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Down's Syndrome: The experiences of adolescents and emerging adults with Down's Syndrome and their siblings.

By

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Abstract

The systematic review explores the lived experiences of Adolescents and Emerging Adults with a diagnosis of Down's Syndrome (AEDS). Following completion of a systematic search, 20 papers were identified, and relevant qualitative data was extracted. A thematic synthesis was conducted, and four analytical themes emerged 'Belonging'; 'Self-Concept'; 'Interdependence'; 'Contemplating the future'. The themes are discussed in relation to existing literature and theory. In addition, the review highlights important implications pertaining to the lives of AEDS including promoting belonging within one's local community as well as enhancing understanding and awareness of Down's Syndrome (DS) in society.

The empirical project qualitatively explores the experiences of individuals who have a sibling diagnosed with Down's Syndrome from Racially or Ethnically Minoritised (REM) communities. Interviews were completed with eight participants. Through Interpretative Phenomenological Analysis (IPA), four Group Experiential Themes (GETs) were identified 'Relationships and Connections'; 'Understanding'; 'Day-to-Day Life'; 'Responsibilities'. In addition, narratives around ethnicity and culture were highlighted within the themes. The research emphasises clinical implications around supporting individuals who have a sibling diagnosed with DS (ISDS) including the need for sibling groups and therapeutic interventions, and that representation from a range of ethnic backgrounds is considered.

Keywords: adolescents; emerging adults; Down's Syndrome; lived experiences; perspectives; siblings; racially or ethnically minoritised; sibling experiences; attitudes.

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Research Thesis: Declaration of Authorship

Print name: Gemma Watts

Title of thesis: Down's Syndrome: The experiences of adolescents and emerging adults with Down's Syndrome and their siblings.

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

I confirm that:

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

Signature: Date: 24/09/2025

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Definitions and Abbreviations

AACODS	Accuracy, Authority, Coverage, Objectivity, Date and Significance
AEDS	Adolescents and Emerging Adults with a diagnosis of Down’s Syndrome
CYP	Children and Young People
DfE	Department for Education
DS	Down’s Syndrome
EDI	Equity, Diversity and Inclusion
EDT	Expanded Developmental Theory
EMDR	Eye Movement Desensitization and Reprocessing
EST	Ecological Systems Theory
GETs	Group Experiential Themes
ID	Intellectual Disability/Disabilities
IDD	Individuals diagnosed with a disability
IDS	Individuals diagnosed with Down’s Syndrome
IID	Individuals diagnosed with (an) Intellectual Disability/Disabilities
IPA	Interpretative Phenomenological Analysis
ISDD	Individuals who have a sibling diagnosed with a Disability
ISDS	Individuals who have a sibling diagnosed with Down’s Syndrome
ISID	Individuals who have a sibling diagnosed with an Intellectual Disability
LeDeR	Learning from lives and deaths – people with a learning disability and autistic people
MMAT	Mixed Methods Appraisal Tool
NHS	National Health Service
PETs	Personal Experiential Themes
PPI	Patient and Public Involvement

PRISMA……………... Preferred Reported Items for Systematic Review

PROSPERO…………. International Prospective Register of Systematic Reviews

QoL……………………Quality of Life

REM………………….. Racially or Ethnically Minoritised

RiDD…………………...Research in Developmental Disabilities

SDD………………….. Sibling (is) diagnosed with a disability

SDQ………………….. Strengths and Difficulties Questionnaire

SDS…………………… Sibling diagnosed with Down’s Syndrome

SID……………………. Sibling diagnosed with an Intellectual Disability

TF-CBT………………..Trauma-Focused Cognitive Behavioural Therapy

UK……………………...United Kingdom

UNCRC………………..United Nations Convention on the Rights of the Child

UNCRPD……………….United Nations Convention on the Rights of Persons with Disabilities

YP…………………….. Young People(s)

Down's Syndrome: The experiences of adolescents and emerging adults with Down's Syndrome and their siblings

Chapter 1. Introductory Chapter

Within this introductory chapter, I aim to provide the reader with additional context surrounding the lives of individuals diagnosed with Down’s Syndrome (IDS), including both the historical and present-day context and the influence that context has on the lives of IDS. I will also discuss Down’s Syndrome (DS) across racially or ethnically minoritised (REM) communities and raise important issues pertaining to the lives of IDS from REM backgrounds. Various terminology and language have been used over time which relates to DS, and I wanted to acknowledge this in relation to the changes and subsequent implications. Furthermore, I aim to share some of my own reasons for completing my thesis within the DS field, discuss reflexivity through sharing aspects of my own identity, and how this has influenced the research. Finally, I will discuss my dissemination plan and how I intend to share the research findings.

1.1 Down’s Syndrome

1.1.1 Historical and present-day context

DS was first described in 1866 by John Langdon Down. Down’s account of DS described the physical characteristics associated with DS, which were linked to the Mongolian community (Wajuihian, 2016). The lives of IDS were somewhat different to the lives of IDS today. There was a stark difference in life expectancy of IDS compared to the general population during the 1920s. The life expectancy of IDS in 1929 was estimated to be around the age of 9 years old (Penrose, 1949) compared with life expectancy of the general population to be estimated around the ages of 56 – 60 years old (Office for National Statistics, 2015). In addition, in 1945 it is noted by George (2020) that dependent upon severity of disability, some children diagnosed with DS would not have been in receipt of an education. Many IDS were placed in institutions also known as asylums (Patterson & Costa, 2005). Individuals resided and participated in skills-based activities within these institutions with the aim of discharging individuals to community care, however, this was not the case and instead individuals were kept segregated from the rest of society and living conditions were reported to be inadequate (Royal College of Nursing, n.d.). Furthermore, it is widely acknowledged that individuals who lived in institutions experienced abuse, and this included IDS (Brown, Dodd & Vetere, 2010). These experiences of abuse would have inevitably had a devastating impact upon the lives of these individuals. Advocates such as Kugel (1969) as cited by Stimson, Merrow, Neal and Grunberg (1973) promoted for community care for individuals diagnosed with intellectual disabilities (IID) to ensure that they became part of their local communities.

