

**Exploring the Positive Experiences of Learners with Down Syndrome in Mainstream  
Education: A Reflexive Thematic Analysis Study**

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## Summary

This doctoral thesis consists of three chapters: a literature review, the empirical research, and a reflective account. The literature review is dedicated to outlining, comprehending, and critically evaluating the present literature that explores the quality of life and educational experiences of individuals with Down syndrome. This includes using a solution-focused underpinning to consider the implications of the research, as well as suggestions for future research. Next, the empirical research consists of a qualitative study using semi-structured interviews to explore the positive experiences of 12 young people with Down syndrome previously educated in a mainstream school. Data was analysed using Reflexive Thematic Analysis. This chapter includes a discussion that incorporates a solution-focused underpinning to consider the implications of the findings, as well as recommendations for future research. Finally, the reflective account describes this research journey. This includes personal reflections on why the research topic was chosen, philosophical positioning and personal growth as well as critical reflections on the choices of methodology and the approaches used in this research. This chapter also considers how the findings of the research will be disseminated.

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## **Chapter 1: Literature Review**

### **Introduction**

This chapter is dedicated to outlining, comprehending, and critically evaluating the present literature that explores the quality of life and educational experiences of individuals with Down syndrome (DS). The inquiry encompasses the insights of their parents, families, educators and, in some research, the view of the individuals with DS themselves. The overarching goal of this literature review is to explore the factors that contribute to a successful and fulfilling life for individuals with DS, with a particular emphasis on their educational experiences.

Understanding the implications of these factors is essential for improving the overall development and wellbeing of individuals with DS. By identifying key aspects such as influencers of quality of life, educational opportunities, social support systems, and access to inclusive learning, the review aims to provide actionable recommendations for educational professionals and policymakers. These recommendations can inform the design of more inclusive educational programs, support services, and policies tailored to the unique needs of individuals with DS, ultimately enhancing their development and promoting their overall wellbeing.

This introductory section of the literature review provides an overview of key concepts and current knowledge surrounding learning disabilities to establish a foundation for understanding the broader context. Additionally, an introduction to DS is presented to ensure a comprehensive understanding of the focus of this literature review. Furthermore, the aims and objectives of the review are discussed.

### ***An Introduction to Global and UK Perspectives on Learning Disabilities and Education***

The global perspective on disability, as presented in the World Report on Disability

(2011) by the World Health Organization (WHO), approximates that 15% of the world's population has some form of disability. In the UK, an estimated 1.5 million individuals have a learning disability (Public Health England, 2016; Office for National Statistics, 2020).

The fundamental principle that all learners possess the right to education, irrespective of disability, is emphasised by UNICEF UK (1989). However, UNESCO (2002) highlighted that there is a persistent struggle faced by learners with special needs in accessing quality education across most countries. The complexities of learning disabilities pose challenges for educators, with evidence indicating that teachers encounter difficulties comprehending concepts related to learning disabilities, both theoretically and in practical application (Lauchlan & Greig, 2015).

This lack of understanding contributes to varied teacher attitudes towards inclusion. This can lead to inconsistent practices, particularly when dealing with children with more complex learning needs (Avramidis & Norwich, 2002; Male & Raynor, 2009; Parey, 2019). Teachers in UK mainstream schools have been found to have apprehensions about resource availability and the potential additional stress of teaching children with Special Educational Needs and Disabilities (SEND) (Warnes et al., 2022). Moreover, a disconnection between the secondary-level curriculum offered to learners with learning disabilities and their post-school desires has been identified, affecting aspects like independent living and employment (Bouck, 2012).

In England and Wales, the Children and Families Act (2014) introduced changes and guidelines for the assessment and identification process of children requiring special support. This marked the first major review and amendment of SEND policy in a decade, resulting in implications for professional practices and provisions for vulnerable children and young people (CYP) (Castro & Palikara, 2016). Key amendments in this act include the strengthened rights of children with SEND, improved child welfare in care and school

settings, anticipated growth in the childcare sector's participation, and the introduction of a new Children's Commissioner role for advocacy. Additionally, a new SEND Code of Practice accompanied the act, offering statutory guidance on duties, policies, and procedures related to the Children and Families Act, extending the age of provision up to 25 years (Department for Education and Department of Health, 2015). This document stipulates that educational settings must recognise and address the need for provision and additional resourcing. Furthermore, the code outlines the responsibilities of mainstream schools in supporting all children with SEND.

### ***An Introduction to Down Syndrome***

Down syndrome (DS), also referred to as Trisomy 21, arises from a genetic condition characterised by an additional copy of chromosome 21 (Jackson et al., 2014; Laws & Hall, 2014). A child being born with DS occurs in approximately 1 in 700 births, making it the most common genetic cause of learning disability, with an estimated 7,000–8,000 school-aged children with DS in the UK (de Graaf et al., 2021; Wu & Morris, 2013).

DS presents unique physical features, learning difficulties, and personality characteristics, setting it apart from other learning disabilities (Mai et al., 2019). The extent of cognitive impairment in individuals with DS varies, ranging from mild to severe (Chapman & Hesketh, 2000; Buckley, 2000). Associated impairments include challenges in memory, attention, motor development, language, communication skills, and a predisposition to health issues such as hearing, vision, and heart defects (Laws & Millward, 2001).

Research has also demonstrated a number of strengths that individuals with DS may have. For example, some individuals with DS demonstrate strong visual memory skills (Daunhauer & Fidler, 2011; Frenkel & Bourdin, 2009; Lemons et al., 2018; Vicari et al., 2004), and studies have found relative strengths in visuo-spatial processing in these individuals (Jarrod et al., 1999; Wang & Bellugi, 1994). As well as this, many individuals with DS attain functional literacy skills (Buckley, 2001). Furthermore, individuals with DS can

develop self-help skills that continue to progress into adolescence and young adulthood (de Graaf & De Graaf, 2016). Many individuals with DS demonstrate a good social understanding (Fidler et al., 2006; Fidler et al., 2008). They have been described as affectionate (Dieleman et al., 2018), happy (Gilmore et al., 2003) and cheerful (Grieco et al., 2015). Those with DS have also been found to actively engage in humour and laughter and are active participants in creating and sharing humour with others. This involvement occurs at both emotional and cultural levels (Reddy et al., 2001).

Legislation can be useful in helping to support individuals with DS. As well as the legislative frameworks discussed in relation to learning disabilities, The Down Syndrome Act (2022) was enacted in April 2022 to ensure the best support for individuals with DS. The aim of this Act is to enhance accessibility to services for individuals with DS and provide support to improve their quality of life. It seeks to ensure that various sectors, including health, social care, education, and local government services consider the specific needs of individuals with DS when delivering or planning services. This legal framework helps to mitigate barriers that individuals with DS may face in accessing essential services and support, thereby fostering greater equity and opportunities for participation in society. Additionally, by requiring the publication of guidance and imposing legal obligations on authorities to adhere to it, the Act establishes accountability and promotes consistency in service provision, ultimately contributing to a more supportive and inclusive environment for individuals with DS and their families.

### ***Aims and Objectives of the Literature Review***

This literature review explores and critically analyses findings from a range of studies and scholarly papers to gain an in-depth understanding of the multifaceted perspectives of parents, families, educators, and individuals with DS. The overarching goal is to identify factors that contribute to a successful and fulfilling life for individuals with DS, including their educational experiences, by providing a comprehensive understanding of their experiences, as well as both the successes and challenges they encounter. By examining existing

literature, this review aims to uncover limitations in current research, and gaps in knowledge, providing a foundation for future studies. Moving from a comprehensive examination of research exploring the quality of life of individuals with DS and the experiences of their families, the review transitions to a more specific focus on education. By doing this, the review explores the intricate factors that shape both the quality of life and educational experiences of individuals with DS. This understanding not only informs academic discourse but also offers practical insights for educational professionals and policymakers. By synthesising and analysing the existing body of research, actionable recommendations for enhancing educational practices, support systems, and policies to better meet the needs of individuals with DS can be implemented to promote their holistic development and wellbeing. This is particularly important for Educational Psychology practice, as it can help to promote inclusion.

Throughout this review, both quality of life and educational experiences are key concepts. Quality of life was chosen for exploration because it has become a central framework for the provision of support and services for people with learning disabilities (Gómez et al., 2021; Verdugo et al., 2021). However, its specific application to individuals with DS has had limited exploration (Lee et al., 2021a; Lee et al., 2021b; Morán et al., 2022; Sheridan et al., 2020). Therefore, gaining a deeper understanding of the quality of life of YP with DS is essential to improving the services and support that can enhance their overall wellbeing.

For the purposes of this review, quality of life is defined using the World Health Organization's (2012) definition: "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 2012, p.11). This definition was selected because it emphasises that quality of life is a subjective evaluation, embedded within social, environmental and cultural contexts. This allows the review to explore perceived quality of life rather than focusing only on research employing specific

measurement tools. Furthermore, this definition offers a clearer and more comprehensive understanding of quality of life compared to previous definitions. For example, Scott et al. (2014) associate quality of life with overall wellbeing, defining it as an individual's perception of having a "good life" (Scott et al., 2014, p.3), which may be oversimplified. Conversely, other definitions, such as Schalock et al.'s (2010) conceptualisation of quality of life across eight domains, may be too complex or restrictive for this review. Therefore, the World Health Organization's (2012) definition was deemed the most appropriate.

The exploration of educational experiences was chosen to ensure the review's relevance to educational practice. This can help to provide practical guidance for educational professionals, including teachers and Educational Psychologists (EPs), as well as policymakers. In the existing literature, the term "educational experiences" has not been clearly defined. To capture a comprehensive understanding across a wide range of ages and settings, this review defines educational experiences as encompassing all aspects of an individual's education. This includes, but is not limited to, academic and learning experiences, as well as experiences relating to social, emotional, and personal development. Educational experiences may occur in various settings, including pre-school, statutory school-age environments, mainstream schools, specialist schools, and alternative provisions such as homeschooling.

In developing this review, a solution-focused psychology framework was used as an underpinning guide. This approach emphasises building on individuals' strengths, abilities, and existing resources to overcome challenges, rather than concentrating on deficits or problems. The focus is placed on identifying what is already working well and using those insights to foster positive change (de Shazer & Berg, 1986). By exploring individuals' goals and the steps needed to achieve them, this framework supports the development of practical strategies for improvement. The ultimate aim is to empower individuals to take small, manageable steps towards positive outcomes, encouraging growth and transformation in the process (Lethem, 2002).

Moreover, more closely relating to education, a solution-focused theoretical underpinning was adopted as literature indicates that centring on YP's strengths and positive school experiences can enhance the wellbeing and engagement of students. For example, by focusing on what is working well, there can be an improvement in students' academic self-concept, social relations, and resilience (Lopez et al., 2019; Sklare, 2014).

By employing a solution-focused framework as an underpinning guide, this review may help to encourage professionals to work collaboratively with YP with DS, their families, and educators to construct interventions and provisions that are effective at supporting them. The findings of the review can be applied practically in educational settings, providing professionals with a structured, strength-based way to support YP with DS in ways that are actionable (de Shazer & Dolan, 2007). This underpinning guide of solution-focused psychology also extends to the empirical chapter of this thesis, guiding the research.

### **Search Strategy**

To identify the factors that contribute to a successful and fulfilling life for individuals with DS, including their education, two review questions were developed to guide the literature search and to organise and shape the structure of the review. These questions were:

- 1) What contributes to a good quality of life for individuals with DS and those around them?
- 2) How do YP with DS experience education and what factors can impact these experiences?

A narrative literature review was chosen as the methodological approach to understand the life and experiences of individuals with DS (Pautasso, 2019). This approach aims to capture the multi-layered dimensions of their life experiences, encompassing their challenges and triumphs and the factors contributing to their overall wellbeing. Central to this

narrative exploration is an examination of the support systems and interventions that facilitate a good quality of life and education for individuals with DS.

Unlike in systematic literature reviews, the research strategy for narrative reviews does not need to be as explicit in detailing the search strategy and the studies included (Bryman, 2012). This is because narrative reviews focus on summarising and synthesising existing literature in a narrative format, often to provide context, identify trends and themes. Unlike systematic reviews, narrative reviews typically do not adhere to a predefined protocol or rigorous search strategy. Instead, they rely on the author's expertise and judgement to select and interpret studies that contribute to the narrative. Interpretation and integration of the literature is key in a narrative review, therefore conducting a narrative review allowed for a more qualitative and interpretive approach (Sukhera, 2022). This methodology was better suited to the nature of the researcher's wider research, facilitating a deeper exploration of the topic (Rozas & Klein, 2010). To uphold rigour and clarity, information on the literature search, encompassing search terms, date ranges, and exclusion criteria is explained below:

In October 2022, comprehensive searches were conducted using EBSCO and PROQUEST, renowned search engines that traverse numerous databases, including those dedicated to Educational Psychology and Education, such as PsycINFO and ERIC (Educational Resources Information Center).

When carrying out the search, a specific date limiter of only including research from the year 2000 onwards was applied. This ensured that the literature reviewed reflected up-to-date understanding, methods, and findings. This is important as the theoretical frameworks and educational policies within the fields of education and psychology are continuously evolving. By restricting the review to literature from 2000 onwards, the research reviewed is grounded in the most current context and reflects relevant educational practices, societal attitudes towards inclusion, and advances in understanding the developmental needs and experiences of YP with DS.



The year 2000 was chosen based on the knowledge that around this time, educational frameworks and policies underwent a transformation regarding inclusive education. For example, key international agreements and policies such as the Salamanca Statement (1994) and the UN Convention on the Rights of Persons with Disabilities (2006), advocated for the inclusion of children with disabilities in mainstream education. Therefore, research from 2000 onwards is more likely to reflect this increasing focus on inclusion, making it more relevant to this review.

As well as this, Educational Psychology as a field has expanded significantly over the recent years and there is now an increasing emphasis on learning disabilities and individualised learning strategies (American Psychological Association, 2006). Limiting the review to literature from the year 2000 onwards ensures that the review captures these developments and that the findings are relevant and applicable in current educational psychology practice.

Moreover, selecting a cut-off point helped to maintain the focus of the review. Including literature published before the year 2000 may have introduced outdated practices that are no longer relevant or widely accepted. For example, previously, educational research concerning individuals with learning disabilities was often framed within medical or deficit-based models, whereas more recent approaches tend to be more strengths-based and focused on inclusivity (Florian, 2008). Therefore, limiting the scope to post-2000 literature ensured that the papers examined align with current values and frameworks in education and psychology, as well as aligning more closely with the researcher's personal values.

Lastly, from a practical standpoint, this approach also made the review more manageable within the confines of a thesis.

An initial search was conducted using generic terms in the title, such as 'Down syndrome,' 'young people,' 'children,' 'experiences,' 'quality of life,' and 'education,' etc.

However, this approach generated a large volume of results, many of which were unrelated to the review's focus, making it difficult to identify the most relevant literature. Consequently, the researcher reconsidered the search strategy and decided to conduct two separate, more specific searches. The first search focused on the quality of life of individuals with DS and was guided by the question "What contributes to a good quality of life for individuals with DS and those around them?". The second search focused on the educational experiences of YP with DS, guided by the question "How do YP with DS experience education and what factors can impact these experiences?" (for full list of search terms, see Appendix 1). These terms were expanded using EBSCO's thesaurus to include synonyms and related words with similar meanings.

To ensure a more focused and relevant review of the literature, all search terms were restricted to the title of the literature. This approach was adopted as the researcher wanted the review to be specifically relevant to DS, rather than generic learning disabilities. Therefore, it was critical that the review remained tightly focused on this population, and restricting the search terms to title only allowed for this. This method has been seen to be effective in literature reviews when the goal is to filter out literature that is not directly relevant to the topic (Gough et al., 2012; Higgins & Green, 2011; Khan et al., 2003). Using this approach in this review helped ensure that only literature with a central focus on DS and the specified themes were included, thereby enhancing the relevance and specificity of the literature reviewed. It also allowed for a more manageable amount of search results, which is particularly important given the scope of the doctoral thesis, where the researcher prioritised depth of analysis over breadth.

As a precaution, the researcher experimented with expanding the search to the abstract. However, this yielded an unmanageable volume of literature, many of which were only tangentially related to the core focus of the review. The researcher acknowledged that abstracts do provide more detail about the study, however, they often include a broad range of topics, including methodological frameworks, population characteristics, or secondary

findings. This may mean that the literature found using abstract searches may not align with the primary interest of the review (Baumeister & Leary, 1997; Jesson et al., 2011; Petticrew & Roberts, 2006). As well as this, the overwhelming quantity of results presented when searching terms in the abstract presented practical challenges in terms of time and feasibility for conducting a thorough analysis within the constraints of a doctoral thesis.

Therefore, the researcher reverted to their original method of restricting the search terms to titles. This aided the selection process by narrowing the scope to studies that explicitly related to the topic of individuals DS, quality of life, educational experiences and other relevant areas. This approach ensured that the review was well-aligned with the chosen focus and also made it more practical to manage the volume of literature. This allowed the researcher to have an in-depth exploration of the most pertinent literature and avoid unnecessary dilution of the review with less relevant material.

The researcher filtered the search to exclude news articles due to concerns regarding their reliability, credibility, and lack of methodological rigour. Additionally, the search was restricted to peer-reviewed literature. Peer-reviewed scholarly work undergoes a rigorous evaluation process by experts in the field, ensuring the validity and accuracy of research findings. In contrast, news articles often provide interpretations or summaries of research rather than presenting original data. Furthermore, news articles can be prone to bias and may oversimplify complex findings, potentially misrepresenting the true nature of the research. By focusing solely on peer-reviewed scholarly literature, the researcher aimed to maintain a higher standard of quality control, align with academic standards, and ensure relevance within the literature review.

Relevant research papers were identified from the search results. In addition, the researcher utilised the 'snowballing technique' to identify further relevant studies. This technique involves following citations or references from one study to another to uncover additional relevant research (Jalali & Wohlin, 2012).

While it is acknowledged that this approach may not capture all available literature, this is a characteristic of narrative reviews. Unlike systematic reviews, narrative reviews do not aim to be exhaustive of all the literature. Instead, they allow for a more interpretive approach, where the author uses their own interpretation to select literature that is most relevant to the research focus (Sukhera, 2022). This flexibility aligns with Braun and Clarke's (2022) suggested approach to literature reviews, which emphasises the importance of constructing a coherent narrative that informs the research question, rather than aiming for exhaustiveness. Braun and Clarke highlight that the aim is not to include every piece of relevant literature but to build an understanding that integrates the most meaningful pieces, chosen based on their relevance to the research questions (Braun & Clarke, 2022). This interpretive method allows the researcher to focus on the key findings that are important for analysis.

For a in depth account of this process, including the number of search results and an explanation of how relevant papers were selected for review, as well as the use of the snowballing technique, see Appendix 2.

This process was repeated in January 2024 to ensure the inclusion of any recent advancements or studies, ensuring a robust and well-rounded analysis.

### **Exploring the Quality of Life and Experiences of Young People with Down Syndrome and Their Families**

This section of the literature review is a comprehensive exploration of the quality of life and experiences of YP with DS and their families. This includes an examination of the factors that influence quality of life for YP with DS and understanding societal perspectives on DS as well as self-image and identity among YP with DS. This section also explores the experiences of family members of individuals with DS, offering insights into the challenges and triumphs faced by these families. By synthesising these diverse perspectives, valuable insights into the life experiences of YP with DS and their families can be understood in order

to inform the development of tailored support strategies aimed at enhancing their quality of life and overall wellbeing.

### ***Understanding the Quality of Life of Individuals with Down Syndrome Using Proxy-Reporting Methods***

Some studies have investigated the quality of life of YP with DS through the use of proxy-reporting methods. This is a method where someone familiar with the individual, such as a caregiver, parent, or educator, provides information about the individual's perceived quality of life on their behalf. This approach is often used when direct self-reporting may be challenging such as in cases where the individual has communication or cognitive difficulties (Schalock et al., 2010).

Haddad et al. (2018) investigated the determinants of quality of life in adolescents and young adults with DS from carer's perspectives. Participants were family members of 197 YP with DS living in Western Australia, aged between 16 and 31. Data was in collected from the caregivers who completed a carer-report questionnaire. The questionnaire had two sections, one about the quality of life of the YP with DS and one about the quality of life of their family. The health-related quality of life of YP with DS was the primary outcome being measured. To do this, the Kidscreen-27 Parent Proxy Report questionnaire was used, which is a well-established tool allowing caregivers to report on the individual's quality of life across various dimensions.

Findings showed that difficulties with mental and physical health contributed negatively to the YP's quality of life. An important factor for a good quality of life was friendships. It was found that those who had three or more friends had better quality of life than those who did not have friends. Those who had more perceived behavioural difficulties were also perceived to have a lower quality of life.

The researchers noted that a considerable strength of this research is that there was a high response rate from the chosen population, ensuring a good representation. They also

noted the comprehensiveness of the instruments used in the research, including psychometrically validated tools.

The findings have implications for Educational Psychology, particularly in supporting YP with DS in educational settings. The link between mental and physical health difficulties and a lower quality of life highlights the importance of early identification and intervention. EPs can play a key role on this. This is because EPs are often responsible to develop holistic support plans that address not only academic but also social-emotional and health-related needs. The findings signify the importance of collaborating with schools, families, and healthcare professionals to ensure comprehensive support for YP with DS in order to improve their overall quality of life and educational outcomes.

Additionally, the finding that friendships significantly contribute to a better quality of life highlights the importance of promoting social inclusion and peer relationships within schools. This positive finding can be used in a solution-focused approach by highlighting what is already working well and building on those successes. EPs can advocate for and support the development of inclusive practices that foster meaningful friendships and social interaction. This could involve facilitating social skills or friendship interventions, facilitating peer mentoring schemes, or training teachers to better understand how to create a classroom environment that encourages positive peer relationships.

Other similar research has used proxy-methods to understand the quality of life of YP with DS. Studies by Lee et al. (2020), Lee et al. (2021a) and Lee et al. (2021b) contribute to a deeper understanding of how various factors influence their quality of life across different developmental stages, including the role of family variables.

Lee et al.'s (2020) study explored the contributions of family-related variables to the quality of life of children with DS. This research aimed to investigate the role of family dynamics, support structures, and other familial factors in shaping the quality of life of CYP with DS in an international context. Lee et al. (2021a) examined quality of life in individuals

with DS aged 4 to 21 years, focusing on developmental differences across age groups and gender, and Lee et al. (2021b) conducted a scoping review to synthesise previous research findings regarding family variables and quality of life in children with DS. Together, these studies can help to provide a comprehensive picture of how family influences, developmental stages, and other variables interact to affect quality of life of individuals with DS.

In Lee et al.'s (2020) study, the participants included parents of children who were diagnosed with DS and ranged in age from 4 to 21 years from various international contexts. The sample was drawn from different cultural and socioeconomic backgrounds, making the findings broadly transferable between different contexts (Lee et al., 2020). Lee et al.'s (2021b) cross-sectional study also focused on children aged 4 to 21 years, exploring how their quality of life varied based on their developmental stages. The scoping review did not involve primary data collection but examined various studies that involved similar participant groups, with an emphasis on the influence of family variables.

Across these studies, several key findings emerged. Lee et al. (2020) found that family variables, such as family appraisal and family problem-solving, significantly influenced the quality of life of children with DS. Lee et al. (2021a) found that younger children had higher quality of life scores in some areas compared to adolescents and young adults. The researchers noted that this could be due to the increasing challenges adolescents with DS face, such as social integration and the growing complexity of educational and social expectations. Lee et al.'s (2021b) scoping review further supported this, finding that family cohesion, parental coping strategies, and social support networks were linked with higher quality of life in children with DS. However, the review also highlighted that gaps existed in the literature, particularly in understanding how different family structures or cultural backgrounds affect these relationships (Lee et al., 2021b).

The findings of these studies have important implications for both practice and policy. First, they suggest that interventions aimed at improving the quality of life of children with DS should not only focus on the child but also on the family unit. Furthermore, these findings stress the importance of social support systems in enhancing both family functioning and the quality of life of CYP with DS (Lee et al., 2020; Lee et al., 2021a). Solution-focused approaches can further guide the development of these support systems by emphasising collaborative, strength-based interventions that empower families to work towards their own goals and positive futures.

One of the strengths of these studies is their large, international sample, which enhances the transferability of the findings. The Lee et al.'s (2020) study is particularly strong due to its inclusion of diverse family backgrounds, which adds depth to the understanding of how family variables shape quality of life across different cultures. Additionally, Lee et al. (2021b) offers a comprehensive synthesis of previous research, providing a strong evidence base for the role of family dynamics in influencing quality of life.

These studies also have limitations. All three studies relied heavily on parental reports, which may not always capture the subjective experiences of CYP with DS themselves. Parents may underestimate their child's quality of life, leading to potential bias (Ijezie et al., 2023). Another limitation is the cross-sectional design of the studies, which restricts the ability to infer causality between family variables and quality of life outcomes. So well as this, the children's level of disability was not considered (Lee et al., 2020). Lee et al., (2021a) suggests that longitudinal research is needed to better understand how these relationships evolve over time.

Another limitation of these studies is that data was collected using the English version (Stone et al., 2020) of the KidsLife scale (Gómez et al., 2016), a quality of life questionnaire designed for people with learning disabilities. Although the scale was originally developed for YP with learning disabilities and significant support needs, its application to



individuals with DS presents some limitations. During the validation process, Gómez et al. (2017) identified that several items within the scale were not well-suited to CYP, potentially influencing the accuracy and reliability of the findings.

To address this limitation, Morán et al. (2022) aimed to identify the predictors of quality of life for YP with DS using an adapted version of the KidsLife scale specifically tailored for this CYP with DS. The study utilised a large sample of YP with DS, aged between 4 and 21 years. The KidsLife-Down Scale was initially developed by Gómez et al. (2017) and has been validated for its reliability and validity (Gómez et al., 2020). However, it had not previously been applied to such a broad sample. Morán et al.'s (2022) study was the first to examine its use with a large group, involving 404 participants with DS.

The findings revealed that quality of life was rated higher in material wellbeing, physical wellbeing, and rights. Lower scores were observed in areas such as self-determination and social inclusion.

The researchers emphasised that a key strength of this study was the use of the carefully designed and validated KidsLife-Down Scale (Gómez et al., 2020). The scale's basis in an empirically validated framework may help to enhance the precision of planning, implementing, and evaluating supports and services for CYP with DS.

The findings have helped to identify priority areas for intervention, particularly in promoting self-determination and enhancing social inclusion for YP with DS. These areas should be carefully considered when designing educational, social, and support strategies. However, it should be noted that these ratings were reported by professionals and relatives, rather than by the YP with DS themselves, which may have influenced the results.

To summarise, the research discussed has helped to identify the factors that shape the wellbeing and quality of life of CYP with DS. Using proxy-reporting methods, health, friendships, and behavioural challenges have been revealed as key influencers of quality of life for individuals with DS. Friendships and social inclusion emerge as significant

contributors to better quality of life, while health issues and behavioural difficulties negatively impact it.

These findings are particularly valuable. Using solution-focused approaches, EPs can utilise the role of friendships and social connections as key strengths that enhance the wellbeing of YP with DS. By fostering peer relationships, promoting social inclusion, and creating environments where these connections can thrive, EPs can support the holistic development of both the social and emotional dimensions of quality of life for these YP.

Furthermore, the research highlights the influence of family dynamics, suggesting that interventions should extend beyond the individual child to include the broader family system. By empowering families through support, education, and resources, EPs can strengthen the family's capacity to positively influence their child's quality of life. This is consistent with the solution-focused philosophy, which emphasises utilising existing resources and fostering resilience within families to achieve sustainable, long-term outcomes.

However, a limitation of the research discussed is the uncertainty surrounding the accuracy of proxy-reporting methods in capturing the subjective views and experiences of the individuals themselves. While the studies identify facilitators of quality of life for YP with DS, they also highlight areas where quality of life is perceived to be lower, such as the effects of health conditions and lack of friendships and self-determination. Research has shown that proxy methods often capture more negative perceptions, whereas YP with DS are more likely to view their lives more positively (Ijezie et al., 2023). Therefore, it is important for research to also explore the quality of life of YP with DS from their own perspectives. Collecting data directly from YP with DS may present challenges but it can provide a more detailed understanding of their quality of life. This highlights the need for qualitative research that explores the personal experiences of YP with DS. Research including the perceptions of YP with DS on their quality of life could also empower this

population to have their voices heard. By integrating these insights, EPs can design interventions that are both evidence-based and person-centred, ensuring that supports are tailored to the unique experiences of YP with DS.

Solution-focused approaches could be used to guide this future exploration. These approaches emphasise existing strengths and resources and the importance of focusing on desired outcomes rather than problems (Gingerich & Peterson, 2013). Amplifying the individual's voice can help to identify these strengths and resources. Applying a solution-focused framework in future research could ensure that the perspectives of YP with DS are central, focusing on what they view as contributing to their quality of life and wellbeing. By framing questions around what is going well and how YP can build on these successes, researchers can gather data that is not only more representative of the YP's lived experience but also directly informs positive, strength-based interventions. This approach could provide EPs with actionable insights that promote empowerment and resilience, aligning with person-centred practice (Ratner et al., 2012). Integrating solution-focused methods would allow future research to both fill gaps in understanding and enhance the relevance of findings for practical application in supporting YP with DS.

### ***The Perspective of Individuals with Down Syndrome on Their Quality of Life***

As recommended above, some research has explored the quality of life for individuals with DS from their own perspective, uncovering what individuals with DS believe can be a contributing factor to a good quality of life.

To understand this, Sheridan et al. (2020) reviewed the current literature at the time concerning the quality of life for adolescents with DS. The authors recognised that there was a lack of research exploring the perceptions of YP with DS and aimed to discover and explain the evidence that exists in relation to the perspectives of adolescents with DS about their quality of life. Despite initially identifying 45 research papers on the topic, only two

incorporated the perspectives of YP with DS, resulting in the exclusion of 43 papers. The two selected studies were Foley et al. (2012) and Scott et al. (2014).

Firstly, Foley et al. (2012) aimed to describe the meaning of wellbeing for children and youth with disabilities from their perspective. Twenty CYP with a range of disabilities, including 3 YP with DS, participated in five focus groups and one interview. Open coding was employed to initially label and categorise the data, while constant comparison methods facilitated the comparison of codes and categories to deepen conceptual understanding. From the data, six themes emerged to understand the meaning of wellbeing, encompassing aspects such as participation, the significance of meaningful friendships, family dynamics, anxiety related to academic performance, coping strategies and resilience, and personal growth and development. The participants' conceptualisation of wellbeing from their perspective was described as feeling supported, included, and respected, as well as valued and capable. While the findings provide valuable insights into the meaning of wellbeing for a diverse range of youth with disabilities, caution must be exercised in generalising the findings to YP with DS, as they constituted a small proportion of the participant sample.

Secondly, Scott et al. (2014) explored what makes a "good life" for YP with DS, from their own perspective. As well as this, they also identified the barriers and facilitators for participation of YP with DS. This investigation employed qualitative methods, utilising individual interviews and focus groups with a cohort of 12 participants. These participants, all young adults with DS aged 18-30, were drawn from the Down Syndrome Needs Opinion Wishes Database in Western Australia. Criteria for participation necessitated minimal speech difficulties. Data analysis encompassed open coding and constant comparative techniques, leading to the delineation of categories which were subsequently amalgamated into overarching themes. The research identified that meaningful relationships, community participation, independence, and aspirations were crucial elements for a good quality of life.

As emphasised in the study's title, the overall findings from this study revealed that the participants' life perspective was positive, with a general consensus of, "I have a good

life.”. The researchers recognised limitations in their research, such as only including participants who had the ability to sustain attention and had good communication skills. Consequently, this suggests a need for future research to explore methodologies that facilitate the inclusion of young adults with intellectual disabilities facing challenges in these domains. Nonetheless, a notable strength of this research lies in its utilisation of the perspectives of YP with DS, diverging from prior studies predominantly reliant on caregiver perspectives (Carr, 2008; Docherty & Reid., 2009; Lee McIntyre et al., 2004)

Whilst these studies offer a unique perspective and are useful in helping us to understand how to facilitate a good quality of life for YP with DS, they both use participants from Australia. While convenient recruitment sampling offers benefits such as streamlining data collection processes and maintaining research consistency, it also raises concerns regarding the broader applicability and transferability of the findings to the wider population of YP with DS. It is important to acknowledge that the positive outcomes of the study may have been influenced by Australian cultural norms and attitudes towards inclusion of individuals with learning disabilities. Despite this limitation, within the Australian context, these studies hold significant implications for the enhancement of service delivery models for YP with DS transitioning from school to post-school life. These studies highlight the importance of interventions targeting employment training and support, acquisition of life skills, promotion of self-determination, and education on navigating relationships with parents, peers, and romantic partners.

Reviewing the findings of Scott et al. (2014), and the findings relevant for the 3 participants with DS in Foley et al.'s (2012) research, Sheridan et al. (2020) identified a recurring emphasis on the importance of social participation, community engagement, friendships, family relationships, and functional independence for adolescents with DS. While identifying what YP with DS value for a fulfilling life, this review also highlighted a significant lack of substantial quality-of-life research involving the perceptions of individuals with DS, contributing to a dearth of information on their self-perceived quality of life. This

knowledge gap, as also noted by Irvine (2010), may impede a comprehensive understanding of their needs and challenges, thereby hindering the development of effective support mechanisms in both daily life and education (Correia et al., 2017).

Since the review, more research into this area has been conducted. For example, Jevne et al. (2021), explored the perspectives of eight 22-year-olds with DS living in Norway on quality of life and wellbeing. Each participant was interviewed, and the data was analysed using content analysis. The findings revealed four key determinants of quality of life: engaging in work aligned with their interests and capabilities, maintaining an active social life, having a secure place to live, and having access to information and communication technology (ICT). These findings corroborate several previous research findings, lending further credence to their validity. For instance, akin to Foley et al. (2012), the results emphasise the intricate interplay between functioning, disability, and contextual factors, identified as pivotal aspects in the multifaceted transition to adulthood. Additionally, the findings align with the previous studies by both Foley et al. (2012) and Scott et al. (2014), which highlight the significance of various factors during the transition to emerging adulthood, including employment, social skills/relations, self-determination, leisure participation, family involvement, and accommodation and support needs. Furthermore, the study supports Scott et al. (2014)'s discovery regarding the importance of independence. However, in this study, independence and self-determination were predominantly associated with living arrangements, specifically regarding decisions about housing.

Moreover, Takataya et al. (2022) sought to gain insight into how young adults with DS perceive their lives. In their study, they conducted both individual and group interviews with 11 young adults with DS in Japan. This approach allowed the researchers to directly capture the subjective experiences and viewpoints of the participants, offering valuable insights into their personal perspectives of their life. Participants were asked questions about work, leisure time, family, friends, disability and the future.

They found that YP with DS are serious about work but struggle to make friendships in the workplace. However, they do enjoy having colleagues. They value friendships and enjoy spending time with friends but spend a lot of time alone. Findings about their disability were mixed, with some not being aware that they have DS. Implications of this include considerations on how to support YP with DS to make friendships and to spend leisure time with friends. Whilst this study successfully gathered data from YP with DS, the researchers did not specifically modify interview techniques to make it more accessible for YP with DS. The researchers observed challenges in participant communication, noting instances where participants found it difficult to articulate themselves clearly. Researchers often had to rely on their own interpretation to discern the intended meaning conveyed by the YP with DS. This prompts the need for future research exploring this perception to consider and use participant-friendly interview methods.

Additionally, Ijezie et al. (2023) reviewed the research investigating the quality of life in adults with DS using a mixed methods systematic review. This review aimed to identify, synthesise and integrate the quantitative and qualitative evidence on quality of life in adults with DS via self-and proxy-reporting and included 39 studies. Findings showed that a good quality of life for adults with DS depended on personal development, self-determination, interpersonal relations, social inclusion, and emotional, physical and material wellbeing. This review is interesting as findings using the perceptions of adults with DS and findings using other perspectives were analysed separately. A notable discovery was that self-reported quality of life for adults with DS was consistently rated higher than proxy-reported quality of life. This suggests that proxy-reporting methods may not always provide an accurate portrayal of the experiences of individuals with DS, as others may struggle to accurately convey or even understand their feelings, opinions, or experiences. This further highlights the significance of research that directly incorporates the perspectives of individuals with DS themselves. Additionally, the review highlighted the necessity for a more systematic approach to enhancing the quality of life for adults

with DS in targeted areas. The authors suggested that future research should focus on evaluating both self and proxy-reporting methods, as well as developing culture-specific quality of life instruments that are more suitable for individuals with DS.

In summary, the research discussed identified key themes of wellbeing, highlighting aspects such as participation, friendships, family dynamics, and personal growth, meaningful relationships, and community participation. These studies offer implications for enhancing service delivery models for YP with DS, particularly in areas such as employment, life skills, and relationship education. This literature also highlights there is a need for more comprehensive research involving individuals with DS as well as research evaluating self- and proxy-reporting methods and developing culture-specific quality of life instruments.

Considering a solution-focused approaches, incorporating the perspectives of YP with DS can enable EPs and other professionals to create interventions that align with the individuals' personal definitions of a good quality of life, including meaningful friendships, independence, and community participation. This approach takes into account the unique life context and strengths of YP with DS and can be used to encourage social inclusion, foster the development of life skills, and promote self-determination. All of which have been identified as significant contributors to a positive quality of life.

### ***Attitudes Towards Down Syndrome: Societal Perspectives and Self Perception***

As highlighted in the discussion above, the quality of life for YP with DS can depend on them having meaningful relationships and being able to participate in the community and make friends. The ability to do this is likely to be influenced by the attitudes that those around them possess towards them, and therefore understanding societal attitudes is paramount.

Societal attitudes towards YP with DS has not been researched in-depth, however there has been some research exploring societal attitudes towards general learning disabilities, particularly in relation to inclusion of people with learning disabilities within the



workplace and inclusive education. In studies examining inclusive workplace environments, both employers and employees have demonstrated favourable attitudes towards employing individuals with learning disabilities (Levy et al., 1993; Unger, 2002). When exploring attitudes towards inclusive education for YP with learning disabilities, some studies have reported positive attitudes towards this (Kasari et al., 1999; Cooney et al, 2006) while others have documented negative attitudes (Burke & Sutherland, 2004; Bhagat, 2007; Smith 2011). Previous investigations have highlighted that individuals who have had prior relationships and interactions with people with learning disabilities tend to exhibit more positive attitudes (Maras & Brown, 1996; Unger, 2002). These findings highlight the importance of educating society about disabilities and fostering interactions with individuals with learning disabilities to encourage more positive attitudes and greater inclusion.

There is limited knowledge of these perceptions in the specific context of DS. To address this, Gannon and McGilloway (2009) explored the attitudes of non-disabled primary school children in rural Ireland towards their peers with DS using data from a sample of 118 children from four mainstream schools. They found that children's attitudes towards the sociability of peers with DS were generally more positive compared to their attitudes towards inclusion. This suggests that while they may feel comfortable interacting with their peers with DS, they are less supportive of integrating them into mainstream educational settings. As well as this they discovered that female participants aged over 10 displayed the highest levels of sociability towards peers with DS. This highlights potential differences in attitudes based on gender and maturity. Factors such as previous experience with peers who have DS did not significantly influence the children's attitudes and there was no measurable change in attitudes following the exposure to the inclusion-focused materials. This could indicate that merely providing information may not be sufficient to alter others' perceptions towards individuals with DS.

Additionally, societal attitudes towards DS have been explored by Pace et al. (2010). They found that societal perspectives of individuals with DS can present a significant

challenge. This research looked at the public's attitudes towards people with DS, using data derived from two 2008 U.S. surveys; the Health Styles survey, targeting adults aged 18 years and older, and the Youth Styles survey encompassing youth aged 9–18. The findings showed a prevalence of negative attitudes among adults, with a noteworthy 25% of respondents advocating for the segregation of pupils with DS into special schools. Additionally, nearly 30% expressed agreement with the notion that the inclusion of pupils with DS in conventional educational settings proves distracting for other pupils in the class. A parallel pattern is evident among the youth cohort, wherein 30% endorsed the idea of pupils with DS attending separate schools, 27% exhibited reluctance to collaborate with a peer with DS on a class project, and almost 40% declared an unwillingness to spend extracurricular time with a pupil with DS.

The data also revealed that women and those with prior relationships with individuals with DS tended to have more positive attitudes. These findings agree with those from Gannon and McGilloway (2009) that gender may influence attitudes towards individuals with DS but differs in that Gannon and McGilloway (2009) did not find that prior relationships affected attitudes.

The implications of these findings are multifaceted. Firstly, when considering the conclusions of Sheridan et al. (2020), they indicate the significant impact that societal attitudes could have on the quality of life of YP with DS, particularly in terms of their ability to form meaningful relationships and participate in the community. Negative societal perspectives, pose a considerable challenge for individuals with DS, potentially hindering their social integration and inclusion. This highlights the importance of addressing and challenging misconceptions and prejudices surrounding DS within society. Additionally, the findings emphasise the critical role of inclusive education environments in fostering positive attitudes towards individuals with DS among both adults and youth. Efforts to promote inclusive educational practices and initiatives aimed at raising awareness and promoting acceptance of diversity could help mitigate negative attitudes and create more supportive

environments for YP with DS to thrive. Moreover, the findings suggest a need for targeted interventions to address the specific challenges and barriers faced by individuals with DS in social and educational settings, including strategies to promote peer collaboration and interaction. Ultimately, fostering a culture of inclusivity and acceptance is essential for promoting the wellbeing and social integration of all YP including individuals with DS, highlighting the importance of broader societal changes and initiatives aimed at promoting diversity and inclusion.

Pace et al. (2010) noted the need to understand societal attitudes towards YP with DS in more depth, indicating a need for future investigations to explore the underlying reasons behind positive or negative attitudes towards individuals with DS. Additionally, they recommended that forthcoming studies should explore additional factors that could influence attitudes towards individuals with DS, as well as conduct more extensive analyses on how the nature, frequency, and quality of past relationships contribute to these attitudes.

It is important to note that this data was collected from the USA and therefore it would be interesting to explore whether attitudes towards individuals with DS are more positive across other countries and cultures.

In Saudi Arabia, Binjahlan et al. (2016) explored the knowledge, attitudes and practice toward DS using cross-sectional analytical questionnaires that were completed by 360 participants who were all considered to be part of the general population of Jeddah city. The findings revealed that many participants demonstrated a limited understanding of DS. Attitudes were generally positive, with many showing support and empathy for individuals with DS. However, there were mixed perceptions about their abilities, particularly regarding independent living and integration into mainstream schools. Moreover, a lack of proactive support was found. In terms of the inclusion in educational and professional settings, participants recognised that limited resources and awareness limited inclusion.

The researchers recommended that increased public education, policy reforms for inclusion, and greater support for families and caregivers of individuals with DS in Saudi Arabia were needed.

This study provides important insights into societal perceptions of DS in Saudi Arabia, emphasising the need to bridge the gap between positive attitudes and practical support through enhanced education and resources. However, it is crucial to recognise that these findings may be context-specific and reflect the unique cultural and social dynamics of Saudi Arabia, which may not be relevant to other settings.

It should be noted that the research discussed above was published in 2010 and 2016. In recent years, there has been a big shift in the ways that knowledge and information is shared, with a large increase in the use of social media (Ahmed et al., 2019; Cocq & Ljuslinder, 2020; Sweet et al., 2020). Research by Gračanin (2020) has shown that media can improve knowledge about DS. This study examined the knowledge and attitudes of secondary school students regarding children with DS. It found that students generally possessed a good level of knowledge, with the majority having learned about DS through media sources. It would be interesting to investigate whether this increased knowledge has affected others' attitudes towards individuals with DS. More specifically, exploring the impact of social media on societal attitudes towards DS could be useful. The rise of platforms such as Instagram and TikTok could potentially be playing a significant role in promoting diversity and representation, including individuals with disabilities. Further research examining how social media platforms contribute to shaping perceptions could provide valuable insights into the evolving dynamics of inclusion in the digital age.

Facilitating a more positive societal attitude towards individuals with DS is crucial for their wellbeing, as negative societal attitudes may negatively affect their self-perception. This can be explained through Social Identity Theory (Tajfel et al., 1979),

which posits that individuals derive part of their identity and self-esteem from the groups they belong to. In the context of individuals with DS, societal attitudes play a key role in shaping their social identity. When society holds negative stereotypes or stigmatises individuals with DS, it creates a negative social identity associated with their group, leading to feelings of inferiority and lower self-esteem as they internalise the stigma. Conversely, when societal attitudes are positive—promoting inclusion, acceptance, and respect for individuals with DS—it fosters a positive social identity. This sense of being valued and respected enhances their self-esteem and overall wellbeing. Thus, Social Identity Theory helps to understand how societal attitudes toward individuals with DS influence their social identity, highlighting the importance of promoting positive societal attitudes to enhance their social identity and psychological wellbeing.

Social Identity Theory complements solution-focused psychological frameworks by highlighting how social factors contribute to the development of individuals' strengths, resources, and self-concepts. Solution-focused approaches enable individuals to reflect on how they draw from their social environments to shape their identities and envision their future goals. Social groups and identities can play a role in creating solution-focused interventions. By acknowledging the positive aspects of group membership, these approaches harness social strengths to help individuals overcome challenges and work toward achieving their desired outcomes.

Others' attitudes towards DS are particularly important to understand and improve. Saha et al. (2014) suggested that even young children with DS have an awareness of their disability and its association with negative social attitudes. The researchers in this study recognised that although self-concept is an indicator of quality of life, very few studies have explored this link in children with DS. To examine this, they analysed the responses of 52 children with DS towards two dolls; one with a typically developing (TD) appearance and one which had features associated with DS. The children with DS exhibited a distinct preference for the TD doll over the DS doll.

