- You have a right to withdraw from this study up until I analyse the data. Therefore, you can withdraw during this interview or afterwards.
- I am interested in your own experiences. There is no right or wrong answer. Please feel free to take your time before answering any questions. I am happy to repeat any questions if need be. There can be multiple ways to interpret the questions I ask, so please answer them in your own way.
- Do you have any questions before I begin recording this interview?

| This interview will contain three elements: |                                   |  |  |  |  |  |  |
|---|-----------------------------------|--|--|--|--|--|--|
| Section 1                                   | Collecting background information |  |  |  |  |  |  |
| Section 2                                   | Conceptualisation of SOSB         |  |  |  |  |  |  |
| Section 3                                   | Advocation of SOSB                |  |  |  |  |  |  |

## **Section 1: Collecting background information**

- I will now begin to record this interview, please can you turn off your camera. Please let me know if you would like to pause the recording at any point.
- I will now ask you some questions so I can gather some relevant background information. I will give you choices for your answers except for question three, where I will ask how old your child is. You do not need to expand or explain your answers, unless you feel none of the suggested answers describe your situation.

| <ol> <li>Do you have a child with down syndrome?</li> </ol>  | <ul><li>Yes</li><li>No</li></ul>  |
|--|---|
| <ol><li>Are you their biological mother or father?</li></ol>   | <ul><li>Mother</li><li>Father</li></ul>   |
| 3. How old is your child?  |   |
| 4. Does your child currently have an EHCP?   | <ul> <li>Yes, my child has an EHCP</li> <li>No, my child does not have an EHCP</li> <li>Myself or my child's school is currently in the process of applying for an EHCP for my child</li> </ul> |
| 5. Is your child currently in primary or secondary school?   | <ul><li>Primary school</li><li>Secondary school</li></ul>   |
| 6. What type of setting does your child currently attend?  | <ul><li>Mainstream school</li><li>Unit within a mainstream school</li><li>Special needs school</li></ul>  |
| 7. (If answered 'special needs school' for Q6) Has your child previously attended a mainstream school? | <ul><li>Yes</li><li>No</li></ul>  |

| <b>Section 2: Conceptualisation of SOSB</b>                                    |   |
|--|---|
| <ul> <li>I will now ask you some questions a<br/>school belonging.</li> </ul>  | around how you conceptualise sense of   |
| 8. In your opinion, what does 'sense of school belonging' mean for your child? | Anything else you would like to add?  |
| Share sense of school belonging definition                                     | "the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment" – Goodenow and Grady (1993)  |
| 9. Now you have read that definition, what are your thoughts and reflections?  | <ul> <li>Has this definition changed how you conceptualise and view sense of school belonging?</li> <li>Do you feel this definition is relevant to children with down syndrome?</li> <li>Is there anything else you would like to add?</li> </ul> |

## **Interview Prompts**

- ⇒ Would you mind telling me more?
- $\Rightarrow$  Could you expand on that point a bit further?
- ⇒ Anything else to add?
- $\Rightarrow$  That sounds really interesting

⇒ Thank you for sharing

| Section 2: Advocating SOSB  |  |
|---|--|
| I will now ask you some questions are<br>belonging for your child.                                      | round how you advocate sense of school   |
| 10. Thinking about your child, what do you think affects their sense of school belonging?               | <ul> <li>Anything else?</li> <li>Do you feel that some of these factors have a bigger impact?</li> <li>Do you think this would differ to their peers who do not have down syndrome?</li> </ul> |
| 11. Did you consider your child's sense of school belonging when selecting a school for them?           | <ul> <li>If no, why?</li> <li>If yes, why?</li> <li>Do you feel it is important for your child to experience a strong sense of belonging?</li> </ul>   |
| 12. What do you think schools do to positively support your child's sense of school belonging?          | <ul> <li>Within the classroom?</li> <li>As part of the wider school?</li> <li>Which factor do you think is most important?</li> </ul>  |
| 13. In school, what do you think acts as a barrier to your child's sense of school belonging?           | <ul><li>Within the classroom?</li><li>As part of the wider school?</li><li>Which factor do you feel is the most significant?</li></ul>   |
| 14.Do you feel schools could do anything differently to support your child's sense of school belonging? |  |

### **Interview Prompts**

- ⇒ Would you mind telling me more?
- ⇒ Could you expand on that point a bit further?
- ⇒ Anything else to add?
- ⇒ That sounds really interesting
- ⇒ Thank you for sharing

| Final      | Is there anything else about your child's SOSB that you feel is |
|------------|---|
| questions: | important to mention?   |

### Closing the interview:

- I have now stopped the recording. Please feel free to turn your camera back on.
- Thank you for participating in my study. I have really enjoyed listening to your views and experiences.
- I was particularly interested in interviewing parents as both research and legislation has highlighted that parents often have to act as educational advocates for their CYP with down syndrome / SEND.