Bringing us closer to the present day, most children with DS grow up in family homes with their parents and are accessing an education provision (Patterson & Costa, 2005). In addition, Fortea, McGlinchey, Espinosa and Rafii (2024) discussed how Quality of Life (QoL) has improved for IDS including increased participation within their communities and wider society, and with advances in healthcare this has also resulted in increased life expectancy. Whilst some things have improved for IDS, it is still widely acknowledged the continued disparities (e.g., health, social inclusion and employment) which this population group experience. The Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) report (White et al., 2023) identified striking differences between IID and the general population, in relation to median age at death (IID = 62.5 years compared with the general population which is suggested to be around 20 years higher) and avoidable deaths (IID = 38.8% compared with the general population = 21.6%). The report also found that IID experience issues regarding care and treatment including delays in treatment and gaps in service provision (White et al., 2023). IDS may have additional co-morbidities that they need to navigate including congenital heart defects (Weijerman & De Winter, 2010), increased risk of respiratory infections (Bull & Committee on Genetics, 2011) and Alzheimer’s disease (Hartley et al., 2015). O’Leary, Hughes-McCormack, Dunn and Cooper (2018) outlined predictors for early death in IDS included respiratory conditions and congenital heart abnormalities. Varshney et al. (2022) suggests that health disparities may also be related to healthcare professionals not having the skills, training, and expertise to manage co-morbidities for IDS. Alongside health disparities, many IID are wanting to access employment. However, it is acknowledged these individuals experience the disability employment gap and therefore have difficulties in being able to access employment (Women and Equalities Committee, 2024). Thus, it would seem reasonable to suggest individuals experience financial implications as a result. From a social perspective, social inclusion has been noted as a key challenge for the DS community (Buckley, 2004) and consequently experiences of isolation are likely for this population group. Therefore, whilst there has been change over the last 100 years, society needs to do more to reduce the disparities in which the DS community and more broadly the Intellectual Disabilities (ID) community experience.

1.1.2 DS and REM Communities

DS is a condition which impacts individuals across different racial and ethnic backgrounds. Cooper-Moss et al. (2025) highlights how intersections of identity for example ethnicity and intellectual disability can lead to dual or double discrimination. Umpleby et al. (2023) published the following report: “We deserve better: Ethnic minorities with a learning disability and access to healthcare” which highlights the health-related disparities in which IID from ethnic minoritised backgrounds experience including health outcomes and barriers to healthcare. For this population group, barriers to healthcare include communication and lack of resources to support this (e.g., interpreters and multilingual documentation), stigma, discrimination and these barriers ripple out to the family members also (Cooper-Moss et al., 2025). More specifically to IDS, O’Leary et al. (2018) highlighted that identifying from a minority ethnic background is another predictor of early death for IDS. These healthcare disparities are within the much broader context of the longstanding issues of racism and discrimination that have been and continues to be experienced by REM communities, and the psychological, emotional, social, and health impact that this can have.

1.1.3 Terminology and language

With links to the Mongolian community when DS was first described, terms used to describe DS had connections to this population group (Mégarbané et al., 2009). In the 1960s, professionals within the field and the Mongolian community requested for these terms to stop being used (Allen et al., 1961; Howard-Jones, 1979). Currently, terms that are most used to describe the condition include ‘Down Syndrome’ and ‘Down’s Syndrome’. However, historical terms previously used to describe DS continue to appear in everyday language and are used in a manner which is disparaging or offensive in the wider society. The National Down Syndrome Society (n.d) highlights the importance of people first language when discussing this population group. Therefore, I will be adopting this throughout my thesis.

1.2 Rationale for Thesis

Taking into consideration the context pertaining to the lives of IDS, this has formed the rationale for my thesis. In addition, my passion for working with IID and this includes working with IDS and their families. Throughout my clinical work, I have become consciously aware of and influenced by Bronfenbrenner’s (1979) Ecological Systems Theory (EST), and how integral it is to consider the many systems which shape and influence an individual's lived experience, and the importance of working with these different systems. Whilst working with this population group and the systems around them, I have noticed how there tends to be a focus on understanding the perspectives of IID/IDS and the whole family through the lenses of parents and carers or professionals. However, what is often missed is gaining a detailed understanding from the individual themselves or gathering narratives from other family members (e.g., siblings). Similarly in DS research, there is an abundance of research which seeks to understand the perspectives of parents and carers. However, there is a paucity of research which is focused upon hearing the voices of IDS and their siblings. In addition, there is a lack of representation from REM communities. Therefore, I wanted to situate my thesis within the field of DS and give voice to those individuals that so often go unheard. Also, to bring to the fore bigger concerns for the DS community including unmet health needs, premature deaths, the stigma and discrimination that this population group and their families experience. In addition, the increased risk of premature death and increased stigma and discrimination that are experienced when an IDS identifies from a REM background. Finally, I want to highlight that IDS can lead meaningful, valued, and fulfilled lives, and the various systems surrounding IDS can support them to do just that.

1.3. Reflexivity

As a researcher it is important to consider my own social graces in relation to the research. Therefore, I am female, in my early 30s, and I identify as White-British. I am an older sibling, and neither myself nor my sibling have any diagnoses. I am educated to a Doctorate-level standard and have clinical experience of working with IID/IDS and their families.

Prior to this research, consideration was given to the broader issues of racism and discrimination that REM communities experience as well as previous sibling literature highlighting stigma within the broader field of ID (Paul et al., 2022). An initial assumption I held for individuals who have a sibling diagnosed with Down's Syndrome (ISDS) from REM communities was the likelihood that their narratives would include stigma and discrimination. In addition, holding assumptions around ISDS experiencing more challenges and consequently a greater impact to wellbeing (e.g. psychological, social, and emotional) compared to individuals who have a sibling of typical development.

Throughout the interviews, it became apparent that many participants, especially the younger ones, did not raise issues of stigma and discrimination. I remember finishing interviews with some of the younger participants and wondering why these issues were not being mentioned. As a researcher, it brought up feelings of frustration, uncertainty for upcoming interviews, and the worry that none of my research participants would highlight these issues. Reflecting on this in research supervision was important. In addition, navigating different opinions within my research team, with some emphasising the importance of looking for narratives around race, ethnicity and culture, while others advised that if narratives were not present then consideration should be given as to why they were not coming through. For the rest of my interviews, I remained open-minded and curious whilst trying to find a balance between the different opinions amongst my research team.

During the analysis, I wondered if my identity of being White-British influenced how I initially looked at each participant's narratives. For example, trying really hard to look for narratives around stigma and discrimination, when there were very limited obvious accounts of this. I realised that I needed to take a step back and hold in mind that whilst these issues may appear to be a bigger concern in wider society, perhaps these issues are not at the fore for participants who participated in my empirical study. In addition, I had gained additional knowledge regarding the development of race and ethnicity in individuals across the lifespan. This extra knowledge started to change my thinking about how to approach the analysis. Thus, I started to consider race, ethnicity, and culture more broadly. When I did this, I recognised that there were subtleties of ethnicity and culture within participant’s responses, and this included some of the younger participants’ narratives. For example, among the younger participants, references to race, ethnicity, and culture were interlinked within their accounts related to culturally related activities they engaged in with their sibling diagnosed with Down’s Syndrome (SDS) as well as limited opportunities to see extended family members due to living overseas. I noted that these narratives appeared to reflect their development level of understanding race and ethnicity.