Furthermore, they tended to associate more positive attributes with the TD doll, implying that these children may perceive TD individuals as more attractive, intelligent, kind, and physically capable compared to individuals with DS. It is important to consider that this understanding of the results was inferred from observations and the researchers cannot be certain why the children were more likely to choose the TD doll and that these results may have also been affected by self-selection bias.

Despite the potential limitations inherent in this study, more recent research by Deakin et al. (2018) yielded similar results, enhancing an understanding of the self-awareness and perceptions of YP with DS. Examining 28 CYP with DS aged 8-17, Deakin et al. (2018) compared their perceptions to those of TD peers. Similar to the findings of Saha et al. (2014), this study revealed that YP with DS develop an early awareness of their differences. As well as this, they found that all participants showed a preference for social interaction with their TD counterparts. Moreover, the participants attributed more positive characteristics to the photographs of TD individuals. However, a noteworthy and positive aspect emerged from the study: despite their inclination towards the TD images, the participants with DS still maintained a positive self-perception. These findings highlight the intricate interplay between self-awareness and identity formation for YP with DS.

The findings of both studies suggest that societal attitudes towards individuals with DS may influence the self-perception of children with DS from a young age. The preference for the TD doll over the DS doll, along with the attribution of more positive qualities to the TD doll, and the preference for interaction with TD peers and TD photographs could indicate that children with DS may internalise societal stereotypes and perceive TD individuals more favourably. This highlights the impact of negative social attitudes on the self-esteem and self-concept of individuals with DS, even at a young age.

The implications of these findings highlight the importance of addressing and challenging societal stereotypes and promoting positive representations of individuals with

DS in society. Moreover, interventions aimed at fostering positive self-perception and self-esteem among CYP with DS should be prioritised to enhance their overall wellbeing and quality of life.

Moreover, the need to promote positive perceptions of YP with DS may highlight growing responsibility for researchers to move purposefully away from 'deficit-oriented research narratives' that focus on limitations or challenges. Instead, future research could prioritise frameworks that acknowledge and empower CYP with DS, focusing on their strengths, successes, and preferred aspects of their lives and identities. A solution-focused psychology framework offers an avenue for this shift, as it centres on identifying strengths and resources, emphasising what is working well, and envisioning positive outcomes. This shift towards strength-based, solution-focused research can help reshape how society views and supports individuals with DS, encouraging an inclusive approach that uplifts and enhances their lived experiences.

Cunningham and Glenn (2004) interviewed YP with DS and their parents (77 YP and 78 parents). They found that not all YP with DS had an awareness of their condition. However, of those who did, males were more likely to have negative, avoidance reactions to questions regarding their disability. As well as this, 20% of participants reported a negative stigma related to having DS. Having said this, interestingly, for most participants having DS was not a particularly significant part of their lives, with almost three quarters of participants saying that it is not important to him.

This research is particularly prominent as it included the views of many YP with DS. The researchers made adaptations to their interview approach to ensure the participants' voices were able to be captured accurately. These adaptations included rewording the questions if participants did not understand and prompts and probes to help explain ideas. The participants were also able to have an accompanying adult if they chose to. The

interview was terminated if the participant did not know how to answer the questions or lost interest.

The participant-friendly interview methods in this study serve as a good example and can be used in future research to gather the voices of YP with DS in different contexts. The researchers suggested that further research is needed to explore the gender difference in the self-perception of having DS to understand why males may have a more negative outlook and how to support them with a positive self-perception.

In summary, the quality of life for YP with DS is intricately linked to their ability to form meaningful relationships and participate in their communities, with societal attitudes playing a pivotal role in shaping these experiences. While research on societal attitudes towards individuals with learning disabilities provides some insights, such as positive attitudes towards inclusive workplaces and education, studies specifically exploring attitudes towards DS reveal significant challenges. These findings indicate the critical need to address societal misconceptions and prejudices surrounding DS, advocating for inclusive environments and educational practices to foster positive attitudes and social integration. Furthermore, understanding the link between societal attitudes and the self-perception of individuals with DS is crucial. Studies have highlighted the impact of societal attitudes on the self-esteem and self-concept of individuals with DS from a young age, indicating the importance of promoting positive representations and fostering self-esteem among this population. It would be useful for further research to explore how societal attitudes to DS and other learning disabilities have changed over time, and whether this is contributing to the increase of children with SEND attending mainstream education. In particular, examining how social media platforms contribute to shaping positive perceptions of disabilities could provide valuable insights into this.

Using solution-focused principles, EPs can help to positively shift perceptions and attitudes towards YP with DS by highlighting and emphasising their strengths and potential.



By fostering environments that promote meaningful social interactions, such as supportive friendships, active involvement in the community, and inclusive educational settings, EPs can help create spaces where YP with DS feel valued and competent. This shift in focus may help to challenge negative societal stereotypes and encourage a more positive outlook toward the abilities and attributes of YP with DS. This can help empower individuals by acknowledging their strengths as well as also work towards broader systemic change, encouraging the development of inclusive practices that enhance the wellbeing and social integration of YP with DS.

### ***Experiences of Down Syndrome: Family Perceptions***

The preceding sections have reviewed research to comprehend how YP with DS perceive their quality of life, alongside societal attitudes towards DS and their own self-perception, recognising their intricate interplay. These factors are pivotal as attitudes towards DS may influence what YP with DS deem essential for a fulfilling life. However, to gain a holistic understanding of the lives and experiences of YP with DS, it is imperative to consider the perspectives of their family members. Family attitudes and experiences can profoundly shape the experiences and opportunities available to YP with DS. By acknowledging and integrating a range of viewpoints, a more detailed understanding of the challenges and triumphs faced by individuals with DS can be attained, facilitating more effective support strategies and interventions to support them to have a successful and happy life.

Hodapp et al. (2001) and Seltzer and Ryff (1994) suggest that, in comparison to family members of children with other developmental disabilities, families of those with DS generally exhibit fewer difficulties. This may be attributed to various factors, particularly the demographic characteristics prevalent among families associated with DS. Notably, parents of individuals with DS are often older (Urbano & Hodapp, 2007), have stable careers (Corrice & Glidden, 2009), and possess higher affluence (Grosse, 2010). Smith et al. (2014) also suggest that parents of YP with DS may experience less stress than parents of children

with other learning difficulties as parents of children with DS perceived their child's communication difficulties as less severe than those of other children with similar challenges.

While this perspective is encouraging, it also highlights important considerations. The limited research on YP with DS may be influenced by the assumption that these individuals and their families are already managing well, which could inadvertently overlook the need for further support and academic investigation. Therefore, this strengthens the need to explore the research aiming to better understand the lived experiences, needs, and perceptions of the families of YP with DS, ensuring that appropriate support and resources are available to promote the wellbeing and enhance the overall quality of life of YP with DS and their families.

Mandleco and Webb (2015) examined existing literature on the perceptions of siblings living with individuals diagnosed with DS or autism spectrum disorder. The review synthesised information from 28 research articles published between 2000 and 2014. This selective approach aimed to consider the most recent and relevant information within the given timeframe. The review identified five overarching themes. First, the theme of "Knowledge of Condition" emerged, revealing that siblings typically acquired information about DS from their parents and various professionals. However, a notable subset expressed a desire for additional knowledge on DS, suggesting potential gaps in understanding that may impact their experiences. The second theme, "Relationships with Others," explored the impact of living with a sibling with DS on interpersonal relationships. This encompassed dynamics with family members, peers, and classmates. Despite the challenges posed, there was a prevalent sentiment of love, care, and pride among siblings, emphasising the resilient and positive aspects of these familial relationships. A third theme, "Perceptions of the Condition," highlighted that siblings often held positive views regarding DS. This positive outlook could contribute to fostering a supportive environment and challenging stereotypes associated with the condition. The theme "Emotional Reactions to the Situation" illuminated the complex emotions experienced by siblings. Frustration related

to communication and behaviours surfaced, along with concerns about their own learning. This dimension highlighted the need for tailored support mechanisms to address the emotional wellbeing of siblings. The final theme, "Behavioural and Personality Outcomes," indicated that, for many siblings, living with a person with DS had a positive influence on their own behaviours. This positive impact included increased levels of caring, patience, and acceptance. Such outcomes highlight the potential for individuals with DS to contribute positively to the development of their siblings and potentially others that they interact with regularly. Adding to this, Mandleco and Webb (2015) suggested that nurses caring for families with youth with DS can play a role in enhancing sibling development. This promotes the importance of interdisciplinary collaboration in addressing the multifaceted needs of such families.

As well as sibling perspectives, parental perspectives have also been researched. For example, many studies have explored the rewards and challenges of raising a child with DS from a parental perspective, which have unveiled noteworthy challenges within the familial context (Bourke et al., 2008; Farkas, et al., 2019; Green, 2003; Green et al., 2005).

Whilst Green (2003) and Green et al. (2005) looked at the difficulties faced by parents of a children with disabilities in general, Bourke et al. (2008) explored this specifically in the context of DS. To do this, they investigated the relationship between parenting a child with DS and maternal health by employing two-part questionnaires. One part focused on the specific traits and needs of the child with DS, while the other centred on the overall health and wellbeing of the family. Their findings revealed that several factors significantly influenced maternal health. These included the child's behavioural challenges, everyday functioning level, progress in community engagement such as shopping and travel, and to a lesser extent, the child's current health status.

Despite notable strengths, such as robust data analysis and a substantial sample size of 250 completed questionnaires from mothers of children with DS in Western Australia,

the study faced limitations. Challenges with follow-up and potential biases stemming from non-responders, particularly with fewer responses from disadvantaged family groups, were acknowledged by the researchers. However, the researchers emphasised the importance of their findings, suggesting that mothers of children with DS may face increased mental health challenges and could benefit from additional support and services, particularly in areas related to behaviour management for their child and their own psychological wellbeing.

More recently, Farkas et al. (2019) identified a spectrum of challenges encountered by parents of children with DS that most parents of typically developing children did not encounter, including social, developmental, and educational dimensions.

When reviewing these studies, results reveal that challenges for parents of children with DS include societal stigma attached to DS, behavioural complexities, and heightened levels of stress experienced by parents in navigating the unique demands associated with parenting a child with DS.

Further research in this area could aim to understand how parental challenges associated with raising a child with DS might directly and indirectly affect the quality of life perceived by YP with DS. This exploration could involve longitudinal studies to assess how parental stress, coping mechanisms, and support systems evolve over time and their impact on the wellbeing of both parents and their children with DS. Additionally, qualitative studies could provide rich insights into the lived experiences of families, shedding light on the specific ways in which parental challenges manifest and intersect with various aspects of the child's quality of life. Gaining a deeper understanding of the complex interplay between parental challenges and the quality of life of YP with DS, researchers can contribute to the development of more effective support mechanisms and interventions to enhance the overall wellbeing of individuals with DS and their families.

The implications of these findings are significant for both research and practice in the field of DS and familial support. Firstly, understanding the experiences and challenges faced

by parents of children with DS improves the understanding of the broader context in which individuals with DS grow and develop. By acknowledging the societal stigma, behavioural complexities, and heightened stress levels experienced by parents, interventions and support services can be tailored to address these specific challenges. Additionally, exploring the potential impact of these parental challenges on the perceived quality of life of YP with DS can provide valuable insights into the nature of their experiences. This research could inform the development of holistic support programs that not only address the needs of individuals with DS but also provide support for their families. Overall, by considering parental perspectives alongside sibling perspectives, a more comprehensive understanding of the familial dynamics and their implications for individuals with DS can be achieved, leading to more effective support strategies and interventions aimed at enhancing the overall wellbeing and quality of life of individuals with DS and their families.

Despite the challenges for parents of children with DS in the research, other research has also acknowledged more positive parental perceptions. Burke et al. (2012) investigated the connection between the behaviours of YP with DS and parent functioning during adolescence. Data on personality traits, intelligence, adaptive skills, and behaviour were gathered from 42 adolescents with DS, correlating these factors with parental depression, coping mechanisms, concerns about the future, and positive perceptions. Overall, the results revealed that parents perceived their adolescents with DS as sociable and outgoing, with minimal behaviour issues. These results are similar to the positive findings of previous research by Poehlmann, et al. (2005) and Skotko et al. (2011) who found that parents often perceive their child's positive personal attributes as contributing to the wellbeing of the entire family. Building on this, more recent research by Skotko et al. (2016) reinforced these findings, with a significant proportion of parents expressing overwhelmingly positive feelings about raising children with DS.

Despite limitations in generalisability, notably the predominantly white and highly educated parent sample and the lack of consideration for changes in perceptions and

parenting strategies over time, Burke et al.'s (2012) findings provided valuable insights into the familial perceptions and dynamics of adolescents with DS. This research served as an initial exploration into the experiences of families with adolescents with DS offering important groundwork for understanding how to best support YP with DS and their families. To expand this knowledge further, future research should explore different cultural contexts and examine longitudinal data to capture evolving perceptions and experiences over time.

Additionally, recent research has highlighted the mixed perceptions of raising a child with DS. Sheldon et al. (2021) explored the rewards and challenges of parenting a child with DS, focusing specifically on the father's perspective. In their comprehensive investigation, they surveyed 175 fathers of children with DS through open-ended questions. The findings revealed that fathers often express the rewards of their child's love, affection, and happiness. Many also believe that having a child with DS has positively influenced their lives, fostering a more optimistic outlook. Additionally, they described an expansion of their social network. As well as these positive perceptions, the study also acknowledged the challenges faced by fathers, such as dealing with behavioural differences, concerns about their child's future, a sense of parental inadequacy, and difficulties accessing necessary resources.

This was a comprehensive investigation, which involved surveying a considerable number of fathers through open-ended questions, allowing for rich and varied responses. However, it is essential to critically reflect on some aspects of the study. While the positive perceptions of fatherhood are illuminating, there may be a risk of social desirability bias in the responses, as fathers may feel inclined to emphasise the rewarding aspects of parenting and downplay challenges. Furthermore, the study primarily focuses on the experiences of fathers, potentially overlooking the perspectives of mothers or other caregivers who play crucial roles in the upbringing of children with DS. Understanding the interplay between different family members' experiences could provide a more holistic understanding of the challenges and rewards associated with raising a child with DS.

Despite these limitations, the study highlights the importance of acknowledging both the joys and difficulties of parenting a child with DS. By recognising the unique experiences and needs of fathers in this context, healthcare professionals and support services can better tailor interventions and resources to provide comprehensive support to families. Moving forward, future research should aim to address the aforementioned limitations by considering diverse family dynamics and exploring the impact of contextual factors on parental experiences.

Understanding how the parents of YP with DS perceived their child's life transitions is also important when considering how to support YP with DS to have a good quality of life. This is because it has been found that well planned transitions can lead to better success during adulthood for YP with DS (Jokinen et al., 2012). To explore these transition periods Leonard et al. (2016) gathered data from the parents of young adults with DS and other learning disabilities using questionnaires. The data collected included qualitative data about parents' concerns about their child's transition into adulthood, any difficulties they face, and any worries about the future. The key findings show that parents of children with learning disabilities view transition into adulthood as a difficult time. A number of themes were identified. This included worries about the YP's ability to adapt to adult life and cope without the support of the school system, difficulty understanding the available support and services, concerns about the ability of their child to build connections in the adult world, strain on family wellbeing and general concerns about the long-term future. The study also highlighted that only around half of YP with a learning disability are involved with planning their own transition. The findings from this study reinforce earlier findings from other studies exploring the transition into adulthood for YP with learning disabilities (Blacher et al., 2010; Davies & Beamish, 2009; Salvador-Carulla & Symonds, 2016). The findings from this study also highlight a disconnect between best-practice and real-world processes – such as not being involved in transition planning themselves even though this has been found to have a positive impact on post-school outcomes (Wehmeyer & Palmer, 2003). This leads to

implications in the need to consider how to make systemic level changes to improve transition experiences. This research is particularly helpful as it used a mixed methods approach which enables an analysis of the processes of transition and the associated concerns, whilst also allowing the parents to voice these concerns in more detail. However, it should be noted that the study did not specifically measure transition success, but rather provided a good insight into the “feelings” of success. Another important point to consider is that the age of YP ranged up to 29 years old. This means that some parents were reflecting on a time that may have been up to ten years ago. This may cause potential issues with recall bias. It should also be noted that transition practises may have changed over time, meaning some reflections may be no longer relevant. Moreover, this study along with others focuses on a range of learning difficulties, with limited specificity to DS. While insights from broader studies can be informative, the unique experiences of individuals with DS must also be explored. Future research should explore these specific experiences, considering the potential differences in the transition challenges faced by individuals with DS compared to those with other learning disabilities.

To summarise, the various studies on familial perspectives surrounding DS provides rich insights into the intricate dynamics and implications for individuals with DS and their families. Exploring sibling perceptions revealed a blend of positive outlooks alongside challenges. In parallel, parental perspectives on raising a child with DS highlight significant challenges alongside positive perceptions and highlight complex interplay between child characteristics and parental wellbeing. Collectively, these studies provide valuable insights into both the joys and challenges inherent in familial experiences with DS. Through a solution-focused approach, this understanding can be used to identify and build on the strengths within families. This perspective can help to inform tailored interventions and support services that empower both individuals with DS and their families to thrive. Moving forward, research should aim to address limitations by exploring diverse family dynamics and contextual factors. While familial perspectives offer valuable insights into the quality of



life and experiences of individuals with DS, the large amount of research using this perspective in comparison to the perspective of YP with DS highlights a conspicuous gap in research focusing on the direct perspectives of YP with DS themselves. This gap indicates the critical need for further investigation into the lived experiences, aspirations, and challenges faced by YP with DS, providing a more holistic understanding of their needs and preferences. Strengthening research efforts in this area will not only amplify the voices of YP with DS but also help to facilitate the development of more tailored interventions and support strategies to enhance their wellbeing, inclusion and overall quality of life. As well as this, future research should aim to be strengths based, as focusing on the capabilities, aspirations, and successes of YP with DS can shift the narrative from deficits to empowerment, enabling more person-centred, solution-focused interventions that are aligned with their positive future outcomes.

### **The Educational Experiences of Young People with Down Syndrome: Exploring Key Influencers and Perceptions**

This section of the literature review offers a comprehensive examination of the educational landscape for YP with DS, exploring the perspectives of educators and parents and understanding the outcomes for learners with DS and the provision available for them. By synthesising these diverse perspectives, this review aims to provide detailed insights into the educational journey of YP with DS. This understanding is instrumental in facilitating the development of tailored support strategies geared towards enriching their educational experiences and fostering positive outcomes. This understanding is essential for school practices to be more able to align the guidance outlined in the Down Syndrome Act (2022), which mandates the provision of optimal support tailored specifically for individuals with DS. By attaining a comprehensive understanding of the educational landscape for individuals with DS, education services can effectively strategize and implement the appropriate and effective measures to meet their unique needs within educational settings. This proactive approach not only ensures compliance with legislative requirements but also empowers

education services to foster an inclusive and supportive environment conducive to the academic and personal growth of individuals with DS.

### ***Academic Abilities and Outcomes of Young People with Down Syndrome***

Whilst historically it may not have been recognised, YP with DS have learning potential, and in some subjects, this potential is comparable to that of their typically developing peers. It is crucial to understand how to support them effectively to help them achieve their full potential in school, while recognising that their learning journey may vary for each individual.

It has been widely demonstrated in both research and practice that individuals with DS have the ability to acquire reading skills, which emphasises the importance of understanding the teaching and learning of reading skills and phonological awareness for CYP with DS in schools (Buckley, 2001; Cupples & Iacono, 2000; Fletcher & Buckley, 2002). Exploring this in more detail, Byrne et al. (2002), conducted a longitudinal study. Recognising that many YP with DS in the past were not afforded the opportunity to learn to read, the researchers noted a positive shift with more children with DS attending mainstream schools and receiving reading instruction. They therefore explored the development of reading skills in this population. They studied a cohort of twenty-four children with DS, ranging in age from 4 to 12 years old, over a period of two years. This group was compared to two control groups: one consisting of 31 children matched for reading age and another comprising 42 children with average reading ability.

They found that children with DS had significant advancements in the word deciphering capabilities, albeit with a comparatively slower growth rate in reading comprehension skills. The discernible disjunction between single-word reading and comprehension is suggested to emanate from an overreliance on visual processing rather than phonological aspects during word processing. The researchers suggested that these findings imply that the initiation of reading instruction for children with DS need not await the maturation of their other cognitive abilities and that they should learn to read at the same

age as TD children. It is important for teachers to understand this in order to teach them at the correct level.

While the research highlights the potential for children with DS to develop reading skills, the observed disparity between word decoding and comprehension raises intriguing questions about the underlying cognitive processes. The researchers suggested that further exploration into the specific cognitive mechanisms influencing reading comprehension is recommended to explain the observed difference between single word reading proficiency and comprehension skills. This deeper understanding could inform the development of more precise and efficient instructional approaches tailored to the needs of children with DS.

Moreover, the findings revealed that, despite consistently poorer language, memory, and general intelligence compared to control groups, children with DS did not exhibit significant differences in single word reading ability over the two-year period when compared to the matched group. This suggests that certain aspects of reading may operate independently of fundamental cognitive processes, aligning with previous research by Stanovich (1992). Consequently, the researchers advocate for a holistic approach to reading instruction for YP with DS, emphasising that the teaching of reading for YP with DS should not be limited by their other cognitive abilities.

However, other research has suggested that academic performance of YP with DS may be limited by their cognitive abilities, particularly executive function. Findings from Will et al. (2017) and Daunhauer (2020) revealed that components of working memory, inhibition and cognitive flexibility seemed to be the primary factors influencing the relationship between executive function and academic success in CYP with DS. In Will et al.'s (2017) study, working memory and inhibition skills emerged as a statistically significant predictor of achievement in both early literacy and mathematics. However, the researchers recognise that they used a very modest sample size of three, and further research is needed to confirm these findings. Moreover, they suggest that future research should focus on translating these

findings into more efficient educational strategies and approaches tailored to individuals with DS.

Diving deeper into the academic attainment of CYP with DS, Turner et al. (2008) conducted a comprehensive study to identify factors influencing the academic attainment of these individuals. The research focused on discovering which factors contribute to reaching their full potential in reading, writing, and numeracy, examining the type of school attended (mainstream or specialist), family-related factors, and specific characteristics of the child. The progress of 71 different CYP with DS was tracked across three distinct age points – approximately 9, 14, and 21.

In the initial phase (age 9), the severity of the learning disability emerged as a robust determinant of progress. At this juncture, fathers' perceived control over factors influencing their children's lives positively correlated with academic success, irrespective of the severity of the learning disability. Additionally, mainstream school attendance was associated with greater success. At age 14, the level of learning disability remained a primary predictor of progress. Furthermore, a pragmatic problem-solving approach adopted by mothers correlated with higher success rates. By the age of 21, individuals who had experienced some form of mainstream education demonstrated more substantial progress.

The researchers asserted that their findings support previous studies highlighting the advantages of mainstream education (Casey et al., 1988; Cunningham et al., 1998; Laws et al., 2000). They concluded that certain children placed in special schools might have achieved better academic outcomes if they had been in mainstream settings. This idea has since been partially supported by de Graaf et al. (2013) who suggested that children with DS in mainstream schools in the Netherlands may perform better academically due to being more exposed to academic teaching and learning. Turner et al. (2008) hope that the factors promoting academic advancement identified in their study can guide parents, educators, and other stakeholders in facilitating the optimal academic potential of children with DS.

Additionally, they hope these findings will encourage broader recognition and belief in the potential of these individuals.

The longitudinal nature of this research contributes to its significance, providing a more holistic understanding of the educational trajectories of individuals with DS. Limitations include the possibility of attrition bias towards more academically able children and inconsistent data collection methods. Varied outcomes measured by tutors and parents may introduce potential biases, with parents potentially overestimating their child's abilities. These limitations should be considered when interpreting the findings and signal areas for improvement in future research.

To summarise, research shows that CYP with DS demonstrate the ability to acquire key academic skills and knowledge in school, and that recognising and understanding these abilities can help educators tailor their approach to effectively engage learners and ensure they meet their full potential. Findings on the impact of cognitive abilities, such as executive function, on learning outcomes have been mixed, highlighting the need for further investigation in this area. Additionally, increased prioritisation of and support with academic learning is likely to enhance academic outcomes, making it essential to consider this when designing lessons for CYP with DS. Taking a solution-focused approach, educators can build on the existing strengths of CYP with DS by emphasising their successes and capabilities, which encourages a positive learning environment. This approach can foster resilience and growth and highlight practical strategies that can be scaled to meet their unique needs, promoting further achievement.

### ***Supporting Young People with Down Syndrome in School***

Research exploring the education of YP with DS can help build an understanding of what provisions schools can implement to help support YP with DS in their educational settings. For example, research has suggested that teaching assistants (TAs) can be useful in supporting YP with DS. Fox et al. (2004) explored the inclusion of primary-aged pupils with

DS. The research investigated how schools manage the inclusion of pupils with DS using 18 case studies. They concluded that there is no single way to ensure effective inclusion of YP with DS. However, they suggested that carefully planned use of TAs, including how they can work with both the YP with DS and the teacher can make an impact. Most effective use of the TA was when there was good communication between the TA and teacher so they could share knowledge about the child. As well as this, effective use of a TA included utilising the TAs knowledge and understanding of the child with DS to inform the planning and adaptation of the work given to these pupils. The findings of this study are useful, and Fox et al. (2004) suggest that they have implications in helping to develop policies and practices that enable learning and participation for YP with DS. For example, it can help inform how TAs can be best utilised.

Understanding how to utilise TAs when supporting learners with DS is imperative as it has been indicated that YP with DS tend to work with TAs a lot. For example, Wren (2017) indicated that most pupils with DS in UK mainstream education are assisted by TAs. Van Herwegen et al. (2018) further contribute to this trend, revealing that 82% of surveyed pupils with DS received support from a TA. This support encompasses both academic assistance as well as social, emotional, and behavioural support.

The findings of Fox et al. (2004) align with the guidelines from the Education Endowment Foundation (Sharples et al., 2016). This guidance cautions against using TAs as substitutes for teaching resources for low-attaining pupils. Instead, the emphasis is placed on these pupils accessing high-quality teaching from a qualified teacher, with TAs playing a complementary role in fostering independent learning skills and managing the learning process. The delivery of evidence-based small group or one-on-one interventions by TAs is recommended, with a significant portion of the learning input retained under the purview of the class teacher. In line with this, Fox et al. (2004) discovered that the support was most effective when teachers were central to the teaching and learning of YP with DS, with the support of TAs to work alongside them and consolidate these skills.

As well as support from TAs, results from other research have suggested that targeted interventions can be useful to support CYP with DS in school. For example, Kennedy and Flynn (2003) investigated the effects of a phonological awareness intervention on the reading proficiency of children with DS. The intervention aimed to develop skills in alliteration detection, initial-phoneme isolation, spelling, and recognition of rhyme across words. Following the intervention, improvements in phonological awareness, including enhancements in the grapheme-phoneme connection were observed. Despite the modest sample size of three participants, the study's methodological rigour and the brief intervention timeframe substantiate the notion that children with DS can enhance their phonological awareness skills—a crucial precursor to proficient reading. This suggests that tailored interventions for YP with DS to support their learning and skill acquisition can be useful. However, further research with larger sample sizes and extended intervention durations would be beneficial to validate and generalise these findings. Additionally, exploring the long-term impact of such interventions on overall reading proficiency and academic success could provide a more comprehensive understanding of their effectiveness.

Linking to this, research has shown a positive impact of early intervention in enhancing the educational outcomes of YP with DS. For example, Paige-Smith and Rix (2006) explored the early intervention experiences of three children with DS by gathering parental perceptions of this during their child's early years education using semi-structured interviews. Whilst the researchers recognised that this was small-scale in terms of number of participants, they emphasised that the detailed case study approach allowed for an in-depth analysis of parents' perspectives on early intervention. Findings showed that early intervention could support YP with DS by enhancing their communication skills, providing links with professionals, and facilitating inclusion. However, parents expressed that they felt they had a big responsibility, as they often had to be involved in the interventions. This caused the researchers to consider that perhaps alternative ways of approaching early intervention programmes should be considered. Interventions need to be based on the

individual child's needs rather than the generic challenges associated with DS. Whilst parents should have an input in what these needs are, the responsibility of implementing the interventions needs to lie predominantly with the professionals rather than the parents.

The benefit of early intervention for children with DS is further elucidated by Van Cleve and Cohen (2006), who suggested that diverse interventions, encompassing specialised programs and resources, are integral to the educational progression of YP with DS. Contributors to these interventions include occupational therapists, speech and language therapists, medical professionals and physiotherapists highlighting the need for cross-disciplinary collaboration. This concept is consistent with findings of research exploring the benefits of early intervention on YP with general learning disabilities. For example, Clibbens et al. (2002) highlighted the substantial benefits of early intervention for children encountering delays in cognitive, motor, and language development.

Another finding within the research is that motor skills interventions or sports programs in school may be useful to support YP with DS in school. Schworer et al. (2022) looked at the patterns and predictors of adaptive skills in 2-7-year-olds with DS, revealing challenges in motor skills. To mitigate the impact of these challenges on their learning experience, there is a suggestion to place emphasis on the development of motor skills for children with DS, potentially incorporating interventions. This proposition aligns with the idea put forth by Cebula et al. (2010), who advocate for pupils with disabilities, including those with DS, to participate in sports programs to acquire knowledge, confidence, and enhance motor skills. This can help YP with DS to overcome physical challenges and contribute to a more inclusive and accessible educational environment.

Additionally, good home-school communication has been highlighted by research as something that can help CYP with DS be supported in school. For example, Mullan et al. (2018) explored experiences of children with DS who transitioned from primary to mainstream secondary school settings in Ireland and investigated what factors influence this



process. They used semi-structured interviews to gather the perspectives of 5 parents and 3 secondary school teachers regarding this transition process and analysed the interview data via thematic analysis. A key finding was the importance of open communication between parents and schools. And therefore, schools should consider how to share information between school and home and vice versa.

The importance of home school communication was also highlighted by Lendrum et al. (2015) who emphasised the crucial role of a strong school-parent partnership in positively impacting the educational outcomes of children with DS. Similarly, Engevik et al. (2018) highlighted the importance of effective collaboration between school staff and parents in creating a supportive environment for pupils with DS. Thus, the relationship between the school and parents and their communication, emerges as an important factor in supporting YP with DS in school.

As well as this good home-school communication, Mullan et al. (2018) also found that teachers played a pivotal role in facilitating the transition by implementing curricular adjustments for pupils with DS. Moreover, the teaching of social skills at school emerged as a beneficial strategy to enhance their experiences. Therefore, curricular adjustments and social skills interventions should be considered by schools when supporting YP with DS.

Mullen et al. (2018) recognise limitations in their study, they note that the parents interviewed were all pro-active and not necessarily representative of all parents of CYP with DS. Moreover, they suggested that future research should consider the role of the primary school in transition preparation for learners with DS, as this focused on the role of the secondary school. Moreover, they suggest that future research should strive to include the perceptions of the CYP with DS too.

As well as this, further consideration of how to support YP with DS includes the use of speech and language interventions or the introduction of sign communication. This is because it is known that individuals with DS commonly encounter challenges in

communication including delays in speech and language development. The extent of language difficulty varies among individuals, but often requires involvement of speech and language therapists (Laws & Hall, 2014). However, Laws et al. (2000) suggested a potential limitation in reliable access to speech and language therapists within mainstream educational settings – something that potentially needs to be addressed. Furthermore, some individuals with DS may not acquire verbal communication skills, making alternative forms such as signing, particularly important (Jackson et al., 2014). The early introduction of sign language, or Makaton (Groen et al., 2006), can be instrumental in bridging language gaps and progressing language and speech development (Thompson, 2013). Based on this, it is important for schools to consider how they can best support with communication and speech and language development for their pupils with DS.

In summary, the research reviewed highlights effective strategies for supporting YP with DS in schools through a solution-focused lens. Central to this support is the careful planning of TA involvement, tailored interventions to enhance the existing skills of these learners, and strong home-school communication to foster collaboration, allowing for a shared focus on positive outcomes. Further exploration into speech and language supports is needed, and future research should investigate speech and language provision can be used to maximise the potential of YP with DS.

### ***Perspectives of Educators: Teaching Pupils with Down Syndrome***

One way to broaden the understanding of how to support YP with DS in school is to identify the attitudes that educators have and any challenges they face. Understanding this can help educational professionals to consider how to overcome these difficulties.

Bills and Mills (2020) conducted a systematic review exploring teachers' perceptions of inclusive education programs for children with DS. They reviewed 11 pieces of research from across the world and integrated both qualitative and quantitative results, allowing for a comprehensive analysis. Among the 11 studies reviewed, only one addressed the attitudes

of both peers and teachers towards children with DS, five studies examined peers' attitudes towards their classmates with DS and seven studies explored teachers' attitudes towards children with DS in inclusive settings.

The review's findings indicated that teachers' attitudes towards inclusion programs for pupils with DS were significantly influenced by their teaching experience and training (Donohue & Bornman, 2015; Georgiadi et al., 2012). Teachers with more experience and training were more likely to support inclusive practices, whereas those with less training, while still supportive, felt less confident in meeting the needs of children with DS. Despite worries about meeting their needs, teachers did believe that inclusion programs could enhance the socialisation skills of YP with DS. These findings are consistent in many parts of the world. For example, Johnson (2006), who used UK-based participants, found that while teachers generally recognised the social benefits of inclusion, they expressed concerns about their ability to meet the diverse needs of pupils with DS due to insufficient training and resources. Similarly, Takriti et al. (2018) reported that teachers from both the UK and the United Arab Emirates expressed a need for more training to effectively teach YP with DS. Furthermore, Opoku et al. (2021) found that teachers in Ghana were more likely to have favourable attitudes towards teaching YP with DS if they had received training on inclusive practices. The researchers concluded that providing teachers with more specialised training is essential for successful inclusion.

These findings suggest that it is crucial that appropriate training is provided to staff when a child with DS enters a mainstream school. As well as this, schools must ensure adequate support for teachers, including additional support staff. This could be essential for facilitating a positive and successful schooling experience for CYP with DS. This finding has also been highlighted in more recent research (Sunko & Kaselj, 2020).

Furthermore, the level of support provided by staff emerged as a crucial factor influencing teachers' attitudes towards children with DS in inclusive environments. Many

teachers expressed a desire to have children with DS in mainstream classrooms but felt inadequately supported by staff, such as TAs, to meet the needs of these students (Campbell et al., 2003; Donohue & Bornman, 2015; Fox et al., 2004). Mainstream teachers indicated that they would be more receptive to having children with DS in their classrooms if additional support staff were made available (Donohue & Bornman, 2015).

This review has many implications, in particular it highlights the necessity that schools employ and provide enough trained support staff, such as TAs to work alongside teachers of YP with DS. The presence of support staff enables teachers to tailor instruction to meet the individual needs of students with DS and their peers effectively. Moreover, the researchers highlight the scarcity of recent studies. Among the 11 studies reviewed, merely seven were conducted within the last decade, with only two completed within the past five years. This highlights the necessity for more recent research focusing on the attitudes of teachers that teach YP with DS. Moreover, it may also be interesting for additional research to explore how YP with DS perceive teachers' attitudes towards them.

Since this review, Boundy et al. (2023) explored the perceptions of teachers and TAs working with pupils with DS in mainstream primary schools in the UK. They used an online survey to collect data from 105 TAs and 94 teachers. Findings showed that both teachers and TAs perceived themselves as having primary responsibilities across various teaching and learning tasks. TAs, who were more likely to have received specialised training on DS, were commonly seen as primarily responsible for teaching learners with DS. TAs felt less supported and did not feel they had adequate time to plan. Despite this, TAs felt more confident and capable in catering to the needs of students with DS than teachers and both teachers and TAs demonstrated positive attitudes towards the inclusion of learners with DS.

Consistent with previous research, these findings highlight the need for schools to provide adequate training for teachers and staff with YP with DS in their class. Moreover, it raises concern about the use of TAs, as advice from the Education Endowment Foundation

(Sharples et al., 2016) states that TAs should not be primarily responsible for the teaching of pupils.

Although the findings offer valuable insights, the researchers recognised a limitation regarding the survey's participant pool. While educators from all placement types were invited to participate, the overwhelming majority were from mainstream primary schools. As a result, the generalisability of the findings to teachers and TAs in different settings may be limited.

In summary, this literature enables an understanding of educators' attitudes to supporting YP with DS in school and the challenges that they face with this. Findings showed that whilst school staff are mainly positive about teaching YP with DS, they do not always feel confident or equipped to do so, emphasising the need for appropriate training and support for staff when a child with DS enters a mainstream school. As well as teachers, the importance of employing and providing enough additional trained support staff, such as TAs to work alongside the teachers of YP with DS is highlighted. Concerns regarding the use of TAs have been highlighted, such as them being primarily responsible for teaching pupils with DS.

From a solution-focused psychology perspective, the findings highlight the importance of building on the existing positive attitudes of teachers and equipping staff with the necessary skills and resources so that schools can adopt a strengths-based approach that empowers both teachers and YP with DS to achieve meaningful and sustainable outcomes.

Further research should explore more recent perceptions of educators and staff working with YP with DS, considering experiences beyond mainstream primary schools to ensure comprehensive insights and practices across educational settings.

### ***Parental Insights: Understanding the Educational Experiences of Individuals with Down Syndrome***

Another way to broaden the understanding of how to support CYP with DS in school is to understand how the parents of CYP with DS perceive their experiences of school. Parents play a crucial role in a child's education, serving as advocates and providing support at home. Their perceptions can offer valuable insights into the familial context surrounding the child's schooling experience, including their expectations, concerns, and aspirations. Moreover, parents are often the first to recognise when their child is facing challenges or experiencing success in school. By understanding their perspectives, researchers can gain valuable information about the specific support needs of YP with DS, whether it be academic, social, or emotional support. This can help inform intervention strategies and improve school policies.

Despite the challenges highlighted by parents of YP with DS concerning the difficulties that they face in everyday life, research exploring the parental views of education has identified more positive findings. Hargreaves et al. (2021) explored parental perspectives on the educational experiences of pupils DS in UK schools. Participants consisted of parents of CYP with DS spanning from Reception to Year 11 (279 males; 282 females aged between 4 and 17 years). The researchers employed an online survey to gather insights from 569 parents, revealing a mixture of experiences. This study not only helped to understand the types of schools that CYP with DS attend, but also how they experience these schools. This study explored parental perceptions in detail and covered multiple subjects including pupil characteristics, school placement, participation academically and socially, support including TAs and external agencies, perceived roles and responsibilities of staff, collaboration between home and school and overall satisfaction with placement.

Findings showed that the majority of CYP with DS were in mainstream provisions, with alternative provisions consisting of units attached to mainstream schools, mixed

provisions, or specialist provisions. Those attending specialist provisions on average were significantly older, and there was some variation depending on geographical location. 78% of CYP with DS learnt core subjects, and 57% did this within the classroom. However, far fewer were included in lessons such as languages or technology. Most pupils were included socially at break, lunch and on school trips. Most pupils had TA support, and many parents viewed TAs as responsible for teaching. Most common external support was provided by speech and language therapists. Most parents recalled having frequent meetings with the school, although this was less often in specialist settings. Overall, 72% of parents across all provisions felt satisfied that the school understood their child's needs and supported them well to make progress.

In their discussion, the researchers questioned why some pupils with DS could access a diverse and well-rounded curriculum, but others could not and noted that the variability in provision across schools emerged as a prominent factor influencing the educational outcomes for this cohort of learners. They acknowledged that CYP with DS deserve the chance to take part in all areas of the curriculum and questioned how schools can provide more support to do this. Furthermore, they point out the variation in external support and suggest that the unevenness in provision can be attributed, at least partially, to the varying levels of funding allocated within Local Authorities (LAs). The researchers note the positive findings of satisfaction with school placement but highlight that parents have concerns about access to certain support services and worry about the level of staff training on DS.

The researchers acknowledge that surveys have limitations, however, they highlight the importance of their research, having gathered the largest number of parental perceptions regarding the education of CYP with DS to date. They suggest that future research should investigate the decline of mainstream attendance with age.

In summary, this research provides us with a broad understanding of parental perceptions of the educational experiences of CYP with DS. Positively, CYP with DS appear to be supported in both mainstream and specialist settings and parents feel satisfied with their progress and experience. However, access to support services may be inequitable and access to a broad range of subjects is not always available. Further consideration needs to be given to how CYP with DS can be supported to be involved in all aspects of the curriculum and beyond. Understanding parental perceptions of educational experiences can guide the development of targeted interventions and support strategies. Solution-focused approaches can be used to build on the effective practices identified, such as successful TA support and positive social inclusion. This perspective helps in creating actionable strategies that enhance the educational experience for CYP with DS by recognising and amplifying what is already working well (de Shazer, 1985). Future research may wish to consider which areas of the curriculum CYP with DS value as important to them and whether they have access to these.

### ***Participation of Pupils with Down Syndrome in Mainstream Settings***

In the UK, inclusive education is an approach that strives to offer equal opportunities to all pupils, irrespective of their abilities, backgrounds, or needs (Norwich, 2014). In inclusive education, every pupil should have access to a high-quality education, supported by tailored assistance and the necessary resources to facilitate academic success and progression. Inclusive education places significance on fostering social, emotional, and academic development for all pupils alongside their peers (Rix & Parry, 2014).

YP with DS have the right to an inclusive education (United Nations, 2006; 2015). The SEND Code of Practice (2015) emphasises the principle of inclusive education, stating that mainstream schools should be the first choice for children with special educational needs or disabilities wherever possible. If a child has an Education and Health Care (EHC) plan, then they may attend a special school, but they should not have to (Children and Families Act, 2014). There has been a rise in the number of pupils with DS attending



mainstream schools (Van Herwegen et al., 2018) and in the UK, research indicates that 65% of CYP with DS attend mainstream schools (Hargreaves et al., 2021).

With the rising number of CYP with DS attending mainstream schools, it becomes imperative to understand their experiences within this educational environment.

Understanding these experiences not only aids in enhancing access to inclusive education but also empowers future parents of children with DS to make more informed decisions regarding their child's schooling, including deciding a suitable setting for them to attend. By gaining insights into the challenges and successes faced by individuals with DS in mainstream education, educators and policymakers can work towards creating more supportive and accommodating learning environments.

Over recent years, attention has been dedicated to examining the notion of inclusion and its potential impact on the education of CYP with SEN within mainstream schools (e.g., Artiles et al., 2006; Dyson et al., 2002; Göransson & Nilholm, 2014; Jigyel et al., 2020; Kefallinou et al., 2020; Kemp & Carter, 2002; Lindsay, 2007; Lui et al., 2017; Oh-Young & Filler, 2015; Rangid, 2022; Ruijs & Peetsma, 2009). The overarching consensus from these research studies and reviews suggests neutral to positive effects associated with inclusive education. With findings indicating that CYP with SEND in mainstream schools may be more likely to gain qualifications and social and academic skills whilst also being embraced by their typically developing (TD) peers. Moreover, some studies have indicated a benefit for TD peers when SEND pupils are included in mainstream classes such as gaining respect, embracing differences, learning patience and cognitive benefits gained from helping others (Kalambouka et al., 2007; Molina Roldán et al. 2021).

Reviewing the literature exploring the experiences of CYP with DS and mainstream schools is useful to get a more thorough understanding of the educational experiences of CYP with DS. By reviewing this literature, it is not intended to conclude whether mainstream

school or specialist provision is better for CYP with DS, but rather to understand the benefits and challenges faced for those who have experienced mainstream school. This understanding is particularly important given that the majority of CYP with DS attend mainstream school. This information can be used to help educators and policymakers be better informed when supporting pupils with DS in mainstream schools in order to facilitate a positive experience of school for them.

Johnson (2006) explored the perspectives of key stakeholders in the inclusion of YP with DS in mainstream school, including teachers, parents, and pupils. The findings showed an overall support for inclusion but identified challenges related to resources and training. As well as this, findings showed that although mainstream schools can foster positive peer relationships, there are still instances of social exclusion and bullying when appropriate support is not provided. This suggests that that successful inclusion requires sufficient resources, teacher training, and effective collaboration between educational professionals to address both academic and social needs.

Additionally, Dolva et al. (2010) explored the experiences of CYP with DS in mainstream schools by conducting research seeking insights directly from the perspectives of the CYP themselves. This investigation focused on peer interactions during school activities conducted in mainstream classes. The aim of this research was to understand what facilitated peer interaction between CYP with DS in mainstream classrooms and their TD peers. The study involved the observation and interviews of six children with DS, who were each the only member of their class with the condition. The analysis of the data concentrated on describing the characteristics of peer interaction within the school activity context. Two principal categories emerged: equal or unequal interaction. Instances of equal interaction, characterised by equitable involvement in initiation, interest, understanding, and competence, were often observed during free times, such as breaks or pupil-driven exercises. This suggests that the participants had a positive experience of being able to socialise in their mainstream setting. Conversely, instances of unequal interaction occurred

when YP with DS worked with peers in a learning environment. In these situations, peers often assumed a more skilled role and adapted the demands of the activity to facilitate successful completion. This support, conceptualised as peers' enabling strategies, played a crucial role in enabling interaction. This finding showed that TD peers were able to perceive the abilities of children with DS and adapt their behaviour to ensure inclusion in school activities, suggesting that the participants had positive experiences of inclusion in mainstream settings.