- Research has also highlighted that many parents feel that school culture and belonging is an important factor to consider when choosing a school for their child.
- With many positive outcomes being associated with fulfilled school belonging, I feel it is an important area to research. However, no research has considered CYP with down syndrome or their parents.
- Finally, are there any further questions you have or any comments you would like to make?

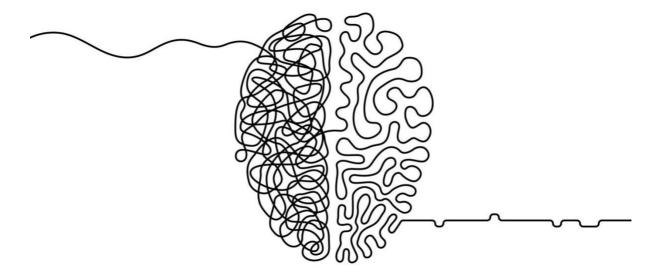
#### **Appendix I – Debrief Sheet**

#### **Debrief Sheet**

# Advocating and Conceptualising Sense of School Belonging for Children and Young People with Down Syndrome: The Views and Perspectives of Parents.

Thank you for participating in this study. Your time and efforts are much appreciated.

The purpose of this study is to understand how parents of children with down syndrome conceptualise and advocate sense of school belonging. With parents often acting as important educational advocates, it is crucial that your perspective is explored. It is hoped that the findings of this study will give an insight into how schools and educational psychologists can further support children and young people with down syndrome, and their parents.



If you have any questions or concerns regarding this study, please feel free to contact the researcher, Isobel Moors (I.Moors@uea.ac.uk) or supervisor (Imogen Nasta Gorman, I.Gorman@uea.ac.uk) of this study. Please note that after the data has been analysed, you will not be able to withdraw your data, as it will be anonymised and will not be identifiable.

You are welcome to review your transcript following the interview. These can be provided to you within four weeks of the interview taking place.

If you are interested in seeing the results from this research project, I can provide you with a summary of my findings once the thesis has been written up.

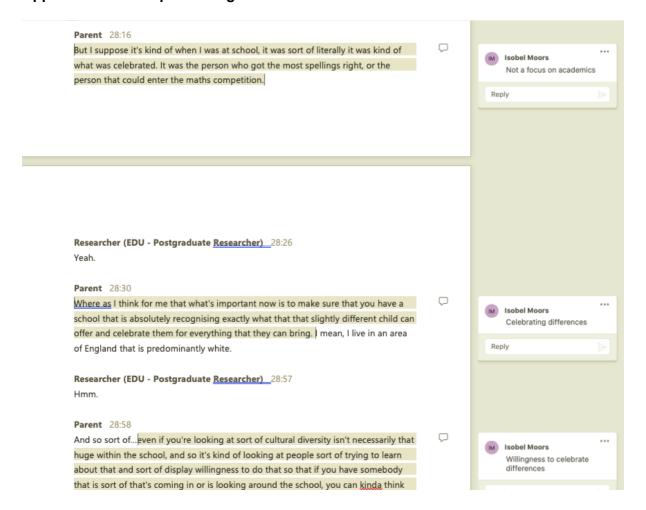
The Down Syndrome Association offer a helpline which anyone can contact related to any topic related to down syndrome: 0333 1212300 (10am-4pm).

You are warmly thanked for your participation.