Finally, I have had ample opportunities, through being a clinical practitioner within the National Health Service (NHS), to work with IID and IDS. Therefore, I feel that I have been able to gain a good sense from a clinical perspective the lived experiences of individuals that I have been fortunate to support. However, I wonder if this aspect of my identity had some influence on my interpretations of the analysis, including assumptions and knowledge gained from my clinical experience, and subsequently the final themes that emerged. Thus, I recognise that involving Adolescents and Emerging Adults with a diagnosis of Down’s Syndrome (AEDS) as members of the research team or Patient and Public Involvement (PPI) would have been extremely valuable for the systematic review.

1.4 Dissemination Plan

The journal that is being considered for both the empirical paper and systematic review is Research in Developmental Disabilities (RiDD). The journal’s aim is centred upon gaining a greater understanding of Developmental Disabilities. Whilst the journal seeks to primarily publish empirical papers it also accepts reviews. From a brief search, RiDD has published over 1,000 papers exploring DS, and research has included both qualitative and quantitative methodologies. Participants of published studies have included IDS, parents and carers and siblings. In addition, the journal has previously published systematic reviews which are specific to DS. Therefore, taking these factors into consideration, my empirical paper: *“It's like a Down’s syndrome, but I think it should be Up Syndrome, cause Down syndrome puts you down”: Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from Racially or Ethnically Minoritised (REM) communities*” and my systematic review: *“A systematic review exploring the lived experiences of adolescents and emerging adults with a diagnosis of Down’s Syndrome (AEDS)”*, RiDD is an appropriate and relevant journal to consider publishing to. Thus, both chapters will be formatted in accordance with the guidelines that are set out by RiDD, and author(s) guidelines can be found in appendix A.

Finally, alongside publishing papers to RiDD, dissemination via alternative means is also being considered. This includes attending DS/Developmental Disabilities research forums or DS/Developmental Disabilities conferences. Furthermore, the creation of accessible summaries to ensure that the research reaches IDS including AEDS, siblings, parents and carers and anyone of whom is part of the DS community.

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Chapter 2: A systematic review exploring the lived experiences of adolescents and emerging adults with a diagnosis of Down’s Syndrome

This chapter has been written with intent to submit for publication to the journal of Research in Developmental Disabilities

For detailed author guidelines please see appendix A.

2.1 Abstract

Background: In accordance with disability rights movement, conventions, and government acts, it is crucial individuals diagnosed with a disability have a voice and are active members in society. Within the area of Down’s Syndrome there is limited research involving individuals diagnosed with Down’s Syndrome and less is known about the lived experience of adolescents and emerging adults with a diagnosis of Down’s Syndrome.

Methods: A systematic review of existing research was conducted, and 20 papers were identified. Relevant qualitative data which met the inclusion criteria was extracted from the papers and a thematic synthesis was completed.

Results: Analytical themes emerged pertaining to the lived experiences of adolescents and emerging adults with a diagnosis of Down’s Syndrome: ‘Belonging’, ‘Self-Concept’, ‘Interdependence’ and ‘Contemplating the future’.

Conclusions: The analytical themes have highlighted the insight that adolescents and emerging adults with a diagnosis of Down’s Syndrome have into their lives. The current review provides evidence that more research is needed for adolescents and emerging adults with a diagnosis of Down’s Syndrome. In addition, it raises important implications that need to be considered including fostering belonging in local communities and more broadly increasing understanding and awareness of Down’s Syndrome within society.

Keywords: adolescents; emerging adults; Down’s Syndrome; lived experiences; perspectives.

2.2 Introduction

Down's Syndrome (DS) is a genetic condition which occurs when an individual has an additional copy of chromosome 21 (NHS England, 2023). There are three types of DS, the most common being Trisomy 21 which is present in around 95% of individuals diagnosed with Down's Syndrome (IDS), Translocation DS which represents 3-4% of cases, and Mosaic DS which is the least common and diagnosed in 1-2% of cases (Agarwal Gupta & Kabra, 2014). The type of DS that an individual has can only be distinguished by examining the individual's chromosomes as each type of DS has a slightly different chromosome abnormality presentation (Perkins, 2017). In the United Kingdom (UK) it is estimated that there are around 47,000 IDS (Down Syndrome Act, 2022). DS has a specific phenotype including unique physical features (e.g. brachycephaly), co-morbid health conditions (e.g., congenital heart disease), and a varied developmental profile (Daunhauer & Fidler, 2011). Furthermore, IDS will have a diagnosis of an intellectual disability (ID; MacLennan, 2020) and are more likely to experience mental health conditions (e.g., depression). It is recognised that IDS are living longer (NHS Inform, 2024), with a life expectancy in the UK estimated to be approximately 60 years old (Department of Health and Social Care, 2022) compared to 12 years old in the 1940s (Down Syndrome Medical Interest Group, 2020).

The Down Syndrome Act (2022) was introduced as part of a broader commitment from UK government to improve outcomes of IDS, with recognition that they have specific needs including an increased risk of health conditions (e.g., seizures) and susceptibility to infections. In addition, unique challenges including delays in development, and difficulties for IDS and their families in being able to access support (e.g., social care, education support, health services) across the lifespan (Down Syndrome Act, 2022). Furthermore, the Down Syndrome Act (2022) ensures that services across various domains (e.g., health, social care and education) are accountable to meeting the specific needs of IDS. The Down Syndrome Act (2022) stipulates that guidance would follow to set out what authorities would need to do to ensure that services are meeting the needs of IDS. However, at present, no formal DS-informed guidance exists within the act for authorities. This suggests that authorities may be referring to broader intellectual disabilities (ID) guidelines (e.g., National Institute for Clinical Excellence, 2024) or developing their own care pathway protocols for IDS (e.g., University Hospitals of Leicester and Leicestershire Partnership NHS Trusts, 2024). Given the specific needs of IDS, broader guidelines may be missing detail relevant to the lives of IDS, and different protocols across regions may lead to inequities of support for IDS.

In addition to the Down Syndrome Act (2022), ‘Nothing about us without us’ is a powerful message from the disability rights movement, ‘Nothing about us without us’ emphasises the importance of individuals diagnosed with a disability (IDD) playing an active and integrative role in society, and systems (e.g., organisational, political, societal) are collaboratively involving IDD in decision-making which is relevant to the lives of IDD (Charlton, 1998). Furthermore, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; 2006) sets out to ensure that countries endorse and promote key principles including active participation, accessibility, autonomy, choice, and equality for IDD. Both ‘Nothing about us without us’ and UNCRPD are applicable to IDS. Therefore, a review of research which aims to synthesise the direct experiences of IDS is needed to gain a greater understanding as to the lives of IDS, which will in turn inform service, policy, and legislation.