This study has significant implications. It demonstrates that CYP with DS can have meaningful interactions within a mainstream setting, and TD peers can be accepting and mindful of them. What is more, successful interactions may encourage learning from both sides, fostering an environment where peers can be helpful and caring. This is similar to the findings of Kalambouka et al. (2007) and Molina Roldán et al. (2021), that the inclusion of learners with SEND within the mainstream classroom can have benefits for TD members of the class.

Moreover, capturing the views and experiences of CYP with DS, as demonstrated in this research, sets a successful precedent for future studies to explore their perspectives effectively. The study emphasises the importance of considering the direct voices of CYP with DS in shaping inclusive educational practices. Whilst this research only primarily focuses on peer interaction, future research can use the techniques employed in this research to explore other aspects of education using the perspectives of CYP with DS. Using this as an example, future research should successfully be able to explore the experiences and views of CYP with DS. The researchers suggest that to improve on this further, consideration needs to be given to how CYP with DS can be supported to access interviews, for example by being given picture cues.

Exploring this further, Dolva et al. (2011) conducted a study to examine the support offered by school staff in mainstream educational settings to foster social integration among

pupils with DS and their TD peers. This investigation involved observations of six pupils with DS, their teachers, and TAs within mainstream classrooms, supplemented by interviews with the educators. The findings revealed that staff implemented environmental modifications and provided individualised support to facilitate peer interactions. A significant discovery was the pivotal role played by TAs in facilitating the engagement of children with DS. The researchers concluded that educators in mainstream schools endeavoured to maintain classroom cohesion by devising various strategies to promote participation among all pupils. The researchers acknowledge that the study only looked at the characteristics of peer interaction, rather than the frequency of it, therefore only providing a limited insight into peer interaction. Having said this, the study has provided a better understanding of the positive role a TA can have when supporting YP with DS in mainstream classes. However, further research should aim to understand the extent to which TAs should be utilised and assess the adequacy of their training given to ensure they can effectively assist learners with DS.

Adding to the understanding of the experiences of CYP with DS in mainstream schools, Kendall (2019) explored parental reflections on their experiences of how their child with DS was supported in mainstream school. To do this, they conducted semi-structured interviews with five parents of children with DS attending mainstream schools in England and analysed the interview data using thematic analysis. From the analysis, the researchers identified five themes regarding the support that parents believed mainstream schools needed to provide for a successful experience. These were ensuring inclusive practices within the school, providing early interventions, provisions to support speech and language difficulties, EHC plans (EHCP) and support with transitions. Whilst the parents had varying experiences of these, the overall findings suggested that mainstream education can provide inclusive opportunities for children with DS, addressing their language and communication needs and fostering a positive partnership with parents throughout different phases of education. However, the research highlighted disparities in access to certain support services across different authorities, and some parents encountered challenges with the

EHCP and annual review processes. As well as this, some of the parents experienced negative responses about their child attending mainstream school due to lack of confidence in teachers and staff training about DS, similar to previous findings of Laws and Millward (2001).

The researchers acknowledged that due to their small sample size, results will not be representative of all parents of CYP with DS in mainstream schools and noted that they did not include the perspective of the fathers or other family members. However, they do state that their findings offer valuable insight into this under researched area. The study's division of information into themes, including inclusive practice, early intervention, supporting language and communication needs, EHCP, and transition, offers a structured understanding of the areas where parents feel confident or face challenges. The research serves as a valuable resource for educators, policymakers, and support service providers, offering insights into areas of strength and areas that need improvement in ensuring the successful integration of children with DS into mainstream educational settings.

Other observed positive experiences of mainstream school for YP with DS include the opportunity to interact with positive role models (Cuckle & Wilson, 2002) and advancements in language skills (Buckley et al., 2006).

Despite these positive findings of CYP with DS being included in mainstream settings, this is not always the case. Some research suggests that individuals with DS are not consistently provided with opportunities for participation. For example, Engevik et al. (2018) conducted research in Norway aiming to gain insight into the quality of inclusion of children with DS in mainstream classrooms. This study analysed questionnaire data from the teachers of 39 8-year-olds with DS. Within the findings it was discovered that while pupils with DS participated alongside their peers in mainstream settings during lunchtimes, music lessons, and physical activities, they were less likely to be included in more academic subjects like mathematics and languages. These findings highlight the risk of a “covert

segregation within mainstream schools,” (Wendelborg & Tøssebro, 2008, p. 317). This is concerning as the International Guidelines for the Education of Learners with Down Syndrome as outlined by Faragher et al. (2020) assert the necessity for individuals with DS to be actively engaged in all facets of the curriculum, emphasising the importance of avoiding restrictions based on others' expectations of their abilities.

The findings of Engevik et al. (2018) highlight the need for some schools to reevaluate their practices and ensure that learners with DS have equal opportunities for inclusion in classrooms alongside their TD peers. EPs could play a crucial role in this context, by ensuring suggested provision that is appropriate for a mainstream setting to implement. More pragmatic guidance from EPs would instil confidence in mainstream schools to meet the outlined needs in EHCPs, thereby expanding the opportunities for YP with DS to participate and collaborate with their TD peers.

In summary, with the increase of the number of pupils with DS attending mainstream school, it is important to understand how they experience their time in these settings, including the benefits they gain, and the challenges they face. The research reviewed revealed that positive experiences of mainstream school included peer interaction, supportive staff, speech and language development, involvement in interventions and support with transitions. However, challenges that emerged included potential segregation in certain subjects, a lack of trained staff and parental difficulty with the EHCP process.

From a solution-focused lens, understanding the experiences of YP with DS in mainstream settings allows educators and policymakers to identify and build on the positive aspects, such as peer interaction and supportive staff. By focusing on solutions and strengths, interventions can be designed to enhance the overall school experience.

Future research should include further exploration using the perceptions of the YP. Incorporating the perspectives of YP with DS can provide valuable insights into their lived experiences, preferences, successes, and challenges in mainstream school settings. Their

voices can offer a unique and authentic understanding of the factors that contribute to their educational journey, which may not be fully captured by parental or educator perspectives. Additionally, involving YP with DS in research empowers them as active participants in shaping their own educational experiences, promoting a sense of agency and self-advocacy. By prioritising their perspectives, future research can ensure that support strategies and interventions are more responsive, inclusive, and aligned with the actual needs and aspirations of YP with DS, ultimately fostering a more positive and empowering educational environment for them. As well as this future research should include an exploration into the training offered to mainstream schools when teaching CYP with DS.

### ***The Perspective of Young People with Down Syndrome on School***

As mentioned in previous sections, incorporating the perspectives of YP with DS in research would be extremely useful in understanding their experiences. A recent advancement in this has been made by Geiger (2023) who explored the views of YP with DS on what is and is not successful or important for them at school. The study used a participatory visual interview approach in order to gather their views. The study used a small sample of three 14-year-olds with DS, two of which attended mainstream school and one that attended a specialist provision. The themes that emerged about what YP with DS liked about school were “Main Class Group”, “Friends and Special Adults”, “Awards and Recognition”, “Lessons with Creativity”, “Having Breaks” and “Food and Drink at Break and Lunch times”. The themes that emerged about what YP with DS did not like about school were “Noise”, “Too Much Adult Talking”, “Too Much Running Around” and “Conflict”. The author recognised that this research provided the opportunity for CYP with DS to express their views, that it provided unique information about CYP with DS’s experiences of school and that there is a potential for these views to be used to influence their school experience. A further strength of this research is the interview approach; using a visual approach helped to reduce language and memory demands, aspects that YP with DS may find difficult. However, the data was limited by the small sample size of participants. In addition, all

participants were of the same age group and currently attending school. This circumstance might have inclined them to focus more on their immediate experiences rather than considering their schooling in its entirety. Furthermore, it is likely that this situation limited their reflections on certain aspects such as examinations and qualifications, as the YP had not reached this stage in their schooling yet.

This research has implications for schools and education professionals. For example, it emphasises the importance of inclusive education, as the participants highlighted enjoying participating in the whole class. It also emphasises the importance of supporting YP with DS to build relationships with both other pupils and members of staff. The findings may also prompt teachers to consider how to ensure creativity within their lesson plans and that YP with DS have regular scheduled breaks. Findings also suggest that addressing environmental factors such as noise levels is crucial, as sensory sensitivities may affect the comfort and focus of YP with DS in the school environment. Minimising auditory distractions and providing quiet spaces for concentration could promote a more conducive learning atmosphere.

Further research can use similar interview approaches to gather the views of YP with DS or other learning disabilities. Studies may aim to have a more specific focus to understand certain experiences in detail. For example, future research should explore the experiences of YP with DS in specific educational settings, such as mainstream school. Moreover, it may be useful to gather the views of older participants, allowing them to reflect on the whole of their education.

### **Summary and Recommendations**

This literature review has examined relevant research to gain insight into the quality of life of individuals with DS and the experiences of their families, as well as understanding the educational landscape for CYP with DS. This exploration not only contributes to understanding how to support those with DS to have fulfilling lives and educational



experiences but also facilitates the identification of important areas that require further exploration and investigation. It is crucial to consider how to address these areas in subsequent research initiatives.

The findings of research using proxy-reporting have revealed that friendships and social inclusion significantly enhance quality of life, while health problems and behavioural difficulties have a negative impact. The findings of key research using the voice of individuals with DS showed that in general, YP with DS believe they have a “good life”, and that there are certain influencing factors that contribute to this, such as relationships, community participation and independence. However, disparities exist between studies examining YP with DS's quality of life from their own perspective and those using alternative perceptions, such as family members' views. This suggests the need for future research to critically evaluate proxy-reporting methods to ensure accurate representation of the experiences of YP with DS. Additionally, given the significance of independence for a good quality of life, further research on the transition into adulthood and the development of independent life skills for YP with DS is essential, addressing unique challenges and experiences they encounter.

This review also considered how the ability to build meaningful relationships and to participate in the community can be influenced by societal perceptions of DS. Findings showed that societal perceptions of DS can affect the self-perception of YP with DS. Future research should delve deeper into the influences of societal attitudes towards DS, for example exploring societal attitudes across diverse cultures and examining changes in perceptions over time. Furthermore, investigating the role of social media platforms in shaping perceptions about YP with DS is recommended.

The research also highlights both the positive impacts and challenges faced by families of CYP with DS, with families generally more positive about DS compared to other learning disabilities. Further research exploring the various family dynamics related to DS is

crucial for tailoring support services effectively. Additionally, further research exploring the impact of parental challenges associated with raising a child with DS on the perceived quality of life among YP with DS has been suggested.

Moreover, research has shown that YP with DS can thrive as learners and have particularly strong word reading skills. Given the reading abilities of CYP with DS, delving into the specific cognitive mechanisms affecting reading comprehension could provide valuable new insights. Moreover, exploring the long-term effects of reading interventions on overall reading proficiency and academic success is recommended. Conflicting findings regarding the role of cognitive abilities, such as executive function, in learning among individuals with DS indicate the need for further exploration in this area.

This review identified the key supporting tools to be used in schools to support CYP with DS. These tools include carefully planned use of TAs, providing tailored interventions and effective home-school communication. Linking to this, it has been identified that future research should aim to understand the optimal utilisation of TAs and evaluate the adequacy of their training to effectively support learners with DS. Additionally, examining the role of primary schools in transition preparation for learners with DS is has been highlighted as important.

Research findings have shown that school staff are mainly positive about teaching CYP with DS, but they do not always feel confident or equipped to do so. This prompts further research to explore how to ensure teacher confidence as well as highlighting the need for additional teacher training to prepare teachers to teach CYP with DS. Having said this, parents of CYP with DS generally feel satisfied with their child's progress and experiences of school.

When specifically exploring mainstream experiences, positive aspects included peer interactions, supportive staff, speech and language development, involvement in interventions and support with transitions. However, challenges that emerged included

potential segregation in certain subjects and a lack of trained staff. These findings again support the need for better staff training, as well as prompting consideration of how to include CYP with DS in mainstream classrooms more consistently. As well as this, investigating the decline in mainstream attendance with age among individuals with DS warrants attention in future research endeavours.

As highlighted by Sheridan et al. (2020), research on the quality of life of individuals with DS often lacks the direct perspectives of individuals with DS themselves, relying heavily on familial perceptions. This trend extends to the literature examining the educational experiences of YP with DS, which predominantly features the viewpoints of school staff and parents.

Previously, Farrell (2000) also highlighted a notable scarcity of studies that explore the perspectives of pupils with disabilities compared to their TD peers. The underrepresentation of YP with DS in research may be attributed to language impairments associated with DS, as effective communication is often integral to meaningful participation (Cole & Donohue, 2011). Additionally, doubts about the credibility and reliability of individuals with disabilities as contributors may contribute to their underrepresentation, as there is a belief among some that individuals with disabilities are perceived as ineffective informants (Beresford, 1998; Middleton et al., 1999).

However, to presume that YP with DS are unable to participate in research due to impairments is unjust and risks the exclusion of this demographic from scholarly inquiry. In accordance with the Mental Capacity Act (2005), YP with DS, aged 16 or older, possess the right to have autonomy in decision making. This legislative framework necessitates the presumption of capacity unless proven otherwise. Consequently, researchers, through meticulous precautions, can presume the capacity of YP with DS to consent to research participation. Therefore, although gathering the voices of those with DS may pose difficulties (Lightfoot & Bond, 2013), it is important that research strives to do so.

Despite the lack of research exploring the perceptions of YP with DS, when exploring self-perception, Cunningham and Glenn (2004) showed that it is possible to successfully interview YP with DS. To do this they made adaptations such as question style, adult support and prompts. As well as this, in an educational context, Dolva et al. (2010) has also explored the perspective of YP with DS. However, this research is limited as it only explored peer interactions, and the interview data was limited due to a lack of consideration of how to make interviews more accessible for YP with DS. Therefore, more research is needed in the context of education. Geiger (2023) took an initial step towards addressing this by conducting interviews with 14-year-olds with DS using visual methods. While these findings offer valuable insights into facilitating positive educational experiences for YP with DS, further research is essential to comprehensively understand the nuanced and individualised educational experiences of this population across various educational contexts.

As well as the adaptations used by Cunningham and Glenn (2004) and the visual approaches used by Geiger (2023), other techniques may also be useful. These include questionnaires and focus groups (Woolfson et al., 2007), pupil views templates (Wall, 2008), 'mind-mapping' exercises (Thomson & Gunter, 2006), and cue cards (Lewis et al., 2008). While these methods have conventionally been used to collect perspectives from young individuals without disabilities, there is a reasonable basis to assume that these same methodologies, or adapted variations of them, could be appropriately tailored to gather insights from pupils with disabilities (Byrnes & Rickards, 2011). This adaptability is crucial in ensuring the inclusivity of research and the meaningful representation of the diverse experiences and perspectives of individuals with DS in the educational context.

Incorporating the voices of YP with DS into research aligns with the principles of solution-focused psychology, to build on existing strengths to facilitate growth and positive outcomes. Utilising the perspectives of YP with DS may help to offer a more comprehensive understanding of their quality of life and educational experiences. This helps researchers better identify each individual's unique strengths and aspirations to help create interventions

that authentically reflect their experiences and enhance their quality of life and educational outcomes (de Shazer, 1985).

By adapting research methods to actively gather these voices, it respects the autonomy and capacities of YP with DS, as supported by the Mental Capacity Act (2005), while also aligning with the solution-focused framework to use their direct feedback to foster long-term, meaningful changes (de Shazer et al., 2007). This approach not only honours ethical inclusivity but also highlights the practical necessity of developing effective, person-centred strategies that support the personal growth and broader development of YP with DS.

To conclude, while the research reviewed provides valuable insights into the quality of life of YP with DS and the positive experiences and challenges faced by them and their families, as well as a foundational understanding of the educational landscape of CYP with DS, more exploration is necessary. The review has highlighted potential areas for further research as well as indicated the necessity for gathering the perceptions of YP with DS directly in future research.

## **Chapter 2: Empirical Research**

### **Abstract**

There is a lack of research in the UK which elicits the voices of young people with Down syndrome and explores their experiences of school. The current study explores the reflections of a group of young people with Down syndrome on their positive experiences of mainstream school. Semi-structured interviews were conducted with 12 participants, who were aged 16 or older. The data collected from the interviews was analysed using Reflexive Thematic Analysis. Participant-friendly resources that had been adapted to the needs of the individuals were used within the interview process to support the participants to share their experiences. Although each participant had unique experiences, when exploring what positive experiences the participants had of school, six themes emerged. These were:

“Socialisation – Positive Memories of Friends and Interactions”, “Many Positive Attitudes from Others”, “Learning Core Skills in Key Subjects”, “Positive Memories of Supporting Staff”, “Exposure to a Range of Experiences” and “Opportunities to Practise Independence”

When exploring how the participants believed positive experiences of mainstream school could be facilitated, five themes emerged. These were “Accessible, Personalised Learning”, “Home-school Partnership and Family Support”, “Physical Memories and Rewards”, “The Opportunity to Learn Alongside Mainstream Peers” and “Carefully Planned Adult Support”. These findings suggest that young people with Down syndrome are able to have positive experiences at mainstream schools, and that there are ways that this can be facilitated. Some of the emerging themes support the findings of previous research, whereas others offer a novel understanding. The findings are relevant to educational professionals, such as school leadership staff, teachers and Educational Psychologists. Key implications and areas for future research are identified.

## **Introduction**

Young people (YP) with Down syndrome (DS) can thrive as learners (Cupples & Iacono, 2000; Byrne et al., 2002; Fletcher & Buckley, 2002) and are entitled to access high-quality, inclusive education (United Nations, 2006; 2015). Nevertheless, there remains a significant gap in the exploration and understanding of their educational experiences. While some research has explored the quality of life of individuals with DS from their own viewpoint (Foley et al., 2012; Scott et al., 2014), this area remains largely unexplored (Sheridan et al., 2020). There has been some investigation into the education of YP with DS, encompassing areas such as academic achievement (Turner et al., 2008; Will et al., 2017), support (Fox et al., 2004; Kennedy & Flynn, 2003; Lendrum et al., 2015; Paige-Smith & Rix, 2006; Van Herwegen et al., 2018; Wren, 2017), school transitions (Mullan et al., 2018) and inclusive education (Bills & Mills, 2020; Dolva et al., 2010; 2011; Engevik et al., 2018; Kendall, 2019).

However, the emphasis in this research has predominantly been on parental and teacher perspectives, with only one recent study exploring education from their own perspective (Geiger, 2023), leaving the crucial voice of YP with DS almost unheard.

### ***Down Syndrome***

Down syndrome (DS) is a genetic condition, commonly caused by an extra copy of chromosome 21 (Jackson et al., 2014; Laws & Hall, 2014). Characteristics of DS include unique physical features, learning difficulties, and distinct personality attributes (Centers for Disease Control and Prevention, 2014). The extent of cognitive impairment in individuals with DS varies, ranging from mild to severe (Chapman & Hesketh, 2000; Buckley, 2000). Associated impairments include challenges in memory, attention, motor development, language, communication skills, and a predisposition to health issues such as hearing, vision, and heart defects (Laws & Millward, 2001). DS occurs in around 1 in 700 births (Esbensen & Maclean, 2017; Mai et al., 2019) and is the most common genetic cause of learning disability (Centers for Disease Control and Prevention, 2006). Therefore, understanding how to support learners with DS in education is paramount.

Research has shown that societal attitudes towards individuals with DS are complex and varied. Pace et al. (2010) found a prevalence of negative attitudes among both adults and children. Whilst Cunningham and Glenn (2004) found that most YP with DS did not consider their condition to be important in life, they did find that some YP with DS have faced negative stigma and that males with DS were more likely to be negative about having DS. As well as this, findings from Saha et al. (2014) and Deakin et al. (2018) have suggested that even young children with DS demonstrate awareness of societal prejudices associated with their disability.

Mandleco and Webb (2015) shed light on the positive potential of individuals with DS to contribute meaningfully to their families and communities. This emphasises the importance of recognising their abilities and valuable contributions to society.

In terms of quality of life, young adults with DS have articulated the essential elements necessary for their wellbeing, including social participation, community engagement, friendships, family connections, and functional independence (Scott et al., 2014; Sheridan et al., 2020). Furthermore, recent research by Jevne et al. (2021) has identified the importance of factors such as engaging in fulfilling work, maintaining an active social life, securing stable housing, and having access to information and communication technology for enhancing the wellbeing of individuals with DS. As well as this, research by Takataya et al. (2022) emphasises the importance of friends and work for YP with DS.

### ***The Education of Young People with Down Syndrome***

There are between 7000–8000 school-aged children with DS in the UK (de Graaf et al., 2021; Wu & Morris, 2013). CYP with DS may experience unique learning challenges and may progress at a different pace compared to their typically developing peers (Doherty, 2011). However, research has showcased their ability to develop key academic skills and knowledge (Cuskelly et al., 2016). Therefore, CYP with DS must be provided with the right environment and learning tools to help them thrive. CYP with DS have a right to an inclusive and equitable good quality education (United Nations, 2006; 2015). In the UK, inclusive education is an approach that strives to offer equal opportunities to all pupils, irrespective of their abilities, backgrounds, or needs (Norwich, 2014).

Key legislation must be used when guiding the education of YP with DS, such as the Children and Families Act (2014) and the SEND Code of Practice (2015). As well as this, in 2022, the Down Syndrome Act was introduced (Down Syndrome Act, 2022). The legislation seeks to introduce formal guidelines that governing bodies responsible for education, health, housing and social care must consider when delivering services tailored for individuals with DS. This should complement existing reforms (Department of Health and Social Care, 2022). Therefore, it is vital for schools to consider this guidance when supporting learners with DS. The UK has seen a considerable increase in the number of pupils with DS attending mainstream schools (Hargreaves et al., 2021; McConkey et al.,



2016; Van Herwegen et al, 2018.), with around 65% of YP with DS attending mainstream schools. The majority of those attending mainstream are primary aged, with fewer in secondary (Hargreaves et al., 2021).

### ***Exploring the Literature***

Research indicates that individuals with DS can learn key academic skills, particularly in areas such as reading skill acquisition and phonological awareness (Cupples & Iacono, 2000; Byrne et al., 2002). This can be enhanced with the use of tailored interventions (Kennedy & Flynn, 2003). However, despite their potential capabilities, challenges in education exist. Transitions between educational stages can be particularly challenging (Mullan et al., 2018). However, factors such as parental involvement, effective communication between schools and parents, and curricular adjustments can play critical roles in facilitating smoother transitions in school (Lendrum et al., 2015). Another challenge, highlighted by Bouck (2012) is that there is a disconnection between the secondary-level curriculum and desired post-school outcomes, affecting aspects like independent living and employment for learners with learning disabilities, such as DS.

Moreover, Hargreaves, et al. (2021) explored parental perspectives on the educational experiences of pupils with DS in UK schools. Findings showed that some pupils with DS could access a diverse and well-rounded curriculum, but others could not. The variability in provision across schools emerged as a prominent factor influencing the educational outcomes for this cohort of learners. Mullan et al. (2018) explored experiences of parents whose children with DS transitioned from primary to mainstream secondary school settings in Ireland. They investigated what factors influence this process, stressing the importance of open communication between parents and schools. Also looking into parental perceptions, Farkas et al. (2019) found that parents and caregivers of children with DS may encounter challenges regarding education that most parents of typically developing children do not encounter.

There is some research that helps to understand how learners with DS may experience mainstream education. Positively, Kemp and Carter (2002) found that pupils with mild to moderate learning disabilities were generally embraced by their peers in mainstream schools and maintained social status levels on par with their typically developing counterparts. As well as this, the inclusion of YP with DS in mainstream classrooms has been found not only to foster meaningful interactions with their non-disabled peers but also yields enduring positive effects on their overall quality of life (Guralnick, 1999a; Pijl & Scheepstra, 1996). Research by Dolva et al. (2010) illustrated that YP with DS can engage in meaningful interactions within a mainstream setting, where their non-disabled peers demonstrate acceptance and mindfulness towards them. These positive interactions have the potential to facilitate mutual learning, creating an environment where peers are supportive and compassionate towards one another. However, Laws et al. (2000) suggested a potential limitation of mainstream education for YP with DS is a lack of reliable access to speech and language therapists within mainstream educational settings.

Other research has found that teachers' attitudes towards inclusive education programs significantly influence the experiences of children with DS in mainstream schools, with teachers who have received more training feeling more positive about teaching learners with DS (Bills & Mills, 2020). Therefore, adequate training and support are essential for educators to create a positive and successful schooling experience for YP with DS (Charley, 2016). Effective training should encompass knowledge about the physical and cognitive requirements of these children, as well as the adjustments necessary to facilitate their success in a mainstream environment (Carbone et al., 2023). Despite varying beliefs in self-competence to teach those with DS inclusively, teachers do believe that inclusion programs can enhance the socialisation skills of YP with DS (Charley, 2016).

Findings from Wren (2017) indicated that most pupils with DS in UK mainstream education are assisted by teaching assistants (TAs). This support encompasses academic assistance as well as social, emotional, and behavioural support. Van Herwegen et al.

(2018) further contribute to this trend, revealing that 82% of surveyed pupils with DS received support from a TA.

Cuckle and Wilson (2002) propose that interacting with and learning from peers in mainstream settings creates a conducive environment for the social and emotional development of children with DS. Relating to this, Buckley et al. (2006) found significant advancements in language skills among those with DS in mainstream schools, surpassing their peers in specialist provisions.

There has been limited research exploring educational experiences from the perspective of YP with DS themselves. However, recently Geiger (2023) explored this, using a participatory visual interview approach with a small sample of three 14-year-olds with DS. The study revealed themes of what YP with DS liked and disliked about school, highlighting preferences for being included in the classroom, having special friends and adults, being recognised for their achievements, having breaks, having time for food and drink and being creative in lessons. While the research provided valuable insights, it has limitations such as sample size and age homogeneity of participants. Implications for schools include promoting inclusive education, fostering relationships, incorporating creativity in lessons, and addressing sensory needs to enhance the educational experience for YP with DS.

### ***Further Research Recommendations***

The literature described here highlights areas for further exploration, particularly regarding the educational experiences of individuals with DS. Existing studies are limited in scope, with a scarcity of recent findings specifically dedicated to DS-related educational contexts (Bills & Mills, 2020). Whilst some research has investigated the views of individuals with DS (e.g. Cunningham & Glenn, 2004; Dolva et al., 2010; Geiger, 2023; Jevne et al., 2021; Scott et al., 2014; Takataya, 2022), Sheridan et al. (2020) highlight that there is still a substantial lack of research exploring the perceptions of YP with DS and emphasised the need for more inclusive research practices. Instead, much of the literature relies heavily on

parental perceptions (Bills & Mills, 2020; Kendall, 2019; Hargreaves et al., 2021; Mullan et al., 2018) and teacher perceptions (Charley, 2016; Donohue & Bornman, 2015; Georgiadi et al., 2012; Mills et al., 2014; Warnes et al., 2022). While these insights are valuable, the absence of the direct voice of YP with DS diminishes the depth of understanding. Whilst research using this perspective is limited, research has shown that gathering these views has been possible. Therefore, similar techniques could be used to explore school experiences in more depth. Whilst Dolva et al. (2010) did explore this perspective relating to education, they focused primarily on interactions and used participants who were currently in school. Moreover, Geiger (2023) explored educational experiences more generally, however their participants were restricted to only three 14-year-olds. It would be interesting to extend this understanding by gathering the perspectives of older YP with DS who may be able to reflect on their whole education, or more of it.

More generally, previous research has demonstrated the feasibility of gathering the views of those with special educational needs (Motherway, 2009), therefore adding to the evidence that gathering the views of YP with DS is possible. To achieve this, careful consideration of research methods is essential. A variety of methodologies can be employed to solicit feedback from children, and it is likely that these methods could be effectively tailored to collect insights from pupils with disabilities (Byrnes & Rickards, 2011), such as those with DS.

Therefore, future research should aim to strengthen the understanding of how YP with DS experience education by prioritising the inclusion of YP with DS in educational research, thereby enriching our understanding of their unique experiences and insights within educational settings.

### **Aims and Rationale of the Current Study**

This research aims to explore the positive experiences of learners with DS in mainstream education by understanding what positive experiences YP with DS have had in

mainstream school, and how they believe these experiences can be facilitated. Conducting research into the experiences of mainstream education from the viewpoints of YP with DS is fundamental for several reasons.

Firstly, DS is the most common genetic cause of learning disability, highlighting the likelihood that Educational Psychologists (EPs) and other professionals will engage with YP with DS throughout their careers. Understanding their educational experiences is essential to equip professionals with the knowledge and insights necessary to support them effectively in educational settings. Although children with DS may face certain challenges, they can acquire new skills and knowledge. Like all children, they have the right to acquire new skills and knowledge through high quality education and it is important to provide them with opportunities to do so. Therefore, understanding how to best support and enhance their learning potential is essential.

Although existing research has provided valuable insights into the education of YP with DS, there has been limited research exploring the critical viewpoint of YP with DS themselves. At the time of writing the Research Proposal and gaining ethical approval for the current study, no recent research using this perception to understand educational experiences of YP with DS existed. Very recently, Geiger (2023) explored this viewpoint, however, there remains a lack of comprehensive research exploring this. Most of the existing research relies on the viewpoints of others, such as parents or educational professions, yet research has suggested that the views of others may not accurately represent the experiences of the YP themselves (Ijezie et al.,2023). Therefore, this research focuses on the view of the YP with DS.

Moreover, legislative frameworks such as the Children and Families Act (2014) and SEND Code of Practice (2015), which advocate for the active involvement of CYP with SEN in decision-making processes, also highlight that it is crucial to elevate the voices of YP with

DS. By understanding their perspectives, professionals and educators can gain a more holistic understanding of the factors contributing to successful education for YP with DS.

The SEND Code of Practice (2015) emphasises the principle of inclusive education, stating that mainstream schools should be the first choice for children with special educational needs or disabilities wherever possible. If a child has an Education, Health Care Plan (EHCP), then they may attend a special school, but they should not have to (Children and Families Act, 2014). As well as this, statistics indicate that a substantial proportion of YP with DS in the UK attend mainstream schools. Therefore, it is essential to ensure that mainstream settings are equipped to provide a positive and inclusive experience for learners with DS. Therefore, this research focuses on mainstream experiences.

Guided by a solution-focused approach, this research focuses on positive experiences. This is in the hope that by identifying and amplifying of what is already working for YP with DS in mainstream school, existing resources and successes can be built upon to promote lasting, positive change (de Shazer et al., 2007). Research has demonstrated that highlighting positive experiences can foster resilience, increase motivation, and enhance wellbeing (Seligman, 2011). As well as this, asking about positive experiences may result in more empowering responses and contribute to increased self-esteem. Focusing on challenges could potentially trigger negative emotions, making it harder for participants to engage meaningfully in the research (Cameron & Jago, 2010).

Moreover, the focus on positive experiences aligns with the researcher's ethical commitment to safeguarding the wellbeing of participants. Considering this, concentrating on successful, affirming experiences, helped the researcher to avoid upsetting individuals by revisiting potentially negative or challenging events and allowed participants to engage meaningfully without being exposed to unnecessary emotional harm. The focus on positive experiences was intended to uplift participants, recognising their contributions and fostering a sense of agency in co-creating inclusive educational practices. This future-oriented,

strengths-based approach was used to provide a richer and more constructive understanding of how to facilitate positive experiences of mainstream education for YP with DS (de Shazer et al., 2007).

The researcher acknowledges that focusing solely on positive experiences has limitations, such as overlooking challenges that could provide important context or failing to fully address the complexity of participants' lived experiences, as well as introducing positive biases (as explained in the limitations section of this chapter). However, the researcher hopes that the findings will offer practical, solution-focused insights that can guide EPs, teacher and school staff and policymakers in developing provisions that help to foster a positive learning environment for YP with DS that are both effective and sustainable.

In light of these considerations, this research focuses specifically on mainstream education and aims to explore the positive experiences of learners with DS in mainstream education. This encompasses understanding what positive experiences YP with DS have had in mainstream school, and how they believe these experiences can be facilitated.

To achieve this aim, the following research questions (RQs) guided the study:

RQ1) What did YP with DS find positive about their experiences of mainstream school?

RQ2) What do YP with DS believe can help facilitate positive experiences of mainstream school for them?

By addressing these research questions, this study endeavours to contribute valuable insights towards enhancing the educational experiences and outcomes of YP with DS in mainstream educational settings. Both research questions are valuable and significant; however, Research Question 2 holds particular importance for its potential contributions to applied practice in the future.

## **Methodology**

This section describes the methodology employed in the present study, encompassing an exploration of the philosophical position of the researcher and its relevance to the study. The characteristics of the participants are described, as well as how they were selected to take part in the study, alongside a brief explanation of the role of their parents/carers. The process of data collection and data analysis is discussed, including an explanation of how rigour was ensured. The last part of this section discusses the ethical considerations of the researcher whilst undertaking this research.

## ***Philosophical Positioning***

This study adopts the perspective of critical realism, as proposed by Bhaskar (1978), which blends elements of both positivism and constructivism. Critical realism acknowledges the existence of an objective reality while also recognising that our understanding of this reality is shaped by both theory and personal experience (Archer, 2016).

Critical realism was developed as an alternative to deductive approaches. It asserts that reality exists independently of our thoughts, but it's not straightforward to observe directly (Sayer, 2004; de Souza, 2014). Essentially, critical realism combines the belief of an independent reality (ontological realism) with the understanding that complete access to truth is challenging (epistemological relativism) (Braun & Clarke, 2021; Levers, 2013). Therefore, critical realism aims to grasp reality comprehensively, acknowledging that the data researchers collect might not perfectly capture this reality (Willig, 2013). However, understanding reality can be aided by considering both individual and collective experiences. For example, Freyd (1983) highlights the 'shareability' of knowledge and experience, and Kelly (2017) suggests that critical realism can reveal a shared reality.

In the context of this study, critical realism is a useful stance as it acknowledges that DS is a real condition with objective characteristics, such as its causes and diagnostic criteria. However, individuals with DS can vary in the degree of cognitive impairment they



experience. Therefore, their experiences of school may be influenced by both the objective reality of DS and the social constructs surrounding it, resulting in unique and varied experiences among participants, with some similarities. Furthermore, the distinct experiences of individuals with DS separate from those of their parents and teachers, offer a novel perspective. This fresh viewpoint, divergent from the perspectives examined in prior research, enhances the ability to comprehend the realities faced by YP with DS. Willig (2013) highlighted that the conclusions drawn by researchers may not necessarily depict an absolute truth, but rather represent the participants' perceptions of their truth. This aspect is crucial for the research objectives of the current study, as the researcher aims to ensure that the findings resonate with and accurately represent the sentiments of individuals with DS themselves, not necessarily those around them. This approach is essential for fostering a sense of positivity and empowerment regarding their education as opposed to decisions being based on others' perceptions of their experiences.

The researcher aims to uncover and understand the experiences that YP with DS had in mainstream school and understand the themes within experiences that are similar between participants (the shared reality) as well as recognising the importance of individual experiences for each participant. The researcher will utilise this information to establish positive experiences within mainstream school for YP with DS and to identify methods or facilitators to promote similar positive experiences for YP with DS in mainstream settings.

Alternative epistemological paradigms were considered for this research, but they did not completely resonate with the researcher's beliefs. For instance, the researcher found that social constructivism did not adequately account for the reality of DS as an inherent truth for the participants, regardless of societal constructs. On the other hand, essentialism was deemed unsuitable because the researcher recognised that participants' experiences were influenced by various factors, including the people involved in their education, the school environment, and their own attitudes. Consequently, critical realism was chosen as it better aligned with the researcher's perspectives on truth and knowledge. An additional

reason it was selected was because its central philosophy aims to promote social change and social justice (Willis, 2023). These are core values of the researcher, who is passionate about promoting social inclusion for those with DS.

### ***Theoretical Underpinning***

This study adopts a solution-focused approach, emphasising strengths rather than challenges and problems (de Shazer et al., 2007). By focusing on practices that have shown to be successful, this research aims to identify, apply and extend on strategies that already support inclusion and engagement for YP with DS in mainstream schools.

Solution-focused approaches suggest that rather than focusing on challenges, greater progress is often achieved by prioritising "what works" to inspire meaningful and actionable change (de Shazer et al., 2007). Central to solution-focused thinking is the concept of "preferred futures," where aspirational goals are co-constructed based on recognised strengths, previous successes, and positive experiences. This forward-looking perspective builds on current successes and encourages innovative ways to enhance future provisions for YP with DS.

This solution-focused framework was chosen as previous research has shown it is particularly relevant to education as centring on students' strengths and positive school experiences can enhance the wellbeing and engagement of students with disabilities. For example, research on solution-focused interventions in educational contexts has revealed improvements in social and emotional aspects of school, such as behaviour, as students are encouraged to draw upon their positive experiences and innate capabilities (Franklin et al., 2008). This strengths-based orientation also has the potential to improve students' self-concept, social relationships, and resilience (Lopez et al., 2019; Sklare, 2014), providing a foundation for developing inclusive, supportive practices in mainstream schools.

Therefore, by using this framework as a theoretical underpinning, this research does not merely describe effective practices but also seeks to shape actionable, future-oriented solutions for YP with DS in mainstream educational settings.

### ***Qualitative Methodology***

In line with the researcher's epistemological and ontological stance, a qualitative approach was used. This allowed for an understanding of the participants' experiences and the meanings they attributed to events (Willig, 2013). This included data collection through semi-structured interviews and data analysis using the six stages of Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022).

These qualitative methods provided the researcher with a depth of understanding, aligning with critical realism's aim of comprehensively understanding reality. As well as this, the data from the semi-structured interviews generated rich, detailed data that capture the individuality and context of participants' experiences, providing insight into the multiple layers of reality acknowledged by critical realism. Furthermore, the researcher prioritised the perspectives and voices of participants, allowing them to contribute to the construction of knowledge. This aligns with critical realism's emphasis on understanding reality through the viewpoints of those experiencing it. Additionally, RTA enabled the researcher to contextualise findings within the social and cultural contexts in which they occurred, providing a deeper understanding of reality as shaped by social structures and interactions. This approach was flexible and adaptive, allowing the researcher to organise data into themes and explore emergent topics that may not have been anticipated initially. This flexibility is well-suited to the interpretative and exploratory nature of critical realist inquiry.

### ***Participant Characteristics***

The inclusion and exclusion criteria for participants and the rationale for this is outlined in the table below.

**Table 1***Participant Inclusion and Exclusion Criteria*

<b>Participant Inclusion Criteria</b>	<b>Participant Exclusion Criteria</b>	<b>Rationale and Explanation</b>
Have a diagnosis of Down syndrome	Does not have a diagnosis of Down syndrome	The research aimed to understand the direct perceptions of YP with DS, rather than using proxy methods
Be aged 16 or above	Is below the age of 16	The post-16 age group was chosen by the researcher in order to allow participants to reflect on their educational journey as a whole
Have attended mainstream education in the UK for all or at least some of their education	Has had no experience of being educated in a mainstream setting in the UK	Participants needed to have attended mainstream settings for the data collected be relevant to the specific RQs. The researcher chose to limit this to mainstream schools in the UK allow the findings to be relevant to legislation, policies and practice in the UK. Participants from all over the UK could take part, allowing the data to encompass experiences across different Local Authorities
Be able and willing to share their positive experiences of mainstream education	Is unwilling or unable to recall any positive experiences of mainstream education	For ethical reasons, participants needed to be willing to take part and share their experiences of mainstream education. To do this, participants needed to be able to. This meant, with reasonable adjustments and participant friendly tools, they could share their experiences in a semi structured interview. Participants had to confirm that they believed they were able to recall such experiences

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Have the capacity to consent according to the guidelines in the Mental Capacity Act (2005) as indicated by parents/carers and pre interview questions	Parents/carers, or questions answered before the interview indicate that they do not have the capacity to consent according to the guidelines in the Mental Capacity Act (2005)	Following the guidelines outlined in the Mental Capacity Act (2005), participants aged 16 are required to provide their own consent for participation if they can do so. The determination of their capacity to consent was based on inquiries directed to parents/carers and through preliminary interview questions crafted according to the criteria stipulated in the Act
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### ***Participant Recruitment***

The research was promoted via DS specific organisations (Project 21, The Down Syndrome Association and the Nottinghamshire Down Syndrome Support Group) as well as on community pages on Facebook. Promotion of the study was done using information posters about the study (Appendix 3) which included the contact details of the researcher. Those who were interested in the study then emailed the researcher, who sent over more information, both in a format for the YP with DS (Appendix 4) as well as their parents and carers (Appendix 5). A link to a video explaining the study was also included, so that the information was accessible to those with literacy difficulties. In line with the Mental Capacity Act (2005), since participants were 16 or older, they consented to the study themselves, via a consent form (Appendix 6). However, to ensure that the YP understood what they were consenting to and were able to take part in the study, their parents or carers also signed a form indicating that they believed the YP had understood the information provided about the study and was happy and able to consent and participate. This form was attached to the parent/carer information sheet (Appendix 5). The participants' understanding of the research

was further checked at the beginning of the interview, where the interviewer asked questions designed using the Mental Capacity Act.

12 participants took part in the study. All participants had DS and had attended mainstream school for some, or all of their education (5 participants had experience of both mainstream and specialist settings and 7 participants attended only mainstream school). All participants were aged 16 or above with a mean age of 22.08 (ranging between 16 and 36). There was an even split between gender, with 6 males and 6 females participating. Among the 12 participants who took part in the study, individuals were educated in various locations, including Suffolk (3 participants), Essex (1 participant), Nottinghamshire (6 participants), London (1 participant) and South Wales (1 participant).

### ***Data Collection***

**Semi-structured interviews.** The participants took part in a semi-structured interview that lasted between 40 minutes and 1 hour and 30 minutes, dependent on participants responses. The structured element of the interview (Appendix 7) ensured that the research questions were framed within the questioning, however, the flexible design of semi-structured interviews allowed for the emergence of unanticipated ideas and allowed the researcher flexibility to adapt according to the participants' responses (Robson & McCartan, 2016; Braun & Clarke, 2022). Interviews took place in a location of each participant's choice, where they were able to feel safe and comfortable to engage in the interview to the best of their ability. Participants were asked a series of open-ended questions and were also given the opportunity to talk about anything else that they thought was important or positive about their school experience.

**Participant-Friendly Resources.** The researcher recognised that due to cognitive impairments, YP with DS may struggle with the traditional interview delivery. Therefore, a variety of methods for obtaining the participants' views were used.

To do this, the researcher considered what methods have conventionally been used to collect perspectives from children in research (without disabilities) and made the reasonable assumption that adapted versions of these methodologies could be appropriately tailored to gather insights from YP with disabilities (Byrnes & Rickards, 2011). For instance, techniques such as 'mind-mapping' exercises (Thomson & Gunter, 2006) and cue cards (Lewis et al., 2008) have been used to gather children's views. These same approaches were integrated into the semi-structured interviews conducted in this study.

Before the interview, the participants were told that they could bring objects with them to help them explain their ideas, including, but not limited to school reports, photos, school timetables, learning aids etc.

During the interviews, participants were provided with paper, pens, and cue cards. They were encouraged to use these resources to write, draw, or map out their answers, ideas, and memories if they needed to. The cue cards included pictures to explain certain vocabulary used in the questions and served as helpful prompts for the YP to structure their answers. The content of the cue cards (Appendix 8) was selected based on an extensive review of the literature concerning YP with DS and their quality of life and educational experiences. After reviewing this literature (Chapter 1), key words, phrases, and ideas were extracted from these previous research findings, themes and discussions and included on the cue cards.

Additionally, similar to previous research by Cunningham and Glenn (2004), participants had the option to bring a trusted adult with them to the interview, if desired. This was intended to assist in conveying the YP's thoughts and responses if verbal expression proved challenging.

Despite the availability of paper, pens, and pencils, none of the 12 participants felt the need to use these tools to draw, write, or map out their answers during the interviews. Instead, all participants felt comfortable and capable of verbalising their responses. 7 out of

the 12 participants brought objects, including photos, school reports, certificates, diaries, schoolwork, and memory books to share with the researcher. Moreover, all 12 participants utilised the cue cards to enhance their understanding of the questions asked. 7 of the participants opted to have an accompanying adult present during the interview. These adaptations and tools were used to support access to the interview, rather than to be used as data to be analysed.

In addition to these participant-friendly resources, the researcher adapted the delivery of the interview process. Therefore, time was dedicated to building rapport with the YP, sometimes leading to brief digressions from the main topic of conversation. This approach helped the participants feel at ease and encouraged open communication. Moreover, the researcher recognised that it was important to consider their own listening skills and understand the potential frustrations of the participants with speech difficulties (McCormack et al., 2010; Paterson, 2013). Therefore, breaks were provided between questions, and participants were given extended time to consider and articulate their responses, taking into account potential speech and language difficulties.

### ***Role of Parents/Carers in the Current Study***

One role of parents/carers was to ensure that participants comprehended the study, had chosen to consent themselves and understood their consent. A second, optional role for parents, was to accompany the YP with DS to their interview if necessary. The purpose was to ensure that the YP felt comfortable during the interview process. Additionally, parents could assist in conveying the YP's thoughts and responses if they faced difficulty expressing themselves, given that parents/carers likely understand their child's communication better than others. However, it was crucial for parents/carers to only convey the YP's perspectives and not introduce their own ideas or opinions, as the research solely aimed to understand the YP's view. To ensure this, the role of the parent was clearly outlined on the information sheets, and if the parent was present during the interview, this was explained again at the



beginning of the interview. Out of the 12 participants, 7 opted to have a parent present during the interview, while 5 chose to participate independently.