**Appendix J – Familiarisation Doodle Example** 



### Appendix K - Example Coding



#### Researcher (EDU - Postgraduate Researcher)\_5:37 Hmm. Oh wow. Yeah. Parent 5:50 $\Box$ He has very little verbal ability, but it also means that other people will approach him Isobel Moors to try and sign with him and to try and make friends. So that's a huge deal for him, Adaptations lead to increased communication / socia because otherwise he has no contact. If you can't speak in a primary school that has a huge impact on your ability to socialise. Researcher (EDU - Postgraduate Researcher) 6:01 Yeah. Absolutely. Parent 6:09 $\Box$ So those little things in the sort of structured class time means that even in the sort Isobel Moors of unstructured social time in the playgrounds he has, you know, it's impacted on Adaptations have helped him to make friends other people approaching him to make friends. And I think a lot of it comes from the $\Box$ whole school ethos about inclusion and how to celebrate differences. So now even Reply so, last year he was in reception, they had a sort of buddy system with the year 6 pupils and he had an adorable buddy, but it meant that everyone in year six got to ... know him as being a bit of a character. And when they were all sort of walking out to leave school, you know, I'd be walking out with him a bit slower because we take a School ethos bit more time. But all the other year sixes would go past and kind of wave and say hi Reply to him and... Isobel Moors Buddy system with older Parent 14:26 $\Box$ Mm hmm. I think they've worked really hard in trying to keep a connection with her Isobel Moors original peer group...that has been a bit of a debate as time has gone on because it Keeping connections with has got trickier because she's now in year six and she's working at a year two level. peers So, we have kind of compromising that she works with year twos for, you know, Reply phonics and literacy and then goes back to her peer group. And it's tricky now because it is more academic, but they try as much as possible to still have that kind of relationship with her original peer group. Researcher (EDU - Postgraduate Researcher) 14:39 OK. Yeah. Parent 15:03 And they're also, you know, very aware of her individual kind of sensory needs and IM Isobel Moors how they have grown in trying to work around that kind of constraints, as it were, in Being aware of individual differences / adaptations trying to put her well-being first, you know in as much things as they can do, and and doing it that way and yeah, yeah. Reply Researcher (EDU - Postgraduate Researcher) 15:26 So it's that balance between keeping that connection with peers, but also having those academic needs there as well. Parent 15:33 Yeah. And I'd also, it's not happening now, but the plans were going to be in place Isobel Moors for residential because they've got a residential in November and there was never All activities / trips have been accessible. Not been kind of an idea because I know some schools would do anything to say, "you can't questioned. do that" or you know, there was never kind of an issue that like we couldn't. So, we did do residential in year four and it was supported you know...and you know, to get Reply

the supports you needed, and I would come and do nights and everything. But there

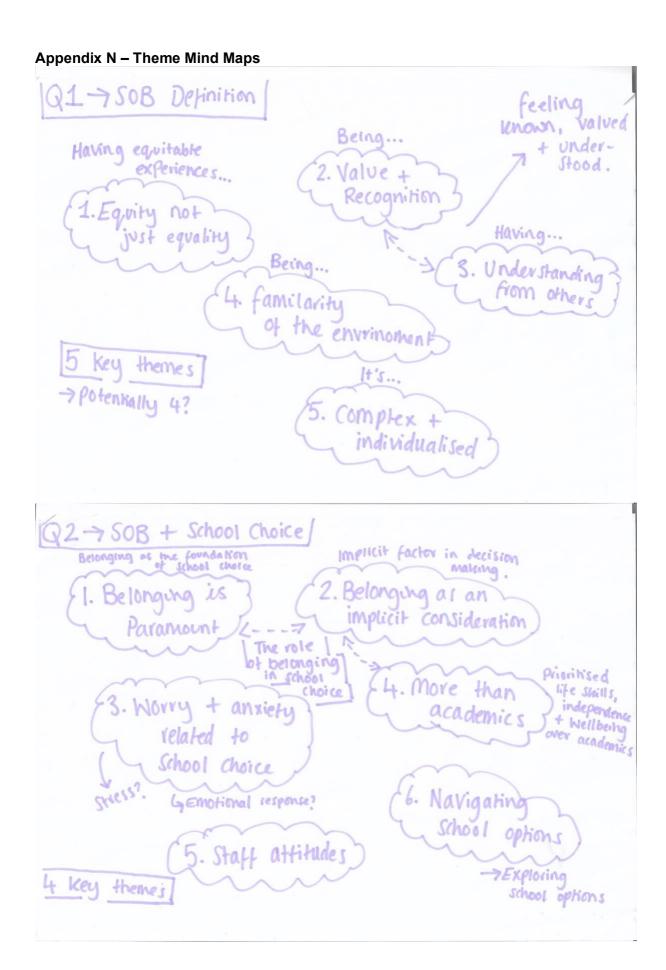
was never kind of like "you can't do this".