Adolescence is a critical time of development whereby an individual will go through their own idiosyncratic changes in physical, cognitive, emotional, social, and moral areas of development (U.S. Department of Health and Human Services, Office of Population Affairs, 2018). Research suggests that adolescence typically spans from around the ages of 10 – 24 years old (Sawyer, Azzopardi, Wickremarathne & Patton, 2018) and emerging adulthood starting from around the age of 18 to 29 years old (Arnett, Žukauskienė & Sugimura, 2014).

From a conceptual perspective, developmental theories including Arnett’s (2000) emerging adulthood theory, Erikson’s (1950) psychosocial theory, Levinson’s (1986) theory of adult development, and Piaget’s (1936) cognitive development theory can be applied when thinking about adolescence and emerging adulthood. Each theory focuses upon aspects of development (for example: psychosocial, cognitive) and outlines the development that individuals’ experience. It is important to note that theories such as Piaget (1936) and Erikson (1950) have been critiqued for having a lack of consideration for individual differences including disability (Hughes & Rodda, 1997) and culture (Babakr, Mohamedamin & Kakamad, 2019). Hodapp and Zigler (1990) acknowledges the importance of such theories (e.g., Piaget, 1936) and further highlights the importance of other aspects related to development, such as self-image and an individual’s environment. Hodapp and Zigler (1990) refer to this as Expanded Developmental Theory (EDT) and note its applicability to the DS population group. EDT encompasses a much broader perspective of development to include both traditional developmental theories and the individual’s ecological context. Hodapp and Zigler (1990) also highlights the relevance of Bronfenbrenner’s (1979; 1994) Ecological Systems Theory (EST). EST proposes five systems: microsystem, mesosystem, exosystem, macrosystem, and chronosystem, which shapes an individual’s development, and the individual’s lived experience (Crawford, 2020). In order of proximity to the individual, the microsystem refers to the individual’s intrapersonal qualities as well as people of whom the individual is in regular contact with (e.g., family members, peers at school or work colleagues). The mesosystem refers to the relationships between microsystems (e.g., day centre and home). The exosystem corresponds to indirect factors, such as extended family, which may affect the individual. The macrosystem relates to societal influences (e.g., politics and societal norms). Finally, the chronosystem refers to changes over time for an individual, for example, starting puberty or school transitions (Neal & Neal, 2013). It is important to highlight that EST incorporates the individual’s needs, their strengths and beliefs (Rothery, 2008).

There are many forms of legislation which highlight the importance of listening to young people’s (YP) voices including the United Nations Convention on the Rights of the Child (UNCRC; 1989), Equality Act (2010) and Children Act (1989). Cunningham and Rious (2015) discussed how research focusing on YP has typically been from an adult perspective, and it is further noted that this may result in specific experiences and views of YP being missed. In consideration of IDS, the research has typically explored parents and carers of IDS including their lived experiences and perspectives of caregiving, wellbeing, and Quality of Life (QoL) (e.g., Cheok et al., 2024; Fucà, Galassi, Costanzo & Vicari, 2022; Oliveira & Limongi, 2011; Rutter et al., 2024; Skotko, Levine & Goldstein, 2011; Zhang et al., 2025). Furthermore, Geiger (2022) highlights that the individual views and lived experience of YP with DS are rarely captured. Taken together it seems fair to suggest that research capturing the narratives of this marginalised group is needed.

Sheridan, OMalley-Keighran & Carroll (2020) completed a scoping review synthesising adolescents with DS perspectives of QoL and emphasised the lack of research of focusing on YP with DS. The review captured eligible literature between January 2006 to March 2017. The review found a lack of research focusing on YP perspectives of QoL and only two studies (Foley et al., 2012; Scott et al., 2014) were identified and included in Sheridan et al.’s (2020) review. Sheridan et al. (2020) reports primarily on the common themes found across the two papers ‘participation’, ‘friendships’, ‘family relationships’, and ‘independence’, and suggests that these areas are important to YP with DS in relation to their QoL. However, it is important to note that additional factors such as one’s identity, challenges of social inclusion (e.g. discrimination and bullying), education and employment whilst they have links to QoL they appear to be missing completely or are briefly highlighted in Sheridan et al.’s (2020) review. In addition, there was very limited participant quotes shared within Sheridan et al.’s (2020) review, and so whilst it is important to acknowledge these areas being important to the QoL of YP with DS, it seems fair that more research is needed to ascertain a much deeper understanding as to how YP with DS make sense of their experiences related to different aspects of their lives. Therefore, a systematic review which expands beyond QoL and explores Adolescents and Emerging Adults with Down’s Syndrome (AEDS) first-hand experiences related to different aspects of their lives for example wellbeing, identity, relationships, participation, inclusion, health, education, employment etc is needed. This will enable AEDS voices to be heard as well as gaining a greater understanding as to the lives of AEDS including their own insights. This systematic review aims to answer the following question ‘what are the lived experiences of AEDS?’

2.3 Methods

This systematic review is registered with the ‘International Prospective Register of Systematic Reviews’ (PROSPERO) (Registration number: CRD42024620444).

2.3.1 Search Terms and Strategy

As recommended by Methley et al. (2014) a search tool was selected to provide a framework for which terms relating to each key concept within a review question are devised. Cherry, Boland and Dickson (2024) suggest using the PICo tool for qualitative systematic reviews. The PICo tool captures three key concepts within a review question, the ‘Population’, the ‘Phenomenon of Interest’ and the ‘Context’. Therefore, applying the PICo tool to the current review question: population refers to “Adolescents and Emerging Adults”, phenomenon of interest corresponds to “Down’s Syndrome”, and context denotes to “Lived Experiences”. Therefore, a comprehensive search strategy with relevant search terms relating to “Adolescents and Emerging Adults”, “Down’s Syndrome” and “Lived Experiences” were developed and used for the searches. Studies were searched for using key electronic databases and grey literature repositories. The electronic databases used were Web of Science, PSYCINFO, MEDLINE and CINAHL. For grey literature ProQuest was searched. The searches were conducted in January 2025.

The search terms and strategy were adapted according to each database including considerations around Boolean operators, types of truncations, and suggested subject headings. Preliminary searches took place on all databases using the search terms related to the three components (population, phenomenon of interest, and context) of the review question. Whilst Web of Science yielded a substantial number of papers, the EBSCO databases yielded a much smaller number. Therefore, the search strategy within the EBSCO databases did not include the search terms for ‘context’ to gain more papers. The final search strategy for each database can be found in the tables below (see tables 1 and 2). There were no restrictions on date of publication nor language of publication.