## **Data Analysis**

### ***Reflexive Thematic Analysis***

The researcher employed an inductive approach to data analysis, wherein both coding and theme development were driven solely by the data, rather than attempting to force the data into pre-existing theoretical frameworks (Braun & Clarke 2022). This approach allowed the researcher to capture a fresh perspective on the experiences of education for YP with DS and to account for the subjective views and experiences of the participants. This approach was particularly relevant given the semi-structured nature of the interview data.

Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2022) was used to analyse the data, with a separate analysis conducted for each research question. The primary aim of RQ1 (What did YP with DS find positive about their experiences of mainstream school?) was to identify positive experiences to inform subsequent interview questions for RQ2 (What do YP with DS believe can help facilitate positive experiences in mainstream school for them?). Despite this focus, it was necessary to analyse RQ1 independently. This is because the insights gained are not only essential for shaping the discussion of RQ2 but also have broader implications when viewed through a solution-focused lens. Solution-focused principles emphasise amplifying existing strengths and effective practices to create meaningful and sustainable improvements (de Shazer et al., 2007). Rather than focusing solely on immediate problems, this approach encourages the identification of successful strategies that have worked in the past to co-create future solutions. Therefore, understanding the positive experiences that YP with DS have encountered in mainstream schools provides a valuable foundation for fostering long-term change and enhancing inclusive practices.

Carrying out separate analyses for each RQ enabled the researcher to explore specific aspects of the participants' overall experiences in greater depth. This approach allowed for a more precise and detailed analysis of each research question, ensuring that the participants' voices were fully represented and addressing ethical considerations surrounding the respectful and thorough handling of data (Creswell & Poth, 2018). While the analyses were conducted independently, some findings from each RTA were later linked in the discussion. By integrating these findings, the final conclusion provided a comprehensive exploration of the positive experiences of learners with DS in mainstream schools.

The researcher used Braun and Clarke's (2022) guide to RTA to guide this process (Braun & Clarke, 2022), which is outlined in the table below.

**Table 2**

*Phases of Reflexive Thematic Analysis*

<b>Phase of Thematic Analysis</b>	<b>How the researcher carried out this phase</b>	<b>Supporting evidence of this phase</b>
1. Familiarisation	<p>Familiarisation of the data set began with transcription. The researcher transcribed the interview data by playing the recorded material out loud and typing this onto a Microsoft Word document. Interview recordings were paused and rewound multiple times during this process to ensure accuracy.</p> <p>The researcher then immersed themselves in the data set by printing the Word Documents and reading and re-reading them multiple times.</p> <p>On the final time of re-reading the transcript, the researcher typed familiarisation notes into a Microsoft Word document, recording their reflections on part of the data that they found "interesting" at that point of time.</p>	<p>See example extract of interview transcription (Appendix 9)</p> <p>See example extract from familiarisation notes (Appendix 10)</p>

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2.	Coding	<p>The transcripts were methodically reviewed, and key 'codes' were generated to capture significant aspects of the data relevant to addressing RQ1. This process involved using the 'comment feature' in Microsoft Word to highlight relevant text and assign codes in a separate column alongside the transcript.</p> <p>Each time data was selected for coding, careful consideration was given to determine whether an existing code applied or if a new code needed to be created. To streamline this process, the researcher recorded each generated code on a separate document for easier access and readability. This approach facilitated quick scanning of all existing codes to identify the need for generating new ones. The data underwent two rounds of coding. Following the guidance of Braun and Clark (2022), the second round of coding employed a different approach. This time, transcripts were coded starting from the middle of the dataset and then moving outwards.</p> <p>Next, all codes were compiled into a comprehensive table. This table featured the codes, along with corresponding supporting data for each code, and indicated which participants provided the data relevant to each code.</p> <p>This entire process was then repeated for RQ2.</p> <p>Most coding was done semantically, exploring the data explicitly (particularly for RQ1). However, some data involved more latent coding, for example sometimes implying what the data meant in terms of facilitating the positive experiences (RQ2) (Braun and Clarke, 2022).</p>	<p>See example extract from coding document (Appendix 11)</p> <p>See example extract of comprehensive tables of codes, data and participants (Appendix 12)</p>
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3. Generating initial themes	<p>All the codes that had been noted down in phase 2 were printed onto paper and then individually cut out. This approach ensured flexibility, allowing codes to be freely manipulated and grouped together by hand to identify broader patterns of meaning. Initially, codes were organised into clusters based on similarities. These clusters were further examined to develop initial themes and subthemes. The placement of codes was reviewed and adjusted multiple times. Subsequently, codes were provisionally grouped under potential theme names, and the researcher created a physical thematic map using the paper cutouts. Finally, each theme was secured together with a paperclip to ensure the codes were stored safely and kept organised.</p>	<p>See photos of how the codes on paper were manipulated by hand at during this phase (Appendix 13)</p>
<p>This phase was carried out individually for both research questions.</p>		
4. Developing and reviewing themes	<p>The themes generated in phase 3 were checked again against the data set, relevant adaptations were made and a thematic map for each research question was made electronically on Microsoft word.</p>	<p>See thematic maps in the 'Findings' section of this chapter</p>
5. Refining, defining and naming themes	<p>The researcher considered the names of the themes and adapted them to be as informative as possible. The researcher then wrote a paragraph about each theme, including what the core concept of each theme was and what different aspects this encompassed. Theme names were adapted on the thematic maps.</p>	<p>See 'Findings' section of this chapter</p>
6. Writing up	<p>Following the previous 5 phases, the researcher presented the identified themes in detail, providing a thorough explanation illustrated by quotes from the dataset. The researcher then compared these themes with existing literature, highlighting areas of alignment and deviation. This discussion was written within the findings. Additionally, the novel insights that emerged from the research were discussed. The main findings were subsequently analysed to consider their implication in practice and further research.</p>	<p>See 'Findings' section of this chapter</p>

## Ensuring Rigour

Throughout this research, and particularly during the data analysis phase, meticulous attention was given to ensuring rigour. To guarantee effective and high-standard RTA, the researcher meticulously adhered to the process outlined by Braun and Clarke in their practical guide to thematic analysis (2022). By closely following the steps outlined in this guide, the researcher ensured that RTA was conducted with precision and rigour. This provided a structured framework for evaluating the rigour and integrity of the reflexive TA process, further enhancing the trustworthiness of the research findings.

Moreover, to further ensure rigour, the researcher drew upon the framework proposed by Guba and Lincoln (1986), which emphasises four key criteria for maintaining rigour in qualitative research: credibility, dependability, confirmability, and transferability. The researcher's consideration of Guba and Lincoln's (1986) framework of rigour is outlined in the table below.

**Table 3**

### *Ensuring Rigour in the Current Research*

<b>Guba and Lincoln (1986) criteria</b>	<b>What this means in research</b>	<b>How the criteria were demonstrated in the current research</b>
Credibility	Credibility refers to the extent to which the findings of the research are believable and trustworthy from the perspective of the participants	The researcher made every effort to ensure that the research accurately represents the participants' experiences and perspectives. This involved employing rigorous data collection in an accessible way for participants and prolonged engagement with the data, to ensure that the findings reflect the complexity and nuances of the research questions

Dependability	Dependability refers to the stability and consistency of the research findings over time and across different contexts	The researcher maintained detailed documentation of the research procedures, including data collection methods, coding processes, and analytical decisions to allow for transparency and reproducibility. Additionally, the researcher engaged in regular meeting and debriefing conversations with their research supervisor
Confirmability	Confirmability refers to the objectivity and neutrality of the research findings, indicating that they are not unduly influenced by the researcher's biases or preconceptions	The researcher adopted reflexive practices, such as keeping reflective journals, and engaging in discussion with their research supervisor to critically examine their own biases and assumptions and mitigate their impact on the research process. The researcher reflected whether these potential biases were beneficial, e.g. researcher bias as a strength as outlined by Braun and Clarke (2022), or if it posed a problem, and made any necessary adaptations based on this
Transferability	Transferability refers to the extent to which the findings of the research can be applied to other contexts or populations beyond the immediate study sample	The researcher provided rich and detailed descriptions of the research context, participants, and data collection procedures, which will allow readers to assess the applicability of the findings to their own contexts. The researcher also considered how the procedures can be used in research to gain the views of other populations, such as those with different learning disabilities and provided rich and detailed accounts of the themes in the analysis to support transferability

Braun and Clarke (2021) advocate that to uphold the quality of RTA, researchers should reflect on the interplay between analytic practices, including quality standards, and the ontological and epistemological underpinnings of their research. They emphasise the importance of employing TA purposefully, consciously, and reflexively. As mentioned in the table above, in line with these principles, reflective diaries were maintained throughout the

research process to support the researcher in this reflexive endeavour (see reflective account).

Ethical considerations were rigorously addressed, as ethical research practices are crucial for maintaining trust and integrity within the research process and among those impacted by it.

### **Ethical Considerations**

This research was approved by The University of East Anglia's Research Ethics Committee in May 2023 and adhered to guidelines outlined in the British Psychological Society's Code of Human Research Ethics (2021). Having viewed posters about the study, prospective participants that had contacted the researcher to express an interest in participating, received an additional information sheet. The information provided was presented in an accessible format tailored to individuals with learning disabilities.

In accordance with the Mental Capacity Act (2005), since the participants were aged 16 or older, they provided consent for their involvement through a consent form. Additionally, to ensure comprehension of the research and the ability to participate, their parents or caregivers also signed a form to confirm their belief in the participant's understanding of the study and their willingness and capacity to consent and partake. Ensuring that the participants understood the study and its aims also meant that they were fully aware of its focus on positive experiences. This transparency ensured that participants knew the findings would primarily highlight their positive experiences, rather than their challenges, preventing any potential disappointment that the research might not fully capture the complexity of their lived experiences, including the more difficult aspects. This approach further ensured that the research remained ethical by aligning participant expectations with the study's outcomes.

Upon receipt of both signed forms, the researcher arranged interviews with participants and/or their guardians at a mutually agreed location, dependent on the YP's

preference. The researcher ensured the location suggested was suitable and allowed for a confidential interview before confirming.

Before the start of each interview, participants were reminded of the researcher's objectives and were requested to articulate their comprehension of the research, providing additional verbal consent. Consent to record interviews and use these recordings for data analysis was reconfirmed before the interview. Participants and their caregivers were informed of their right to withdraw transcripts and when this is possible, pose inquiries, and access findings at a later stage.

Recognising that not all school experiences may have been positive for the participants, the researcher framed questions in a positive light and redirected conversations to positive topics if negative experiences arose, aiming to mitigate distress. Recognising that YP with DS often have speech and language difficulties, the researcher ensured that the participants had ample time to think about and explain their answers and offered breaks if the participants were finding it difficult or showing signs of fatigue. Following each interview, participants received a debriefing sheet (Appendix 14), which the researcher read and reviewed with them. Participants were reassured of their ability to reach out to the researcher for support or with any further queries post-interview.

Data collection and analysis adhered to the General Data Protection Regulation Act (2018) and the University of East Anglia Research Data Management Policy (2019). Personal participant information, including names, ages, and contact details, were retained on the university One Drive solely for the research duration and will be promptly deleted upon study completion. All subsequent data used underwent anonymisation, with names removed from transcripts and participants assigned numerical labels that did not correspond to interview completion order. These ethical considerations were explored in detail when applying for ethical approval from UEA's Research Ethics Committee. Evidence of ethical approval can be found in Appendix 15.



## Findings and Discussion

This section presents the findings of the current study, organised around the key themes identified through Reflexive Thematic Analysis (RTA). In line with Braun and Clarke's (2022) methodology, the findings and their discussion are integrated. By relating the findings to existing literature, this section provides a comprehensive understanding of each theme. Contextualising the findings within the broader body of research offers deeper insights into the themes and their implications (Beres & Farvid, 2010).

Initially, RQ1 was used primarily as a facilitator to shape and direct the interview questions for RQ2. However, as the researcher began familiarising themselves with the transcripts during Phase 1 of the RTA, it became evident that significant findings emerged from RQ1. Consequently, the decision was made to conduct separate RTAs for RQ1 and RQ2. This separation was crucial to ensure that the participants' voices were accurately heard, and their perceptions precisely represented, addressing ethical considerations related to the thorough and respectful analysis of participant data (Creswell & Poth, 2018). By conducting detailed analyses of both RQs, this study provides a comprehensive exploration of the positive experiences of learners with DS in mainstream schools. This solution-focused approach enables an understanding of how these findings can inform practices aimed at positively impacting the future education of YP with DS in mainstream settings.

Each theme identified through RTA is presented with supporting examples from the data. The findings are discussed in relation to existing research, offering a deeper understanding of each theme and its implications for educational practice. It is important to note that while this section includes a selection of supporting data, additional data exists beyond what is presented, further enriching the study's findings.

### Key Themes and Discussion: Research Question 1

RQ1 - What do YP with DS find positive about their experiences of mainstream school?

RQ1 was employed to explore and understand the positive experiences of mainstream education from the participants' perspectives. By posing open-ended questions about their positive experiences in mainstream school, RQ1 served as an initial conversation starter that guided the direction of the interview questions. This approach enabled the researcher to identify key positive experiences and develop subsequent questions to explore why these experiences were perceived as positive and how they occurred. Consequently, this facilitated a more detailed investigation into how to support YP with DS in mainstream schools. The insights gained from this exploration of positive experiences therefore contributed to addressing RQ2.

Although RQ1 was designed to facilitate the exploration of RQ2, the findings of RQ1 were also analysed independently. This is because the findings can be used to understand 'what works' for YP with DS in mainstream schools and to help create meaningful, long-term change (de Shazer et al., 2007). By acknowledging the positive experiences identified by the participants, this research aligns with solution-focused psychological practices, which emphasise identifying and amplifying effective strategies and strengths.

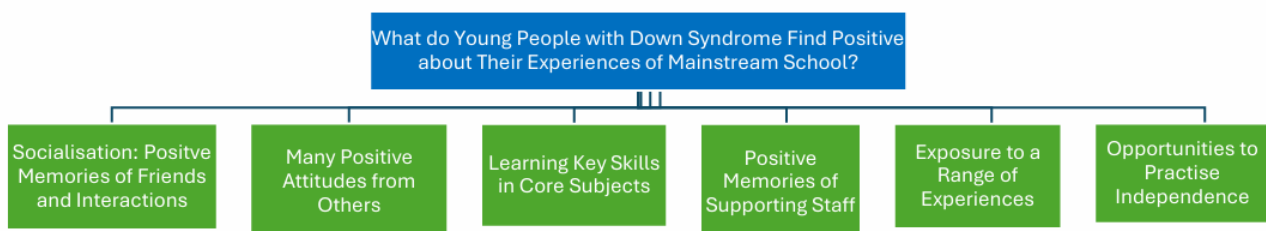
Solution-focused approaches are grounded in the belief that recognising and utilising existing strengths and effective practices can lead to sustainable improvements and enhanced overall outcomes and best hopes for the future (de Shazer et al., 2007). Based on this, the findings from RQ1 not only provide insights into what is working well in mainstream education for YP with DS, but also inform how these successful elements can be utilised and expanded upon to support and improve educational practices. This provides actionable insights into how to effectively support YP with DS in mainstream educational settings.

The participants found answering RQ1 relatively straight forward. They were able to reflect on their experience of mainstream school and identify elements that they remembered as positive experiences. For this reason, analysis of this RQ has a more semantic orientation, using what they said to directly understand what positive experiences were for learners with DS in mainstream school.

Analysis of the data for RQ1 revealed 6 key themes. These were “Socialisation – positive memories of friends and interactions”, “Positive attitudes towards them – from many around them”, “Learning core skills in key subjects”, “Positive memories of supporting staff”, “Exposure to a range of experiences” and “Opportunities to practise independence”. This showed that participants really valued their interactions and relationships in mainstream schools with both peers and staff. Interestingly, they placed a lot of emphasis on learning opportunities and exposure to a range of experiences. These themes are displayed below in a thematic map.

## Figure 1

*Thematic Map of Research Question 1 Findings*



### ***Theme 1: Socialisation – Positive Memories of Friends and Interactions***

The theme "Socialisation – Positive Memories of Friends and Interactions" explores a central concept echoed throughout the dataset, emphasising the positive recollections YP with DS hold regarding the social dimensions of their experience in mainstream school. Participant responses highlight the importance of friendships, portraying them as meaningful and cherished aspects of their time in school. Within this theme, participants also highlight how the socialisation process positively contributed to their understanding of others. Interactions with peers can be described as enriching experiences that enhanced their broader comprehension and appreciation of different perspectives and personalities. Additionally, the theme captures the joyous moments of play and break times, portraying these instances as enjoyable and pivotal in creating positive memories within the school

environment. In essence, "Socialisation – Positive Memories of Friends and Interactions" encapsulates the multifaceted ways in which social aspects, particularly friendships and interactions, contribute to the participants' positive narrative of mainstream school.

For the participants, having friends at school was a positive aspect of their mainstream experience. With many participants expressing that they had friends at school and that they liked having friends.

**Participant 1:** *"Yes! My friends. I love my friends!" ... "I liked school because I have friends. In my class I always had friends."*

**Participant 2:** *"I like school because I have friends. In my class I always had friends." .... "I didn't have TAs with me at break and lunch time because it is better to be with my friends."*

**Participant 5** *"It was a good experience having friends."*

And that a good experience of school was the opportunity to spend time with their friends.

**Participant 3:** *"I had a best friend in primary school who I did spend most of my time with."*

**Participant 9:** *"And I made so many friends there (names a lot of friends). It was at school when I learnt how to play with other children, and I made so many friends" .... "Having friends made me happy and it was the best part of school. Every single day I got to spend time with my friends."*

**Participant 11:** *"I had some really lovely friends because they were outgoing and included me and chatted with me."*

**Participant 12:** *"Friends are important because they were always there every time that I needed them. I had lots of friends at school."*

During discussions about friends, many participants expressed that friends were a very important part of their school experience, suggesting that friends can be a motivator for YP with DS to attend school.

**Participant 3:** *“I had friends at school and made me like school more” .... “One friend in particular was XXXX, we started school together. We helped each other. I felt happy and motivated to go to school to see XXXX. People in the school were all nice, understanding and accepting.”*

**Participant 4:** *“Friends were important for me at school and helped me enjoy school.”*

**Participant 6:** *“I had friends that helped me feel happy at school. I made them myself and they helped me be excited about going to school. I was with them at playtime and in lessons. And they invited me to their house to play games. It made me feel important.”*

**Participant 7:** *“I had lots of friends. I was excited to go into school to see my friends. I loved going to school.”*

**Participant 10:** *“Having friends made me happy and it was the best part of school. Every single day I got to spend time with my friends.”*

**Participant 11:** *“I enjoyed school because of my friends.”*

With one participant even recognising that going to mainstream school specifically enabled them to stay with friends they already had.

**Participant 4:** *“Mainstream high school was the best option to be with my friends.”*

This indicates that friendships are clearly very important for YP with DS and that they felt that even in mainstream school, they were able to successfully make friends and that this was something they remembered positively about school. Friendships are important as they enjoyed spending time with friends and these relationships strengthened motivation to attend school.

The positive perception of school friendships among the participants is consistent with previous literature findings. It is not surprising that YP with DS perceive friendships at school positively, given the significant role friendships play in enhancing their quality of life (Sheridan et al, 2020) and education (Geiger, 2023). The current findings further confirm this, in the context of mainstream education. Additionally, insights from Dolva et al. (2014) emphasise the importance of friendships for YP with DS, as observed from a parental standpoint. While Dolva et al.'s (2014) study primarily focused on friendships cultivated through organised leisure activities tailored for individuals with learning disabilities, it is encouraging to find that participants also express positivity regarding friendships with typically developing peers and believe that they were able to build relationships with these children in the mainstream school setting. Additionally, these findings emphasise the positive impact friendships have on YP with DS and how they value the opportunity to be able to interact with peers in mainstream settings.

Moreover, this theme has emphasised that the opportunity to socialise with a diverse group of children at school has been beneficial for the participants as it has facilitated a deeper understanding of others. This aspect of their mainstream school experience was perceived positively by the participants.

**Participant 2:** *“I talked to people more at break time than in lessons. I talked to people so I could learn about them.”*

**Participant 11:** *“Being in mainstream helped me understand different abilities and be aware of other people” .... “Different people had different abilities. For me, it’s a good thing, because we learn from each other.”*

They recognised, that even though they were different from others in their school, they felt that this is positive thing. They enjoyed the opportunity to interact with a range of different children.

**Participant 4:** *“I liked being in range, with different children in each class. I like different experiences.”*

**Participant 5:** *“It was nice to be friends with people that didn’t have special needs.”*  
 .... *“It was helpful to be exposed to the good and bads of teenagers. It taught me a lot.”*

**Participant 12:** *“My class with all the different children was a very nice class”* .... *“I remember people in my primary school class. They were very nice to me even though I was different.”*

Previous research conducted by Sheldon et al. (2021) indicated concerns among fathers of individuals with DS regarding their children's engagement in social groups compared to peers. However, the current findings offer an alternative view, as the participants in this study perceived themselves as having ample opportunities for social engagement within the school environment. While it is acknowledged that participants were specifically asked to reflect on positive aspects of their school experiences—therefore not explicitly invited to focus on potential challenges with social interaction—the substantial volume of data related to social engagement suggests that the participants viewed their social experiences favourably.

For the participants, opportunities to socialise and improve their social skills was a positive memory of school.

**Participant 5:** *“I liked the chance to go on residential. They were very social and fun.”*

**Participant 7:** *“Having the opportunity to work in a team was really helpful because before I wasn’t good in social situations. I have learnt lots of things at school, like how to be social.”*

**Participant 9:** *“I love being with lots of children, it is amazing. It’s important for me to be with other people because I am very social.”*

This highlights the positive impact of socialising with a diverse group of peers in mainstream school settings on YP with DS. It emphasises that interacting with a variety of children fosters a deeper understanding of others, which the participants viewed positively.

These findings align with previous research that YP with DS perceive social interaction positively, such as Jevne et al. (2021), who highlighted the importance of an active social life for enhancing their overall quality of life. On the other hand, these findings diverge from the challenges identified by parents in the study conducted by Farkas et al. (2019). In their research, parents expressed concerns about the social difficulties encountered by YP with DS. These findings suggest that YP with DS may perceive their social experiences differently from how their parents perceive them. While parents in the previous study expressed concerns about social difficulties faced by YP with DS, the current findings indicate that YP themselves may view their social interactions more positively. This is highlighted by the fact that the participant voluntarily decided to talk about this topic when asked about positive experiences. This is interesting as Ijezie et al. (2023) has previously highlighted a discrepancy in findings from self-reporting tools when compared to proxy methods, finding that self-reported quality of life by adults with DS was consistently rated higher than proxy-reported quality of life. Therefore, these current findings also amplify the need for future research to focus on evaluating both self- and proxy-reporting methods. With so much previous research focusing on alternative perspectives, it is important to understand that these may not always be accurate or align with the YP with DS's own understanding of their experiences.

Moreover, the current findings could imply that YP with DS are finding ways to navigate social challenges or are experiencing social relationships more positively than their parents might expect. It may also suggest that interventions or support systems aimed at improving social inclusion for YP with DS could be having a positive impact.

As well as this, the current findings further validate teachers' beliefs, as articulated by Charley (2016), regarding the beneficial effects of peer inclusion on social skills development and overall wellbeing. Additionally, the fact that participants experienced a degree of social integration in mainstream school environments aligns with the principles advocated in the



SEN code of practice (2015), which emphasises the significance of social inclusion for learners with SEN.

A large part of these positive memories of social interactions were centred around playtimes and break times.

**Participant 1:** *“So, I like playtime with my friends. I enjoyed it in primary school a lot.”*

**Participant 2:** *“I was with them (friends) at playtime and in lessons. And they invited me to their house to play games. It made me feel important.” ... “I loved playtime and playing with other children. I played with children who were all different ages.”*

**Participant 3:** *“It (playtime) was a happy time for me because I played a lot with my friends.”*

**Participant 5:** *“I loved playing with my friends (at playtime).”*

**Participant 12:** *“I liked it. It was a time I could play games, and it was a good opportunity for kids and myself and I really like it.”*

This shows that break times (lunch and playtimes) were clearly a very important part of school for these YP, and a positive memory. This finding is consistent with Geiger (2023) who found that break time was important for learners with DS. Moreover, this finding relates to the findings of Engevik et al. (2018) who found that YP with DS were most able to participate in activities alongside their mainstream peers at times like lunch time. Although, it is worth noting that some participants did also use breaktime to have time to themselves, away from others.

**Participant 10:** *“Break was important to have some time to myself. I listen to my music I love music. I and singing and dancing like a big monkey. I love musicals. It is important to be able to switch off at play time and listen to my music.”*

In summary, this theme recognises the positive impact of social experiences, particularly friendships, on the overall school experience of YP with DS in mainstream

settings, highlighting the enrichment of their understanding of others and the cherished memories of play and interaction. This theme contributes to the understanding of friendships and interactions between peers of YP with DS, particularly from the perspective of their own views, which have been less explored in previous research.

However, it is important to acknowledge that participants were specifically asked to reflect only on the positive aspects of their experiences. This focus may have limited the opportunity to explore any challenges or difficulties they might have faced in developing or maintaining friendships. As a result, the findings may not fully capture the complexity of their social experiences, particularly for those who may have encountered obstacles. Despite this, the fact that participants highlighted social engagement as a key theme suggests that these interactions were genuinely meaningful to the participants interviewed. It also indicates that, for some YP with DS, friendships and social interactions are a significant and positive aspect of attending mainstream school.

These findings highlight the importance of educational professionals facilitating and prioritising peer interactions and friendships, as these are clearly an integral and enriching part of the school experience for many YP with DS

### ***Theme 2: Many Positive Attitudes from Others***

The theme “Many Positive Attitudes from Others” explores the positive reception surrounding YP with DS, shedding light on the optimistic recollections the participants have surrounding other people’s attitudes towards them. People from different groups—like school staff, family, and classmates—all showed positive feelings towards the participants. They believed in the abilities of individuals with DS and tried to understand them better. They also tried to include them at school and showed kindness. The individuals with DS interviewed felt listened to and cared for because of these supportive actions. Overall, these positive experiences have shaped how they positively remember others' attitudes and behaviours towards them at school.

**Participant 6:** *“Their (the school’s) attitude towards me was positive. I enjoyed school and I miss it.”*

A significant positive experience of mainstream school for the YP with DS interviewed was that they felt included. Many spoke fondly of their memories of inclusion.

**Participant 2:** *“I felt included, and people wanted me to do well.”*

**Participant 7:** *“At primary school they included me in everything.”*

Feeling included encompassed memories of being able to join in with a range of activities, alongside their peers.

**Participant 6:** *“I loved to be able to have a disco and being with my friends.” .... “I went on a residential to Snowdonia. Mum and dad were able to come along when I was younger and then when I was older, I went on my own. I felt proud to be trusted to go on my own and the school included me with everything, and we managed ok.”*

And feeling included was an important aspect of having a positive school experience and made them feel proud.

**Participant 11:** *“It’s important for me to be included in all of the activities that the other children did, like swimming.”*

**Participant 6:** *“I felt proud to get this alongside my friends.”*

This shows that a sense of inclusion may significantly influence a positive school experience, as numerous participants emphasised feeling included when reflecting positively on their school experiences. This positive observation that the participants had positive feelings of inclusion aligns with earlier research by Kemp and Carter (2002), which revealed that pupils with mild to moderate learning disabilities were typically accepted by their peers in mainstream school settings.

As well as positive attitudes towards inclusion, many of the participants felt that other children were kind to them and reflected positively on their memories of other children's attitudes towards them.

**Participant 1:** *"The children were kind. They were friendly, and I could learn from them. It was nice that they let me play. In the lessons I could use their ideas and share mine."*

**Participant 5:** *"People in the school were all nice. Understanding and accepting."*

**Participant 12:** *"They were so kind to me, and I understood I was different. They were good to talk to."*

Among these positive memories, they spoke about how their friends were supportive of them.

**Participant 9:** *"My friends were amazingly supportive."*

**Participant 10:** *"They (friends) were always there every time that I needed them."*

Also relating to positive attitudes, many participants expressed how they had positive experiences of other people believing in them.

**Participant 1:** *"My teachers believed in me at primary school and my mum and friends."*

**Participant 2:** *"People wanted me to do well."*

**Participant 3:** *"The whole of my family believed in me and believed that I could go to that school with everyone else. It made me happy because my friends too."*

**Participant 4:** *"My teachers believed in me at primary school and my mum and friends." ... "I do think they believed in me. Like my teachers. They knew I could do well."*

**Participant 5:** *"People wanted me to do well." "My English teachers were amazing because she saw my potential in English and championed me. She really believed in me."*

**Participant 6:** *"They knew I could do it."*

**Participant 7:** *“They believed in me and really wanted to do well. So, I could do my best.”*

**Participant 8:** *“People definitely believed in me.”*

**Participant 12:** *“The teachers believed in me. I would say my mum really believed in me.”*

People believing in them was a positive experience for them in school, as it increased their motivation.

**Participant 2:** *“Yeah, people believed in me. It helped me feel good about school.”*  
 .... *“Yes. It made me feel amazing. It helped me try harder at school, even when it was hard. I wanted to do well in my education because my friends, teachers and parents believed in me. It made me feel happy.”*

**Participant 7:** *“I did the Duke of Edinburgh. It made me happy to work towards something and that people believed that I could do it.”*

**Participant 10:** *“They believed in me. It helped me like school more.”* ... *“My family, parents and teachers believed in me. It made me feel proud and sometimes speechless. It was a happy feeling.”*

They often felt supported by others who expressed confidence in their abilities, which contributed to their positive experiences in mainstream schools and facilitated their achievement of personal goals.

**Participant 8:** *“I got a GCSE in cooking because my TA believed I could do it. My key worker believed in me too.”*

**Participant 10:** *“The school helped me achieve massive goals like Duke of Edinburgh.”*

These findings are especially significant in light of prior research findings. Prior studies have indicated that while teachers tend to want to be positive, their actual attitudes towards including pupils with DS were notably influenced by their levels of teaching experience and training (Donohue & Bornman, 2015; Georgiadi et al., 2012). Educators with greater experience and training tended to be more supportive of inclusion, while those with less training, though still supportive, expressed lower confidence in meeting the needs of

these YP. However, the present study indicates that the participants often perceived the attitudes of their teachers positively and felt believed in, suggesting that either these educators were more confident and adequately trained to support them, or the YP did not discern any lack of confidence and often felt content, included, supported, and understood.

Other positive memories that the participants had regarding other's attitudes towards them included that they felt listened to and cared about in mainstream school.

**Participant 1:** *"They made me feel supported at school and listened to. I feel so happy knowing that they know me and care about me."*

**Participant 5:** *"She (TA) was there to listen to me. It was also emotional support."*

**Participant 7:** *"Because if I told them I had a problem, they changed things for me" ... "They were good at listening to me. I did lots of art and design because it was my favourite."*

**Participant 12:** *"People listened to me when I talked about stuff."*

Despite previous research suggesting that teachers may not always be adequately trained to work with YP with DS (Bills & Mills, 2020; Boundy et al., 2023; Kendall, 2019; Laws & Millward, 2001), many participants in the current study believed that those who they worked with often demonstrated an understanding of DS.

**Participant 7:** *"When the teachers understand, it makes it better for them to teach me."*

**Participant 11:** *"My friends did, they tried to. They spoke to me and tried to understand me."*

**Participant 12:** *"They knew it meant that I have special needs. They listened to me and my needs."*

And the participants recognised that if people were not sure, they made an effort to learn about DS.

**Participant 5:** *“Yes, I had a key worker who really understood me, and she wanted to learn more about it. She wanted to learn as much as possible so she could be led by me. I was very lucky. I was grateful!”*

**Participant 6:** *“Yes, the school tried to understand Down syndrome, and they learnt with me and about me.”*

This willingness of others to try and understand DS, may have led to the participants feeling understood, and they believed that most people fostered a positive attitude towards DS. This added to their positive experiences of mainstream school.

This highlights the overall positive experiences YP with DS had regarding others' attitudes towards them in school. This finding is interesting in light of prior research indicating less favourable social attitudes towards individuals with DS. For example, Pace et al. (2010) identified a significant prevalence of negative attitudes among both adults and youth. Similarly, Saha et al. (2014) and Deakin et al. (2018) found that even young children with DS may be aware of negative social attitudes towards their disability. In contrast, participants in the current study reported many positive attitudes and interactions in their mainstream school experiences.

It is acknowledged that the study's focus on positive experiences may have influenced participants' responses, making the absence of reported negative interactions somewhat expected. However, participants voluntarily chose to highlight others' attitudes towards them as a key positive topic. While this does not eliminate the possibility of negative attitudes, it challenges the prevalence or dominance of such attitudes as proposed in the literature. The participants' emphasis on largely positive interactions suggests that negative experiences, if present, were likely less frequent or impactful than what previous research may have suggested.

Additionally, despite concerns among teachers in UK mainstream schools, including apprehensions about resource availability and the potential additional stress of teaching

children with SEN, as identified by Warnes et al. (2022), most participants in the current study expressed feelings of being supported, believed in, and welcomed by their teachers.

The emergence of this theme highlights some of the positive experiences of inclusive education, aligning with the principles outlined by Faragher et al. (2020), which advocate for welcoming all pupils into local education settings and providing necessary support for active engagement in all aspects of learning.

In summary, this theme reveals some optimistic perceptions that the participants have of the supportive attitudes and behaviours exhibited by various groups, including school staff, family, and classmates, which positively shape their overall school experiences. This highlights the importance of social attitudes in shaping educational outcomes. While previous research has examined societal attitudes toward YP with DS, this study provides insights into the specific impact of others' attitudes within the school context and the keen awareness YP with DS have of these dynamics.

However, it is important to critically reflect that due to the solution-focused theoretical orientation of the research, the data does not fully capture the full experience of participants in relation to societal attitudes, but nonetheless illuminates an important aspect.

Moreover, while the findings highlight the profound influence that positive attitudes from peers and educators can have on enhancing the educational journey of YP with DS in mainstream settings, it is essential to recognise that the mere presence of positive attitudes does not automatically equate to comprehensive support. Positive attitudes must be accompanied by effective, evidence-based practices and adequate resources to address the diverse needs of YP with DS (Faragher & Clarke, 2014). Research has shown that inclusion is not solely dependent on attitudes but requires systemic efforts, including specialised training for educators, tailored resources, and inclusive practices to ensure meaningful participation (Booth & Ainscow, 2011). The focus on positive experiences could also mask underlying structural or systemic challenges that YP with DS may face, such as inadequate



access to resources or specialised support (Guralnick, 1999b). Without these, positive attitudes alone may not fully support the educational and developmental needs of YP with DS.

Nonetheless, this revelation promotes the urgency of fostering inclusive and supportive environments in schools, as this new perspective from YP with DS emphasises their appreciation of feeling valued and empowered to thrive. These findings can be used to help educational professionals understand the significance of holding and conveying positive attitudes towards YP with DS and can inform the development of future policies and training programmes aimed at fostering inclusive environments. By integrating strategies to cultivate and sustain positive attitudes, alongside practical support and resources, educators can create more supportive and empowering spaces for YP with DS within mainstream education.

### ***Theme 3: Learning Core Skills in Key Subjects***

The theme of "Learning Core Skills in Key Subjects" explores the positive experiences of the participants in learning key academic subjects within their mainstream school setting. This notion is intricately woven throughout the interview data, with the participants expressing the positivity of learning key subjects such as maths, reading, and writing. Their accounts highlight the joy derived from the learning experience and the perceived usefulness and transferability of these key subjects to other academic areas and personal contexts. Additionally, this theme highlights the optimistic reflections stemming from the pursuit of qualifications, emphasising the positive journey towards academic achievements.

***Participant 1: "I just like working. I like to learn!"***

This quote is particularly powerful as it signifies the importance and joy of learning for the participants.

Participants expressed how learning key areas of the curriculum was important to them, and that having the opportunity to do this was a positive experience of mainstream school.

**Participant 6:** *“Mainstream is really good to learn to read and write.”*

**Participant 9:** *“I feel proud that I learnt to write, and I can now use it every day and school helped me do that.”*

**Participant 11:** *“I think I have learnt a lot in schools. I learnt maths, English, how to be sociable and how to be independent”.*

**Participant 12:** *“I liked reading and maths and I did it all”. .... “I am good at maths; I had the opportunity to do it.”*

Participants spoke specifically about core subjects such as maths.

**Participant 1:** *“Learning numbers is really important to understand things in life.”*

**Participant 2:** *“I think maths is important and useful. I use my fingers to help me, and my class teacher showed me how to use cubes to help me too. Maths was my favourite classroom, and I was in a big class with lots of children and it made me feel good about maths and learning.”*

**Participant 6:** *“I learnt how to add and take away” ... “I did do entry level maths.”*

**Participant 9:** *“Maths makes me feel good because I am good at maths.”*

**Participant 10:** *“I loved maths a lot.”*

In particular, they positively reminisced about how learning maths increased their key skills.

**Participant 1:** *“In maths I learnt time, shapes, measurements and tallies and adding and taking away.”*

**Participant 5:** *“School made me focus on maths a lot, but it has given me life skills. Like learning time, adding and take away.”*

**Participant 10:** *“I learnt money skills. I liked learning skills for real life.”*

**Participant 11:** *“I liked learning maths with the others my age and having it as a core activity because it is important for life, I could learn from others.”*

Participants were equally as positive about learning how to write.

**Participant 1:** *“Yes they did (teach me how to write) and I enjoy writing.”*

**Participant 2:** *“I did a lot of writing, especially in secondary school. Knowing how to write well made me feel amazing.”*

**Participant 5:** *“I enjoyed learning to write. It was fun learning to spell. I’ve got a photographic memory so I can spell anything. It gave me confidence that my teachers knew I was good at it.”*

**Participant 3:** *“It’s good I learnt to write.”*

**Participant 6:** *“Learning to write was good.”*

**Participant 9:** *“When they taught me how to write I felt amazing.”*

**Participant 10:** *“I enjoyed learning to write.”*

**Participant 11:** *“School helped me to learn to write, I did a lot.”*

**Participant 12:** *“I really liked learning to write. Now I can write stuff, for example I signed your form.”*

They also talked about learning to read, expressing a positivity about both reading in school and continuing to enjoy reading now.

**Participant 3:** *“I like reading.” ... “I read at school, and I had reading books. Learning to read at school means I can read at home, and I like reading at home.”*

**Participant 4:** *“I love reading. I liked books ever since I was little.”*

**Participant 10:** *“I remember about reading. I love reading.”*

Interestingly, similar to their experiences with maths, the participants discussed the positive impact that learning to read and write had on their general life skills. Making learning to read and write a particularly positive aspect of their time at mainstream school.

For example, participants spoke about how learning to read and write aided them with other areas of the curriculum.

**Participant 1:** *“Understanding how to write helped me feel like I can learn well.”*

**Participant 7:** *“Reading helps me understand things.”*

**Participant 8:** *“Reading was helpful.”*

**Participant 11:** *“Yes, so reading helped me learn key information.”*

They also expressed how learning to read helped them in general life too.

**Participant 6:** *“Because I do writing and I use it in life, like for writing lists.” ...*

*“Reading is important so I can read things around the place. Like the names on my DVD cases and stuff.”*

**Participant 7:** *“Because reading helps me understand things. I can read signs and stuff, or I can read on my phone like text, and I read games on my iPad.”*

**Participant 9:** *“I feel proud that I learnt to write, and I can now use it everyday and school helped me do that.”*

**Participant 11:** *“I can read signs and cards and things I need in life. I can read DVD cases and also, I watch TV with subtitles.”*

Some even spoke about how reading and writing has helped them to communicate.

**Participant 1:** *“I didn’t talk much so writing helped me explain things.”*

**Participant 6:** *“It is also good because I can text now. It’s a good way for me to communicate because I have longer to think and express myself. So therefore, it was so important for me to learn to write. It has helped me as an adult.”*

**Participant 9:** *“Learning to read and write is important so I can talk on WhatsApp and be social and talk to my friends.”*

**Participant 10:** *“Writing has been good to me because I can write to express myself.”*

**Participant 11:** *“Writing helped me communicate.”*

And others spoke about how learning to read has been a means to regulate.

**Participant 7:** *“I was also able to use reading time to switch off when I needed space.”*

**Participant 10:** *“Reading is relaxing, and it helped me at school when I got stressed.”*

Many participants also expressed that learning to read and write was a positive experience of school as the skills they have learnt have been embedded into new hobbies.

**Participant 2:** *“Learning how to read helped me have an interest and read books at home.”*

**Participant 3:** *“I read at school, and I had reading books. Learning to read at school means I can read at home, and I like reading at home. I like Matilda and Roald Dahl.”*

**Participant 8:** *“It was also good to learn to read because now I can read for fun. I like to read David Walliams, Roald Dahl, Miranda Hart. Miranda Hart is hilarious!”*

**Participant 11:** *“I write fan fiction for a hobby. I write it by hand then type it up. I write loads.” ... “I loved learning to read because now as an adult I read fan fiction for fun.”*

**Participant 12:** *“I read books and magazines for fun. I really love reading and I am glad I could learn.” ... “I like watching count down and reading the words. I can read from learning what the words look like. I am glad I got the chance to learn.”*

These findings show learning academic subjects in mainstream school was not only a positive experience while at school, but it also continues to have a positive impact on their lives now. In addition, it is noteworthy that participants highlighted their involvement in academic lessons, which contrasts with previous research suggesting their exclusion from more academically rigorous subjects, such as mathematics, despite participation in non-academic activities like lunchtime, music, and physical education (Engevik et al., 2018).

Moreover, previous research by Turner et al. (2008) highlighted the academic achievement of YP with DS may be determined by their level of learning disability. However, the current study's findings suggest that, regardless of their achievement, participants still valued their inclusion in academic lessons. Therefore, academic lessons should not be restricted according to their learning disability, regardless of their outcomes. This is because despite variations in academic ability and the severity of their learning disabilities among participants, all individuals reported positive experiences of academic learning regardless of this and valued the opportunity to engage in educational activities. These findings really

emphasise the significance of learners with DS being included in core learning and should prompt more schools to consider how they can ensure this. Moreover, these findings showcase how the participants were able to reflect on the importance of academic learning, its meaning and significance in their lives and why they enjoy it. Previous research using the perceptions of YP with DS on education has not captured this to the same degree and with the same level of insight and nuance. For example, the participants in Geiger (2023)'s research tended to focus on creative lessons.

The data within this theme also highlighted how learning key subjects had the potential to lead to the completion of qualifications. This was positive for the participants as they felt proud of their qualifications.

**Participant 2:** *“I didn’t do GCSEs, but I did get ready for them. I did entry levels, and I am proud of my certificates and qualifications. I could still be with friends doing GCSEs and work towards my own level.”*

**Participant 6:** *“I did get to do entry level maths. Getting a qualification was good.”*

**Participant 7:** *“I got some qualifications, and I have the certificates. Things like English and Maths, it helped me get my job today” .... “I am on entry level 4 now. Qualifications are good.”*

**Participant 10:** *“I got 1, 2 and 3 in English and maths, I’m working towards 4. I got 5 vocational studies too. I feel proud of my qualifications and school helped me work towards them.”*

**Participant 11:** *“I have qualifications in history, science, child development, ICT and maths! I have entry level 2 in English. Getting these awards for learning made me feel proud about school.”*

The participants' emphasis on qualifications highlights their appreciation for the learning process and the tangible evidence of their achievements, which they perceive as beneficial in their post-school lives. It also emphasises that YP with DS can have high hopes for their future, and that this should be recognised and supported. This unique finding

emphasises the importance of academic qualifications for some YP with DS, a perspective that hasn't been highlighted in previous research. Hence, this provides a fresh insight that some YP with DS value the opportunity to pursue qualifications. This shows that opportunities for YP with DS should not be limited due to other's perceptions and that their high expectations for themselves need to be acknowledged.

The study's focus on individuals who attended mainstream schools may have facilitated this discovery, aligning with Kefallinou et al.'s (2020) observation that inclusive settings offer diverse opportunities, including access to qualifications. This insight is further supported by Rangid's (2022) discovery that YP with SEN are more likely to pursue higher education if they attended mainstream schools.

Additionally, it is worth noting that these participants may have held a particularly positive attitude towards qualifications compared to YP in previous research due to the influence of their mainstream education experience. Other studies have also indicated that YP with DS tend to excel academically in mainstream settings (Buckley et al., 2006; Rojewski et al., 2015; Schwab et al., 2016; de Graaf et al., 2012), suggesting that a mainstream environment may be influential in YP with DS holding positive attitudes and aspirations for qualifications.

In summary, this theme highlights the possible positive implications of offering individuals with DS the opportunity to acquire foundational academic skills within mainstream schools. The findings reflect participants' enthusiasm for learning subjects such as mathematics, reading, and writing, and highlight the perceived value and applicability of these skills across both academic and personal domains. Furthermore, participants expressed optimism about pursuing qualifications, emphasising the importance they place on academic achievement. This appears to be the first study to truly capture the significance of academic learning from the perspectives of YP with DS, a finding that cannot be ignored. The participants are articulately and evocatively communicating that academic learning holds

substantial meaning for them, which highlights the importance of educational professionals and schools to prioritise access to academic learning and qualifications for YP with DS.

It is important to consider the exclusive focus on positive experiences. This focus might mask structural barriers, such as limited access to differentiated resources, inadequate teacher training, or systemic exclusions from certain academic subjects, which have been noted in previous research (Booth & Ainscow, 2011; Guralnick, 1999b). Without considering these potential challenges, the findings provide an incomplete picture of the educational experiences of YP with DS in relation to accessibility to academic learning.