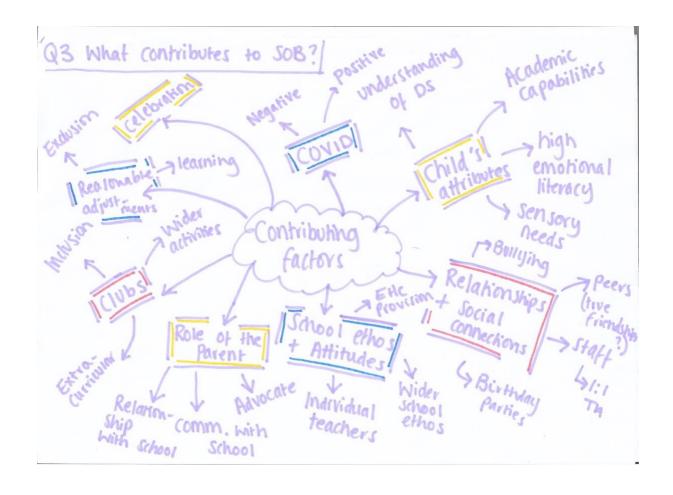
# Appendix L – Codes Transferred to Microsoft Excel

| 1                  | Question       | ₩Ť       |                    | Code           | •        | Referred Text   |  |  |  |  |  |
|--------------------|----------------|----------|--------------------|----------------|----------|---|--|--|--|--|--|
|                    |                |          |                    |                |          | So it's very very basic. It's an understanding that it's a location where she goes every day and  |  |  |  |  |  |
| 2 <mark>1</mark> . | SOB Definition | A far    | miliar location    |                |          | where she has   |  |  |  |  |  |
|                    |                |          |                    |                |          | she either used to use the word and sometimes still uses itShe doesn't really use the word  |  |  |  |  |  |
| 3 <b>1</b> .       | SOB Definition | Som      | ewhere with frie   | ends           |          | school, she calls it friends.   |  |  |  |  |  |
|                    |                |          |                    |                |          | So it's for her. I think the the best description of a school is is where there are people that she is  |  |  |  |  |  |
| 4 1.               | SOB Definition | Bein     | g with friends     |                |          | like friends with and people that she likes and enjoys spending time with.  |  |  |  |  |  |
|                    |                |          |                    |                |          | So learning is interesting and not so much part of that, although sometimes just out of the blue  |  |  |  |  |  |
|                    | SOB Definition | Lear     | ning is not a big  | element        |          | she sometimes tells what they learnt and kind of increasingly nowadays.   |  |  |  |  |  |
| 6 <mark>1</mark> . | SOB Definition | Lear     | ning is not a big  | element        |          | But learning is not is not like the essential part of that.   |  |  |  |  |  |
|                    | SOB Definition | Fami     | iliar routines     |                |          | It's more like the the place, the people and the regularity.  |  |  |  |  |  |
| 8 1.               | SOB Definition | Frier    | nds are importar   | nt             |          | We often refer to it as, yes, this is the friend's place.   |  |  |  |  |  |
| 9 1.               | SOB Definition | In ag    | reement            |                |          | Yes, yes, I would say that that's that it would be part of that.  |  |  |  |  |  |
| 10 1.              | SOB Definition | Too      |                    |                |          | But I think this for for like her particular case, this is slightly too theoretical and and I don't thinkyeah, there are there are lots of elements of itpersonally accepted, yes, but I don't think she Our child with Down syndrome would necessarily conceptualise thatrespected, yes, respected and included are obviously important and I think inclusion would be my main my key element. |  |  |  |  |  |
| 11 <b>1</b> .      | SOB Definition | Socia    | al environment i   | s key          |          | And the the main the main element is theI would say is included in the social environment.  |  |  |  |  |  |
| 12 1.              | SOB Definition | Wou      | ld be used in a fo | ormal setting  |          | No, no, because again this for me in the everyday use this is notI would use it inI'll tell you what I would use itI wouldI would use it in aif we had a meeting with The the head of the whatever the the head mistress or not, or the head of school. And then I I would use it as a kind of basis on where to say OKthat's not happening that's happening that's not happening               |  |  |  |  |  |
| 13 <b>1</b> .      | SOB Definition | Not      | used in everyday   | y interactions |          | So that's kind ofthat is where I would use it, but not in like in in any way with when we interact with REDACTED NAME.  |  |  |  |  |  |
|                    |                |          |                    |                |          | I would say again that goes back to the original and that is that is that she isshe's part of a class whichwhere the pupils accept her as she is and I think that acceptance is quite important   |  |  |  |  |  |
| - ■                | Parent 1       | Parent 2 | Parent 3           | Parent 4       | Parent 5 | Parent 6 Parent 7 Parent 8 Parent 9 QUESTION 1 QUESTION 2   |  |  |  |  |  |