Table 1

Search Strategy for Web of Science

Key Concept	Search terms

Adolescents and Emerging Adults (Population)	(young NEAR/2 (people OR person OR adult*)) OR emerging adult* OR adolescen* OR teen* OR Youth
Down's Syndrome (Phenomenon of interest)	"down's syndrome" OR "down syndrome" OR trisomy
Lived Experiences (Context)	experience* or perception* or attitude* or view* or feeling* or qualitative or perspective*

Note. *= truncation; NEAR/2 = Near 2 words

Table 2

Search strategy for EBSCO databases (PSYCINFO, MEDLINE and CINAHL)

Key Concept	Search terms
Adolescents and Emerging Adults (Population)	(young N2 (people OR person OR adult*)) OR emerging adult* OR adolescen* OR teen* OR Youth
Down's Syndrome (Phenomenon of interest)	"down's syndrome" OR "down syndrome" OR trisomy

Note. * = truncation; N2 = Near 2 words

Grey Literature was also searched using ProQuest. The search strategy that was used was: down syndrome OR down's syndrome OR Trisomy 21 AND (young N2 (people OR person OR adult*)) OR emerging adult* OR adolescen* OR teen* OR Youth. The search strategy was limited to all abstract and summary text.

2.3.2 Inclusion and Exclusion Criteria

Inclusion criteria and exclusion criteria were developed and applied during the screening process (see table 3).

Table 3

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
• Participants can be of any gender. • Participants must have a diagnosis of DS. • Participants aged 10 – 29 years old. • Studies directly capture the voices of IDS. • Studies explicitly focusing on the lived experience of IDS. • Papers which focus on the narrative of IDS about their experiences and therefore may be across a variety of domains e.g., wellbeing, relationships, social participation etc. • Qualitative studies (e.g., involving interviews, focus groups, qualitative questionnaires/surveys). • Studies must be written in English.	• Participants outside ages of 10 – 29 years old. • Participants do not have diagnosis of DS. • Studies which do not explicitly focus on the lived experience of IDS. • Research which does not directly capture the voice of IDS e.g., second-hand through a parent/carer and/or professional. • Papers which do not focus on the narrative of IDS about their experiences. • Quantitative studies. • Non-empirical literature (e.g., book chapters). • Single Case studies

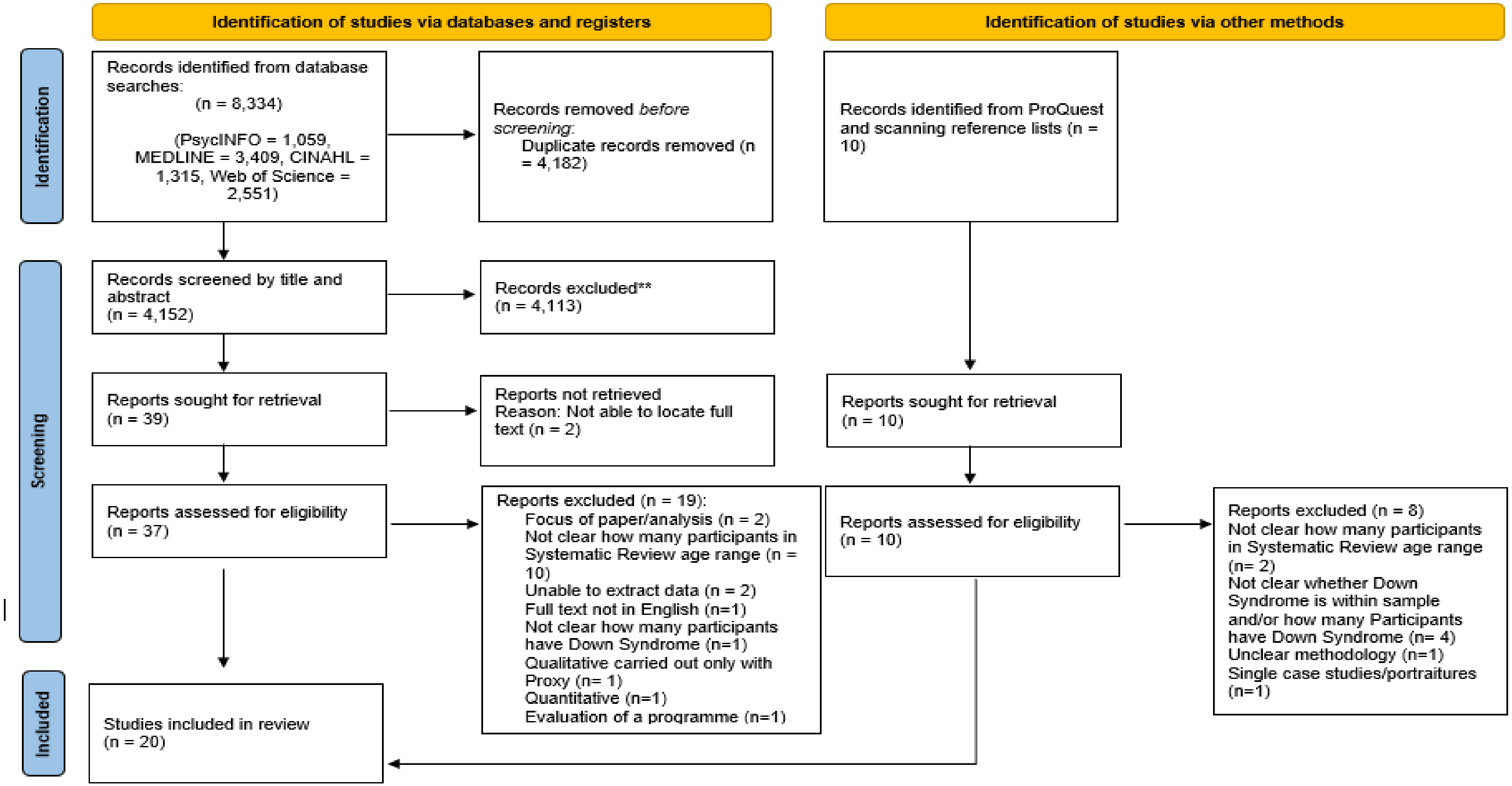
• Mixed methods studies will be considered as long as the Qualitative elements can be extracted and used for the thematic synthesis. • Papers with multiple cases and qualitative analysis has been completed across the case studies. • Research which has been published or found within grey literature e.g., ProQuest.	• Studies which aim to measure/explore an intervention/programme. • Studies which are not written in English. • If there are no direct quotes nor author interpretations within the studies which can be extracted to be used for the thematic synthesis.

2.3.3 Screening Process

The Preferred Reporting Items for Systematic Review (PRISMA) flow diagram (see figure 1) summarises the screening process that was completed for this systematic review. A total of 8,334 papers were found across the four electronic databases. 4,182 papers were duplicates and were removed and 4,152 papers were retained for screening. The screening process was completed in two stages: the first stage was the initial title and abstract screen and the second stage was the full text screen. The first stage was completed by the primary researcher and involved screening 4,152 papers by title and abstract. A total of 4,113 papers were excluded at stage one, and 39 papers were retained. A second reviewer dual screened 20% of the 39 papers at title and abstract stage, with 100% agreement. The second stage was completed by the primary researcher and involved full text screening for the 39 remaining papers. Articles for the 39 papers were sought for this stage. However, two papers were not available for retrieval. Therefore, 37 papers were screened at full text, 18 papers were found to be eligible, and 19 papers were excluded. In addition, the ProQuest search and scanning eligible paper reference lists was also completed and ten papers were sought for retrieval. The ten papers were full text screened, and two papers were deemed to be eligible. The reasons for exclusion included: the focus of the paper or analysis, uncertainty as to how many participants met the age criteria, DS criteria, and type of methodology (additional reasons for exclusion can be found in figure 1). In total, 20 papers were retained, and all papers were dual screened by the second reviewer, with 100% agreement.