Despite this consideration, the findings remain valuable and provide an important contribution to the literature on DS and education. The fact that the participants emphasised the importance of academic learning and the pursuit of qualifications is noteworthy. These findings can inspire educational professionals to expand the role of academic learning in the education of YP with DS, ensuring that their needs and ambitions are met through inclusive, supportive, and high-quality educational practices, along with teachers who hold high expectations for their success.

#### ***Theme 4: Positive Memories of Supporting Staff***

The theme "Positive Memories of Supporting Staff" highlights a favourable perception among participants regarding their close collaboration with school staff, creating positive school memories. Whilst Theme 2 captured the positive attitudes of others, this theme delves deeper by emphasising the importance of YP with DS feeling supported by staff members. The foundation of this theme lies in the universal acknowledgment from almost every participant, that they had adult support in school, and this is something that they liked. As well as TAs, participants also had positive memories of the teachers they worked with.

Previous studies have established the practice of assigning TAs to pupils with the lowest attainment levels or those with SEN (Keating & O'Connor, 2012; Graves, 2013; Roffey-Barentsen, 2014). There are mixed and conflicting research findings about whether



this is good practice, with some research suggesting that it is crucial for the inclusion of these pupils (Masdeu Navarro, 2015) but others suggesting that pupils with SEN perform worse with the presence of a TA (Blatchford et al., 2012). Despite conflicting evidence on the benefits of TAs, studies exploring the education of YP with DS have also found that this group of YP also often work with a TA (Van Herwegen et al., 2018; Wren, 2017).

Similarly, the current study also highlighted the prevalence of TA support, finding that all of the participants received frequent help from a supporting adult. This was in the form of a TA that worked directly with them. All 12 participants in the current study recognised that they had this support.

**Participant 2:** *“I always had adults with me to help me.”*

Participants were able to explain the role of the TAs that supported them.

**Participant 1:** *“Miss XXXX used to help me in primary school. She was a TA. She sat with me in most lessons. She also helped me with going to the bathroom. She helped show me around and be less nervous and become more brave. At secondary school I had some TAs too. They came in most of my lessons with me.”*

Participants liked having this support and reflected on it positively – adding to their positive experiences of mainstream school.

**Participant 1:** *“Yes I really do (like having a supporting adult).” ... “She was great and always helped me!”*

**Participant 3:** *“They sat with me in the lesson, and I liked having them with me.”*

**Participant 5:** *“It was good to have a TA when I needed it.”*

**Participant 6:** *“I preferred working with adults, they could help me more.” ... “I liked having someone with me to help me.”*

**Participant 7:** *“It (having adult support) made me happy and safe, and it was always the same people. They knew me really well.”*

**Participant 8:** *“Having a TA made me happy, they did an amazing job to help me out.”*

**Participant 11:** *“My TA was amazing, I remember her from a long time ago.” “TAs helped me a lot. When the main teachers were teaching, she always gave me extra help and helped me to think.”*

**Participant 12:** *“They (the TAs) were so supportive. They helped me a lot.”*

Participants’ frequent use of the word “happy” when referring to working closely with a TA highlights how positively they viewed this support, adding to their positive experiences of mainstream school. Participants also express how they found this TA support “helpful”. This finding is particularly interesting, as the guidance from the Education Endowment Foundation (Sharples et al., 2016) caution against using TAs for constant support in every task, but rather suggest that TAs should be used to help pupils develop independent learning skills and manage their own learning. However, it is not the first time that TAs have been found to be helpful for learners with DS; Fox et al. (2004) also found that it was useful for a TA to work alongside YP with DS – particularly as they tended to be the ones who knew them best, making them well informed to help to plan and adapt lessons. This finding may prompt further exploration into what TA support should look like for learners with DS in order to be the most effective, while still helping them to feel happy and supported.

In addition to positive experiences with teaching assistants, participants also recognised their teachers as contributing to a positive experience in mainstream schools.

**Participant 1:** *“I had a teacher called XXXX who was a great, lovely, sweet teacher. She helps me learn. She is special to me because she is a lovely person with a good soul, and she spent time to get to know me. Teachers that helped me get around the new buildings were my favourite because sometimes it was hard finding my way around. But lots of teachers were kind and have good souls. XXXX was a good teacher too. I think she was good because she was strict, and it helped me learn. Being strict can be both good and bad. But I know she cared. She protects me and wants me to do well.”*

**Participant 2:** *“Teachers in school always wanted to help me and checked if I was ok.”*

**Participant 7:** *“My sixth form teacher was good because she was caring and knew me well. I like them to show an interest in who I am and learn from me.”*

**Participant 10:** *“The teachers are a big part of my life. They are kind of like friends and not just teachers. They know me really well.” .... “I liked him (teacher) because he talked to me, and he was so nice and friendly. He was my favourite.”*

**Participant 12:** *“XXXX was a nice teacher, he was a nice man who understood me and different people. Because I am so good, and he knew that. He understood me. He supported me and my friends. And I would say he is a very special person; he could teach me anything.”*

This outcome is especially pertinent given prior research documenting the challenges that teachers may encounter in addressing the complexities of learning disabilities (Lauchlan & Greig, 2015). Contrary to these documented challenges, the current findings reveal that the participants often perceived their teachers as adept in teaching, feeling understood and well-supported. This enhanced the effectiveness of teaching, contributing to their positive experiences of school. This finding aligns with Florian and Graham’s (2014) assertion that teachers have a crucial responsibility to remove obstacles to learning and foster an environment conducive to the flourishing of all pupils alongside their peers. Additionally, it highlights the importance of a strong teacher-student relationship, as suggested by Koca (2016).

In summary, this theme illustrates the participants’ favourable perception of close collaboration with school staff, highlighting the significance of adult support and good relationships with adults in creating positive school experiences. In particular, it emphasises that the participants view working with a TA positively. Due to the mixed understanding of the impact and use of TAs, this finding prompts further exploration on how TAs can be best used to support YP with DS in mainstream education, as this is something that the participants in this study suggest they like. Additionally, the findings that the participants valued their relationship with teachers also highlights the significance of teachers and other professionals

developing supportive relationships with YP with DS in mainstream schools, as well as the TAs.

### ***Theme 5: Exposure to a Range of Experiences***

The theme "Exposure to a Range of Experiences" refers to the substantial body of data reflecting positive experiences of taking part in activities beyond the core subjects within the mainstream school environment. Participants express enthusiasm for the broad spectrum of subjects offered, including history, ICT, and drama, among others. Moreover, they fondly recollect engaging in extracurricular activities such as sports and school performances. Additionally, the enjoyment derived from participating in school trips with peers is a notable aspect of this theme. Collectively, these reflections emphasise that the participants perceived the opportunity to partake in a diverse array of experiences as a notable positive aspect of their education within a mainstream school setting and emphasise the need for a broad and balanced curriculum.

As discussed in Theme 3, participants expressed the importance of learning core, academic subjects in school. However, additionally, many participants also spoke positively about how attending a mainstream school gave them the opportunity to learn a variety of different subjects, not just English and maths. Participants spoke about how they enjoyed being able to explore different topics and felt that this helped them decide what subjects they were most interested in.

***Participant 2:*** "I liked doing different subjects. History and music were amazing. We got to try lots of things in music. We sometimes used a computer in music. It was good to learn lots of different things and decide what I wanted to pick when I got older."

***Participant 3:*** "I liked trying new things to decide what I was good at."

***Participant 4:*** "It was good to be able to try all of the different subjects, just like my friends did."

**Participant 6:** *“I liked being able to learn about lots of different things and not just English and maths.”*

**Participant 10:** *“I liked having lots of different lessons, it helped me decide what I like. My favourite is history!”*

Some participants were able to express in more detail why it was important to them to learn a range of subjects and how this added to their positive experiences of school.

**Participant 1:** *“I really love history; it is so interesting. I love learning about the past. It is great. I’m so happy I got to learn about different things, it helped me know what I like and what I am interested in. Especially history and sport. I was happy to learn art because I like to be creative. I really like music too; I like making up songs and using special effects. I like to do coding in ICT too. Art and ICT are good because I can put them together. For example, to make a game, you need to be good at art for the animation, but coding to make it. You can put the two subjects together to do something well.”*

The participants positive accounts may suggest that most of them had access to a diverse range of subjects, a positive aspect of their educational experience. However, this has been identified as a potential issue in the literature. Previous research by Hargreaves et al. (2021) revealed discrepancies in access to a broad curriculum among pupils with DS. Given the overwhelmingly positive reflections in the current study regarding access to various subjects, it highlights the significance of providing YP with DS with a comprehensive curriculum, allowing them the chance to explore diverse areas rather than limiting opportunities based solely on perceived strengths and weaknesses. Moreover, this is crucial to foster inclusive education, as inclusive schooling ensures that all pupils receive adequate support to participate fully in all aspects of learning (Faragher et al., 2020). Moreover, findings from Bouck (2012) suggested that curriculum decision-making at the secondary level should align better with YP's desired postschool outcomes. Hence, exposing these YP to a variety of subjects can aid in this process, allowing them to determine their areas of interest, as echoed by the participants in the present study. The view that inclusion in a variety of subjects helped participants identify the ones they enjoyed most and excelled at

aligns with the findings of Jevne et al. (2021), who found that a good quality of life for those with DS depended on being able to do work based on their interests and capability. Participants also noted that they enjoyed being able to do all subjects, “just like their friends” suggesting that involving YP with DS in all aspects of the curriculum can also be beneficial for fostering a sense of inclusion. This highlights the importance of having a holistic understanding of the learning of YP with DS and their preferences, rather than focusing on their disability and deficits areas.

Moreover, participants revealed that the opportunity to do sports was also a particularly positive for them.

**Participant 1:** *“All sports, I love them all. I like it when school sees how good I am and helps me.”*

**Participant 2:** *“PE is my favourite lesson, and I got to do sports in after school clubs. I like gymnastics and basketball.”*

**Participant 4:** *“I loved multi sports festivals. We could go to other schools and complete. I had a morning off timetable to go.” ... “I liked doing cricket, dance, swimming and tennis.”*

**Participant 7:** *“I loved PE. I loved football the most and frisbee golf.”*

**Participant 12:** *“I really like playing football. PE was my favourite subject. I also played football with my friends.” ... “Yes, I had a nice time, we always played football. Football is really important to me.”*

This finding indicates the importance of sports and physical activity for YP with DS, this can include both PE lessons, as well as involvement in sports clubs and additional activities. Much other research has also highlighted the importance of sport and physical activity for YP with disabilities. For example, Cebula et al. (2010) suggested that attending sports programmes was extremely positive for pupils with disabilities and found that they can help enhance knowledge, confidence, and motor skills. This study adds to the body of research in articulating the importance of sport from the perspective of YP with DS themselves.

As well as being able to access a range of subjects in the curriculum and participation in sports, a key finding within this theme is that the participants also enjoyed engaging in extra-curricular activities.

**Participant 11:** *“Extracurricular things were important to be involved in.”*

Extra-curricular activities that they enjoyed included taking part in performances.

**Participant 6:** *“I took part in extracurricular activities like singing and acting and I got to perform in shows, and we went on stage in front of a lot of people. And we even got on TV once.”*

**Participant 10:** *“I liked being in the pantos and school shows. I love acting. It made me feel happy to perform.”*

They also enjoyed attending school trips and taking part in school events.

**Participant 5:** *“I liked the chance to go on residential. They were very social and fun.”*

**Participant 6:** *“I went on a residential to Snowdonia. Mum and dad were able to come along when I was younger and then when I was older, I went on my own. I felt proud to be trusted to go on my own and the school included me with everything, and we managed ok.” ... “The leaver’s prom was great!”*

**Participant 10:** *“School trips were a good memory. Going to Southwold. I loved it and I felt happy.” ... “I really liked school trips. To the museum and Wales and loads.”*

**Participant 11:** *“I liked going on school trips.”*

These findings can be likened to Dolva et al. (2014) who found that participating in leisure activities was important for YP with DS. Moreover, some of the findings within this theme may overlap with those of the previous theme, as the data highlights how participation in extracurricular activities contributed to feelings of inclusion among YP with DS, enabling them to engage in the same activities as their peers. This is particularly significant given that 40% of children surveyed in Pace et al.'s (2010) research expressed an unwillingness to

spend extracurricular time with a student with DS. The fact that participants in the current study shared such positive experiences of extracurricular activities alongside their mainstream peers may suggest that they believed they had many opportunities for inclusivity.

It is important to acknowledge that participants were prompted to reflect on positive experiences, which whilst this made visible the value and significance of accessing a range of experiences, it does not foreground the potential challenges that may also exist for them in this area. Given what we know from the literature, there may also be stories of challenge or exclusion for these YP in gaining access to rich and diverse experiences at school.

In summary, this theme highlights the positive impact of diverse educational opportunities in mainstream schools for the participants; experience of mainstream school, encompassing various subjects, extracurricular activities, and school trips, contributing to positive experiences in mainstream school. This contributes to the understanding of how to support learners with DS in school. An implication of these findings is that schools, educational professionals, and families need to ensure that the curriculum is not limited for these learners and that YP with DS supported in school to access a rich range of experiences. It is important to move away from designing their curriculum around their disabilities and struggles, but rather consider how to support YP with DS in accessing a broad and balanced curriculum that they can have a say in.

### ***Theme 6: Opportunities to Practise Independence***

The theme “Opportunities to Practise Independence” explores the different ways that the participants spoke positively about independence. This includes their reflections that learning to be independent was important for them at school and that being given independence was a happy memory for them. Within this theme, different ways of how the participants were given independence is explored. These encompass instances such as autonomously managing break and lunch times, as well as independently commuting to school.



Furthermore, the theme extends its view to explore the positive reflections of the participants regarding schools actively aiding them in preparation for independence beyond the school context. This forward-looking approach involves not only equipping pupils with life skills but also instilling a readiness for the future, thereby contributing to a comprehensive understanding of independence within and beyond the educational setting.

Many of the participants discussed how they felt that they were given independence at school.

**Participant 1:** *“I am learning to do things on my own in sixth form and it is good for me. In Key Stage 4, I learnt how to be more independent too. For example, I had to independently learn about the new building in school.”*

**Participant 4:** *“Sometimes I was given independence.”*

**Participant 6:** *“I was able to do things with my friend without a teacher.”*

**Participant 9:** *“I do a life skills group with things like cooking and how to get the food and make my own lunch.”*

**Participant 12:** *“When I felt more confident, I could do things independently.”*

Within their discussions of independence, participants expressed how they liked having independence, insinuating that opportunities for independence were a positive experience of school.

**Participant 2:** *“I could do things on my own. This made me happy.”*

**Participant 4:** *“I did like to be independent.” .... “I liked doing things for myself.”*

**Participant 6:** *“I felt proud to be trusted to go on my own.”*

**Participant 7:** *“It’s good for people to let me try and do things on my own.”*

**Participant 11:** *“I was allowed more independence at high school. It made me feel proud of myself.”*

**Participant 12:** *“I could do things independently and it made me happy.”*

This data highlights the importance of granting YP with DS a degree of autonomy within their educational environment, affirming their capability for independence. Participants responded positively to opportunities for independence, which is echoed in numerous studies examining the quality of life among individuals with DS (Scott et al., 2014; Sheridan et al., 2020). Consequently, it makes sense that YP with DS value this sense of independence within the school setting as well. The data highlights the confidence of the participants in their ability to take on independent responsibilities within mainstream schools. This perspective may serve to encourage school staff to have confidence in the abilities of YP with DS to handle such responsibilities.

When talking about independence, participants recognise that a key time that they experienced independence was at break and lunch times.

**Participant 2:** *“I didn’t spend play time with an adult, they let me do my own thing.”*  
*... “I didn’t have TAs with me at break and lunch time because it is better to be with my friends.”*

**Participant 4:** *“I had independence with getting my lunch, once I got to know the school.”*

**Participant 5:** *“I was independent with getting my school lunch.”*

**Participant 7:** *“I am independent at break at lunch time. Get my food on my own and hang out with my friends.”*

**Participant 10:** *“Break was important to have some time to myself.”*

**Participant 11:** *“I was independent in the playground. I didn’t need help from adults. I could hang about and play with my friends as I wanted.”*

These findings differ from those of Hargreaves et al. (2021) who found that most learners with DS in mainstream schools had an adult with them some of the time at break (primary: 82.76 %; secondary: 76.67 %) and lunch (primary: 79.69 %; secondary: 70.00 %). Based on the results of the current study, the necessity and benefits of providing support

during break and lunch times for these YP may be questioned. The participants reflected positively on their experiences of having independence during these times.

Some participants also shared that a positive element of going to mainstream school is that due to being able to attend their local school, they were able to independently commute to school.

**Participant 1:** *“I liked primary school because it was close and I could walk there myself, when I moved to another school I have to have a long taxi drive.”*

**Participant 3:** *“I was able to get the bus to school as we didn’t live too far, and it helped me learn how to do it.”*

**Participant 4:** *“It was good that being in a mainstream school meant that I could walk to school as it was close, and I could be independent.”*

These findings are important because while previous research has emphasised the importance of independence for YP with DS, it has not been explored within the context of school. Therefore, prior to the current study, there was limited understanding of how YP with DS perceive independence within the school setting or how to promote this. However, these findings offer valuable insights into this matter. They reveal that break and lunch times serve as periods where many YP with DS feel secure enough to act independently, without constant adult support. As well as this, the findings prompt reflection that mainstream schools could be potentially beneficial environments for promoting independence, as attending such schools increases the likelihood that YP with DS can attend their local school. This, in turn, provides them with opportunities to develop independent skills, such as traveling to school independently.

As well as speaking positively about being given independence while at school, participants also felt that they had positive experiences of the schools preparing them for the future and learning how to be independent in the wider context. This included the school helping them to think about their future.

**Participant 1:** *“Yes! I like talking about that (the future). We have careers meetings.” ... “Careers fairs helped me to talk about thing that I wanted to do, like thinking about jobs and where I should go to school or college in the future. I even think about university. I really liked this because it makes me think people want me to do well. I already have been thinking about my next college. I feel excited about this, and I know I have lots of options.”*

**Participant 3:** *“My teacher told me about different colleges that are out there, it made me excited, and I asked my mum if she could take me to look at the college.”*

**Participant 7:** *“We talked about jobs. I want to work in a café or be a hairdresser or a football coach.”*

**Participant 10:** *“Well, every year, I went on the computer to see what jobs were suitable for me after I wrote things I liked to do.” ... “It helped me enjoy school to think about the future. I want to be a famous actor.”*

And equipping them with life skills and providing work experience to embed these.

**Participant 3:** *“I got to learn life skills. I had separate work to do life skills and easier things I use every day.”*

**Participant 9:** *“I do want to be independent and move out. I learn life skills at college to help me with this. I do a life skills group with things like cooking and how to get the food and make my own lunch.”*

**Participant 6:** *“Yes, when I was at school I did work experience. I worked in Tesco. It helped me get ready for work. And I worked in the café there.”*

**Participant 7:** *“They helped give me the experience I needed to do my internship now.”*

**Participant 10:** *“I got to do work experience to get me ready for real life. I loved work experience.” ... “We had to do planning activities, that prepared me for real life. Like doing a BBQ and planning who brings what.”*

**Participant 12:** *“I did work experience at school. I did catering. I worked in the kitchen. I did it for 6 weeks one day a week. I enjoyed my responsibilities.” ... “Yes, the school said it was important to do work experience. I thought it was important too.”*

This shows the importance of preparing for a future job for the participants. This relates to the findings of Takataya et al. (2022) who found that YP with DS were serious about work and believed having a job is important. This highlights the importance of supporting YP with DS to feel prepared and able to get a job.

Considering the findings of Sheldon et al. (2021) that fathers of children with DS worried about their children's future and Leonard et al. (2016) that parents were concerned about their children being prepared for adulthood once the support of school had ended, the present study's finding that participants reported positive experiences in preparing for the future and felt adequately supported by their schools is noteworthy. While it cannot be concluded that all schools are addressing these concerns, these findings may indicate that some schools are making progress in supporting YP with DS in their transition to adulthood. This highlights the potential impact of educational support systems in enhancing the perceived readiness of YP with DS for life beyond formal schooling.

Moreover, Bouck (2012) explored the relationship between school curriculum and post-school outcomes for YP with learning disabilities. The findings highlighted the importance of aligning secondary school curriculum decisions with YP's desired post-school outcomes to improve their chances of success, as indicated by low rates of independent living, employment, and post-school education reported among individuals with learning disabilities. However, the results of the current study suggest that the schools that the participants attended had considered this aspect, which was positively received by the participants, indicating a positive step forward in addressing these concerns and leading to positive experiences of school and beyond.

In summary, this theme explores the participants' positive reflections on the importance of independence at school, including memories of being given autonomy, and explores various ways in which YP with DS experienced and were supported in practicing independence, both within and beyond the school context, ultimately contributing to a holistic

understanding of independence in education and beyond. This prompts consideration of how to ensure schools can provide opportunities for independence for YP with DS. Key educational professionals and school staff need to be aware how to plan and facilitate experiences that allow YP with DS to feel ready for independence. Moreover, a wider structure needs to be considered to help prepare YP with DS for life beyond school.

It is important to acknowledge that participants were specifically asked to focus on positive experiences, which will have influenced their reflections on independence. While the depth of their reflections and the variety of aspects of independence discussed suggest they genuinely had positive experiences in this area, it is also possible that they were reflecting on only a few instances of independence. As with the preceding themes, caution is necessary when interpreting these findings. Although participants identified and articulated independence as a positive experience, it is important not to generalise this to their overall experience, given the study's focus. Access to or opportunities for independence may still be an ongoing challenge for many of these YP.

Nevertheless, following a solution-focused approach, it is important to explore and amplify these positive experiences of independence. By understanding these experiences, schools can implement strategies that replicate such opportunities for independence in other educational settings, ensuring that other YP with DS have similar opportunities to thrive academically, socially, and personally and feel confident to complete some tasks independently. This approach can help foster more inclusive and empowering environments that prioritise the development of essential life skills for YP with DS.

Overall, the analysis of RQ1 showed that participants were able to discuss the positive aspects of their mainstream education, providing clear examples of what they enjoyed about their school experiences. This led to the identification of six themes that helped clarify their experiences. Whilst some findings aligned with previous research, others provided valuable new insights into the experiences of YP with DS in mainstream schools.

## **Key Themes and Discussion: Research Question 2**

RQ2 - What do YP with DS believe can help facilitate positive experiences of mainstream school for them?

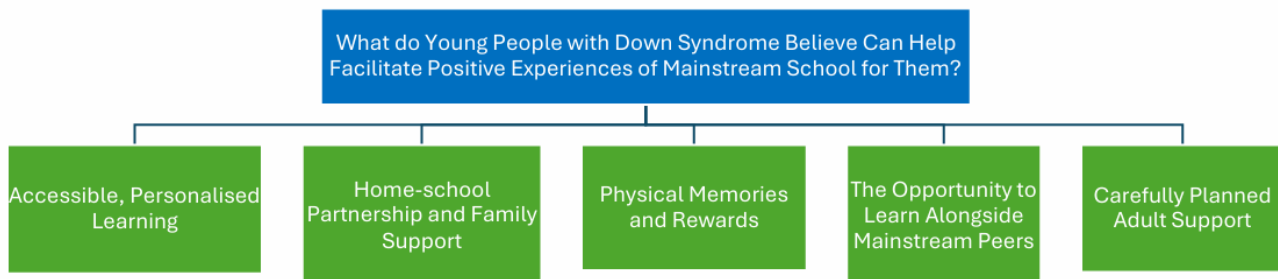
The participants found responding to RQ2 to be more complex. It was essential for the researcher to carefully interpret their answers to understand what they identified as contributing to their positive experiences. For this reason, the analysis of RQ2 took on a more latent orientation (Braun & Clarke, 2022), focusing on what the participants described as helpful in school to infer and deduce strategies for facilitating positive experiences in mainstream education for learners with DS.

RQ1 was designed solely to highlight positive experiences, thus creating bias. While this bias still exists in RQ2, it may be less pronounced. This distinction arises from the nature of the questions and the depth of participant engagement. Whereas RQ1 sought to identify positive experiences, RQ2 goes further by exploring the mechanisms and practices that facilitated these outcomes. This shift prompts participants to reflect not only on their experiences but also on the broader context of support, strategies, and actions that contributed to those successes, offering richer insights into how they can be replicated or enhanced. By encouraging participants to think carefully about the factors that supported positive outcomes, RQ2 expands the scope beyond simply identifying what worked. The open-ended nature of this inquiry invites deeper reflection and dialogue, providing a more nuanced understanding of effective practices. The continuation of the focus on positive experiences in RQ2 aligns further with solution-focused principles by seeking to understand what might work best for YP with DS in the future. This approach ensures that RQ2 not only identifies successes but also provides practical, actionable insights into how schools and educators can build on those successes to foster more inclusive and supportive environments.

Analysis of the data for RQ2 revealed 5 key themes. These were “Accessible, personalised learning”, “Home-school partnership and family support”, “Physical memories and rewards”, “The opportunity to learn alongside mainstream peers” and “Carefully planned adult support”. The YP with DS interviewed were able to articulate what helped them at school and why this was useful. These themes are displayed below in a thematic map:

**Figure 2**

*Thematic map of Research Question 2 Findings*



***Theme 1: Accessible, Personalised Learning***

In RQ1 two of the themes linked directly to learning, including the learning key academic subjects and the opportunity to engage in a range of different subjects. Within this current theme, the participants expand on this further, describing how they believe their learning can be enhanced and supported, so that a positive experience of learning can be facilitated.

The theme “Accessible, Personalised Learning” encompasses a variety of ways that the participants express how the work was made accessible for them in order for them to be able to learn successfully, and thus enabling a positive learning experience in school. The strategies employed encompass various adaptations tailored to individual needs, ensuring successful comprehension and engagement with schoolwork. Participants report instances of work modifications and adjusted completion methods, supplemented by targeted



interventions designed to facilitate skill acquisition. Practical learning opportunities, learning linked to things they liked, and the provision of information and communication technology (ICT) equipment are also highlighted as crucial forms of support. The amalgamation of these supportive measures helped to create an environment in which the YP with DS interviewed felt assisted in their learning journey and supported to meet the demands of mainstream education. This comprehensive approach can enhance accessibility and contribute to a positive and inclusive educational experience for YP with DS.

Participants reflected that schools wanted to adjust their practice based on their needs.

**Participant 7:** *“If I told them I had a problem, they changed things for me.”*

**Participant 10:** *“It also helped me at school when I could fill in evaluations so I can tell the teachers how I feel about school and how to help me.”*

Participants expressed that they found it useful when the work given to them at school was adapted. This included having work adjusted to their ability as well as having additional help such as scribes. Participants also expressed how if they had a problem with work, they could voice this, and the work could be adapted accordingly. This meant they were able to complete the work successfully, contributing to their experiences of mainstream school that they viewed positively.

Therefore, the participants' responses suggested that ensuring the work is adapted to their needs can help facilitate a positive experience of school for learners with DS in mainstream education.

**Participant 2:** *“I preferred the lessons when I had sheets because it is easier for me to do. I like it when the work is made a little bit easier for me.” ... “I did some different work. Sometimes the teachers changed the work, so I didn't find it so hard. It made me feel happy so I could do the work.”*

**Participant 4:** *“I did get the same work as everyone else but sometimes they made the writing bigger so I could see the worksheet better.” ... “I found it helpful because it*

*made it accessible.”*

**Participant 5:** *“My key worker tailored the sheets for me. Sometimes she scribed for me too.”*

**Participant 7:** *“They made it (the work) more simple. It helped me tackle it. It made it easier. It was a good thing.”*

**Participant 8:** *“XXXX knows how to make the work suitable for me. And going over work, that is important for me. Like learning about safety and other stuff. And making the work the right level for me.” ... “He said the work being done was too hard for me. So, he prepared different work for me, and my TA did it with me.”*

**Participant 9:** *“The teachers helped by giving me worksheets, different to other children.”*

**Participant 10:** *“When the writing tasks were long, I talked, and the TAs wrote it down for me. That was helpful.”*

**Participant 12:** *“I had extra counting games instead of maths and more worksheets in some lessons. But when I was confident, I did the same. Like I was good at reading and writing and my passion of history.”*

When talking about adaptation to work, participants also highlighted that being given extra equipment to do the work was useful. This included manipulatives for maths and the use of ICT equipment.

**Participant 1:** *“At primary I went on the computer to help me, in the lessons and I could use them for work.” ... “I mainly used laptops. They help me learn. So do iPads.”*

**Participant 2:** *“I used a computer. I did a mock market. This is where I could learn to sell and buy and use money. I liked using the computer it helped me with my learning.”*

**Participant 3:** *“Sometimes I used a laptop to help me write when we had a lot to do.”*

**Participant 7:** *“Sometimes everyone used computers but sometimes I had one on my own to help me. I liked it because I don’t like writing.”*

**Participant 9:** *“I used Word to write which helped me with my spelling.”*

**Participant 1:** *“I was also given objects to help me with maths.”*

**Participant 2:** *“I use my fingers to help me, and my class teacher showed me how to use cubes to help me.”*

**Participant 10:** *“I used objects and toys to help me count in maths.”*

As well as adapting the work given in lessons, the participants also appreciated having qualifications adapted so that they were able to complete them successfully. Having an accessible qualification to work towards helped facilitate a positive experience of education for some of the participants. Adaptations included offering alternatives to GCSEs such as Entry Levels and adapting the way the YP completed the exams.

**Participant 2:** *“I didn’t do GCSEs, but I did get ready for them. I did Entry Levels, and I am proud of my certificates and qualifications. I could still be with friends doing GCSEs and work towards my own level.”*

**Participant 5:** *“A scribe in exams so I could show my knowledge by talking. I do love to write but I am slow.”*

**Participant 6:** *“I had an adapted qualification so I could do it in the same class as the others. They had to write lots, but I got to video mine instead.” ... “I didn’t do GCSEs, but I did get to do Entry Level maths. Getting a qualification was good.”*

These findings are interesting as previous research has indicated that not all teachers felt confident or knew how to adjust the curriculum to suit learners with DS (Mills et al., 2014). However, the current findings may suggest that some teachers could now be better prepared to do this, such as the teachers of the participants. As well as this, they emphasise the importance of adapting the curriculum to meet their academic needs while still providing opportunities for academic engagement. This echoes the principle of inclusive education, which emphasises the necessity of providing the right support tailored to individual needs (Norwich, 2014). Moreover, the idea of customising the curriculum to suit the needs of YP with DS is supported by previous research conducted by Mullan et al. (2018), who

discovered that making curricular adjustments for pupils with DS resulted in a smoother transition between primary and secondary school. The suggestion of adaptations to qualifications is a new perspective offered by the current study, providing further insight into what adaptations YP with DS find beneficial.

Moreover, personalised learning helped facilitate a positive experience for the participants. Participants expressed that they felt more positive about schoolwork when it was linked to things that they personally liked, or real-life experiences relevant to them.

**Participant 1:** *“I learnt skills in maths that can help me in life, and I can use in the real world. Learning numbers is really important to understand things in life. Like 100s and 1000s. I also need to know how to use money and tell the time.”*

**Participant 2:** *“They give me lots of confidence and they relate the topics to things I like.”*

**Participant 5:** *“She knew me well and she tried to connect what I was learning to things I liked, like songs and Disney and how I remembered things.” ... “School were good at tapping into my interests and gave me extra lessons on what I liked.” ... “Going on trips to the shops and doing real life things. Practical learning. School used to take us to the local shops. And they took us to the park to do activities too, like following coordinates.” ... “School made me focus on maths a lot, but it has given me life skills.”*

**Participant 7:** *“I did lots of art and design because it was my favourite.”*

**Participant 10:** *“I loved maths a lot, I learnt money skills. I liked learning skills for real life.”*

**Participant 11:** *“Learning maths makes life easier, like when I go to the shop and need to pay.”*

Hence, to foster a positive school experience, it may be advisable to connect learning to real-life contexts and the interests of learners with DS. This discovery builds upon the findings of Jevne et al. (2021), who identified that engaging in work aligned with their interests and capabilities positively influences the quality of life of individuals with DS,

extending this concept to the educational setting. However, a potential barrier to being able to do this is limited resources, as Warnes et al. (2022) highlighted that teachers in UK mainstream schools were concerned about the resources available to teach children with SEN, therefore this could restrict the ability for teachers and school staff to implement this personalised learning for learners with DS.

Finally, data within this theme highlighted found that the participants believed that bespoke interventions could help facilitate a positive experience of learning. They found interventions enjoyable and useful. Some participants reflected that interventions help facilitate learning as they provide a quieter environment, and some also acknowledged that interventions can be used to promote other key skills such as speech and language.

**Participant 2:** *“The teaching assistants did take me out. It was useful because there were less people. Usually, I went out in the middle of the lesson after the teacher had explained the work and then I went out for the intervention and then I came back and finished the work with the class.”*

**Participant 4:** *“It happened a lot in lockdown, my online schooling was in smaller groups away from the class. And I had extra help. I also had extra literacy interventions with about 6 of us that did that instead of an extra language. From year 7 to year 9. The sessions were really helpful.”*

**Participant 8:** *“I needed separate maths interventions. It meant that the maths was easier for me.”*

**Participant 12:** *“I had XXXX outside of the classroom for other skills. I really liked it because XXXX helped me to work hard. And it was a good support.”*

Participants were able to articulate the kind of interventions they had and why they were useful to them.

**Participant 1:** *“I did do this (intervention). I liked it. It was because it was quieter.” ... “I find ICT useful for programmes like Nessy, it can help me learn to read and write and spell. It is fun. And there’s maths games too on the iPads.” ... “In primary school they gave me speech and language, and this really helped me.”*

**Participant 12:** *“I did Lego therapy. I love Lego and I loved that intervention I am skilled at Lego, and I could show off. Lego therapy also helped me to learn to communicate and you know, it was good.” ... “We had a speech and language therapist in the mainstream school. I think it was lucky to have her. I loved doing my sessions with her.”*

With some of the participants finding the small group atmosphere in interventions useful.

**Participant 5:** *“I did catch up lessons. Sometimes they were one to ones and sometimes small groups. That was helpful.”*

**Participant 10:** *“The teaching assistants did take me out. It was useful because there were less people.” ... “It was helpful to be in a small group outside of the room.”*

These findings add to the existing body of research emphasising the importance of interventions for YP with DS. For instance, Cupples et al. (2016) demonstrated that language-focused interventions delivered by parents at home resulted in significant enhancements in language comprehension and expressive language skills in children with DS. Moreover, previous research indicates that early intervention can be particularly beneficial for children experiencing delays in cognitive, motor, and language development (Clibbens et al., 2002). Additionally, studies have identified the critical role of early intervention in facilitating improved educational outcomes for children with DS (Paige-Smith & Rix, 2006; Roberts et al., 2007). Therefore, it can be interpreted that intervention programs are useful for learners with DS to achieve better educational results. By providing timely and targeted interventions, educators and caregivers can support the learning and development of YP with DS ultimately enhancing their experiences of school, educational outcomes, and quality of life.

Whilst previous research shows evidence of the effectiveness of interventions, the current findings offer us a unique perspective, understanding why the YP with DS

themselves found interventions positive – focusing on their enjoyment of intervention sessions, rather than solely focusing on their impact.

In summary, this theme encompasses various tailored adaptations and interventions that facilitated successful comprehension and engagement with schoolwork for participants with DS, including modifications, practical learning opportunities, and learning linked to personal interests, contributing to a positive and inclusive educational experience. The quotes from the participants included within this theme highlight the impressive ability of these YP to speak knowledgably about their own learning experiences; that they value learning and can unpick what helped them to be successful. This further justifies the use of YP with disabilities in research. Moreover, these findings help add to the understanding of how to adapt work to the needs of YP with DS, but also emphasises that these adaptations may not only aid them academically but also helps facilitate a happy, positive educational experience based on their preferences.

### ***Theme 2: Home-school Partnership and Family Support***

This theme can be linked to the findings of RQ1, that YP feel positively about being given opportunities to learn. Within this theme, participants describe how a good homeschool partnership can facilitate a positive learning experience at school.

The theme “Home-school Partnership and Family Support” describes how the participants shared that good collaboration between their educational setting and their family members helped facilitate a positive experience of school. Central to this collaboration is the recognition that good cooperation plays a pivotal role, with participants emphasising the importance of seamless communication channels between the school and parents. In this reciprocal relationship, it is important for both the school to initiate contact with parents, as well as the parents having avenues to communicate with the school. Beyond communication, the home-school partnership extends to active involvement of parents in the educational process. Participants elaborate on the significance of parents participating as valued

contributors to the school community. Furthermore, the theme highlights the practical dimension of this collaboration, with the participants sharing how they could reinforce learned skills at home to enhance their learning experience. Additionally, parents and siblings are portrayed as pillars of support, assisting with both academic learning and addressing any challenges encountered at school. This theme emphasises the holistic and collaborative approach that may be necessary to foster a positive educational experience for YP with DS.

Participants recognised that good communication between school and home helped to facilitate positive experiences of school.

**Participant 2:** *“Mum could also talk to my TA over WhatsApp, so she knew how my day was going.” ... “If I had a problem the school rang my parents. It made me feel safe that they could call my parents if I needed them.”*

**Participant 4:** *“My parents came into school, and they phoned them if there was a problem. This happened sometimes. There were emails too.”*

**Participant 6:** *“They would phone my mum if there was a problem or mum could call the school, my mum had good contact with the teaching assistant.”*

**Participant 7:** *“It helped because my mum and dad knew how was school doing and helped motivate me. It helped both me and my mum and dad I think.”*

**Participant 9:** *“She (my mum) writes it (my feelings) in my diary. And then I get my diary out and I can show it to teachers in my school.”*

**Participant 12:** *“There was good conversation between mum and school which was good.”*

These findings align with previous research; for instance, Mullan et al. (2018) emphasised the crucial role of parent-school communication during transition phases, emphasising the need for parents to advocate for their children's needs and strengths. Similarly, Lendrum et al. (2015) emphasised the pivotal importance of a strong school-parent partnership for maximising the educational outcomes of children with DS, a sentiment also



shared by Engevik et al. (2018), who highlighted the significance of collaboration between school staff and parents in supporting pupils with DS. Thus, fostering a positive education experience for YP with DS in mainstream schools may rely heavily on the relationship between the school and parents, facilitated by open communication channels. Importantly, while previous research predominantly captured parental perspectives, the current study emphasises the viewpoint of YP with DS, offering a new insight that showcases the direct positive impact of such collaboration on their educational journey, as evidenced by their own feelings of support.

Participants also recognised that family involvement helped facilitate their positive experiences in school. This involvement included parents being actively involved in school, as well as parental and sibling support with schoolwork at home. Some parents had a large influence in the school, which the participants found useful.

**Participant 6:** *“My mum could also suggest ideas that she knew worked for me.”*

**Participant 8:** *“Mum made demands from school so they would do the right thing.” ... “Mum was a school governor for SEN in secondary school which made it able to mum to make sure that the right things happened for me. I liked my mum having influence.”*

**Participant 12:** *“Mum became the safeguarding officer of the school which was good because she knew everything that was going on. I felt support when my mum was a school governor. My mum could support me and other people it was very important.”*

Parents were also useful to help the YP understand the problems they were having at school, meaning that problems were more easily solved, and participants were more able to have positive experiences of school.

**Participant 1:** *“I also told my mum how the school day was when I got home.” ... “My mum helped me understand but she also spoke to the school about why I did it.”*

**Participant 3:** *“I could tell mum when I got home if I was finding things tricky.” ... “My mum and dad helped because they asked questions if I was stuck in school.”*

**Participant 7:** *“We also chat if things haven’t gone well. My family have been around me to support me at school and college.”*

Participants also noted the influence siblings has on their experiences of school.

**Participant 1:** *“Sometimes my brother helps me learn, especially in lockdown when I had to learn at home.”*

**Participant 2:** *“XXXX (older sister) is supportive because she can do things first and tell me what to do.”*

**Participant 7:** *“He (older brother) understands me well and he wants to help me and support me. He is a lovely brother.”*

These findings can be further understood by looking at the results of Mullan et al. (2018), who found that siblings can be a source of support for individuals with DS. Given that participants in the current study also highlighted sibling support as contributing to a positive school experience, further research is needed to explore how this resource can be effectively utilised further within the school setting.

Participants also reflected that it was useful for them to be able to practise key skills at home, likely adding to their positive experiences of learning at school.

**Participant 3:** *“My mum and dad helped because they asked questions if I was stuck in school. I could tell mum when I got home if I was finding things tricky. Also helped support my reading at home.” “I learnt it at school, but my mum and dad helped me practise at home.”*

**Participant 6:** *“I read at school, and I had reading books. Learning to read at school means I can read at home, and I like reading at home.”*

**Participant 10:** *“Mum and dad helped me read at home which was helpful. Practise made me confident.”*

The findings within this theme are significant as they reinforce the established understanding of the importance of effective home-school communication, while also enriching this understanding by adding the new detail of insights from the perspective of the YP themselves. Additionally, the findings add to this understanding further by highlighting the

role of school support at home, emphasising that practising key skills, such as reading books and completing homework at home, can enhance the experiences of YP with DS in mainstream school.

These findings highlight the impact that parents and family can have on positive experiences of mainstream school. Therefore, this may be considered when planning how to support YP with DS in mainstream school. However, navigating this could be complicated by the reality that not all parents may have the availability to be actively engaged in school affairs. While some participants mention their mothers holding official roles within the school, such scenarios may not be feasible for all families due to other commitments such as work. However, a more pragmatic approach would be to advocate for strong communication channels between schools and families, fostering mutual support in aiding the child's development and enhancing their experiences of school.

In summary, this theme indicates the importance of the collaboration between educational settings and families in fostering a positive school experience for YP with DS. It emphasises the importance of seamless communication channels, active parental involvement, and practical reinforcement of learned skills at home. These findings are useful for encouraging educational professionals and school staff to consider the multiple systems around the child that can impact their learning. This can be understood using the Ecological Systems Theory (Bronfenbrenner, 1992) and should be considered when planning the support of YP with DS in mainstream schools.

### ***Theme 3: Physical Memories and Rewards***

The theme "Physical Memories and Rewards" highlights the significance of tangible elements in aiding the participants to comprehend their progress in school, thereby fostering positive perceptions of themselves and their educational experiences. Participants expressed the utility of physical items, particularly photos, as valuable aids in recollecting positive school memories. Many individuals curated memory books to document and

celebrate their achievements, serving as a tangible testament to their progress. Moreover, participants emphasised the pivotal role of rewards as a motivational tool for them. Certificates were highlighted as essential motivators that not only acknowledged accomplishments but also contributed to sustained enthusiasm. This theme further explores the use of reports as informative documents that enabled individuals to grasp and appreciate the strides they were making academically. The clarity provided by these tangible indicators played a crucial role in shaping an overall positive and empowering experience for the participants in their educational journey.

Participants expressed that they liked having physical memories of school such as photos and achievement records. This helped them understand and remember their school experiences to facilitate a positive reflection of their experiences. This was also highlighted by 7 participants bringing memory books to share during the interviews.

**Participant 1:** *“Pictures of me for school are important for my memories.”*

**Participant 4:** *“So, I have this folder of stuff. It’s a memory file. I used it to show my family what I was doing when I was at school.”*

Within these memory books, many participants had certificates. They explained that receiving certificates helped them feel happy and motivated and thus contributed towards the experiences of mainstream school that they considered to be positive.

**Participant 1:** *“Certificates are important, so I know when I am working hard and doing the right thing. It helps me feel good. I really like certificates a lot. I feel happy.” ... “I liked getting certificates and collecting certificates. I put them all in a book.” ... “Getting a certificate makes me work harder, I worked really hard to get them. I also like the birthday certificates because it makes me feel loved and remembered.”*

**Participant 4:** *“I love getting certificates and I like knowing I am doing well and people recognising that I am doing well. Certificates help me know I am doing well.”*

**Participant 7:** *“And I have certificates, like star of the week. They made me feel so proud. Like I was doing good. It motivated me to do things.”*

**Participant 11:** *“I have a folder, my national record of achievements. I am proud of my qualifications.”*

**Participant 10:** *“Certificates help me to remember all of the hard work I have done and make me feel proud, it gives me good memories of school.” ... “And I have certificates, like star of the week. They made me feel so proud. Like I was doing good. It motivated me to do things.”*

**Participant 12:** *“And I have certificates. It was so important for me to get certificates I got. They are my achievements.”*

These findings offer a new insight into what YP with DS found helpful. Whilst research from Geiger (2023) found that YP with DS expressed the importance of being celebrated with recognition and rewards, Geiger’s (2023) study did not provide any insight into what kind of awards the YP valued and why these were important to them. This current finding allows for a deeper understanding of the importance of awards for YP with DS. Currently, the only other research directly exploring the impact of rewards in school for learners with DS dates back to 1973 (Dalton et al., 1973). The study investigated the efficacy of a token economy system in enhancing the academic performance of children with DS. One cohort comprising seven children received token reinforcement for accurate responses, resulting in significant improvements in both arithmetic and language skills. Conversely, a matched group of six children received solely verbal praise for correct responses, demonstrating negligible enhancement in arithmetic but notable gains in language proficiency. Upon retesting one year later, the Token Group sustained their academic progress in both subjects, while the No-Token Group exhibited a significant decline specifically in language performance. This shows how rewards may help YP with DS to progress academically. However, it does not explore how the rewards made the YP feel, and whether they had emotional/motivational gains from these rewards. Sanz et al. (2011) also

explored the use of rewards with children with DS, however this was not in the context of school. This study explored the impact of different social rewards used in the early stimulation of children with DS. This study included 20 infants with DS aged between five months and two years, who were exposed to two types of social reinforcements: verbal and physical. Each participant received stimulation targeting gross motor skills, fine motor skills, language development, and social skills. The results suggest that combining verbal approval with positive physical gestures leads to improved outcomes. The researchers concluded that providing verbal praise along with affirming physical gestures enhances the performance of children with DS, emphasising the importance of both types of social approval in their development. Whilst this study focuses on young children rather than children who have experienced school, it does highlight the benefit of positive reinforcement for YP with DS. Therefore, it is interesting that this aspect is also significant for the participants in the current study, specifically in the context of their school experiences. This highlights not only the potential role of extrinsic reinforcement but also the role of these rewards as tangible reminders of learning, helping learners to recognise and understand their achievements.