## Appendix M – Initial Themes

| G H I J  | K L   | M N  | O F  |  | R S                         | Т           | U  | v w        |   | Y  | Z AA                 |   | AC  |
|--|---|--|--|--|-----------------------------|-------------|--|------------|---|--|----------------------|---|---|
| Belonging is paramount. Captures the idea that parents prioritised their child's | Theme 2 Code  | Referred Text  | Theme 3 Co   | de Referred Text   | Theme 4                     | Code        | Referred Text  | Them       | e 5 Code  | Referred Text  | Them                 | e 6 Code  | Referred Text   |
| that once belonging is established,  | Belonging as an Implicit<br>Parents valued belor<br>wasn't always a consciou<br>factor in their schoo | nging, but it<br>usly articulated  | experienced sign<br>anxiety when de                    | dety - Parents<br>nificant stress and<br>ciding on the right<br>their child. | prioritised l<br>and overal | well-being  |  | re<br>dete | taff attitudes,<br>sponsiveness<br>rmining whet |  | exp<br>provisi<br>ch | ting School Opt<br>ored a range of<br>ons to find the b<br>ld's needs while<br>all and personal o | est fit for their<br>balancing  |
| Considered Yeah. I belonging thought when about what choosing she'd be like.     | An  | Yes, although maybe I didn't perceive it as such when we were doing that, but yes, definitely we looked around mainstream and special schools because at the time we weren't really sure what level of learning needs he had or you know what would be suitable. | Stres<br>anxi<br>relat<br>to<br>scho<br><b>P1</b> choi | social side,<br>but then I had<br>to look at the<br>ol academic and          | Pi                          | Life skills | She's gonna<br>learn more<br>life skills in<br>a SEND<br>school<br>because<br>they're<br>more<br>equipped. | P2         |   | I knew that<br>it was the<br>right place<br>and the<br>reason that<br>I knew it<br>was the<br>right place<br>was<br>because of<br>the way as I<br>was being<br>ure<br>shown<br>around. | Р1                   | Considere<br>a variety o  | And I did go<br>and look at<br>two<br>d mainstream<br>f sand the<br>SEN school. |





# Appendix O – PfA Implications

| Finding (Theme)                       | Research | PfA Link                        | Practical Implication  |
|---------------------------------------|----------|---------------------------------|--|
|                                       | Question |                                 |  |
| Having equitable                      | RQ1      | • Community                     | Schools must offer the same opportunities to all children with the           |
| experiences                           |          | inclusion                       | acknowledgement that support, or adaptations may be needed for some          |
|                                       |          | <ul> <li>Health</li> </ul>      | children.  |
| Feeling known, valued,                | RQ1      | <ul> <li>Community</li> </ul>   | School staff must develop an understanding of each child, promoting          |
| understood                            |          | inclusion                       | belonging through celebrating achievements and differences.                  |
| <ul> <li>Understanding and</li> </ul> |          | <ul> <li>Health</li> </ul>      |  |
| acceptance                            |          |                                 |  |
| - Being valued and                    |          |                                 |  |
| recognised                            |          |                                 |  |
| Being familiar with the               | RQ1      | <ul> <li>Community</li> </ul>   | Consistency within the school environment (e.g., members of staff,           |
| school environment                    |          | inclusion                       | routines, physical buildings) helps to promote confident engagement. Any     |
|                                       |          | <ul> <li>Health</li> </ul>      | transitions or changes should be planned and scaffolded.                     |
| It's complex and                      | RQ1      | • All                           | School staff and professionals to recognise that belonging is an             |
| individualised                        |          | outcomes                        | individualised concept. All planning must be personalised, whilst aligning   |
|                                       |          |                                 | with PfA outcomes.   |
| Belonging as foundation of            | RQ2      | <ul> <li>Independent</li> </ul> | Support to be given to parents when making decisions about school            |
| school choice                         |          | living                          | placements, particularly in relation to aspects of belonging and inclusion.  |
|                                       |          | <ul> <li>Community</li> </ul>   | It's important that families engage in long-term planning early, considering |
|                                       |          | inclusion                       | which areas they would like to prioritise (e.g., independence skills).       |