Figure 1

PRISMA flowchart



2.3.4 Quality Assessment

A quality assessment check was completed on all 20 papers. For grey literature (Hunter, 2005; Nadjari, 2023; Segev & Hellman, 2001), the Accuracy, Authority, Coverage, Objectivity, Date and Significance (AACODS) checklist (Tyndall, 2010) was used. The AACODS checklist appraises the quality of unpublished research against the following six criterion (Accuracy, Authority, Coverage, Objectivity, Date and Significance). Each criterion is assessed, and the researcher assigns a rating of ‘yes’, ‘no’ or ‘can’t tell’ to each criterion (see Appendix B ACCODS checklist). For published literature (Adenan et al., 2024; Chadwick & Fullwood, 2018; Cunningham & Glenn, 2004; Dolva, Kollstad & Kleiven, 2019; Downs et al., 2013; Faragher, Cooke & Lloyd, 2024; Foley et al., 2012; Geiger, 2023; Glenn & Cunningham, 2004; Groves, Rayner & Muncer, 2018; Jevne, Kollstad & Dolva, 2022; Li, Liu, Lok & Lee, 2006; Santoro et al., 2023a; Santoro et al., 2023b; Scott et al., 2014; Takataya, Kanzaki, Mizuno & Sakai, 2022; Thompson et al., 2020), the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018) was used as it assesses the quality of a range of research designs including qualitative, quantitative, and mixed methods research. The MMAT has six categories, each category corresponds to a specific study design: screening questions, qualitative, quantitative randomized controlled trials, quantitative non-randomized, quantitative descriptive and mixed methods. Within each of the categories, there are a set of quality criteria to appraise the study against. All papers will be appraised against the two screening criteria within the screening questions category, and the researcher will assign a rating of ‘yes’, ‘no’ or ‘can’t tell’. For each study, the researcher will choose the appropriate set of criteria to assess quality (e.g., a qualitative study will be assessed against criteria items within the qualitative category. Whilst a mixed methods study will be assessed against criteria items within the mixed methods category, qualitative category and dependent upon the quantitative element within the specified study either the quantitative randomized controlled trials, quantitative non-randomized or quantitative descriptive category will be appraised also). The researcher will assign a rating of 'yes', 'no' or 'can't tell' to each criteria item based upon appraisal of the study (see Appendix B MMAT checklist).

All papers were quality assessed using either the AACODS or MMAT and ratings 'yes', 'no' or 'can't tell' were applied to each criteria item. An overall score indicating the quality of each paper was not completed, as Hong et al. (2018) advises against calculating an overall 'quality' score and Tyndall's (2010) checklist gives no formal scoring method. However, in line with guidance (Hong et al., 2018), the primary author provides more detailed quality appraisal descriptions to ratings assigned for each paper (see Appendix C). The second reviewer completed quality assessment checks for 20% of the 20 papers to check inter-rater reliability and 100% agreement was reached. MMAT (Hong et al. 2018) guidance stipulates that no papers are removed if they are deemed to be of low quality. Therefore, all papers were retained for data extraction and analysis.

2.3.5 Data Extraction

In line with recommendations by Thomas and Harden (2008), participant quotes and author interpretations were extracted from papers. Study characteristics (the author(s), country of research, title, publication date, topic of research, sample method, sample, data collection and analysis) were also extracted from each paper (see table 4).

Table 4

Study Characteristics

Author/Year/Country	**Title**	**Research Topics**	**Sampling Approach**	**Study Sample (Inclusion/Exclusion** distinguished based on Systematic Review Criteria)**	**Data Collection**	**Analysis**
Adenan et al. (2024) **(Malaysia)**	Employment Opportunities and Benefits for People with Down Syndrome in Malaysia: A Qualitative Research	Employment; Benefits in Employment	Snowball	Inclusion: 6 Participants (aged 18-29 years old; DS diagnosis) *Exclusion** 39 other participants*	Interviews	Reflexive Thematic Analysis
Chadwick & Fullwood (2018) **(United Kingdom)**	An Online Life Like Any Other: Identity, Self-Determination, and Social Networking Among Adults with Intellectual Disabilities	Identity; Self-Determination; Online Social Networking	Purposive	Inclusion: 2 Participants (aged 27-28 years old; DS diagnoses) *Exclusion** 9 participants (other diagnoses)*	Interviews	Semantic and Latent Thematic Network Analysis
Cunningham & Glenn (2004) **(United Kingdom)**	Self-awareness in Young Adults with Down Syndrome: I. Awareness of Down syndrome and disability	Self-awareness	Convenience	Inclusion: 77 Participants (aged 17-24 years old; DS diagnosis) *Exclusion** 78 parents*	Interviews Standardised Assessments Photograph task	Mixed Methods
Dolva, Kollstad & Kleiven (2019) **(Norway)**	Friendships and patterns of social leisure participation among Norwegian adolescents with Down syndrome	Friendships; Relationships	Convenience	22 Participants (all 17 years old; DS diagnosis)	Interviews and observations	Ethnography
Downs et al. (2013) **(United Kingdom)**	Exploring opportunities available and perceived barriers to physical activity	Physical Activity	Purposive	Inclusion: 7 participants (aged 12-21 years old; DS diagnosis)	Interviews	Comparison of quotes, cluster of quotes and

	engagement in children and young people with Down syndrome			*Exclusion** 1 Participant (6 years old)*		emergence of themes.
Faragher et al. (2024) **(Australia)**	Gen Zest: the lived experiences of adult Gen Zs with Down syndrome	Lived Experience	Convenience	26 Participants (aged between 12-29 years old; DS diagnosis)	Focus Groups and interviews	Reflexive Thematic Analysis
Foley et al. (2012) **(Australia)**	To Feel Belonged: The Voices of Children and Youth with Disabilities on the Meaning of Wellbeing	Wellbeing	Purposive	Inclusion: 3 Participants (aged between 15-16 years old; DS diagnosis) *Exclusion** 17 participants; other diagnoses*	Focus Groups	Open Coding with Constant Comparison
Geiger (2023) **(United Kingdom)**	Views of school held by children and young people with Down syndrome. How do we ask and what do they report?	Education;	Purposive	Inclusion: 3 participants (all aged 14 years old; DS diagnosis) *Exclusion** 6 other participants.*	Interviews	Qualitative analysis not specified
Glenn & Cunningham (2004) **(United Kingdom)**	Self-awareness in Young Adults with Down Syndrome: II. Self-understanding	Self-Awareness; Self-Understanding	Convenience	Inclusion: 77 Participants (aged 17-24 years old; DS diagnosis) *Exclusion** 78 parents*	Standardised Assessments Interviews	Mixed Methods
Groves, Rayner & Muncer (2018) **(United Kingdom)**	“It’s good, they’re like me; the same but different.” An interpretative phenomenological analysis of the identities of women with down’s syndrome	Identity	Purposive	Inclusion: 3 Participants (aged 21 – 28 years old; DS diagnosis) *Exclusion** 5 Participants (aged 30 years and older)*	Interviews	IPA