Also, within their memory books, many of the participants had old school reports. They explained that reports were useful to facilitate a positive experience at school as it helped them to understand their progress.

**Participant 1:** *“Report cards are good too because they tell my mum how I am doing at school and then she can help me.”*

**Participant 10:** *“I have some report cards here. Report cards help me know how well I am doing but it also helped my mum know what I was doing.”*

**Participant 11:** *“It’s important to get feedback so my parents and family can see how I am doing. Like school reports or writing.”*

Despite the discovery that YP with DS place value on tangible objects like certificates and school reports being a novel revelation, it resonates with the earlier theme of effective home-school communication. These physical items can both serve as tangible markers of

achievement and enhance the communication between home and school. Certificates may enable YP to share their successes with their family and school reports allow their families to have a better understanding on their progress and achievements. Moreover, physical memories such as pictures and photos may help them to understand and showcase their experiences of school, where they may find this difficult to do verbally due to speech and language difficulties.

It is important to note that the concept of rewards originates from a behaviourist approach, and in recent years, the application of behaviourist methods in the classroom has faced some criticism. For example, when looking at how rewards are used in education, Reeve (2006) suggested that rewards can have a negative effect on intrinsic motivation, and there is concern that if some children receive rewards and others do not, this can lead to learned helplessness (Maier & Seligman, 1976). However, Lepper et al. (2005) explored the relationship between intrinsic motivation and extrinsic rewards in educational settings. They found that the relationship between intrinsic motivation and extrinsic rewards is nuanced and complex and not always negative. While some research suggests that tangible rewards can undermine intrinsic motivation, particularly when they are perceived as controlling, other studies indicate that rewards can enhance intrinsic motivation, especially when they are delivered in a supportive and autonomy-supportive manner. Moreover, Blackwell et al. (2007) highlighted that positive feedback such as reward and praise can shape pupils' beliefs about their abilities and their motivation to learn, when this feedback is focused on effort and strategy. This helps to promote a growth mindset and foster pupils' motivation and resilience in academic settings. Therefore, when rewards are used correctly, and fairly, giving each child a chance to receive them, they can have a positive impact in the classroom. In the case of the participants in the current study, rewards and certificates are viewed as beneficial to the participants and particularly motivating for them. However, the rewards not only serve a motivator, but they also help the participants to understand their achievements, share their achievements with their family, and to be become a keepsake oh which they are proud of.

In summary, this theme highlights the important role that YP with DS perceive tangible rewards and keepsakes play in helping them understand their progress and fostering positive perceptions of their educational experiences. This perspective sheds fresh light on strategies for nurturing a positive educational journey for learners with DS, offering valuable insights for educators. Such insights include recognising that tangible artefacts are important for supporting the learning of YP with DS, as they may enhance both their motivation and their understanding of their own progress. School professionals may wish to consider the use of artefacts when working with YP with DS, and that YP with DS may benefit from this more than their peers.

#### ***Theme 4: The Opportunity to Learn Alongside Mainstream Peers***

In RQ1, participants spoke fondly about how they enjoyed being social and interacting with their peers. Within this current theme, the participants extend on this further, describing how they believe their learning and school can be enhanced and supported by being given the opportunity to work with and learn from their mainstream peers.

The theme "The Opportunity to Learn Alongside Mainstream Peers" highlights how participants articulated the positive impact of learning alongside children with diverse abilities. Participants emphasised that being in the company of peers with varying skills and abilities contributed to a positive learning experience. They valued communication, highlighting the utility of engaging in conversations and actively listening to other children. The diverse mix of peers was seen as instrumental in facilitating learning from and about others. Participants shared how being in the presence of a varied peer group provided them with valuable opportunities for social growth and positive interpersonal encounters. In particular, the theme highlights the potential learning benefits derived from mainstream peers, including improvements in speech through exposure to other children who communicated confidently. Overall, this theme highlights the enriching and positive outcomes associated with an inclusive learning environment that fosters interaction and collaboration among children with diverse abilities.



As also discussed in RQ1, participants expressed that they enjoyed being with a mix of children.

e.g. **Participant 4:** *“I liked being in range, with different children in each class. I like different experiences.”*

However, in this theme, the data reveals why the participants found this useful and how it helped facilitate positive experiences of education. Participants particularly liked group work.

**Participant 1, 4, 9, 7 & 11:** *“I liked group work.”*

Participants found group work useful to learn from others, talk to others, to learn new skills and to practise being in roles of responsibility.

**Participant 2:** *“Yes, I did some group projects. We had to sell sweets, and we did a Christmas project. And I’ve had to work in a team for a recycling project. In primary they helped me do lot with team skills.”*

**Participant 7:** *“Having the opportunity to work in a team was really helpful because before I wasn’t good in social situations.”*

**Participant 8:** *“We do group work. Like working in a team. It was amazing and good. I liked working with other children my age.”*

**Participant 9:** *“I liked to be able to talk to others about the work.”*

**Participant 11:** *“Sometimes I even lead group work, I liked responsibility.”*

Participants also expressed how having the opportunity to work alongside other children in mainstream schools promoted positive learning experiences as they could learn from their mainstream peers.

**Participant 1:** *“I could learn from them (other children). It was nice that they let me play. In the lessons I could use their ideas and share mine.”*

**Participant 2:** *“I liked having different people because I could learn from them.”*

**Participant 3:** *“Yeah talking was good, it also helped me to listen to others so I could learn.”*

**Participant 5:** *“It (working with other children) was useful to share ideas.”*

**Participant 10:** *“I think it helped me learn (working with other children).” ... “I got some ideas off of other children.”*

**Participant 12:** *“They gave me support by giving the opportunity to learn from them.” ... “Working with children is different to working with a member of staff. I can learn from other children.” ... “Going to school with other people learning it helped me learn maths better.”*

Participants recognised that learning alongside other children not only improved their learning skills but also facilitated a positive experience improving their speech and language.

**Participant 1:** *“I also improved my talking because I was with other children that talked a lot.”*

**Participant 10:** *Talking to my friends and teacher was good. I spoke slowly to get better at talking.”*

The perceived benefits of working alongside their mainstream peers as outlined by the participants is similar to the findings to previous research. For example, Buckley et al. (2006) compared the achievements of teenagers with DS educated alongside mainstream peers versus those who learn alongside learners with SEN and found that those who had the opportunity to learn from their mainstream peers showed significant gains in expressive language and literacy skills. Moreover, Cuckle and Wilson (2002) suggested that integrating children with DS mainstream classrooms can yield significant advantages for their social and emotional development. Additionally, Dolva et al. (2010) suggested that successful interactions between YP with DS and their mainstream peers may encourage learning for both the YP with DS and their peers. More recently, Geiger (2023) also discovered that YP with DS think it is important to be included in the main classroom. The results from these

studies may show that by interacting with their peers in a mainstream educational setting, children with DS can learn from their classmates, develop social skills, and build friendships and that being included in mainstream classrooms can enhance their self-esteem and sense of belonging, as they become valued members of the school community. This may be why the participants in the current study perceived learning beside their mainstream peers to be positive and can describe how and why this can facilitate positive experiences of school. Participants were not only able to describe why they enjoyed working beside mainstream peers, but they could also share specific details of how it contributed to their learning and wellbeing at school. Therefore, in order to facilitate positive experiences of school for learners with DS in mainstream settings, it may be important to ensure that they have opportunities to learn beside their peers within this setting.

In summary, this theme highlights how YP with DS perceive integration with their peers to be a positive influence on their educational experiences. Participants emphasised the value of diverse peer interactions, citing enhanced communication skills and positive social encounters as key benefits. This theme highlights the enriching outcomes of inclusive learning environments that promote collaboration and interaction among children with diverse abilities. Ultimately, the participants expressed that inclusive practice is essential for an overall positive experience, including learning development and wellbeing. Therefore, school staff and educational professionals may wish to consider this in their planning and delivery when teaching YP with DS in mainstream schools.

### ***Theme 5: Carefully Planned Adult Support***

In the exploration of RQ1, participants identified that a positive experience of school was having supportive adults that worked with them, with the YP expressing a preference for having a dedicated and supportive adult working alongside them. Participants further elaborate on this within the current theme, sharing why the adults helped facilitate a positive experience of school and how adults can best support them in school. This also links to the

discovery of positive experiences of independence in RQ1, as participants explain how the correct level of adult support can lead to increased independence.

The theme "Carefully Planned Adult Support," explores the participants' favourable reception of one-to-one TA support, particularly during lessons and in day-to-day activities. Notably, the participants appreciated an adaptive approach to support, with the level of assistance tailored to each individual's confidence in various lessons. This flexibility allowed for the promotion of independence in areas where they felt proficient, contributing to a more positive and empowering learning environment. An important aspect highlighted within this theme is the significance of consistency in adult support. Participants expressed a preference for adults who were familiar with them and understood their unique needs. This familiarity not only facilitated a more personalised approach to support but also contributed to a sense of trust and rapport, ultimately fostering a positive experience of adult support. This theme provides evidence of adult support as a facilitator of a rich inclusive experience, rather than as a barrier as suggested in some previous research.

Despite guidance from the Education Endowment Foundation (Sharples et al., 2016) suggesting that one-to-one TA support is not always used efficiently, the participants expressed that it was useful to have one-to-one support.

***Participant 4:*** "I find 1.1 work helpful."

***Participant 8:*** "I had someone talk to be about it one-to-one."

They found this particularly useful in lessons to support their learning and understanding, and thus facilitate a positive experience of mainstream school.

***Participant 7:*** "Sometimes when I found it difficult to do my work. But my TAs came into the class and sat next to me. They helped me out with understanding the meanings of things."

**Participant 12:** *“They came with me to every lesson. I liked having someone with me to help me.”*

However, alongside this, participants appreciated when this support was extended to other aspects of school.

**Participant 1:** *“She also helped me with going to the bathroom. She helped show me around and be less nervous and become more brave.”*

**Participant 12:** *“There was a lot of different teaching assistant that helped me to feel comfortable in the school building.”*

Drawing this all together, positive experiences of adult support were more likely if there was always an adult available when they needed them.

**Participant 3:** *“I had a TA available for when I needed her. she gave me space when I needed it, but she was always available. I shared her with one friend.” “I always had adults with me to help me.” ... “I did always have someone though. They sat with me in the lesson, and I liked having them with me.”*

**Participant 5:** *“But always had the key worker to talk to and one to one meetings to discuss the week.”*

**Participant 8:** *“It was important to have my TA with me in case things went well or were tricky.” ... “TAs were always there to help me.”*

As mentioned in the discussion of RS1, there is much research that indicates that TAs are used in schools to support learners with DS. However, there is a lack of research investigating the specific roles and responsibilities of teachers and TAs in the education of YP with DS, and what they specifically do to facilitate positive experiences of school this group. Limited research exploring this includes Hargreaves et al. (2021) who offered some insights from the perspective of parents. They found that parents believed that in mainstream schools, TAs have primary responsibility for various tasks, such as delivering instruction, preparing teaching materials, managing behaviour and motivating pupils. Whilst it is interesting to understand how parents believe their child is being supported by a TA, it may

not necessarily reflect the realities of how TAs are used in schools. A better understanding may come from those who are actively involved in the experience themselves, such as the TAs, or YP with DS. Boundy et al. (2023) attempted to address this by collecting data from TAs and teachers that have worked with YP with DS. Findings showed that TAs assigned themselves as primarily responsible for many activities, including delivering teaching and adapting lesson plans. Results also suggested that TAs tended to have more training to work with learners with DS and felt more equipped to do so. However, this research only explores what TAs perceive their roles to be, and not why they are successful and how this facilitates positive experiences for their learners. Therefore, the current study offers a novel perspective of this, through the lens of the YP with DS.

Whilst Boundy's findings indicated that TAs were primarily responsible for learners with DS, the participants in the current study did not explicitly suggest this and spoke about their teachers too. The main role for TAs for the current study's participants was more of a supporting role than a leading one. This perspective can add to the understanding of how to tailor adult support to suit the needs of learners with DS.

While participants appreciated knowing that adult support was available if needed, they also emphasised the importance of being given independence when appropriate. Having a TA who recognised when the individual could handle tasks independently contributed significantly to the most effective experiences of adult support for the participants.

**Participant 5:** *"It was good to have a TA when I needed it but given space once I was confident to do things and manage on my own."*

**Participant 9:** *"It is good when they help me a bit, and then let me have a go on my own. And they go and do something else and leave me alone for a bit."*

**Participant 10:** *"I had a TA available for when I needed her. she gave me space when I needed it, but she was always available."*

Having a TA who was always available but recognises when the YP can work independently is important as it may help the YP themselves recognise their own skills and strengths and when they are able to work independently, thus increasing their confidence. Moreover, this kind of use of a TA aligns with the guidelines from the Education Endowment Foundation (Sharples et al., 2016), that TAs should be to help pupils develop independent learning skills and manage their learning.

More generally, participants found it useful when the adults they worked with, including TAs, key workers and teachers, were consistent. Consistency was a key factor in facilitating a positive experience of mainstream education for the participants.

**Participant 1:** *“I had a few. The best thing was when I had them for a long time, and they knew me.” “I liked having one teacher for all of my lessons.”*

**Participant 2:** *“I had the same key worker throughout all of school. It was helpful to always have the same.”*

**Participant 5:** *“She knew me well and she tried to connect what I was learning to things I liked, like songs and Disney and how I remembered things.” .... “Having the same key worker all of the way through was really really useful and helped me stay confident and it was someone I could trust.”*

**Participant 7:** *“Good, it made me happy and safe, and it was always the same people. They knew me really well.”*

**Participant 8:** *“It helps me that XXXX knows me since I was little. She knew me at all ages. She knows me so well and it’s helpful.”*

**Participant 9:** *“I got to stay there for a long time, so I knew people really well.”*

**Participant 10:** *“I like it when I know teachers for a long time. It’s important to know them and they know me. I like it when things are not new, and faces are familiar.”*

**Participant 11:** *“The best thing was having a TA that followed me across the year groups.”*

**Participant 12:** *“One good thing was I had the same teacher for year 1 and 2 then the same teacher for year 3 and 3 then the same for 5 and 6.”*

While previous research has explored how school staff can assist learners with DS (Hargreaves et al., 2021; Boundy et al., 2023), such studies primarily focus on the primary roles of different staff members, rather than their attitudes and approaches to their work. The current study delves deeper into this aspect, with participants articulating the importance of support from adults and providing insights into why and how it is significant and useful. Notably, consistency emerged as a recurring theme. This concept has been somewhat overlooked in prior research but may be important for YP with DS to feel secure and well-supported. Participants highlighted the value of having consistent support from familiar individuals.

In summary, this theme reflects participants' views on how to ensure positive, effective adult support, particularly during lessons and daily activities. This emphasises the importance of tailored assistance to promote independence and highlights the significance of consistency and familiarity in fostering trust and rapport. This understanding has implications for schools and educational professionals to consider and establish effective use of TAs and highlights that TAs may need to be further trained and supported.

Overall, the analysis of RQ2 allowed the participants' responses to be used to understand how to facilitate the positive experiences that were identified in RQ1. Participants were able to articulate the successful strategies and interventions implemented by their schools and to reflect on the reasons these provisions had been effective. This led to the identification of five themes. Whilst some findings aligned with previous research, others provided valuable new insights into how to facilitate a positive experience of mainstream school for learners with DS.

It is important to acknowledge that the findings are not exhaustive in terms of potential support strategies. The problems that YP experience, as well as the many potential solutions to those problems, were not explored, which is a limitation of this study and may



serve as a direction for future research. Instead, by adopting a solution-focused lens, this research aimed to build upon the positive experiences of YP with DS and centre their knowledge in developing effective strategies.

### **Implications of Findings**

This research offers an exploration of the positive experiences of mainstream school from the perspective of YP with DS. Using a solution-focused approach, the YP's insights and reflections can inform efforts to foster positive experiences for future learners with DS in mainstream settings. This includes implications for schools and educational professionals, who can use this knowledge to implement tailored support and adapt their environments to better support YP with DS.

Furthermore, the findings may be useful for policymakers, as they highlight some aspects that YP with DS may feel need to be addressed in policies to promote inclusivity in mainstream education for learners with DS. Additionally, educational professionals such as EPs can benefit from these findings by gaining insights into how best to support schools in catering to the preferences and needs of learners with DS. For instance, the research lays the groundwork for developing training programs and understanding many necessary provisions that may need to be included in documents like EHCPs.

Overall, these implications have the potential to contribute to promoting inclusivity and enhancing the educational experiences of learners with DS in mainstream settings. As well as this they promote the voice of the YP with DS and the importance of their participation in research.

### ***Emphasising the Need for Inclusive Practices***

The participants' responses emphasise the importance of inclusive practices in fostering a positive experience, while also promoting their overall learning development and wellbeing. This is highlighted by the participants expressing the importance of learning academic subjects alongside their peers, as well as their emphasis on friendships and

socialisation. Participants also recognised how they learnt from others. Schools and school professionals should consider this in their planning and delivery when teaching and including YP with DS, for example, careful consideration needs to be given to how YP are included in lessons. Schools may wish to consider how to ensure that YP with DS are not removed from academic lessons on account of their ability, but rather are supported to access learning alongside their peers. These findings may be used to support models of inclusive education rather than remedial or special education.

### ***Implications to Support Learning and Wellbeing in School***

The findings showed that the participants place great value on their learning experiences, expressing enthusiasm for learning and recognising its impact on their lives. This carries implications for both schools and policymakers. It highlights the importance of ensuring that learners with DS have equitable access to core subjects such as reading, writing, and mathematics. This highlights the need for educational settings to carefully consider inclusive practices that cater to the diverse learning preferences and needs of students with DS, fostering environments where they can thrive academically and personally. Policymakers must recognise the fundamental right of learners with DS to receive quality education that empowers them to reach their full potential, advocating for policies that promote inclusive education practices and allocate resources to support the educational needs of YP with DS.

Participants emphasised the significance of others believing in them, and findings showed the participants were very attuned to the attitudes of those around them, recognising that school staff cared about them, listened to them, and made an effort to understand more about DS and their unique needs. The implications of this can be understood using Social Identity Theory (Tajfel et al., 1979). According to this, individuals derive part of their self-concept from their membership in social groups, and this identification can influence their attitudes, behaviours, and perceptions. In this case, the participants, are attuned to the attitudes of school staff towards them. If school staff exhibit positive attitudes and beliefs

about the capabilities of YP with DS, it fosters a positive social identity for the YP, contributing to their sense of belonging and self-esteem within the school environment. Therefore, YP with DS are more likely to have self-confidence and belief in their academic ability as well as their right to be included with their TD peers. This highlights the vital need for school staff to understand DS and the unique needs of YP with DS. School staff must understand that they can enhance social identity in schools for YP with DS by showing acceptance, respect, and inclusivity. Moreover, this signifies the need for school staff to have confidence in the abilities of YP with DS and to create an environment where they are encouraged and supported to engage with academic subjects such as reading, writing, and mathematics, as well as a range of other activities. By fostering a belief in the capabilities of YP with DS, school staff can play a crucial role in promoting their academic success and overall wellbeing. When individuals feel understood and valued by their social group, it reinforces their sense of belonging and validates their identity within that group. Therefore, by school staff recognising and affirming the capabilities of YP with DS, they may help to contribute positively to their academic success and overall wellbeing.

Moreover, participants recognised the importance of experiencing a variety of subjects and having the opportunity to determine their preferences, showcasing the need for access to a broad and balanced curriculum. This highlights the significance of providing YP with DS with diverse educational opportunities that allow them to explore and engage with different subjects, empowering them to make informed choices about their learning experiences. Additional activities should also be offered, such as sports, drama groups and school trips.

As well as this, learning independence skills was found to be important for YP with DS. Therefore, school staff may wish to consider how school policies and curriculums can ensure the teaching of independent skills for YP with DS and consider ways that independence can be promoted within the school setting.

By highlighting the importance of learning opportunities for YP with DS, the findings have also prompted consideration of how to best support this learning. Key implications for supporting learning include school staff recognising the significant impact of their attitudes on YP with DS. It is crucial to ensure that teachers are adequately equipped and trained to effectively teach YP with DS, as this can foster a more positive attitude towards their abilities. By expressing belief in the capabilities of YP with DS, teachers can enhance their motivation to learn and succeed. Therefore, investing in teacher training and providing ongoing support may be important for creating a supportive learning environment that promotes the academic and personal development of YP with DS.

Moreover, the findings prompt consideration of the use of TA support. Recognising that a TA can contribute not only to YP with DS's access to learning but also to their overall wellbeing too. TAs play a multifaceted role in supporting YP with DS, providing academic assistance as well as emotional support and encouragement. By acknowledging the holistic impact of TAs on the wellbeing of YP with DS, schools can ensure that appropriate resources and support are in place to promote both their academic progress and their social and emotional development. Schools need to strive to ensure consistency in teaching and support staff so that YP with DS feel known and understood. As well as this, staff should recognise the YP with DS's strengths to consider how to give them independence when they are capable. This signifies a potential need for schools to prioritise the development of a clear understanding of effective TA support and commit to implementing this in practice. TAs may require comprehensive training to enhance their skills and effectiveness in supporting YP with DS. Additionally, teachers may also need to be equipped with the knowledge and strategies to effectively utilise and support TAs in the classroom. To achieve this, training and development programs tailored to both TAs and teachers could be established. EPs and other professionals can play a vital role in supporting schools with the implementation of these initiatives.

The findings showed that the participants valued differentiation and adaptations to support their learning. The data highlights that these adaptations are helpful for more than just supporting achievement as they may also help to improve their overall quality of life at school. These can range from small adaptations, such as larger font on work sheets, to larger adaptations such as tailored interventions and access to alternative qualifications. Based on this, schools and professionals should consider and carefully plan such adaptations to support YP with DS both academically and emotionally.

The participants' recognition of the importance of differentiated work, as well as a preference for TA support along with the want for independence can be understood through Vygotsky's Zone of Proximal Development (Vygotsky, 1978). YP with DS should be given the opportunity to engage in learning activities but it must be recognised that at first, they may find this difficult. Therefore, it is crucial that tasks are scaffolded effectively and modelled by a teacher or a more capable peer. Initially, learners with DS require structured support to build confidence and competence. As they progress and gain confidence, adult support should gradually diminish to foster independence. It is imperative for teachers and staff to maintain high expectations and ensure that tasks are appropriately challenging, yet manageable with the necessary support. This approach ensures that learners are continually working within their Zone of Proximal Development, maximising their learning potential.

Further implications of the findings highlight the importance of providing YP with DS with a diverse array of tangible resources to support their learning. These may include manipulative learning tools such as cubes in maths, physical rewards such as certificates and physical records of their progress such as school reports. The findings suggest that these resources can play a crucial role in enhancing motivation, facilitating learning and development, bolstering self-esteem and confidence, and fostering shared understandings. School professionals, including teachers and EPs should consider the integration of these resources into the learning environment, recognising their possible significance for YP with DS. This necessitates the development of skills and abilities among professionals to create

and utilise various artifacts effectively, potentially making them an integral part of everyday practice. Additionally, collaboration among different professionals, such as speech and language therapists and EPs, may need to involve the consideration of how their work with YP can be documented and shared using accessible artifacts so that the YP are able to understand and record their own progress.

### ***Emphasising the Need for Good Home-school Communication***

Participants emphasised the importance of home-school collaboration. Therefore, this signifies the importance in considering how communication can be most effective between schools and families. This includes parents having a clear and accessible way to inform the school of any events that have happened at home that may impact school. Similarly, schools should establish a transparent communication channel with parents and caregivers to provide updates on the YP's progress, acknowledge their strengths, and address any challenges they may encounter. A way to understand this further is through the Ecological Theory (Bronfenbrenner, 1992) This theory suggests that human development is shaped by the dynamic interplay between individuals and their environment, comprised of various interconnected systems. Educational professionals need to recognise the complexity of these systems surrounding YP with DS and their potential impact on their school experiences. Professionals, including EPs may find it useful to adopt an ecological perspective when crafting support strategies for CYP with DS.

### ***An Example for Future Research***

This study amplifies the voices and experiences of an underrepresented group in education research. Previous studies exploring the school experiences of YP with DS from their own perspectives are scarce. Research specifically focusing on the mainstream education of YP with DS from their viewpoint is particularly lacking. By exploring the perspectives of YP with DS, this study has effectively addressed the research questions.

Not only did this study address the research questions, but it showcased the strong abilities that the participants had in being able to express their views. Participants effectively articulated their positive experiences in mainstream school, reflecting thoughtfully on the factors contributing to their satisfaction and the utility of the support received. Their reflections offered fresh insights into diverse topics, demonstrating an ability to comprehend their own learning processes and to articulate the significance of learning for them.

Therefore, a further implication of this research is that it serves as an example that the voices of this group of individuals can and should be heard. The participant friendly methods used to elicit the voices of YP with DS can be transferred to future studies to gather the voices of similar groups, such as YP with other learning disabilities. The detailed, unique reflections of the participants emphasise the rich detail that YP with DS are able to contribute to educational research and justify why these voices should be gathered.

## **Limitations of this Research**

### ***Verbal Abilities of Participants***

A limitation of this study is that it may have a form of elite bias (Miles & Huberman, 1994). Elite bias implies that research tends to prioritise individuals who are more articulate and easily accessible within a community, thus restricting the broader relevance of the study's outcomes. This is because despite the use of cue cards, drawing, pictures and objects in the interviews, the interview process in this study still required participants to possess adequate verbal skills to participate effectively (Willig, 2013). Consequently, a significant limitation of this research lies in its exclusive focus on the viewpoints of a specific subset – YP with DS who had the ability to comprehend simple questions, reflect on previous experiences and express their thoughts verbally. Consequently, the perspectives of non-verbal or YP with DS with very limited language were not captured in this study. However, it should be noted that many of the participants did have speech and language difficulties and were still included in the research.

### ***Differing Educational Experiences***

Another limitation of this study is the diversity of the educational settings that the participants had attended. While six participants attended mainstream schools for the entirety of their mandatory education, the other six participants spent some of their schooling years in mainstream school, but then moved on to specialist provision. Whilst the study aimed to explore experiences of mainstream school, some of the participants discussed their experiences of specialist provision and compared their mainstream experiences to this. Whilst this was an interesting comparison, it was not the aim of the research. Therefore, the researcher needed to decipher between mainstream and specialist experiences. Whilst this seemed to be achieved, the researcher cannot be completely sure that the participants were accurately distinguishing between their experiences of different types of school setting themselves. Moreover, some of the ideas that the participants gave regarding how to facilitate positive experiences of school were based on their specialist experiences but were still relevant to mainstream provisions, posing the difficulty of deciding whether to include this data when developing the themes in the data analysis stage.

### ***Positive Bias***

In adopting a solution-focused approach to the research, there is an inherent positive bias that has shaped the findings. Positive bias refers to a situation where the focus is primarily on eliciting or highlighting positive experiences, which may downplay or omit negative aspects.

With ethical consideration, the researcher decided to only focus on the positive experiences of mainstream school so that the participants felt comfortable when reflecting and did not have to discuss negative experiences that may upset them. This decision was supported and encouraged by the university ethics committee. Whilst the researcher stands by this decision, they understand that this is a potential limitation of the study.



For example, only focusing on positive experiences may have caused selection bias. By specifically asking participants to reflect on positive experiences, the study may have inadvertently attracted participants who had largely positive perceptions of their mainstream schooling. As a result, individuals who faced significant challenges or negative experiences might have been less inclined to participate, thereby skewing the sample towards those with more favourable experiences of mainstream education. This creates a bias in participant recruitment, as the voices of those who may have struggled within mainstream settings, or who found these environments less inclusive, may have been underrepresented in the findings. Thus, the study may not fully capture a wide range of experiences, limiting its transferability across the broader population of YP with DS.

Moreover, only focusing on positive experience means that the findings offer a limited perspective. Whilst it offers a rich understanding of what is positive experiences learners with DS had of mainstream school, it doesn't help develop understanding of the potential difficulties these learners may face. This can limit the development of interventions or policies aimed at addressing these issues effectively. This is because understanding both positive and negative aspects of educational experiences is crucial for identifying areas for improvement or intervention. By focusing solely on positive experiences, researchers may overlook opportunities to address shortcomings and to make enhancements.

Another limitation of focusing exclusively on positive experiences is the risk that participants may have discussed certain topics more positively than they actually perceived them. This may have been either to please the researcher or because they felt that they needed to provide the "correct" response. This is known as social desirability bias (Crowne & Marlowe, 1960) and could lead participants to overemphasise positive aspects of their experiences, even if those experiences were not entirely favourable. To minimise this risk, the researcher employed open-ended questions and refrained from directing participants toward specific subjects. The participants were given the freedom to discuss the aspects of

school they found positive in as much detail as possible, while avoiding topics they did not perceive as positive.

### ***Potential Leading Questions***

To develop participant friendly methods of data collection, the researcher created cue cards to help prompt the participants to reflect on certain elements of school. These cards were used when the participant had difficulty of deciding what to talk about, or if they needed support to structure their answers. The cue cards were developed based on the findings of previous research exploring various aspects of the life and education of individuals with DS. Whilst these cards proved extremely useful for the participants, being used by all 12 participants, they posed the possibility of leading questions. This is because they could have potentially biased participants' responses by guiding them towards certain answers or influencing their perceptions of the topic being discussed. The cue cards may have hindered the exploration of diverse perspectives and have limited the richness of the data obtained.

To reduce this bias, the researcher ensured that they included a variety of open-ended questions that allowed the participants to express their views freely without being unduly influenced by the researcher's biases, assumptions, or knowledge of previous research findings. The emergence of novel reflections in the themes are a positive indication that the data had not been too heavily biased using cue cards.

### ***Interpretation of Latent Codes***

Whilst the data analysis of RQ1 was completed using primarily semantic codes, with clear explanations from the participants of what they liked about school, RQ2 involved more semantic coding and interpretation of this. The subjectivity of interpreting the latent codes introduces bias as different researchers may have interpreted the data differently. However, the researcher acknowledged that due to the qualitative nature of the research, the researcher subjectivity was necessary and in fact contributed to an in depth and well

considered analysis. Braun and Clarke (2019) emphasise the interpretative nature of RTA and the importance of the researcher's subjectivity in the data analysis process.

However, to address any potential issues, the researcher adopted a rigorous and transparent analytical method, engaging in reflexivity to acknowledge their own biases and consider alternative interpretations of the data in discussion with their supervisor. The researcher also repeated each step of RTA to ensure they were confident with their interpretations.

## **Further Research Recommendations**

### ***Including the Views of Young People with Down Syndrome with Limited Language***

Whilst the current research represents progress in amplifying the voices YP with DS, it is acknowledged that the research does not include the perspectives of non-verbal YP with DS or those with significantly limited language skills. It's recognised that the speech and language abilities of YP with DS vary widely, with some being unable to communicate verbally effectively (Roberts et al., 2007). As a result, the varying levels of speech, language, and communication skills among YP with DS may necessitate different priorities for support. Therefore, it may be crucial to gather the perspectives of YP with DS who have more limited language and communication skills to better understand how to provide optimal support for this subgroup. This need has been highlighted in previous research too. For example, Scott et al. (2014) explored the quality of life of YP with DS from their own perspective but recognised that their research only consisted of participants who had the ability to sustain attention and had good communication skills. To address this, Geiger (2023) used visual interview approaches to gather the voices of YP with DS without needing to rely on verbal communication. However, their research only consisted of three participants. Consequently, more research should aim to include the voice of the subgroup of YP with DS with more limited language, to have an increased understanding of their experiences. This can be achieved using creative tools to capture these perceptions. These may include the visual

approaches used by Geiger, talking mats (Rabiee et al., 2005) or mosaic approaches to data collection (Beresford et al., 2004).

### ***Understanding Supportive Tools for Schools in More Depth***

The current research, along with the findings of previous research, has provided an understanding of what tools can be used to support YP with DS in schools. Whilst this gives us a brief overview of supporting strategies that can be implemented, it would be useful to research these identified supportive measures in more detail. Each theme identified in the current research can be used as a topic to explore in future research.

For example, both in the current research, and previous research (Fox et al., 2004), carefully planned use of supporting staff was identified as a good support for YP with DS in schools. However, research indicates a discrepancy in understanding the roles of TAs (Boundy et al., 2023; Hargreaves, et al., 2021). Therefore, further research is recommended to further identify the characteristics of good TA support for YP with DS. This inquiry should encompass academic support as well as support in fostering overall happiness and wellbeing, as both aspects have been acknowledged as areas where TAs can provide valuable support, as evidenced by findings from the current study.

Moreover, family support was highlighted in the current study's findings. For example, participants recognised that siblings helped them to have a positive experience of mainstream education. Other than the previous finding that siblings can support YP with DS in times of transition (Mullan et al., 2018), this is a relatively novel finding. Therefore, it is recommended that further research explores how the support provided by siblings of YP with DS can be utilised in schools.

Furthermore, previous research explores the use of intervention for supporting the academic and communication skills of YP with DS (Kennedy & Flynn, 2003; Paige-Smith & Rix, 2006) and the current research also recognises the benefits that interventions can have on YP with DS in mainstream schools. However, along with academic skills, the current

research also recognises the positive impact that interventions can have on their enjoyment of school and wellbeing. Therefore, it is recommended that further research explores the different benefits of interventions in more detail, considering a larger focus on overall happiness and wellbeing rather than only academic skills.

### ***Including Reflections of Challenges Faced by Young People with Down Syndrome in Mainstream Schools***

Previous research has shown that whilst the majority of CYP with DS go to mainstream school in the UK, this is more common for primary aged children, with a decline of secondary aged YP with DS attending mainstream school (Hargreaves et al., 2021). Similarly, in the current research, whilst all the participants attended mainstream school for at least some of their primary education, only 7 of the 12 participants attended mainstream secondary school. Whilst 6 of these participants stayed in mainstream secondary school until the end of Year 11, one transferred to specialist provision in Year 8.

To understand why many YP with DS transfer from mainstream school to specialist provisions as they get older, it would be useful to understand the current barriers and challenges faced for learners with DS in mainstream schools. This understanding could be used to help schools to ensure they can support learners with DS and put provision in place to avoid such challenges. Therefore, future research should consider how to include the exploration of negative experiences in the most ethical way. If this is done successfully, a balance in exploring both positive and negative aspects could ensure a robust and nuanced understanding of the educational experiences of YP with DS. This understanding could be used to understand how to better support learners with DS in mainstream secondary schools and thus increase the number of YP with DS attending mainstream secondary schools.

### ***Exploring the Experiences of Young People with Down Syndrome in Specialist Provisions***

As mentioned above, whilst many YP with DS attend mainstream school, there is also a large amount who attend specialist provisions, particularly in secondary school.

Therefore, to get a more holistic understanding of their educational experiences future research should explore their experiences in specialist provisions. The results could then be compared to the findings of the current study to have a better understanding of how to support learners with DS to have a positive experience of school across different settings.

### ***Using the Methodology to Explore Other Aspects of the Life of Young People with Down Syndrome***

Whilst there is some research exploring other aspects of the life of YP with DS from their perception, this perception is still relatively under researched. For example, Sheridan et al. (2020) pointed out a deficiency in research that takes into account the perspectives of YP with DS when examining their quality of life. At the time of their literature review, only two studies were available on this topic. Therefore, the methodology used in the current study should be used to explore other aspects of the life of YP with DS from their own perception. This would help to provide an understanding of how to support YP with DS extending beyond education.

### **Conclusion**

This study aimed to retrospectively explore the positive experiences of mainstream school for YP with DS. Additionally, the study aimed to explore any factors that facilitated positive experiences for these individuals. This is the first study in the UK to explore the experiences of mainstream school from the perspective of the YP with DS themselves. As a result, this study has not only contributed to the body of research investigating the education of individuals with DS but has also provided a platform for a marginalised group that has often been overlooked in the literature, giving them a voice and shedding light on their personal experiences. The findings of the study highlight the experiences of mainstream school that participants found particularly positive. This includes their experiences of socialisation within the school, including peer interaction and friendships, positive experiences of other people's attitudes towards them at school, positive experiences of the

staff that supported them, positive experiences of being exposed to a range of subjects and experiences, and positive experiences of being able to have some independence in school. The research also helped to build an understanding of how the participants felt that they could be supported to have a positive experience of school, such as by providing them with accessible personalised learning, ensuring a good home-school partnership, providing physical memories and rewards such as certificates, reports and photos, ensuring they have the opportunity to learn alongside their mainstream peers and carefully considering how adult support is given, such as ensuring that it is consistent and adapted as their abilities evolve. The findings of this study can build on previous research, which has primarily focused on understanding the perspectives of parents and teachers regarding the experiences of YP with DS in school. By incorporating these findings, along with those of Geiger (2023), a more holistic and triangulated understanding of the education of YP with DS can be achieved. This has key implications for educational professionals, including school staff and EPs as well as educational policy makers, in providing a clear understanding of what to prioritise for YP with DS in mainstream schools and how to facilitate positive experiences of mainstream school for this group of learners. This study highlighted the participants' strong ability to express their views, as they effectively articulated their positive experiences. It demonstrates that the voices of this group of individuals are valuable and should be included in research and decision-making processes. The participant friendly methods used to elicit the voices of YP with DS can be transferred to future studies to gather the voices of similar groups, such as YP with other learning disabilities as well as the perceptions of YP with DS in different contexts. Further research is recommended to explore the identified themes in more detail. As well as this, future research should aim to explore other aspects of education for YP with DS, including challenges that they face and experiences of specialist provisions. Additionally, there is a need to consider methodology for future research that can be used to include participants with DS who have more limited language skills.

## Chapter 3: Reflective Account

### Introduction

My journey as a Trainee Educational Psychologist (TEP) started in September 2021. Having previously been a teacher, I felt confident with the education system in the UK, as well as the roles, responsibilities and workload of school staff. This was a fantastic foundation to my journey to become an Educational Psychologist (EP). As well as this, placements throughout my training have led me to gain a better understanding of Local Authority (LA) practice and the day-to-day role of an EP. However, research was an area I was not confident. I understood that in order to be a well-rounded EP, I needed to develop research skills. This is because having proficient research skills is paramount in enhancing EP practice as research findings can be directly applied to improve outcomes for YP (Topping & Lauchlan, 2013).

Having not been involved in research since my undergraduate project in 2015, I felt nervous about this challenge. Although my previous experience had given me confidence with most aspects of the EP training, the idea of conducting research and writing a thesis was something I acknowledged would be a big learning process for me. I understood that every TEP and EP should be a reflective practitioner, as outlined in British Psychological Society Proficiencies (BPS, 2017) and the Health and Care Professions Council Competencies (HCPC, 2023). However, I acknowledged that my lack of confidence in this area made it even more essential for me to be reflective at every point of my research journey. This meant I needed to consistently consider if my practice could be adapted or improved, consider the strengths and limitations of my work, and recognise my limited knowledge. This would enable me to decide which questions to bring to supervision and to develop my “research resilience” (Rahman et al., 2021, pg. 1).

This chapter describes my research journey – from initially lacking confidence to ultimately feeling proud of the research I've conducted and its meaningful implications. In this chapter, some



of the reflection points that I made throughout this research journey are outlined. These reflections ensured that the decisions that I made throughout the process were legitimate and valid (Mortari, 2015) and that the research was conducted with rigour (Guba & Lincoln, 1986).

### **Developing an Interest in the Topic**

I developed an initial interest in understanding the school experiences of children with learning disabilities during my time as a primary school teacher. After spending two years in a mainstream educational environment, I sought to broaden my experience by transitioning to a special needs provision for YP with moderate learning disabilities. It was during this time that I observed that some of the learners in this provision may have had the potential to thrive in a mainstream setting with adequate support. This has also been suggested in previous research (Artiles et al., 2006; Dyson et al., 2002; Göransson & Nilholm, 2014; Jigyel et al., 2020; Kefallinou et al., 2020; Kemp & Carter, 2002; Lindsay, 2007; Lui et al., 2017; Oh-Young & Filler, 2015 Rangid, 2022; Ruijs & Peetsma, 2009).

Returning to mainstream teaching for an additional two years prompted me to reflect on the challenges faced by learners with disabilities in the mainstream classroom, and why some parents chose to send their children to specialist provision rather than mainstream schools. It became evident to me that as educators, we lacked specific training on facilitating the progress of these learners within mainstream settings (Bills & Mills 2020; Senarath, 2019; Vickerman & Coates, 2009)—an issue that I felt compelled to address.

My personal encounter with a young lady with DS profoundly influenced my perspective on inclusive education and furthered my understanding of the potential capabilities of YP with DS. Learning about her positive experience of academic achievements in a mainstream primary school, where she developed essential literacy and numeracy skills, was inspiring. However, the disappointment her family expressed about the lack of suitable mainstream secondary school options for her highlighted a systemic issue.

Despite her demonstrated abilities and success in primary education, the barriers she faced in accessing inclusive secondary education were disheartening.

This poignant conversation not only highlighted the importance of inclusive education but also shed light on the systemic challenges that learners with disabilities encounter within mainstream educational settings, as outlined in previous research, e.g. Ferguson (2014), Hove (2014) and Sigstad (2017). It reinforced my commitment to advocating for equitable access to education for all learners, regardless of their abilities or disabilities. This personal experience solidified my determination to explore these issues further in my thesis, particularly with the subgroup of YP with DS.

Being a person-centred practitioner, I wanted the focus of my research to be on the views of the YP with DS themselves. This idea was further strengthened by the gaps in research that emerged, and suggestions from Sheridan et al. (2020) that more research using the voice of YP with DS needs to be conducted.

### **Philosophical Stance and Personal Values**

Before beginning this doctorate, I had never explicitly considered what my epistemological and ontological views were. However, I am aware that my practice in all of my previous roles has been led by the understanding that children view and experience the world differently from one another, and that a “once-size fits all” approach, is not suitable in most contexts. Once I started to explicitly learn about epistemology and ontology, I quickly realised that this resonated with constructivism, e.g. Vygotsky (1978). However, once understanding the different philosophical positionings further, I began to realise that I resonated more with Critical Realism (Bhaskar, 1978). This is because I believe there are some inherent truths in the world, however, how we experience these and interpret information depends on our own individual differences (Sayer, 2004). This philosophical positioning influenced both how I understood and conducted my research (Patomäki &

Wight, 2000). I understood that there are objective realities about DS. For example, DS is a real condition, which has a real cause and a real diagnosis. However, YP with DS are individual people with individual experiences and varying abilities. Therefore, these YP may experience and interpret the world differently from each other. Therefore, when I conducted my research, it was important for me to capture their individual views and experiences.

Moreover, I recognise that my axiological standpoint (my personal values and beliefs as well as my prior experiences working with children) significantly influenced how and why I carried out this research (Carter & Little, 2007).

For example, I was inspired by the ethos of the local authority during my second and third-year placements, which emphasised solution-focused approaches (De Shazer & Berg, 1997). I found I was strongly drawn into adopting a similar approach in my research and considered how to best do this. This consideration involved exploring both solution-focused and solution-oriented frameworks. After examining both frameworks, I determined that my research aligns more closely with a solution-focused framework rather than a solution-oriented one. This is because solution-focused methodologies concentrate on recognising existing strengths and achievements rather than focusing on challenges (de Shazer et al., 2007). This is reflected in my first research question, which aimed to uncover the positive aspects of the participants' school experiences. The second RQ also corresponded with a solution-focused approach by exploring how to create a "preferred future" (Ratner et al., 2012) by prompting participants to consider what could improve their experiences. As well as this, the RTA approach to data analysis was used reveal practical insights that can influence teaching methods and enhance educational experiences, aligning with the proactive aspect of solution-focused approaches, by finding actionable implications. While solution-oriented approaches share some similarities with solution-focused approaches, I determined that it does not align as well with my research. One key reason for this is that solution-oriented approaches usually explore both positive and negative experiences (O'Hanlon & Weiner-Davis, 2003). For example, participants might be encouraged to reflect on challenges as well

as successes to develop solutions. However, the current research intentionally limits the focus to positive experiences and therefore aligns more closely with solution-focused approaches. By aligning with solution-focused principles, the aims and objectives of this research are more defined, highlighting successful experiences and deriving actionable insights from them. While I acknowledge the potential bias in focusing on positive experiences, this choice reflects a commitment to amplifying what already works for YP with DS in mainstream settings and learning from and extending those positive experiences.

Moreover, my want to use the voices of the YP with DS directly was inspired by my previous work as a teacher. This work taught me how amazing children can be, regardless of backgrounds and abilities. I thoroughly enjoyed listening to their ideas and opinions and embedding these into my lesson planning, to make the lessons tailored to both the children's abilities and interests. This is something I loved about teaching, and I wanted to ensure I continue to use child-centred approaches in my work as a TEP, and eventually an EP. Therefore, in relation to my research, effectively gathering the views and experiences from the YP with DS directly was paramount for this.