| - Belonging as the        |              |  |   |
|---------------------------|--------------|--|---|
| foundation of school      |              |  |   |
| choice                    |              |  |   |
| - Belonging as an         |              |  |   |
| implicit consideration    |              |  |   |
| - More than academics     |              |  |   |
| Worry and anxiety related | RQ2          | <ul> <li>Community</li> </ul>                        | Schools and relevant professionals should support families emotionally  |
| to school choice          |              | inclusion  Health                                    | during transitions, offering consistent, transparent processes.   |
| Navigating school options | RQ2          | <ul><li>Independent living</li></ul>                 | Providing accessible information allows parents to choose schools which are aligned with PfA goals.   |
| Staff attitudes           | RQ2 +<br>RQ3 | <ul><li>Community inclusion</li><li>Health</li></ul> | School staff to have access to training and reflective practice to promote inclusive attitudes and improve CYP well-being and school belonging. |
| Relationships and social  | RQ3          | <ul> <li>Community</li> </ul>                        | Schools should actively foster opportunities for positive peer and adult  |
| connections               |              | inclusion  | relationships to support inclusion and future workplace / volunteer settings.   |
| - Relationships with      |              | <ul> <li>Employment</li> </ul>                       |   |
| peers                     |              |  |   |
| - Relationships with      |              |  |   |
| adults                    |              |  |   |
| Inclusive adaptations and | RQ3 +        | <ul> <li>Independent</li> </ul>                      | Inaccessible classrooms and resources limit opportunities for CYP with DS.  |
| adjustments               | RQ4          | living   | Ensuring adjustments are in place to encourage current and future   |

| Lack of classroom                      |       | Community   | independence. These should be reviewed regularly. This is essential for      |
|--|-------|-------------|--|
| adaptations                            |       | inclusion   | equitable learning and preparation for work.                                 |
| <ul> <li>Exclusion from the</li> </ul> | •     | Employment  |  |
| classroom                              |       |             |  |
| - Teacher attitudes,                   |       |             |  |
| experience and ethos                   |       |             |  |
| <ul> <li>EHCP not being</li> </ul>     |       |             |  |
| followed                               |       |             |  |
| School ethos and attitudes             | RQ3   | All         | Whole-school commitment to inclusion creates consistent environments         |
|  |       | outcomes    | that promote long-term belonging.  |
| Extracurricular activities             | RQ3 + | Independent | Participation in extracurricular activities builds independence, confidence, |
|  | RQ4   | living      | and wider social connections. Opportunities must be equitable.               |
| Access and inclusion to                |       | Community   |  |
| extracurricular activities             |       | inclusion   |  |
| The role of the parent                 | RQ3 + | Independent | Exclusion of parents weakens planning. Schools should actively               |
| <ul> <li>Advocacy and</li> </ul>       | RQ4   | living      | collaborate with parents when discussing educational and PfA pathways.       |
| support                                |       | Community   |  |
| - Communication and                    |       | inclusion   |  |
| partnership with the                   |       |             |  |
| school                                 |       |             |  |
| Parental involvement (as a             |       |             |  |
| barrier)                               |       |             |  |
|  |       |             |  |

Child's personal skills and attributes

RQ3 + RQ4 • All outcomes

Staff training and responsive planning are critical to preparing CYP for all areas of adulthood, whilst considering individual differences and profiles associated with DS.

Lack of understanding and support for individual needs