Hunter (2005) **(United States)** **(Grey Literature)**	The Opinions of Young Adults with Down Syndrome About Their Classroom Experience: An Ethnographic Study	Education	Purposive	Inclusion: 6 Participants (aged 23-29 years old; DS diagnosis) *Exclusion** 2 Participants (aged 30 years and older)*	Interviews Field Notes Observations	Ethnography
Jevne, Kollstad & Dolva (2022) **(Norway)**	The perspective of emerging adults with Down syndrome – On quality of life and well-being	Quality of Life; Wellbeing	Convenience	8 Participants (all 22 years old, DS diagnosis)	Interviews	Content Analysis
Li et al. (2006) **(China)**	Successful experience of people with Down syndrome	Successful experiences	Purposive	Inclusion: 9 Participants (aged 14-28 years old; DS diagnosis) *Exclusion** 1 Participant (age above 29 years old)*	Interviews	Content Analysis
Nadjari (2023) **(United States)** **(Grey Literature)**	Understanding the Lived Experiences of Young Adults with Down Syndrome as Emerging Societal Members – A Phenomenological Study.	Lived Experience;	Snowball	Inclusion: 5 Participants (aged 24-27 years old; DS Diagnosis) *Exclusion** 8 parent/carers*	Interviews, Focus Groups, Artefacts and Document Review	Phenomenology
Santoro et al. (2023a) **(United States)**	Indicators of health in Down syndrome: A virtual focus group study with patients and their parents	Health indicators	Purposive	Inclusion: 8 Participants (aged 13-21 years old; DS diagnosis) *Exclusion ** 20 parent/carers*	Focus Groups	Thematic Analysis
Santoro et al. (2023b) **(United States)**	Views on the impact of the COVID-19 pandemic on health in people with Down	COVID-19; Health impact	Purposive	Inclusion: 8 Participants (aged 13-21 years old; DS diagnosis) *Exclusion: ** 129 parent/carers*	Focus Groups Questionnaire	Mixed Methods

	syndrome from diverse backgrounds					
Scott et al. (2014) **(Australia)**	"I have a good life": the meaning of well-being from the perspective of young adults with Down syndrome	Wellbeing	Purposive & Convenience	12 Participants (18-29 years old, DS diagnosis)	Interviews and Focus Groups	Open coding method.
Segev & Hellman (2001) **(United States)** **(Grey Literature)**	The Experience of Students with Down Syndrome as They Transition from School to Employment	Transitions; Education; Employment	Purposive	2 Participants (both 18 years old; DS diagnosis)	Interviews	Narrative reasoning
Takataya et al. (2022) **(Japan)**	Thoughts of young adults with Down syndrome	Thoughts; Daily Life	Purposive	Inclusion: 7 Participants (20-29 years old; DS diagnosis) *Exclusion** 4 Participants (30 years and older)*	Interviews (Individual and Group)	KJ method (Kawakita, 1967, 1970)
Thompson et al. (2020) **(United States)**	Thriving with Down syndrome: A qualitative multiple case study	Thriving; Positive Psychology; Strengths	Purposive, Convenience and Snowball	Inclusion: 1 Participant (21 years old; DS Diagnosis) *Exclusion** 3 participants (aged 30 years and older); 13 other participants.*	Interviews Direct Observations Document Review Standardised Assessments	Within-case and Cross-case Analysis.

2.3.6 Thematic Synthesis

Following data extraction, data was synthesized using thematic synthesis to explore experiences (Thomas & Harden, 2008). A three-step protocol for completing thematic synthesis was conducted by the primary researcher. Firstly, the extracted data was read so that there could be familiarisation with the data set, and line-by-line coding commenced whereby codes were assigned to participant quotes, key concepts or author interpretations which were relevant to the review question. Secondly, descriptive themes were developed which involved the merging of codes and organising codes into groups. The final stage involved the generation of analytical themes. The thematic synthesis process was completed by the primary researcher, and consultation was held with the research team to discuss and agree on the final analytical themes.

2.3.7 Researcher Reflexivity

The primary researcher has had clinical experience of supporting AEDS and more broadly ID. This experience has been invaluable and has enabled a degree of insight and understanding as to the lived experiences of this population group from a clinical viewpoint. From a research perspective, it is important to notice any assumptions that may arise during the research process. In addition, to note that none of the research team have a diagnosis of DS, and this is crucial to hold in mind when interpreting the data and subsequent emergence of themes in relation to the lived experiences of AEDS. Therefore, it was important to raise and discuss aspects related to reflexivity during research supervision.

2.4 Results

2.4.1 Characteristics of included studies

This systematic review included 20 papers published between 2001 and 2024. Across the 20 studies there were 282 participants. It is important to note that this number is skewed due to the high numbers of participants in Glenn and Cunningham (2004) (n=77) and Cunningham and Glenn (2004) (n = 77). In addition, duplication of participants across studies, Glenn and Cunningham (2004) (n=77) and Cunningham and Glenn (2004) (n=77); Santoro et al. (2023a) (n=8) and Santoro et al. (2023b) (n=8); Dolva et al. (2019) (n=22) and Jevne et al. (2022) (n=8), as participants were part of a larger study or a longitudinal study. Apart from a higher reported number of participants within the review, it is felt that this has not impacted upon findings as studies were exploring different aspects of lived experience. For example, Santoro et al. (2023a) focused on indicators of health and Santoro et al. (2023b) considered the impact of COVID-19 upon health. All participants had a diagnosis of DS and were between the ages of 10-29 years old. This systematic review cannot comment on additional demographics (e.g., gender, ethnic/racial background) of included participants due to variability in reporting demographics across papers. For example, Santoro et al. (2023a) included additional demographic information including gender and ethnic/racial background of participants. Whilst Faragher et al. (2024) did not include any additional demographic information. Studies were either qualitative (Adenan et al., 2024; Chadwick & Fullwood, 2018; Dolva et al., 2019; Downs et al., 2013; Faragher et al., 2024; Foley et al., 2012; Geiger, 2023; Groves et al., 2018; Hunter, 2005; Jevne et al., 2022; Li et al., 2006; Nadjari, 2023; Santoro et al., 2023a; Scott et al., 2014; Segev & Hellman, 2001; Takataya et al., 2022; Thompson et al., 2020) or mixed methods (Cunningham & Glenn, 2004; Glenn & Cunningham, 2004; Santoro et al., 2023b). Data collection methods included interviews and focus groups. Analytic methods included reflexive thematic analysis and interpretative phenomenological analysis.