### **Reviewing the Literature**

Literature reviews are something that I find particularly challenging. However, once I began to uncover and understand the existing literature, my passion for this subject grew and grew. After browsing the literature, I decided to do a narrative literature review. This is because the literature surrounding YP with DS is extremely varied, with little focus on education and more focus on general life experiences. Therefore, I thought it would be both important and useful to understand the "story" of the life experiences of YP with DS, eventually narrowing down to a specific focus on discovering the optimal ways to support YP with DS in their educational journey. Opting for a narrative literature review enabled the creation of a thorough overview and synthesis of the current research findings concerning YP with DS. In contrast to a systematic review, which typically adheres to a structured and rigorous methodology for identifying, evaluating, and synthesising research evidence,

conducting a narrative review allowed for a more qualitative and interpretive approach. This methodology was better suited to the nature of my research (Sukhera, 2022), facilitating a deeper exploration of the topic.

Doing a narrative review allowed me to organise and present the findings in a coherent and logical manner and helped me to prioritise the inclusion of studies that provide rich insights to understanding the experiences of YP with DS.

Further examination of the literature reinforced my existing belief that the voices of YP with DS are inadequately represented in research, with most existing research using the perspectives of parents (e.g. Hargeaves et al., 2021) and school staff (e.g. Boundy et al. 2023). Therefore, this strengthened my desire to gather these missing voices in my own research, and I went on to consider the best way in which to do so.

A challenge I faced when writing the literature review was how to accurately describe and evaluate the existing research in a way that remained true to the findings, while also aligning with my personal values. For example, for me personally, the fair and equitable treatment of all YP, including those with disabilities, is extremely important. I believe that inclusivity should be prioritised and that it should be ensured that all individuals feel valued. This belief is strongly reflected in my practice as a TEP, where I often employ strengths-based approaches. For example, during EHC needs assessments, my priority is to identify and amplify individuals' strengths and use these to inform their educational provision, even when they face significant challenges. As I engaged with the literature, I found that some of the language used in the previous research had a negative tone. For example, some literature used terms like "exposure to individuals with learning disabilities." To me, the word "exposure" carries negative connotations, potentially implying something undesirable or harmful. This kind of language does not align with my values. This presented a dilemma for me, as I wanted to remain faithful to the original research findings, while avoiding such language that potentially insinuated negative or deficit-based views of YP with disabilities. To

address this, I carefully considered how to rephrase the language without distorting the research's original findings or outcomes. This involved critical reflection both on the wording used and how the portrayal of YP with disabilities could influence the perceptions of the reader. My aim was to strike a balance to present the research accurately whilst also ensuring the language used was respectful, inclusive, and aligned with my values. This challenge also highlighted the importance of language in shaping the understanding and treatment of marginalised groups within both academic and practical contexts.

## **Research Design**

### ***Developing the Research Questions***

As mentioned in the literature review and empirical paper, there is a clear lack of research eliciting the voice of the person with DS. Therefore, I wanted to focus my research on gathering the YP's views. This combined with my passion for inclusive education and solution-focused approaches led me to focus on positive experiences of mainstream education.

Although some research has explored the views of YP with DS on education (Geiger, 2023) no research has used this view to understand mainstream education specifically. This led me to create RQ1 "What did YP with DS find positive about their experiences of mainstream school?". Originally, this was my only RQ. However, reflecting on the feedback from my research proposal, I realised that only using this question would leave me with a basic understanding of mainstream school for YP with DS, which although may be interesting, the findings might not necessarily have many implications. Therefore, I decided it would be useful to consider how these positive experiences can be facilitated, as this would create implications for schools, policy makers and educational professionals in aiding their considerations when tailoring education for learners with DS in mainstream education (Miliband, 2006). This reflection led me to the creation of RQ2 "What do YP with DS believe can help facilitate positive experiences of mainstream school?".

I believe the RQs were effective in meeting the aims and objectives of this study, providing a comprehensive exploration of the positive experiences of YP with DS in mainstream education. However, I do acknowledge that focusing solely on positive experiences introduces biases and limitation, which I have outlined in the “Limitations and Challenges” section of this chapter.

### ***Considering the Methodology***

At the beginning of my research journey, I considered using Participatory Action Research (PAR) as explained by Chevalier and Buckles (2019). This approach emphasises collaboration between researchers and participants to address real-world problems or issues. In PAR, participants are actively involved in all stages of the research process, from problem identification and data collection to analysis, interpretation, and action planning. I originally considered this because the collaboration ensures that the research is relevant, inclusive, and grounded in the perspectives of those directly affected by the research question. Moreover, through active participation, individuals are empowered to voice their concerns, advocate for change, and contribute to meaningful solutions – aligning with my values. Additionally, PAR is action-oriented and seeks to effect positive change in the real world, and I am passionate about positive changes in education for learners with DS.

However, despite all of this, I decided that PAR was not the most appropriate approach as it can present certain difficulties (Grant et al., 2008). For example, participating in all stages of the research process, as required in PAR, may be challenging for individuals with DS due to cognitive and/or communication limitations. Many YP with DS may struggle with tasks such as problem identification, data analysis, and action planning, which could lead to frustration or disengagement. These additional expectations for participants may have led to more difficulty in participant recruitment. With the limited time to conduct this research, and these potential difficulties, I decided it would be more appropriate to use semi-structured interviews analysed using Braun and Clarke’s (2022) Reflective Thematic Analysis (RTA).

This is because semi-structured interviews allow for flexibility in questioning, which can

accommodate the communication abilities and preferences of individuals with DS. I recognised that I would be more able to adapt the interview format, language, and pace to suit the needs of each participant, which could promote greater comfort and engagement.

Moreover, RTA focuses on understanding participants' perspectives and experiences in depth (Braun & Clarke, 2022), aligning with the principles of person-centred approaches. By prioritising participants' voices and insights, I recognised that this analytical approach would be able to acknowledge their agency and contributions to the research process.

### ***Making the Research Accessible***

As described in more detail in the empirical paper, I had to adapt the delivery of my semi-structured interviews to ensure they were accessible for YP with DS. This is because it is important to ensure that interviews are inclusive and allow the participant to feel at ease (Knox & Burkard, 2009) These adaptations included the use of tangible objects, pens, pencils and paper for mind mapping, cue cards, the use of an additional adult to explain their ideas when necessary (a successful adaptation on previous research in 2004 by Cunningham and Glenn) and conducting the interviews in a place of their choice where they felt comfortable.

Whilst most of these adaptations were utilised by participants, no participants used the pens, pencils, and paper. This may have been purely because they didn't feel that they needed to use this aid. However, this potentially could have been because they were not sure how to use these in the research. Upon reflection, I should have taken more time at the start of the interview to demonstrate how to utilise these objects and provided more clear examples of mind mapping.

Upon reflection, I recognise that piloting my semi-structured interview questions and participant-friendly resources could have enhanced the quality of my research. I know that pilots are widely regarded as a critical component of the research process (Silverman, 2010; Bryman, 2008) and can be valuable for improving the validity and reliability of research



(Marshall, 2005). While I fully acknowledge the importance of piloting, it was not feasible in my case. Although I ultimately secured a sufficient number of participants, recruitment was initially challenging and slow, which complicated the logistics of conducting a pilot study.

Pilots should be conducted in a realistic context, utilising participants from the same population but who are not part of the main study (Drever, 2003). In my case, however, it was important for me to prioritise individuals who met the criteria and were willing to take part to be participants in the actual study. This is because, due to delays in gaining ethical approval, particularly as I needed to justify that YP with DS had the capacity to provide informed consent before my study was approved, my timeline for data collection became limited. Once I was able to start recruiting participants, I initially had difficulty to locate participants that met the criteria, and recruitment was initially fairly slow. Therefore, at first, I thought my sample size was going to be small. For this reason, I decided that rather than splitting participants into separate groups for piloting and interview participants, I decided to begin collecting data as soon as participants consented to take part. Waiting to determine the final number of participants and then dividing them into pilot and main study groups did not seem practical within my time frame.

To reduce the impact on this limitation, I employed the "shedding process" Drever (2003, p. 31). This involves refining interview questions and resources without a formal pilot by running interview schedules and materials past professionals with relevant expertise for feedback. In my case, I sought input from professionals who work closely with YP with DS, including support workers at Project 21, a DS charity, as well as my supervisor, an EP with significant research experience. These individuals were able to provide constructive feedback on the appropriateness and clarity of my interview questions, giving reassurance that my data collection methods were robust. Furthermore, after each interview, I asked participants and their accompanying adults (if they had them) for feedback on how they felt about the process and whether there were any aspects that could be improved. Fortunately, the feedback I received was positive, and no major amendments needed to be made.

While I was unable to pilot the participant-friendly resources themselves, I ensured that the adaptations I made were based on evidence. Therefore, each tool I used was selected due to its successful implementation in previous research. For example, Cunningham and Glenn (2004) effectively used both supporting adults and prompts when conducting research with a similar participant group, which gave me confidence in the reliability of my approach. By relying on established methods to gather feedback, I was able to conduct my data collection in a way that balanced rigour with the practical limitations I faced.

At the beginning of each interview, I ensured that participants had a clear understanding of the term "positive" by first asking for their interpretation of the word and then collaboratively exploring its definition in different contexts. I acknowledge that this co-construction of the definition will have influenced the data collected by guiding participants to filter their experiences through the lens of our shared understanding of "positive." This means that the findings may reflect both the participants' personal views as well as the collaborative understanding developed during the interview process. This added to the complexity of the data interpretation.

I acknowledge that this discussion of the definition influenced the participants' responses. For example, there is a possibility that participants may have shaped their answers to align with the definition I provided, even if their initial understanding of "positive" differed. This could have potentially limited the natural diversity in how participants might have interpreted their positive experiences.

In light of these considerations, I believe that the advantages of providing and discussing a definition outweighed the potential risks. Whilst I have acknowledged impact of the co-constructed definition of the word "positive" on the research findings, I also understand that this is not necessarily a limitation. This is because I followed Braun and Clarke's (2022) approach to data analysis. Braun and Clarke emphasise that in qualitative

research, data is shaped by the interaction between the researcher and the participants, and they consider co-construction as a strength rather than a limitation. This is because it integrates both the participants' experiences and the researcher's interpenetrative, knowledgeable view. Rather than aiming for complete objectivity, they suggest that the researcher's involvement and reflexivity are important to generate new, rich and meaningful findings. Therefore, the researcher is seen as an active part of the research, shaping the data through their own subjective understanding. Moreover, the feedback during the shedding process indicated that a discussion to clarify the concept of "positive" may empower participants, particularly those with communication difficulties, by providing them with a framework to articulate their experiences. Therefore, it is possible that this approach helped the participants to feel more comfortable and confident when discussing their experiences.

### ***Potential Problems with Reflexive Thematic Analysis***

While Braun and Clarke's RTA framework (2022) is a useful tool for analysing qualitative data, before using it, I considered its limitations. One concern is that RTA heavily depends on how researchers interpret the data. Critics argue that this reliance on interpretation can be problematic because researchers' preconceptions, theoretical perspectives, and personal biases may influence the identification and understanding of themes, potentially leading to biased or incomplete interpretations of the data. Additionally, some researchers have raised concerns about the lack of transparency in RTA, particularly in the process of developing and selecting themes. Critics suggest that the criteria for identifying themes and determining their significance may not always be clearly explained, making it difficult for readers to evaluate the accuracy and reliability of the analysis. Furthermore, RTA's emphasis on identifying and summarising key themes may oversimplify the richness and complexity of qualitative data. There are concerns about the reliability and validity of RTA as a qualitative analysis method. Some critics question the lack of established criteria for assessing the credibility, dependability, and confirmability of findings produced

through RTA, potentially undermining the trustworthiness of the research outcomes. (Finlay, 2021; Javadi & Zarea, 2016; Mayring, 2022; Morgan, 2022).

While I took these critiques into careful consideration, I recognised that many stem from a positivist approach, which prioritises objectivity, transparency, and replicability in research methods (Crotty, 1998). However, my research is framed by critical realism, which acknowledges the value of both subjective experiences and objective realities (Bhaskar, 1978; Maxwell, 2012). Within this framework, concerns about bias and subjectivity are less problematic, as knowledge is understood to be interpreted by the researcher. Braun and Clarke's (2022) RTA aligns with qualitative research grounded in critical realism, where the aim is not to remove subjectivity but to engage with it reflexively in order to enrich the interpretation of data, as my research does.

To ensure rigour in this approach, I used the framework proposed by Guba and Lincoln (1986), (see table 2 in empirical chapter). Moreover, I followed Braun and Clarke's (2022) practical guide closely, recognising that my subjective perspective—rather than being a source of bias to be avoided—could be leveraged as an interpretive tool. In reflexive thematic analysis, researchers are encouraged to acknowledge and reflect on their own preconceptions and theoretical lenses. This reflexivity allows for a more in-depth and nuanced analysis, where the researcher's personal engagement with the data enhances the interpretation. By actively incorporating my own insights, I was able to engage more deeply with the data, using my perspective to highlight meanings and themes that might otherwise have been overlooked.

After considering the specific aims, context, and requirements of my study, I decided that while RTA may have its limitations and criticisms, its versatility, accessibility, ability to gather rich data, practical utility and participant-centred approach made it an appropriate choice for this research.

### ***Reflections on the Reflexive Thematic Analysis Process***

Reflections I made throughout the data analysis process are outlined in the table below.

**Table 4**

*Researcher Reflections of using Reflexive Thematic Analysis*

<b>Phase of Thematic Analysis</b>	<b>Researcher Reflections of this Phase</b>
Familiarisation	<p>When I began to read and familiarise myself with the data, I realised that I would need to do a Thematic Analysis of both research questions, rather than one that encompassed both. This is because the participants answered the questions quite differently and I could see from the data that RQ2 would require more interpretation and inference. Moreover, I felt that two separate thematic analyses would allow for a more in-depth consideration of the participants views and theme development, ensuring that I had really listened to each participant and was not trying to “squish” their responses into limited themes.</p> <p>During this phase I acknowledged that it was difficult to decide how to include all details of participants’ responses, such as smiling and body language. Therefore, I used this as an opportunity to record this and understand what it meant.</p> <p>Moreover, I recognised that not all of the data would be used in the themes, as only some participants mentioned certain topics, but regardless of that, some of this data was still very interesting. Therefore, I used this phase as an opportunity to reflect on this additional data and keep a record of it beyond the thematic analysis.</p>
Coding	<p>I was aware that some qualitative research methods recommend using a second coder to ensure reliability of the codes. However, in line with Braun and Clarke’s (2022) recommendations, I made a deliberate decision not to involve another coder in my analysis. Braun and Clarke advise caution in using multiple coders, as this approach can reduce the researcher’s direct engagement with the data and</p>

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potentially compromise the depth of insight. By taking sole responsibility for coding, I ensured my full immersion in the data, which allowed me to develop a more nuanced understanding of the themes. Given that I conducted all of the interviews myself, I felt I had the closest connection to the data and was therefore best positioned to interpret it. My aim was not to find an objective "truth" but to construct meaningful interpretations based on the participants' experiences. In this sense, my single-coder approach, following Braun and Clarke's guidance, became a strength, allowing for deeper reflexivity and a richer analysis. To further ensure the validity of my coding, I revisited the data multiple times, starting from different points to ensure consistency and thoroughness in my interpretations.

I decided to take an inductive approach rather than deductive. This means I used the data as a starting point to develop themes, rather than fitting the data into existing themes based on previous research or hypothesis. One reason I did it this way was due to the lack of previous similar research. However, I also chose this approach because I wanted to get the participants' voices truly heard, and not adapted to fit with previous themes.

I had to ensure I had the RQs in mind as I coded. I had to make a conscious decision to simply "code" and not start to try and make themes in my head. This was difficult as it was natural to try and spot patterns, however I understood the importance of avoiding this.

I coded for each research question separately. However, when reviewing my codes, I realised that some codes matched the other RQ more and moved them across the Word documents that I was working on.

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#### Generating initial themes

Generating initial themes for RQ1 was time consuming. It was more difficult to generate the initial themes for RQ2 as many of their suggestions overlapped and could be suited to multiple themes. Following the advice of Braun and Clarke (2022), I also had to consider my interpretation of the data and ensure that I wasn't changing this in order to fit the themes.

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#### Developing and reviewing themes

During the process of developing themes, I realised the importance of going back and reviewing the data. This helped me to catch any new ideas or patterns that I might have missed

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before. By doing this, I was able to get a better understanding of the data and find connections that I hadn't noticed at first.

I also thought a lot about how my own thoughts and feelings could influence the analysis. I realised it was important to be aware of any biases or assumptions I had, and to make sure that the themes I develop truly represent the participants' experiences, rather than just my own ideas. It was important that I was looking at the data with fresh eyes and was not just making themes that I had begun to create previously in my mind as I had gone through the interview process. This kind of self-reflection was key to making sure the analysis was accurate and fair.

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Refining, defining and naming themes

During this theme it was essential for me to liaise with my supervisor. I wanted to show my supervisor my thematic maps, with no explanation, to see what his initial understanding of these were. This helped me understand from a different perspective whether the names of my themes really captured what I intended. After this discussion I made a few adaptations to the theme names. I then wrote a paragraph for each theme, to ensure I fully understood what each theme encompassed and that they made sense.

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Writing up

I truly enjoyed writing up my findings as it was chance to really showcase the views of the YP with DS. Since the themes were quite diverse and separate from one another, I decided to write a small discussion within the write up of each theme, rather than having an entire discussion section at the end. This method helped explain and explore my themes in more detail.

The nature of my data, due to my participants' language and communication skills, was often presented as short, concise sentences. Therefore, in order to really show how the themes were formed, I included a lot of data from multiple participants to illustrate each theme, as there was less rich, detailed data to use as an example.

In examining the themes of RQ2, I found that some were directly connected to those identified in RQ1. For instance, RQ1 revealed positive experiences, while RQ2 delved into ways to foster these specific experiences. However, not all themes in RQ2 aligned with the findings of RQ1. Consequently, I chose to present the findings of RQ1 and RQ2 separately, while still

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highlighting any connections that emerged between them.

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I recognise the importance of ensuring that the research accurately represented the participants' perspectives, which I believe I achieved through my interview approach and delivery style. I listened attentively to the participants and made sure to record their responses exactly how they expressed them. When necessary, I asked them to repeat or reword certain parts for clarification. I also checked with them to ensure I had correctly understood their responses before moving on. Additionally, I fully engaged with the data during the familiarisation and coding stages, immersing myself in the material to ensure a thorough understanding. I also utilised my supervisor for in-depth discussions about my methods and findings, which helped refine my interpretations.

I acknowledge the absence of traditional credibility checks, such as member checking. The absence of traditional credibility checks was an intentional decision, informed by Braun and Clarke's (2006, 2022) approach to RTA, which emphasises reflexivity and the researcher's active role in interpreting the data themselves, rather than seeking to "verify" findings through external checks or triangulation. Therefore, traditional credibility checks were not conducted. This because traditional credibility checks, such as inter-rater reliability or the need for external validation through second coders, were inappropriate as they suggest that there is a "correct" or singular interpretation of the data. Braun and Clarke (2020) suggest that thematic analysis should not aim for consensus between multiple coders, as doing so does not emphasise the importance of individual researcher interpretations. Thus, the subjective insights derived from RTA do not need to be judged by another coder but should instead be evaluated by how clearly and reflexively the researcher engages with the data and theory.

Member checking is also a method used in some qualitative research to check credibility, which is where findings are presented to participants for validation. According to Braun and



Clarke (2019), member checking assumes that participants' views should validate the researcher's analysis, which can undermine the interpretative nature of RTA. In RTA, the researcher's interpretation of the data is seen as an active process, rather than replication of the participants' exact words. Therefore, involving participants in validating the themes would contradict the epistemological assumptions of RTA, which prioritises the researcher's interpretation over a consensus with participants. For these reasons, member checking was not employed in the research.

To enhance reflexivity, quality and methodological rigour, I frequently engaged in dialogue with my supervisor. Throughout my research, I regularly discussed and clarified my ideas and interpretations of the data with my supervisor. This process provided valuable opportunities for critical reflection, allowing me to refine my thematic development and ensure transparency in my decision-making (Braun & Clarke, 2022). These discussions helped deepen my understanding and challenge my own assumptions, ultimately contributing to the rigour of my analysis.

## **Reflections on Participants and Recruitment**

### ***Participants***

After deciding that my research was going to involve YP with DS, I needed to decide what age group to focus on. Initially, it seemed like school-aged children would be a good option, since my research concerned the education of YP with DS. However, I decided against this for a variety of reasons. Firstly, focusing on school aged children would limit the amount of people that meet the criteria and therefore make it more difficult to recruit participants. This is because the age range of school aged participants is much smaller, and therefore it could have been more difficult to find YP that wanted to participate within this range. Moreover, choosing participants under the age of 16 would have meant needing to gain consent from their parents or carers, and may have caused ethical issues concerning whether the participant had definitely agreed and wanted to take part themselves (Edwards

& Alldred, 2001). I decided to interview YP with DS who had been to mainstream school for at least some of their education, who were 16 or older and had finished secondary education. This means that the YP were able to consent for themselves (how the consent was gained is explained in the empirical chapter) and were also able to reflect on their education as a whole, retrospectively. I chose to exclusively include YP who had experience in mainstream schools to concentrate on enhancing the inclusivity of all educational settings for YP with DS, an area I am deeply passionate about. Despite concerns raised by university staff regarding potential limitations in participant recruitment, and suggestions to open up my research to those who only had experience in specialist provisions too, I felt confident in my ability to find suitable participants and remained driven by my unwavering commitment to my research topic. Therefore, all participants had at least some experience of mainstream school. With 50% having spent all of their statutory education in mainstream and the remaining 50% of participants having had experience in both mainstream and specialist provisions.

I also ensured that I included participants across different local authorities in order to understand the experiences of YP with DS in mainstream education in a UK-wide context. This involved participants from my local county of Suffolk but also required me to travel to Essex, Nottinghamshire and South Wales in order to interview participants. Whilst I understand that not all doctoral students are able to do this due to the limitations of time and cost of fuel, I decided it was necessary as I didn't want to exclude participants who had expressed interest in my research and I believed it would increase the transferability of my findings (Guba & Lincoln, 1986) As well as this, it aligned with my believe that every individual deserves a chance to get their voice heard.

By choosing this group of participants I understand that the content of the interview data may have been restricted. For example, YP with DS did not tend to talk about the EHCP process, which has been mentioned in previous literature (Kendall, 2019). Perhaps interviewing both parents and teachers could have provided a broader spectrum of data on

various topics. Yet, I was determined to grasp the significance and positivity from the YP's viewpoint. Consequently, the data solely accentuated aspects that resonated with them, rendering concepts like EHCPs irrelevant in this instance. By focusing solely on the perspectives of YP with DS, I was able to delve deeper into their thoughts, suggestions, memories and positive experiences without potential biases or influences from other stakeholders. This approach allowed for a more nuanced understanding of their experiences. In fact, when parents were in the room with the YP during the interview, sometimes they tried to change the YP's responses. They had to be reminded frequently that I needed to understand the YP's perspective, not their own, and I had to be careful to only record the responses that came solely from the YP's own thought process. This highlights how my data may have been changed if I had decided to include parents or teachers.

When interviewing YP with DS, I realised that it was extremely important to give them time to think about their answers and structure their responses. Many participants had speech difficulties, whilst this did not make the data impossible to collect, it did mean I had to give them extra time to respond and listen carefully to ensure I understood what they were conveying. This involved repeating what they had said and checking my understanding with them. After the interview, some parents reflected how they appreciated that I gave their child the time and patience to explain their ideas and feel heard. I also realised that some YP openly talked about having DS, whereas others did not. I had to take careful consideration of this when asking my interview questions. For example, some were able to explain if others in school had an understanding of DS, whereas others did not have an understanding of this themselves or see themselves as different to others. Therefore, it was important to spend time in the interview to get to know them and assessing their acknowledgment of their condition before asking them any questions directly about DS. This adaptation highlights the importance of the semi-structured aspect of the interview (Dearnley, 2005). Reflecting on this, in future research, it would be advisable to incorporate a question on the parent information sheet regarding the YP's understanding of DS and their comfort level with direct inquiries

about it during interviews. This proactive approach would enable researchers to frame their questions accurately, eliminating the need to assess this aspect during the interview itself.

A potential problem with my chosen group of participants is that some were reflecting on a long time ago. Whilst some participants had gone to mainstream school for both primary and secondary school and only finished school earlier that year, others had only attended mainstream for part of primary school and had finished statutory education several years ago. This may have caused memory bias, where their recollection of events, emotions, and perceptions may be influenced by the passage of time. This can lead to inaccuracies or distortions in their accounts (Barclay & Wellman, 1986), impacting the reliability of the data. Moreover, participants who attended mainstream school more recently may have fresher and more detailed memories of their experiences compared to those who finished schooling several years ago. This discrepancy in recollection could result in unequal representation of perspectives within the research findings. As well as this the educational landscape and societal attitudes towards inclusion and special education may have evolved over time. Participants who attended school in different time periods may have been exposed to varying levels of support, resources, and attitudes, which could influence their perspectives and experiences. Failing to account for these contextual changes may lead to a superficial understanding of the complexities surrounding the topic (Robson, 2024).

To address this challenge, I ensured that the participants knew what the study involved and felt confident to reflect on this topic before they participated. This was also assessed by their parents, adding an additional layer of confidence that the YP would be able to remember and explain their experiences accurately. Furthermore, I actively encouraged participants to bring tangible items that could enhance their explanations and illustrate their experiences. Participants shared an array of items, such as school reports, photographs, and certificates. These objects consistently corroborated the narratives provided by the participants, lending confidence to the accuracy of their recollections.

I believe my choice in participants can be justified as it promotes inclusive representation. The research inclusively represents the experiences of YP with DS who have attended mainstream education, regardless of the time elapsed since their schooling experiences. This is necessary as it is important to capture a diverse range of perspectives to gain a comprehensive understanding. Moreover, it emphasises the value of individual narratives and subjective experiences, which are important in qualitative research (Muylaert et al., 2014). The participants' recollections varied based on their personal circumstances, memories, and reflections which allowed for richness and authenticity of the research findings.

Positively, at the end of each interview every participant expressed that they were happy to have taken part in the research. They described how they enjoyed being part of it and were grateful to be listened to and share their ideas. This further reinforced my conviction that I had chosen the right participant criteria and that the research held significant value.

### ***Recruitment***

As described in more detail in the empirical chapter, the recruitment process for this research included a poster advertising the study being shared by various DS charities and on DS and community pages on Facebook. Those who were interested in taking part (or their parents/carers) then contacted me using the details on the poster. Next, I sent those who had contacted me additional information including a link to a video explanation of the study and information/consent forms for both the parents and YP.

I started this recruitment process in July 2023 and interviewed all participants in October and November 2023. At first recruitment was slow, with only one participant signing and returning the consent and parent form over the summer holiday period. In September, 2 more participants returned the forms. Once I started to interview these YP, the participants realised they enjoyed the process and spoke to their friends. This resulted in many more YP

wanting to receive the information and participate. When speaking with the families of some of the participants, many explained that they had seen the research advertised but had not originally got in touch because they thought the participants needed to have attended a mainstream setting for all of their education. Although this was explained in both the participant information sheet and advertisement poster, perhaps if similar research is done again, the participant criteria must be emphasised even more clearly, so that there is no confusion around this.

An additional restriction in recruitment was that the charities were sharing the advertisement poster with the YP in the sessions, and although the YP were expressing how keen they were to take part, they were not always passing on the information to their parents, and therefore they were not able to contact me to express an interest. Reflecting on this, in future research it may be useful for researchers to go along to charity sessions where both parents/carers and the YP with DS attend, so that the information can be effectively shared.

Having said this, with extra promotion from the various charities and through word of mouth of the participants who had already been interviewed, I managed to successfully interview 12 participants – a good amount for my qualitative research. Recruiting 12 participants was a fantastic achievement, especially given the questions and doubts raised by others regarding participant recruitment during the research proposal and ethical approval stages.

After I had completed the interviews and had begun analysing the data, three more families of potential participants contacted me to ask if their YP could take part. However, unfortunately, by this point in time I had concluded my interviews and was in the next stage of my research. Due to time constraints of the thesis, I was unable to include these additional YP. This was challenging for me to navigate as a major driving force in this research for me was giving YP with DS a voice, so it felt uneasy to explain to the participants and their

families that they were unable to take part. To overcome this, I explained to them why it was not possible. I then asked if they would like me to share the details of any upcoming similar studies I knew about. Lastly, I offered to share my research findings directly with them. Reflecting on this, in future research I would include estimated times for each stage of the research in the information sheets, this way participants would know when they need to express interest by.

### **Other Interesting Findings**

It is important to note that while RTA proved valuable in uncovering a "shared experience" among participants (Kelly, 2017) and identifying compelling themes that shed light on the schooling experiences of YP with DS in mainstream education, not all aspects could be fully captured within these themes. Some participants shared other noteworthy experiences or offered different insightful suggestions on fostering a positive school experience. However, because these ideas were unique to individual participants and lacked similar suggestions or experiences from others, they did not align with the overarching themes identified through the analysis, resulting in them not being included in the write up of the study's findings. However, despite not being part of the themes that were developed, these experiences and suggestions may still be useful to understand. For example, Participant 3 spoke about how teaching sign language to other pupils in school was useful, as it helped them to better communicate and feel included. Participant 4 spoke about transition, and how their transition from primary school to secondary school was positive due to certain provisions that both schools had put in place. Moreover, Participant 10 spoke about how he was given evaluations to fill in regularly, so that the school could gain an understanding of his own views of his school experiences and make adaptations accordingly. Braun and Clarke (2022) emphasise the importance of meticulous recoding and theme development, along with thoughtful consideration of decisions and interpretations. Despite thorough recoding and reconsideration, these factors still did not align with any themes.

This reflection highlights the inherent complexity of qualitative research, particularly when employing methods like RTA. While RTA offers a structured approach to identifying and analysing themes, it also presents challenges in capturing unique insights that may not neatly fit within themes. Other qualitative approaches such as narrative approaches (Clandinin & Connelly, 1989), may be more aligned to this.

### **Challenges and Limitations**

In the empirical paper, I outlined potential limitations and biases in my research. This included elite bias due to the verbal capabilities of my participants, the effect of different educational experiences between participants on their reflections, positive bias due to exclusively focused on eliciting positive experiences of mainstream schooling, potential leading questions caused using cue cards and subjectivity and interpretation bias during the data analysis.

While I recognise these biases and limitations, I address them through a range of considered strategies. Firstly, the elite bias resulting from my focus on individuals with adequate verbal skills was necessary to ensure effective communication and meaningful participation in interviews. However, to address the exclusion of non-verbal individuals or those with limited language abilities, I have suggested that future research should incorporate alternative research methods and communication aids to facilitate their involvement. Secondly, the diversity of participants' educational backgrounds highlights the importance of acknowledging and considering the influence of varied schooling experiences on their perspectives. However, to help me overcome this challenge I carefully documented participants' educational histories, by asking questions to understand when they went to mainstream school and when they went to specialist provision. This helped me to conduct a carefully planned data analysis that distinguished between mainstream and specialist experiences, only including the mainstream experiences in the coding. Additionally, to mitigate biases introduced by cue cards and interpretation of latent codes, I implemented rigorous methodological approaches peer debriefing, and transparency in data analysis



methods. Engaging in reflexivity and critical self-awareness throughout the research process helped me to identify and address biases as they arose, ultimately enhancing the validity and reliability of the study finding.

Finally, the positive bias inherent in focusing solely on eliciting positive experiences required careful consideration. In the literature review, it is stated that “by gaining insights into the challenges and successes faced by individuals with DS in mainstream education, educators and policymakers can work towards creating more supportive and accommodating learning environments,” yet in my own research, I decided to focus on only the successes and not the challenges. I recognise that the decision to focus exclusively on positive experiences may inadvertently limit the scope of the findings, as it risks underrepresenting the struggles and challenges that some YP with DS face in mainstream education. This focus on positive experiences introduced bias into the research, leading to an incomplete and skewed understanding of the overall experience.

Another form of bias that may have emerged is confirmation bias (Nickerson, 1998), where focusing only on positive experiences might unconsciously have led me to seek out or emphasise evidence that aligns with my expectations, while neglecting counterevidence or more negative experiences. Additionally, there is the risk of premature closure (Connelly & Peltzer, 2016), where the focus on positive experiences might have led to prematurely concluding that the educational experience of YP with DS is overwhelmingly positive, without fully considering the complexity of their experiences. For example, one of the findings of this research was that the participants had positive experiences related to friendships, potentially suggesting that mainstream school environments may facilitate the development of meaningful peer relationships. However, had the study also focused on the challenges of the participants, it might have uncovered different or more complex social dynamics, potentially revealing difficulties that could alter this interpretation.

Finally, there is the risk of bias blind spot (Pronin et al., 2002), where I might not have been fully aware of the ways my focus on positive experiences could have shaped the data collection and analysis process, despite my efforts to remain objective.

Moreover, an exclusive focus on positive experiences runs the risk of underplaying the challenges and difficulties that YP with DS may face in mainstream education. While the study provides valuable insights into what works well for YP with DS, it does not explore the challenges that they encounter, which are equally important for informing practice and policy. As Ryff and Singer (2003) suggest, both positive and negative experiences are interconnected and contribute to a more nuanced understanding of human wellbeing. Therefore, a balanced approach that acknowledges both successes and struggles is necessary for a comprehensive understanding of the educational experiences of YP with DS. Ignoring the challenges can lead to an incomplete picture of their needs and hinder efforts to create fully supportive and inclusive educational environments.

However, after consideration, the decision was made not to explore the challenges faced by YP with DS within the scope of this thesis. Asking participants to discuss their negative experiences could have been potentially distressing or traumatic, which posed ethical concerns. This is likely to have affected participant recruitment, as it may be less likely that individuals would want to talk about their negative experiences. Additionally, gaining ethical approval for the study already presented challenges, particularly regarding the ability of YP with DS to provide informed consent and the potential risks associated with asking them to reflect on their education. Introducing questions about their difficulties and challenges would have added another layer of complexity to the ethical approval process. Therefore, I made the decision to focus on positive experiences, which was more aligned with the ethical and practical constraints of the research, as well as my personal strive to ensure participants were protected from harm.

Despite the potential risks of bias, the findings remain important and meaningful. Whilst the findings may not capture the challenges faced by YP with DS, they do highlight what is working well for some individuals with DS in mainstream education. This is valuable in its own right, as it can inform solution-focused practices that focus on building upon successes to create actionable, long-term change (de Shazer et al., 2007; Ratner et al., 2012). The positive experiences identified in this study can be used to guide educational practitioners and policymakers in shaping interventions that enhance what is already effective, while future research can focus on exploring the challenges to provide a more holistic understanding.

Whilst my research focused exclusively on positive experiences, I have acknowledged the importance of understanding the challenges YP with DS face in mainstream education and I have recommended this as a focus for future research. By examining both positive and negative experiences together, future studies can provide a more comprehensive understanding of the educational experiences of YP with DS, thereby contributing to the development of more inclusive and supportive learning environments.

As well as these limitations, I also faced challenges navigating the interview process. For example, I had to ensure a balance between adhering to the ethical guidelines outlined in my ethical approval, ensuring the participants' wellbeing, and being careful not to influence the findings. Specifically, I had to manage instances where negative experiences emerged during the interviews. To manage this, I made sure I listened to and acknowledged the participant's reflections before gently reorienting back to the positive focus of the research. Reorienting conversations away from potentially upsetting topics was necessary, however, it presented dilemmas, as I was conscious of not wanting heavily influence the participants' responses or the overall findings.

This introduced the risk of response bias (Podsakoff et al., 2003), which is the risk of participants altering their answers to align with a perceived desired response, or of the

researcher inadvertently steering the conversation towards more favourable topics. To mitigate this, I was careful to gently reorient the direction of conversations only when it became apparent that a participant was on the verge of discussing a distressing or traumatic experience. For example, if a participant indicated that a particular situation had been difficult or negative, I ensured that I listened to what they wanted to share but refrained from probing further, ensuring that I did not encourage them to revisit potentially painful memories. While this approach may have limited the scope of the data by not exploring both positive and negative aspects of their mainstream school experience, it also safeguarded the emotional wellbeing of the participants, which was my ethical priority.

To ensure the integrity of the data collected, I adopted a participant-led approach during the interviews. If a participant subtly indicated that a particular experience was not positive, I did not press them further on that subject. Instead, I guided the conversation back to topics they felt comfortable discussing. As a result, this enhanced the likelihood that the themes that emerged from the data genuinely reflected the aspects of mainstream schooling that participants found positive, rather than being artificially skewed towards positivity due to researcher interference. This approach aligns with the principles of participant autonomy and respect (Braun & Clarke, 2022), ensuring that the participants were empowered to share their experiences on their own terms, rather than being pressured to conform to the research's focus on positivity.

Another challenge I faced was ensuring that I fully understood the context behind the participants' responses. Given the diversity of their educational experiences, it was essential for me to be aware of their specific backgrounds in order to interpret the data accurately. For example, one participant spoke about having many friends in primary school but noted a decline in friendships during sixth form. Although this might initially seem like a negative experience, I recognised that their sixth form setting was a specialist school, while the focus of my research was on mainstream education. Therefore, I unpicked their comments to highlight the positive aspects of their friendships in mainstream primary school, as this was

the relevant setting for the RQs. The participant's comments about their sixth form experience were not probed for further exploration, both because they were not pertinent to the research focus and to avoid delving into a potentially distressing topic.

Similarly, during a discussion on home-school communication, one participant recalled an incident where they bit another child. Although the act of biting could be perceived as negative, the participant used it to illustrate how effective communication between the school and his family had helped resolve the situation positively. In this case, I ensured the following conversation explored the participant's intended message—highlighting the strength of the home-school communication—rather than the negative incident itself. This decision allowed me to stay aligned with the research's focus on positive experiences, while still acknowledging the complexity of the situations the participants described.

Reflecting on these challenges, I recognise that my decision to avoid exploring the participants' difficulties inevitably shaped the findings. By focusing solely on positive experiences, the research cannot make claim to the overall experiences of mainstream education for learners with DS. However, the depth and richness with which participants were able to reflect on their positive experiences suggest that the participants did have some positive experiences of mainstream school. By focusing on successes, my research contributes to a solution-focused understanding of how mainstream education can work well for YP with DS, while acknowledging the need for future research to explore the full spectrum of their experiences.

### **Reflections on Findings**

This research has successfully gathered the views of YP with DS and produced detailed findings that highlight the importance of such research. In particular the fact that so many participants thoughtfully reflected on academic aspects of their education, in

comparison to previous research by Geiger (2023) was particularly interesting and showed the in-depth understanding that YP have about their own learning. The quote from Participant 1 "*I just like working. I like to learn!*" summarises just how important learning is to these YP.

### **Implications of the Research**

As described in the empirical chapter, there are implications of this research, the study provides schools with a better understanding of what YP with DS find positive about school, potentially guiding inclusive education policies and practices, including teacher training, parental involvement, accessibility of resources, and creating supportive environments. Additionally, the findings can inform EP practice by tailoring support interventions based on the identified themes, enhancing EP professional development, and aiding them to create training packages for schools based on the findings.

However, additional implications to those previously mentioned are a result of the research process itself. For instance, it prompted reflection within the university ethics board team. Initially, there were concerns raised regarding the feasibility of conducting the research based on my participant criteria, particularly regarding issues of consent. However, driven by my passion to amplify the voices of YP with DS, I remained committed in my decision, and did not want to alter the participant selection to include parents or teachers, as doing so would exacerbate existing gaps in the literature. Instead, I dedicated time to researching legislation that supports such research and strategies to address these challenges. I studied relevant legislation such as the Mental Health Capacity Act (2005), as well as ethical guidelines from organisations like the British Psychological Society (BPS) and the British Educational Research Association (BERA). By compiling a comprehensive document outlining how I would adhere to these ethical guidelines and ensure participant wellbeing and informed consent, I successfully obtained approval from the ethics board. An implication of this experience is that it has increased awareness and understanding within the ethics panel regarding the importance of the Mental Health Capacity Act and the significance of

amplifying the voices of people with disabilities, thereby streamlining the ethical approval process for similar research endeavours in the future.

Another significant aspect of the research process was the feedback received from parents. Several parents expressed gratitude for taking the time to listen to their child and understand their experiences, and they appreciated the exploration of such an important topic. Therefore, an implication of the actual research process was that it facilitated positive feelings and reflection for the parents and families of the participants as well as the participants themselves.

### **Dissemination of Findings**

I am committed to sharing the findings of my research, as I believe they hold significant importance in enhancing the educational experiences of learners with DS in mainstream schools. Without dissemination, the opportunity for actionable change, a key focus of this research, would be lost. One avenue for dissemination is through publication, with journals such as “Educational Psychology in Practice” being well-suited for this purpose.

Additionally, I am dedicated to sharing the findings with the participants and their families, as per their request on the consent forms. Furthermore, I will ensure dissemination to the DS charities that aided in participant recruitment, including Project 21, The Down Syndrome Association, and Nottinghamshire Down Syndrome Support Group. This step is crucial for reaching YP with DS who were not directly involved in the study, as well as their parents and carers. Moreover, I intend to leverage the connections of these charities with other DS organisations and educational providers to broaden the reach of the findings.

To raise awareness among EPs I aim to present at both the Eastern Region Conference and the Division of Educational and Child Psychology (DECP) TEP Conference. By doing so, I hope to spark the interest of other TEPs who may explore the education of YP with DS in their theses.

Furthermore, by enhancing understanding of how to facilitate a positive educational environment for young people with DS in mainstream schools, particularly among TEPs and EPs, I aim to initiate conversations within the broader EP community. TEPs play a pivotal role in shaping practice and disseminating their knowledge to supervisors, tutors, peers, and others. Additionally, I will share a summary of findings with my placement LA and other Educational Psychology services. This dissemination aims to equip EP with a better knowledge when writing psychological advice for learners with DS and to assist them in developing training packages to support teachers and school staff in feeling confident and equipped to teach and support learners with DS effectively. Ultimately, this approach aims to enhance provision for learners with DS in mainstream educational settings.

### **Contributions to Personal Development**

Conducting this research has made me grow in many ways. Firstly, it taught me that I did not need to fear research and that I am an able researcher who can work thoroughly in order to present useful findings. Moreover, due to my initial lack of confidence, I learned how to embrace supervision and make the most of this time to discuss my ideas and ask any questions.

Moreover, from this research journey, I have discovered my capacity to advocate for what I believe in. Despite encountering suggestions to simplify my recruitment process by broadening the scope beyond mainstream experiences, and initial challenges with the ethics process that cast doubt on the feasibility of interviewing YP with DS, I remained confident in my commitment to exploring what I believed was essential. By standing firm in my beliefs and persevering through these obstacles, I ultimately overcame them, reaffirming the significance of staying true to my values in the research process.

As well as this, I have broadened my own understanding of DS and challenged some of my own unconscious assumptions. For example, the YP interviewed astounded me with some of their choices in language, using words such as “gratifying” and “speechless” and



impressed me with their ability to retrospectively label emotions that they had felt. Witnessing their independence and adept social skills, such as confidently introducing themselves, was truly enlightening. Additionally, one participant's passionate discussion about the intricacies of the Harry Potter series left a lasting impression on me. They shared their insights into the themes of the books and compared them to the film adaptations, highlighting elements of the books that were not included in the films. I was taken aback by their depth of understanding of such a complex book series, prompting a realisation: I shouldn't have been surprised at all! I should have had more faith in their abilities. This experience served as a powerful reminder to challenge my unconscious biases and it has prompted me to adopt a mindset of "assuming capability unless proven otherwise," a perspective I am eager to apply in my future interactions as an EP. I think this is an incredibly positive shift in mindset.

Lastly, the research process has deepened my commitment to supporting individuals with specific learning disabilities and has provided me with a richer understanding of this field, particularly in gathering the perspectives of YP with such disabilities. This improved interest, knowledge, and skill set will undoubtedly contribute a unique perspective to the EP team that I join once qualified. Additionally, it has equipped me with valuable insights and approaches that can enhance my practice as an EP, enabling me to provide more effective support to individuals with learning disabilities in various educational settings.

## **Conclusion**

In summary, this chapter has outlined my rationale behind specific decisions made in this research, including the selection of the research topic and methodology, and has explained the influence of my philosophical and axiological perspectives on these decisions. I have acknowledged the imperfections within the research and reflected on how these insights can inform future improvements. This process has contributed to the enhancement of my research skills, fostering growth as a researcher. Additionally, I have reflected on my personal development throughout this journey and outlined plans for disseminating the findings to generate positive impacts. This research has highlighted how the views of YP with

DS can be used to facilitate positive experiences of mainstream education. A successful education can lead to a more successful life - *“I feel proud that I learnt to write, and I can now use it every day and school helped me do that”.*

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## Appendices

### Appendix 1: Literature Review Search Terms

#### ***Search 1: Exploring the Quality of life and Experiences of Young People with Down Syndrome and Their Families***

Guided by the review question: What contributes to a good quality of life for individuals with DS and those around them?

<p>Key word list 1:</p> <p>Down syndrome</p> <p>Down's syndrome</p> <p>Downs syndrome</p> <p>DS</p> <p>Trisomy 21</p> <p>(Searched using "or". Searched for in the title)</p>	<p>Key word list 2:</p> <p>Quality of life</p> <p>Attitudes</p> <p>Wellbeing</p> <p>Self perception</p> <p>Family variables</p> <p>(Searched using "or". Searched for in the title)</p>
<p>Inclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Only literature published from the year 2000 onwards</li> <li>• Only peer-reviewed articles were included</li> <li>• Only literature accessible in the English language was included</li> </ul> <p>Exclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Literature published prior to 2000 were excluded</li> <li>• Non-peer-reviewed documents were excluded</li> <li>• Papers not accessible in English were excluded</li> <li>• News articles were excluded</li> </ul>	

**Search 2: The Educational Experiences of Young People with Down Syndrome:**

**Exploring Key Influencers and Perceptions**

Guided by the review question: How do YP with DS experience education and what factors can impact these experiences?

<p>Key word list 1:</p> <p>Down syndrome</p> <p>Down's syndrome</p> <p>Downs syndrome</p> <p>DS</p> <p>Tristomy 21</p> <p>(Searched using "or". Searched for in the title)</p>	<p>Key word list 2:</p> <p>Academic</p> <p>Education</p> <p>Special school</p> <p>Mainstream school</p> <p>Inclusion</p> <p>Teachers</p> <p>(Searched using "or". Searched for in the title)</p>
<p>Inclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Only literature published from the year 2000 onwards</li> <li>• Only peer-reviewed articles were included</li> <li>• Only literature accessible in the English language was included</li> </ul> <p>Exclusion Criteria:</p> <ul style="list-style-type: none"> <li>• Literature published prior to 2000 were excluded</li> <li>• Non-peer-reviewed documents were excluded</li> <li>• Papers not accessible in English were excluded</li> <li>• News articles were excluded</li> </ul>	

## **Appendix 2: Explanation of How the Search was Conducted and Research Papers were Selected to be Reviewed**

The researcher began the literature review by engaging with general reading on DS to familiarise themselves with key concepts and develop a deeper understanding of the condition. This initial exploration informed the researcher's decision on review's specific focus, objectives, and aims. After determining the review's scope, the researcher compiled a list of relevant search terms. However, this preliminary set of generic terms yielded an overwhelming volume literature, including some that was unfocused and unrelated. To address this, the researcher formulated two specific review questions, which provided a clear framework to structure and organise the review. Subsequently, search terms were systematically grouped according to the review questions, allowing for two targeted searches to be conducted. Carefully selected search limiters were applied to the searches, as well inclusion and exclusion criteria to ensure relevance and manageability.

After completing each search, the researcher reviewed the results by first scanning the titles of the papers to assess their relevance to the literature review.

The first search yielded 167 results. Papers were considered relevant if they focused on the quality of life of individuals with DS, attitudes towards individuals with DS, or the experiences and perceptions of family members related to having a child with DS. Papers that were primarily health-related or those that examined highly specific topics, such as the impact of a particular intervention, were excluded in favour of studies that provided a broader perspective on the general lives and quality of life of YP with DS.

The second search yielded 144 results. To be included, papers from this search needed to be directly related to the educational experiences of individuals DS or their academic abilities and outcomes. Studies that were overly specific, such as those focusing on the effects of interventions like motor skills training, were excluded to maintain a broader focus on general educational experiences. The researcher did not include papers that focused primarily on children with DS who were younger than school aged.

If a paper's title was deemed relevant by the researcher, they then went on to read the abstract. If the abstract proved useful, the researcher went on to review the whole paper.

As the researcher went on to read and review the literature, they highlighted any additional relevant research discussed within the identified papers, and then reviewed these if they were relevant. Whilst the original searches only included papers from the year 2000 onwards, a small amount of research identified as relevant from within these papers was from before the year 2000. These earlier studies were only included if they contributed to validating more recent findings or were referenced in discussions of more recent research, rather than being subjected to in-depth review themselves. The snowballing technique also proved valuable in gathering additional information about DS as a condition, which contributed to developing the introduction of the literature review.

Whilst it is recognised that the initial searches yielded a lot of papers, the researcher was able to use their own interpretations to select the relevant papers (Sukhera, 2022). To do this, the researcher carefully reviewed the titles and abstracts of these papers, eliminating those that did not strongly align with the focus on the topic of the review questions. This approach aligns with the suggested approach outlined by Baumeister and Leary (1997), who emphasise the importance of starting with a comprehensive collection of literature and then narrowing it down to the most relevant studies. Ultimately, this process allowed the researcher to focus on a manageable number of high-quality papers that contribute meaningfully to the narrative review, ensuring a robust synthesis of the literature while maintaining a clear focus on the research questions.

### Appendix 3: Research Information Poster used for Promotion



**Did you know, the voice of young people with Down syndrome is underrepresented in research exploring education?**

**I am a Trainee Educational Psychologist, and I want to make a CHANGE**



Hi, my name is Nicola, and I am a Trainee Educational Psychologist at the University of East Anglia. My email address is nicola.baker@uea.ac.uk

I am carrying out some research to explore the experiences that young people with Down syndrome have had in mainstream schools to understand how to facilitate a more positive education for those with Down syndrome. To do this, I will be chatting to young people with Down syndrome to find out what they liked about their mainstream education. I will use this information to discover how this can be implemented into mainstream schools consistently.

To be part of my study, you need to:

- Have Down syndrome
- Be 16 or older
- Have been to a mainstream school for at least part of your education
- To be able to share what you remember positively about your mainstream education
- To want to be a part of my study! This means you will want to share some information about your experience of school with me

For a video explaining this study: <https://www.youtube.com/watch?v=KQKp-Lvh-cA&fbclid=IwAR3d8nqoyZJc4k9pYUtrQWmYQkpPyjImWBcc8IGnjPhabt3javgfugqCV0k>

I would love to be able to meet you and ask you some questions about when you went to school! We will focus on what you **liked** about school and the **positive** experiences you had. You can bring anything along with you to help you explain your school experience! This could be pictures, letters, objects, toys, books, school reports or ANYTHING! You can even bring another adult with you to support you and help explain your ideas. If you want to take part, follow the steps below!

First, you or your parent or carer must email nicola.baker@uea.ac.uk to show your interest

Then, I will return some information sheets and consent forms via email. You must read these documents with a parent, carer or trusted adult

Next, if you want to take part, sign the consent form. Your parent or carer must also read and sign the guardian information sheet. Both documents must be emailed back to me

Afterwards, I will contact you and your parents or carers to arrange a suitable time and place to meet you

Finally, you will take part in an interview and chat about your positive experiences of mainstream school

## Appendix 4: Participant Information Sheet

Faculty of Social Scienc  
Miss Nicola Baker School of  
Trainee Educational  
Psychologist  
University  
6.5.2023



Education and  
of East Anglia

Norwich Research Park

Norwich NR4 7TJ

**ON THE LAST PAGE OF THIS PACK, THERE IS A CONSENT FORM THAT MUST SIGNED IN ORDER TO PARTICIPATE** United Kingdom

### Study Information Sheet: Exploring the positive experiences of learners with Down syndrome in mainstream school: A Reflexive Thematic Analysis study



For a video version of this letter, right click here and open the hyperlink:  
<https://www.youtube.com/watch?v=KQKp-LvhcA&fbclid=IwAR3d8nqoyZJc4k9-pYUtrQWmYQkpPyjImWBcc8lGnjPhabt3javgfuqCV0k>

Hello. My name is Nicki.

I am doing a research project to find out more about how children with Down syndrome experience mainstream school and what they liked about school.

I am asking you to be in my study because you would be perfect for it as I need the help of people with Down syndrome that have been to a mainstream school – just like you!

You can decide if you want to take part in the study or not. You don't have to - it's up to you.

This sheet tells you what I will ask you to do if you decide to take part in the study. Please look at it carefully, with an adult who knows you well, so that you can make up your mind about whether you want to take part. Your parent or carer has received an information sheet too, so they can help you understand. I've also made a video for you about the study – right click on this link and open the hyperlink to watch it <https://www.youtube.com/watch?v=KQKp-LvhcA&fbclid=IwAR3d8nqoyZJc4k9-pYUtrQWmYQkpPyjImWBcc8lGnjPhabt3javgfuqCV0k>

If you decide you want to be in the study and then you change your mind before we start, that's ok. All you need to do is tell me that you don't want to be in the study anymore. You or your family or someone who looks after you can email me on [Nicola.baker@uea.ac.uk](mailto:Nicola.baker@uea.ac.uk)

If you have any questions you can speak to me or your family or someone else who looks after you. If you want to, you can contact me on [Nicola.baker@uea.ac.uk](mailto:Nicola.baker@uea.ac.uk)

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



- I will invite you to come to an interview, where I will ask you some questions
- The interview will be in a place that you know well and feel comfortable
- I will ask you some questions about when you went to school
- All of the questions will be about your **positive** experiences in school, this means things you

enjoyed, or that helped you to learn or feel welcome and happy

- You can bring anything you like to the interview to help you answer the questions, this might include objects, toys, letters, report cards etc.
- There will be some picture cards to help you answer too, you can also draw or write if it helps you
- If you don't want to do the interview on your own, you can bring an adult that you trust with you, they can help you to explain your answers
- You will be with me for around an hour. You can stop the interview whenever you want

When I ask you questions, you can choose which ones you want to answer. If you don't want to talk about something, that's ok. You can stop talking to me at any time if you don't want to talk to me anymore.

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

If you say it's ok, I may take some photos of the objects you bring in or any drawings/writing you might do.

After you have finished talking with me, I won't be able to take out the things you say after you have said them. This is because I will be talking to other young people too, and I will not know who said what. You can choose which questions you want to answer. If you don't want to talk about something that's ok

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



I won't tell anyone else what you say to me, except if you talk about someone hurting you or about you hurting yourself or someone else or doing something you should not be doing. Then I might need to tell someone to keep you and other people safe.

All of the information that I have about you from the study will be stored in a safe place and I will look after it very carefully. I will write a report about the study and show it to other people, but I won't put your name in the report and no one will know that you're in the study.

### How long will the study take?



The study will take around 60 minutes. You can choose how long you want to talk to me for and how much detail you answer in. You can have breaks if you need them.

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



research

- This study will help the voice of people like you be heard!
- This study will help schools to understand what young people with Down syndrome find positive about mainstream school
- This study will help schools to understand how they can make school a positive experience for young people with Down syndrome
- You won't get anything for being in the study, but you will be helping me do my

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



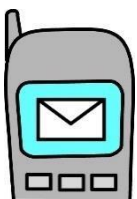
- This study will take up some of your time
- Sometimes, you may find it tricky to explain your answers
- If you didn't enjoy school, some questions might be tricky for you to answer

Remember – you don't need to answer anything you don't want to

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

Yes, I will if you want me to. There is a question on the next page that asks you if you want me to tell you what I learned in the study. If you circle Yes, when I finish the study, I will tell you what I learned by emailing you, or your parent/carer a one-page summary.

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



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

- Write an **email** to me on [nicola.baker@uea.ac.uk](mailto:nicola.baker@uea.ac.uk)
- Write an **email** to my supervisor on [ryan.cullen@uea.ac.uk](mailto:ryan.cullen@uea.ac.uk)
- Write an **email** to the Head of School [Y.Lebeau@uea.ac.uk](mailto:Y.Lebeau@uea.ac.uk)

Please read the next page to consent to take part in the study

This sheet is for you to keep.



## Appendix 5: Parent/Carer Information Sheet

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



**THERE IS A SHEET AT THE BACK OF THIS DOCUMENT THAT THE PARENT/CARER MUST SIGN IN ORDER FOR THE YOUNG PERSON TO TAKE PART**

### **Exploring the positive experiences of learners with Down syndrome in mainstream school: A Reflexive Thematic Analysis study**

Your young person has been invited to take part in a research study about the experiences of learners with Down syndrome who have been educated in mainstream education for at least part of their education.

They must be able to willingly consent to take part in this research themselves, in order to take part. To do this, they must understand what the study will entail and why they have been asked to participate. They also must understand the benefits and the risks involved with being in the study.

In order to ensure that your young person has the capability to consent, it is advised that you, as their parent or guardian, read through the following information about the study. You can then advise whether you believe that your young person is able to willingly consent to and understand this research.

In line with the Mental Capacity Act, in order for your young person's consent to be valid, you must believe that they:

- show some understanding of the information given to them
- are able to retain the information for long enough
- can weigh up information and use it to make the decision
- can communicate the decision

Please read the information below about the research and chat with your young person about it to decide whether you believe your young person is able to consent to take part.

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

Your young person has been asked to take part in this study about the experiences of learners with

Down syndrome who have been educated in mainstream education for at least some of their education. This study will explore what learners with Down syndrome consider a positive experience in school. The study aims to use this information to build an understanding on how to best facilitate these positive experiences in school for all learners with Down syndrome in mainstream settings.

To do this, we are asking young people with Down syndrome, aged 16 or older, who have been educated in mainstream education for at least some of their education, to reflect on their experiences in a semi-structured interview. This interview doesn't need to involve only speaking. Your young person can use objects and pictures to explain their experiences too. They can talk about any experiences they want, including, but not limited to: primary school, secondary school, college and further education settings.

Participating in this study is voluntary.

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

The study is being carried out by the following researcher:

Miss Nicola Baker at the University of East Anglia

Trainee Educational Psychologist

Contact email: [nicola.baker@uea.ac.uk](mailto:nicola.baker@uea.ac.uk)

This will take place under the supervision of the following university tutor:

Mr Ryan Cullen at the University of East Anglia

Contact email: [ryan.cullen@uea.ac.uk](mailto:ryan.cullen@uea.ac.uk)

## **(3) What will the study involve for your young person?**

This study involves completing a semi-structured interview. The interview will take place at a location familiar and comfortable for your young person. In the interview, your young person will be asked questions about the **positive** experiences they person had at school. The researcher will take notes about what they say. If your young person struggles to answer verbally, they can use pictures, prompts, symbols and objects to help. They can even draw pictures if they would like. Prompt cards will be provided, but they can also bring along anything they want to help them. Your young person can also be accompanied by an adult who knows them well, such as yourself. This adult can help your young person to express or explain their views but cannot add their own personal views.

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

The interview will take around 1 hour, depending on how much your young person wishes to share with me. This can be shorter if they like. Your young person is also welcome to have a break whenever needed.

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

Being in this study is completely voluntary and your young person does not have to take part.

The decision to participate or not will not affect your young person's current or future relationship with the researchers or anyone else at the University of East Anglia now or in the future.

If they choose to take part in the study, their answers will be anonymous. If they decide that they want to withdraw part-way through completing the interview, they can leave whenever they want, and their answers will not be stored. However, once data analysis of the interviews has begun, they will not be able to withdraw their answers from the study. This is because the answers will have been anonymised and used to find themes. Due to the anonymised data, it will not be possible to identify their answers and remove them.

**(6) Are there any risks or benefits associated with being in the study?**

I understand that answering questions about school and trying to remember back in time may be stressful for some people. While the questions are not designed to be sensitive, school could potentially be a difficult subject for some participants. Your young person will be encouraged to stop the interview if at any time they may feel uncomfortable. Moreover, the interview style will be flexible and adapted to your young person's needs, in the aim to make a comfortable experience for them.

If they feel affected by or worried about anything discussed in the interview after it is completed, they should contact the researcher for support, who can discuss any key issues with the YP and/or their guardian. If they are unable to resolve any issues, they will signpost the young person/guardian to other organisations that will be able to help.

It is hoped that being in this study will also be beneficial. It is hoped that this research will further the understanding that schools and education settings have surrounding the education of young people with Down syndrome in order to help support a positive education for children and young people with Down syndrome in mainstream classrooms. Moreover, it is hoped that your young person will feel that their voice has been listened to and heard. In addition, the methods used to gather views will hopefully provide other researchers in Educational Psychology with confidence that it is possible to capture the views and experiences of those with Down syndrome or other learning or communication difficulties. This should provide methods for further research gathering the voices of these groups.

**(7) What will happen to information provided by your young person and data collected during the study?**

By consenting to participate, your young person is agreeing to their responses being anonymously collected and used for the purpose of this study. Personal data will be removed and data collected during the study will be studied in order to find key themes within the data and then report the findings of the study. Any data collected will only be used for the purpose of this study. All data will be stored on the UEA One Drive. Only Nicola Baker and Ryan Cullen will have access to the data. The overall results of the study will be written up into a thesis and submitted as part of the Educational Psychology Doctorate that the researcher is undertaking at UEA. Your young person's data and information will only be used as outlined in this Participant Information Sheet. 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. Although every effort will be made to protect your identity, there is a risk that you might be identifiable due to the nature of the study and/or results.

Study data may also be deposited with a repository to allow it to be made available for scholarly and educational purposes. The data will be kept for at least 10 years beyond the last date the data were accessed. The deposited data will not include your name or any directly identifiable information about you, but there is a risk that you might be identifiable due to the nature of the study and/or results.

**(8) What if I would like further information about the study?**

When you have read this information, Miss Nicola Baker ([Nicola.baker@uea.ac.uk](mailto:Nicola.baker@uea.ac.uk)) will be available to discuss it with you and your young person further and answer any questions you or your young person may have.

**(9) Will I be told the results of the study?**

You and your young person can receive feedback in the form of a one-page lay summary in July 2024, once the research is complete, if your young person wants this. You will also be able to read the full thesis, should you want to, once it becomes available. The researcher will email you to notify you when this is possible.

**(10) What if I have a complaint or any concerns about the study?**

If there is a problem, please let the researcher know. You can contact them via the University of East Anglia at the following address:

Miss Nicola Baker  
School of Education and Lifelong Learning  
University of East Anglia  
NORWICH NR4 7TJ  
[Nicola.baker@uea.ac.uk](mailto:Nicola.baker@uea.ac.uk)

Please email to arrange a telephone call

If you are concerned about the way this study is being conducted, you can contact the researcher's supervisor via the University of East Anglia at the following address:

Mr Ryan Cullen  
School of Education and Lifelong Learning  
University of East Anglia  
NORWICH NR4 7TJ [ryan.cullen@uea.ac.uk](mailto:ryan.cullen@uea.ac.uk)

Please email to arrange a telephone call

If you wish to make a complaint to someone independent from the study, please contact the Head of School of Education and Lifelong Learning:

Professor of Higher Education Research  
Yann Lebeau  
Contact email: [Y.Lebeau@uea.ac.uk](mailto:Y.Lebeau@uea.ac.uk)

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

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

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

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

In addition to the specific information provided above about why your young person's personal data is required and how it will be used, there is also some general information that 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](mailto:dataprotection@uea.ac.uk)
- You can also find out more about your young person's data protection rights at the [Information Commissioner's Office \(ICO\)](#).
- If you are unhappy with how your young person's personal data has been used, please contact the University's Data Protection Officer at [dataprotection@uea.ac.uk](mailto:dataprotection@uea.ac.uk) in the first instance.

### **(13) OK, I believe my young person has the capability to consent– what do I do next?**

Please sign this form electronically (using Microsoft word) and return via email to [nicola.baker@uea.ac.uk](mailto:nicola.baker@uea.ac.uk)

By signing this form, you are advising that you believe your young person has the capability to consent to take part in this research.

Once the researcher receives this signed form, along with your young person's signed consent form, your young person can take part on this study. The researcher will be in contact shortly to provide more details and organise an interview time and location.

Thank you,

Nicola Baker (Trainee Educational Psychologist)

### **(14) Further information**

This information was last updated on 25<sup>th</sup> September 2023.

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

### **(15) Confirmation of consent**

I agree that ..... is capable to consent to take part in this research

PRINT name: .....

Relationship to  
young person: .....

Signature: .....

Date: .....

## Appendix 6: Participant Consent Form

### Consent Form

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

- **write** your **name** in the space below
- **sign** your **name** at the bottom of the page
- put the **date** at the bottom of the page
- email this signed form back to me on Nicola.baker@uea.ac.uk

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

I, .....[PRINT NAME], am happy to be in this research study.

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

I know what the study is about.

I know what I will be asked to do.

Someone has talked to me about the study.

My questions have been answered.

I know that I don't have to be in the study if I don't want to.

I know that I can pull out of the study at any time if I don't want to do it anymore.

I know that I don't have to answer any questions that I don't want to answer.

I know that the researchers won't tell anyone what I say when I talk to each other, unless I talk about being hurt by someone or hurting myself or someone else.

If you agree to take part in the study, you will be asked a few questions at the start of the interview to ensure you understand what the research is about. If you show that you understand, we will continue with the interview. If you do not understand, then I won't ask you to answer anymore questions.

**Now I am going to ask you if you are happy to do a few other things in the study. Please highlight 'Yes' or 'No' to tell me what you would like.**

Are you happy to **speak just to me?**

(with an adult you know in the room if you prefer)

**Yes**

**No**



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

Are you happy to take some photos of objects you bring to the interview or any drawings/writing you may do?                      **Yes**                      **No**

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

.....

**Signature**

**Date**

## Appendix 7: Plan for Semi-Structured Interviews

The following questions will be asked at the interview. However, this is a semi-structured interview. Meaning that although these questions will be asked, the order may change, or the time spent on each topic may differ. The questions may also be reworded to suit the language ability and understanding of the individual. At times, the answer may be reworded by the participant's chosen adult, so that the researcher can better understand their response.

When previously organising the interview time and location etc, participants will have been asked to bring in any objects, pictures or things that they can use to explain their positive experiences in school. Therefore, it is likely that the participants will have objects with them.

Moreover, there will be a variety of resources available for them to use. This will include:

- Picture cards. Picture cards will consist of a picture and a corresponding word. Pictures will include a variety of different people represented on them, for example, different races and genders. The picture cards have been designed by the researcher. They have been designed using previous research findings (as outlined in my literature review)
- Pens
- Pencils
- Paper

Before the interview, it will be explained to the participants that they can use these resources, and examples of how to use them will be given.

Questions to ensure informed consent is valid (that the participant had the capacity to consent)

- 1) Do you want to be in this study?
- 2) Can you tell me a little bit about the study and what you might have to do?

- 3) Why do you want to be part of this research?
- 4) Do you understand what benefits this study has? Could you explain some?
- 5) Do you understand any risks with this study? Could you explain some?
- 6) Did you make the decision to take part in the study yourself, or did somebody tell you to?
- 7) Are you happy to continue?

Questions to ensure understanding of topic:

- 8) What is a mainstream school and what is a specialist school? Do you understand the difference? (If participants do not understand, this will then be explained to them – detail will vary between participants. This may not be necessary if participants ONLY went to mainstream school)
- 9) What does the word positive mean for you? (participants will then be given a definition of the word positive and this will be discussed)

It is then explained to the participant that the following questions are regarding their mainstream education.

Questions to gather the views of the participants:

- 10) Please can you tell me anything you enjoyed about school? (Words adapted according to understanding, e.g. “liked” may replace “enjoyed”)
- 11) Please can you tell me anything that helped you to have a good experience at school?

Participants will be prompted to extend conversation with follow up questions like “Can you tell me a bit more about that?” and “Why did you enjoy that?”, “Can you explain why that was useful?” etc.

If participants are finding it difficult to answer, or need help to answer, picture cue cards will then be placed on the table. These pictures have been chosen based on findings from previous research. The intention of these cards is to facilitate initial conversation and to give the participants some ideas – not to limit what they say. Due to the nature of the unstructured part of the interview, the cards will either be used at different parts of the interview, dependant on the participant.

- 12) Please can you look at these pictures (researcher explains each picture). If any of these were positive for you in school, please put them under this heading (a sticker labelled positive), if they were not, then put them back into the pile
- 13) (For each picture that the child has identified as positive) – can you please explain what this positive experience was (children can use words, drawing, or objects to respond)
- 14) (For each picture that the child has identified as positive) did anything or anyone at school or home help this to be a positive experience?
- 15) Can you please show, and explain to me anything you brought to this interview with you today?
- 16) Are there any other positive memories you have of school? (Researcher then reads aloud the list of positive experiences that they have collected. Participant is given the opportunity to confirm that these are experiences that they regarded as positive or not)
- 17) What helped make this a positive experience? (Participant answers for each additional positive experience)
- 18) Is there anything else that you think is important to tell me about?

Appendix 8: Cue Cards Used in the Interviews



## Appendix 9: Example Extract of Interview Transcription

The following extract has been randomly selected from within the interview transcription document. The red text is data from the researcher and the black text is data from the participant's responses.

**You mentioned you liked play time; can you tell me a little bit more about playtime?** In the past, I would make up imaginary games on my own. I didn't always spend it with other people, but I enjoyed the chance to be alone. But I did have friends.

**Can you tell me a little bit about your friends?**

I had sooooo many friends at primary school. I have less friends at sixth form than I did at primary school. But I do have 2 great friends and we are the 3 musketeers. We are a bit silly together a lot of the time and I get into trouble. But I am trying to be more mature. In class I need to be more sensible.

**It is lovely to hear you have so many friends**

Yes, especially in primary school. My friends helped me to be happy. People I was friends with in school still remember me. I saw someone from primary school on the bus the other day and they chatted to me. They don't care that I have Down syndrome. It is nice to be remembered.

**You told me that your family helped you in school. Can you tell me a little bit about how your family made school a better experience?**

My mum would talk to the school if I had a problem. She was part of the team. She could come into school and talk to the school if I needed something. She was involved in school. The school knows my mum well. Which is important. It was useful that my mum knew if my day had been good or bad so we could talk about it. Like the time I bit someone. My mum helped me understand but she also spoke to the school about why I did it. The school can talk to my mum over email.

**You told me that you did lots of different lessons in school and that you liked this, can you tell me a little bit more about what subjects you learnt about?**

There are loads of subjects. English, maths, history, science, PE, art, music, Geography and ICT

I really love history; it is so interesting. I love learning about the past. It is great. I'm so happy I got to learn about different things, it helped me know what I like and what I am interested in. Especially history and sport. I was happy to learn art because I like to be creative. I really like music too; I like making up songs and using special effects. I like to do coding in ICT too. Art and ICT are good because I can put them

together. For example, to make a game, you need to be good at art for the animation, but coding to make it. You can put the two subjects together to do something well.

That's so true, and such a good link to make – I like that way of thinking. Wow you've answered so well, and you have answered all of my questions. Could I possibly see what you've got here in your folders to show me?

These are all my certificates and pictures. Pictures of me for school are important for my memories. Certificates are important so I know when I am working hard and doing the right thing. It helps me feel good. I really like certificates a lot. I feel happy.

Getting a certificate makes me work harder, I worked really hard to get them. I also like the birthday certificates because it makes me feel loved and remembered.

Report cards are good too because they tell my mum how I am doing at school and then she can help me.

Is there anything else you want to add about school and what made it successful that I didn't ask you about or that you haven't mentioned yet?

I'm so good at sports and I might be going to the Special Olympics for basketball or hockey. I also love to dance a lot. I have also been famous on BBC sports for football.

Wow that is amazing, what is your favourite sport?

All sports, I love them all. I like it when school sees how good I am and helps me. Is there anything else positive about school that you wanted to add?

I want to go to university, but I need people to be strict with me so that I can learn and get to where I want to go. I need help to do my work and not be distracted by things like my Xbox.

I liked primary school because it was close, when I moved to another school I had to have a long taxi drive.

I didn't talk much, but in primary school they gave me speech and language, and this really helped me. I also improved my talking because I was with other children that talked a lot. I learnt to speak so much better because of primary school. I was so quiet but now I am happy to talk and explain things.

## Appendix 10: Example Extract from Data Familiarisation Notes

### Quotes I liked

I could learn from other children. I could use their ideas and share mine

Learning number is important to understand things in life

My brain is so active

Art and ICT are good because I can put them together. For example, to make a game, you need to be good at art for the animation, but coding to make it. You can put the two subjects together to do something well.

I didn't talk much, but in primary school they gave me speech and language and this really helped me. I also improved my talking because it was with other children that talked a lot. I learnt to speak so much better because of primary school. I was so quiet but now I am happy to talk and explain things

I was in a big class with lots of children and it made me feel good about maths and learning I was able to get the bus to school because we didn't live too far and it helped me learn how to do it

We had a tour before we started, and they showed me the learning support centre to help with transition

I was given a photo of my new class with their names on so I could remember the over summer

Mainstream high school was the best option for me to be with my friends

Doing things for real like, practical leaning

She saw my potential in English and championed me, she really believed in me

Yes, the school chose me a friend monitor and it helped me be included on the playground. School always looked at way to support me with friends

Yes, they wanted to succeed. It made me happy and proud. People listened to me and what I needed.

I liked working in a team, it was amazing and good. I liked working with other children my age

It is important for me to be with other people because I am very social

I didn't mind having different children, it helped me learn

I spoke better to get better at talking

I got some qualifications and I have the certificates. Things like English and maths, it helped me get my job today

For me, being in mainstream helped me understand different abilities and be aware of other people



Different people had different abilities, for me, it's a good thing, because we learn from each other

It is important for people to understand Down syndrome. I made a project about Down syndrome and shared it with people to help them understand.

I liked learning it with the others and having maths as a core activity because it is important for life

Learning maths makes life easier, like when I go to the shop, and I need to pay Friends gave me support by giving me the opportunity to learn with them

### Interesting things I noticed

Some mentioned friendships lasting into adulthood, bumping into people know, these people understanding Down syndrome

Lots describing learning to feel amazing

All interviews start with basic method of interview .. questions with cards, explanations in more detail, anything they want to add or show.

RQ2 interesting ideas - Residential to show independence, being close to home, work experience, enjoyed reading writing – facilitated by differentiated work, extra-curricular activities, certificates

Positive adult support, facilitated by the same adult

Positive – believing in them, facilitated by exams and rewards

Positive – parents helping, facilitated by communication with school

Positive – friends, facilitated by lessons with different children and breaks

Reading writing and maths – facilitated by adapting lessons and work, facilitated by interventions

Positive – praise, facilitated by certificates

Positive – people that new them well, facilitated by adult support

Positive support from parents, facilitated by becoming involved in the school

Positive talking about future, facilitated by work experience

Positive independence – facilitated by life skills

Positive – teacher support and knowing well, facilitated by an understanding of DS

## Appendix 11: Example Extracts from Coded Transcript

I liked being in the pantos and school shows. I love acting. It made me feel happy to perform.

The school helped me achieve massive goals like Duke of Edinburgh. It is volunteering.

**How did you feel about doing that?**

It made me happy; I like to be challenged and try new things

I got some qualifications, and I have the certificates. Things like English and Maths, it helped me get my job today.

It is important that I am busy in school to keep me entertained. School helped me get involved in lots of things

I liked being in charge of things, like in the Christmas far I ran the tombola

**The tombola is the best stall isn't it! You are doing so well, you've been talking to me for a whole hour.**

Wow I love it

We had to do planning activities, that prepared me for real life. Like doing a BBQ and planning who brings what



Liked extra curricular activities

Reply

**Nicki Baker** ...

Qualifications are important

Reply

**Nicki Baker** ...

Liked being busy and having responsibilities

Reply

**Nicki Baker** ...

Practical activities helped for life skills

06 January 2024, 21:20

Reply



I was independent in the playground. I didn't need help from adults. I could hang about and play with my friends as I wanted

I was allowed more independence at high school. It made me feel proud of myself.

**You should be, and you are super independent now, aren't you?**

Yeah, I am.

**Can you tell me a little bit more about when you used ICT in school, you mentioned a desktop?**

Yeah, like an old-fashioned computer. I used it in some lessons, just for IT really, it wasn't especially for me. I learnt typing, publisher, creative writing. Now at work I have to write on the computer, and I do some research.

**Wow you sound very busy. Can you tell me a little bit more about your teachers? You told me before they were great?**

We had one teacher who helped me a lot. So many memories with her. We laughed a lot, she was fun and she knew me so well

TAs helped me a lot. When the main teachers were teaching, she always gave me extra help and helped me to think.

My TA was amazing, I remember her from a long time ago.

The best thing was having a TA that followed me across the year groups



Reply

**Nicki Baker** ...

Independence is important

Reply

**Nicki Baker** ...

Teachers knew them well

Reply

**Nicki Baker** ...

Positive reflections on supporting adult

07 January 2024, 08:43

Reply

### Appendix 12: Example Extract from Comprehensive Table of Codes, Data and Participants

Code	Supporting data	Participant
Enjoyed learning to read	<p>I did love learning to read</p> <p>I feel happy I learnt to read</p> <p>I learnt quickly because I love books</p> <p>Yes I read Biff and Chip books quite a lot. I also like kids series books. I mostly loved reading from a very early age</p> <p>I remember about reading. I love reading</p>	1, 7, 9, 10
Enjoyed talking about their future	<p>Yes! I like talking about that. We have careers meetings.</p> <p>My teacher told me about different colleges that are out there, it made me excited and I asked my mum if she could take me to look at the college</p>	1, 3
Liked having support from an adult	<p>Yes I really do (like having a supporting adult)</p> <p>Yes I had ***** she was great and always helped me</p> <p>I liked having them with me</p> <p>They sat with me in the lesson and I liked having them with me</p> <p>I liked having the support with me</p> <p>I had a key worker, she helped me with a lot.</p> <p>Yes, I had a key worker who really understood me and she wanted to learn more about it. She wanted to learn as much as possible</p>	1, 2, 3, 4, 5, 6, 7, 8, 11, 12

	<p>so she could be led by me. I was very lucky. I was grateful.</p> <p>It was good to have a teaching assistant when I needed it but given space once I was confident to do things and manage on my own. The TAs role grew with me throughout the stages</p> <p>I preferred working with adults, they could help me more</p> <p>I had a few different TAs in school, but always one at a time. They came with me to every lesson. I liked having someone with me to help me</p> <p>I liked having the help</p> <p>TAs were always there to help me</p> <p>Having a TA made me happy, they did an amazing job to help me out</p> <p>My TA was amazing, I remember her from a long time ago.</p> <p>TAs helped me a lot. When the main teachers were teaching, she always gave me extra help and helped me to think.</p> <p>They worked with me; they were so supportive. They helped me a lot.</p>	
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<p>Liked learning a range of different subjects</p>	<p>Yes!! I liked learning lots of different things</p> <p>I liked doing different subject. History and music were amazing. We got to try lots of things in music. We sometimes used a computer in music. It was good to learn lots of different things</p>	<p>1, 2, 3, 4, 6, 9, 10, 12</p>
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	<p>and decide what I wanted to pick when I got older</p> <p>I did lots, I did art. I don't like maths. I liked trying new things to decide what I was good at.</p> <p>It was good to be able to try all of the different subjects, just like my friends did.</p> <p>I liked being able to learn about lots of different things and not just English and maths</p> <p>Lots of sessions, like speech language on Mondays and music on Tuesdays and Thursdays I do maths and stuff. I have lots of great sessions</p> <p>I like having lots of different lessons, it helped me decide what I like. My favourite is history!</p> <p>I liked food tech and making things</p> <p>One thing that was good was that I really like cooking</p> <p>I think I really liked doing cooking and mosaics in art. I worked with south bank mosaics</p>	
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<p>Had a positive experience of friendships</p>	<p>Yes! My friends. I love my friends</p> <p>I like school because I have friends. In my class I always had friends.</p> <p>I had a best friend in primary school who I did spend most of my time with.</p> <p>I didn't have TAs with me at break and lunch time because it is better to be with my friends.</p>	<p>1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 12</p>
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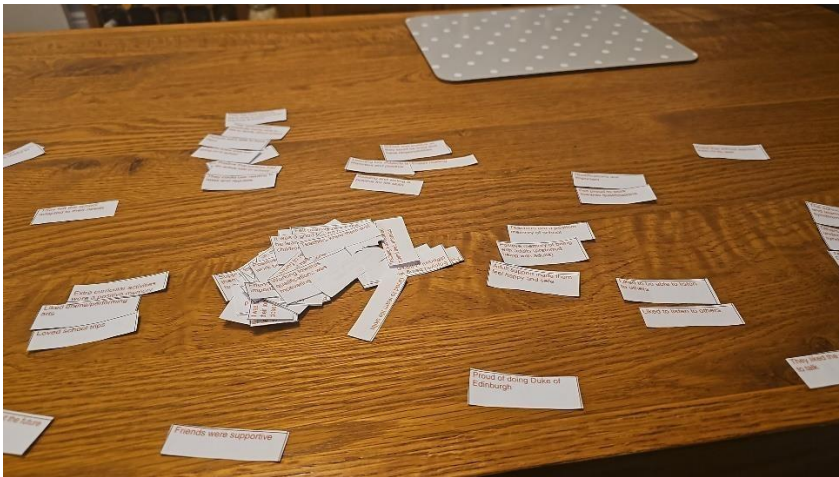
	<p>Friends were important for me at school and helped me enjoy school.</p> <p>One friend in particular was XXXX, we started school together. We helped each other. I felt happy and motivated to go to school to see XXXX . People in the school were all nice. Understanding an accepting.</p> <p>I had friends that helped me feel happy at school. I made them myself and they helped me be excited about going to school. I was with them at playtime and in lessons. And they invited me to them house to play games. It made me feel important.</p> <p>I think at school I had friends, and it was a really good thing</p> <p>Mainstream high school was the best option to be with my friends. I remember my friends at school. It was a good experience having friends</p> <p>I could play with them. And I had a playtime monitor who was my friend. I am still friends with him now. I'm still friends with them now. I had lots of friends. I was excited to go into school to see my friends. I loved going to school.</p> <p>And I made so many friends there (names a lot of friends). It was at school when I learnt how to play with other children, and I made so many friends.</p>	
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	<p>Having friends made me happy and it was the best part of school. Every single day I got to spend time with my friends</p> <p>I enjoyed school because of my friends</p> <p>Friends are important because they were always there every time that I needed them/ I had lots of friends at school</p> <p>I liked being with my friends</p> <p>I had some really lovely friends because they were outgoing and included me and chatted with me.</p> <p>Friends are really important to me. My friendships at school were really really strong</p>	
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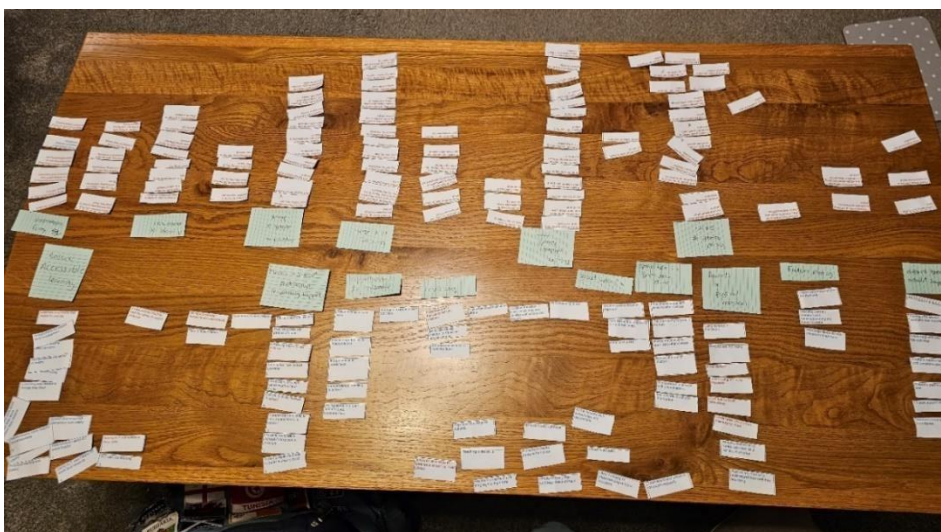


### Appendix 13: Photos of How the Codes on Paper were Manipulated by Hand During Phase 3 of Reflexive Thematic Analysis

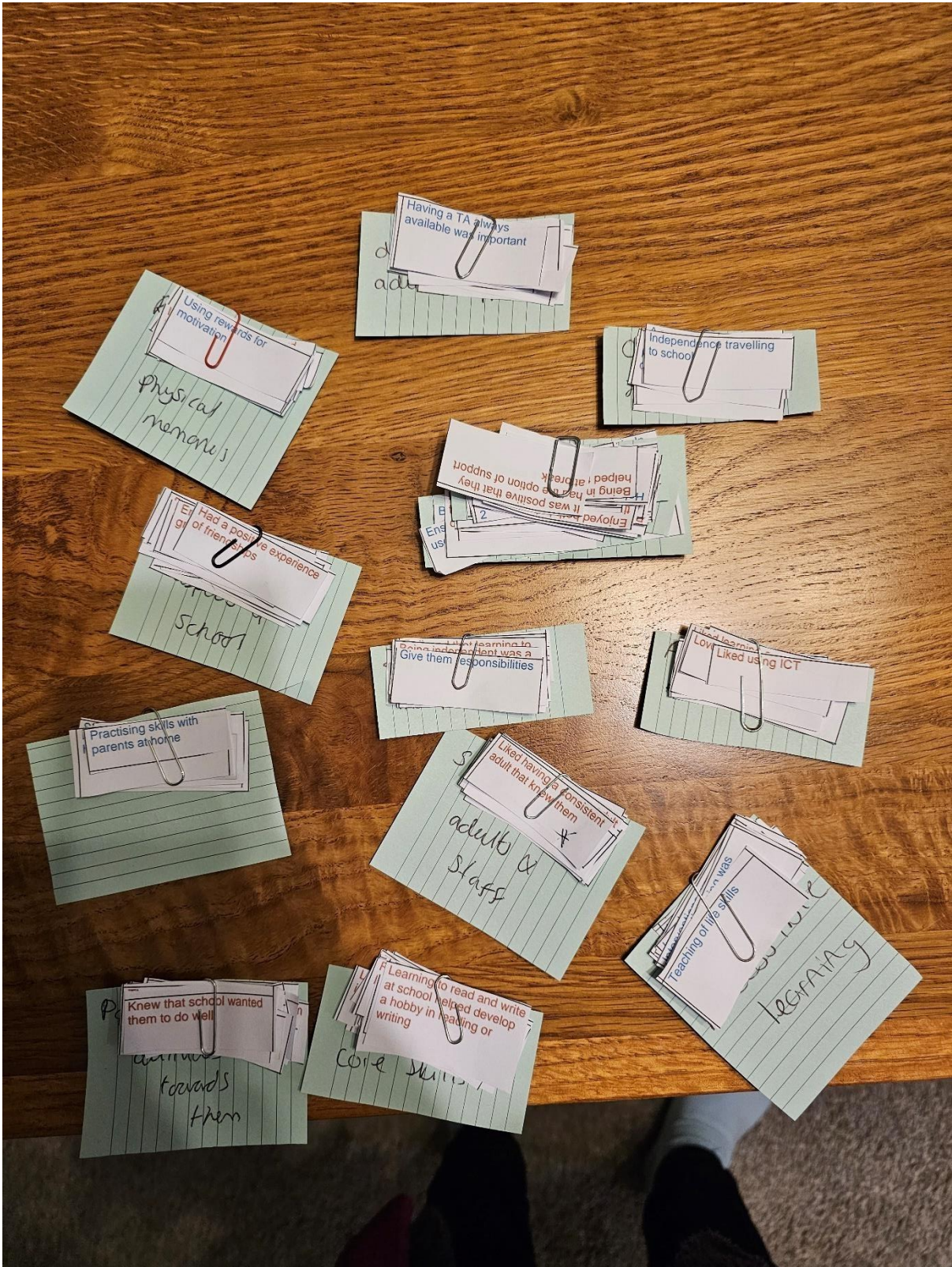
Codes were printed in orange for RQ1 and blue for RQ2. Initially these were read through and began to be sorted into groups.



Afterwards, the researcher began to sort these into themes and started to experiment with theme names (written on blue card). The researcher identified that a few codes were more relevant to the other RQ, and moved them across to the appropriate place. Codes that did not fit the themes were placed separately.



The theme name cards and codes were then paper clipped together to be stored so that they could be easily sorted into the themes again.



## Appendix 14: Participant Debrief Sheet

Nicki Baker

Trainee Educational Psychologist

6.5.2023

Faculty of Social Sciences

School of Education and L

University of East Anglia

Norwich Research Park

Norwich NR4 7TJ

United Kingdom

### Participant debrief sheet



Thank you so much!

Thank you so much for being part of my research. By completing this interview, you have helped me:



- Understand what you found positive about your experience in mainstream school
- Understand how I can help schools to make mainstream education a better experience for other children with Down syndrome
- To share the voice of young people with Down syndrome



If you are feeling worried about anything you said, or are upset by any of the questions asked, please let me or a grown up that looks after you know. I will help you to find a service that can help you with these feelings or worries. My email address is [Nicola.baker@uea.ac.uk](mailto:Nicola.baker@uea.ac.uk)



Don't forget I won't tell anyone else what you said to me. All of the information that I have about you is stored in a safe place and I will look after it very carefully. I will write a report about the study and show it to other people, but I won't put your name in the report and no one will know that you're in the study. You can find out what I found in the study once I have looked at all of my results. I can send this to you!



Thank you again for being part of my research and answering my questions. You did so well! I really enjoyed meeting you and learning about your school experiences.

Together, we can make a difference!

## Appendix 15: Ethical Approval Letter



University of East Anglia  
Norwich Research Park  
Norwich, NR4 7TJ

Email: [ethicsmonitor@uea.ac.uk](mailto:ethicsmonitor@uea.ac.uk)  
Web: [www.uea.ac.uk](http://www.uea.ac.uk)

**Study title:** What facilitates a positive experience of school for children and young people with Down syndrome educated in a mainstream setting? A Reflexive Thematic Analysis study

**Application ID:** ETH2223-1565

Dear Nicki,

Thank you for considering the comments of EDU REC and making the amendments to your project.

Your application was considered on 16th May 2023 by the EDU S-REC (School of Education and Lifelong Learning Research Ethics Subcommittee).

The decision is: **approved**.

However, I would like you to check the two comments I have put in the application form and address these before you start your research, particularly as one relates to accessing the video, which while I was able to do was rather complicated and participants just want to be able to click the link and it work.

Please confirm to your supervisor that you have addressed these two points in order to begin contacting participants.

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

This approval will expire on **1st August 2024**.

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 ([dataprotection@uea.ac.uk](mailto:dataprotection@uea.ac.uk)).

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)

Yours sincerely,

Victoria Warburton