2.4.2 Thematic Synthesis

The lived experiences of AEDS can be summarised in four analytical themes: (1) *Belonging,* (2) *Self-concept*, (3) *Interdependence,* and (4) *Contemplating the future.* Table 5 includes the four analytical themes and associated sub-themes.

Table 5

Analytical themes and sub-themes

Analytical Theme:	Sub-themes:
Theme 1: Belonging	1. Interpersonal relationships 2. Forming and maintaining connections 3. Education and work experiences 4. Social acceptance and social adversity
Theme 2: Self-Concept	1. Self-awareness 2. Personal Qualities related to self-determination
Theme 3: Interdependence	1. Balance between independence and dependence 2. Factors which may influence the balance.
Theme 4: Contemplating the future	

2.4.2.1 Belonging

AEDS reflected upon the experiences of belonging and having connections with the different systems that exist around them. Participants shared how they experience connections from the various relationships that they have as well as how connections are formed and maintained. In addition, AEDS highlighted some of the benefits and challenges that they experience with these connections and with the community including experiences of social acceptance and social adversity including experiences of bullying and discrimination.

2.4.2.1.1 Interpersonal Relationships

A common pattern which was reported were participants narratives around the variety of interpersonal relationships they have, including parents, family, friendships, and community membership. These were experienced by AEDS by feeling connected and belonging to the community (Nadjari, 2023) and participants feeling safe in trusted relationships (Faragher et al., 2024). One participant expressed: *"I feel happy because I have a community full of people. Like my family, my friends, my neighbors from where I live"* (Santoro et al., 2023a). Some AEDS experience relationships with their parents as supportive (Jevne et al., 2022; Li et al., 2006), whilst Scott et al. (2014) interpreted that some familial relationships may be experienced by participants as smothering. AEDS also reflected on different types of friendships (Dolva et al., 2019). In addition, AEDS highlighted many opportunities that they have to spend time with friends including through participation in sports and attending community or social groups: *"On Friday evenings I go to the Cafe Club … Lauren and me we do dancing on Friday evenings ... I do weights with my best friend. He is a really good friend"* (Scott et al., 2014). Participants highlighted the importance of their long-standing friendships and shared activities they do together: *"I do the same activities with my friends who I met when I was little"* (Takataya et al., 2022).

Participants reflected on the difficulties of making new friendships and this taking time: *"At first it takes time to meet friends with the same values you do…"* (Hunter, 2005).

2.4.2.1.2 Forming and maintaining connections

Forming and maintaining connections refers to participants discussing various methods to form and maintain connections including personal (e.g., technology) and in the community (e.g., day programmes, support groups, activities). Provision in the local community was shared by AEDS as a way in which they maintain current friendships as well as forming new ones, *"I love [name day programme] and meeting new people and going there and seeing new people that I don't know that are in [name day programme]"* (Nadjari, 2023). In addition, team sports were noted by participants: *"I play soccer, I'm [on] a team"* (Faragher et al., 2024) and how this can be experienced by AEDS as a social opportunity in exploring and making connections. Participants also noted the participation of physical activity in the community, *"… I love going somewhere where I can walk slow pace or something like that it just breaks the day up things like that … I think might be happy."* (Downs et al., 2013). Some papers (Chadwick & Fullwood, 2018; Takataya et al., 2022) shared participants experiences of using technology to keep in contact with others, *"For me it's great because I can talk to people I know on here. some of my sisters and cousins and friends, also my boyfriend"* (Chadwick & Fullwood, 2018). Participants adapted to utilising technology more to connect with friends during the COVID-19 pandemic (Santoro et al., 2023b). Whilst it was noted that participants use different applications to support with communication (Faragher et al., 2024), some participants face difficulties communicating via technology: *"Sometimes it's back and forth on communication and understanding stuff. And almost back and forth with confusion or miscommunication … the main two that I'm kind of struggling at"* (Santoro et al., 2023a).

2.4.2.1.3 Education and work experiences

AEDS reflected upon education and work experiences. There seemed to be a sense from participants that their education placements brought about varying degrees of belonging (Hunter, 2005) as well as experiences of feeling supported in school (Li et al., 2006). However, some participants reflected upon different challenges that were experienced within education placements, including aspects related to sensory challenges (Hunter, 2005; Geiger, 2023) and difficult relationships with teachers (Faragher et al., 2024). Participants expressed challenges around getting a job or tasks being too difficult (Jevne et al., 2022; Nadjari, 2023), *"The work everyone is doing is too difficult for me to do"* (Takataya et al., 2022). It was also suggested that employment promotes acquaintances through working with others (Jevne et al., 2022; Scott et al., 2014), "*I want friends and want work with my friends. It is fun."* (Adenan et al., 2024).

2.4.2.1.4 Social acceptance and social adversity

This sub-theme illustrates how AEDS experience variable degrees of social connectedness from acceptance to adversity. Reflections discussed the need for participants to feel welcome as well as being accepted within society (Hunter, 2005; Santoro et al., 2023a). Hunter (2005) suggests that the experience of feeling welcomed by others may take time. Participants spoke about their experiences of social adversity including bullying (Faragher et al., 2024; Scott et al., 2014) and discrimination (Groves et al., 2018). One participant expressed their experiences of being bullied and how this made them feel: *'Sometimes I got bullied [by] someone in a classroom and it hurt my feelings … I feel a bit upset'* (Faragher et al., 2024). Participants reflected upon the experience of difference. Whilst some participants did not feel that they were treated differently by those around them, other participants spoke of the discrimination that they experience*: "Because I'm different,* *sometimes they discriminate me for who I am”* (Groves et al., 2018) and that having a diagnosis of DS contributes to being treated differently: *“I think it the Down Syndrome that I have.”* (Hunter, 2005). Despite these social adversities, some narratives highlighted how resilient they could be in overcoming responses from others as well as standing up for themselves and finding their own ways of coping (Faragher et al., 2024). One participant movingly expressed: *“I wear earplugs at work when people are bullying me so I can’t hear what’s going on”* (Scott et al., 2014).

2.4.2.2 Self-Concept

Participants across some of the papers commented on aspects of their self-concept including self-awareness and personality qualities related to self-determination. AEDS had varying levels of self-awareness. In addition, participants talked about a range of personal qualities that they have which collectively contributes to self-determination including advocacy and autonomy.

2.4.2.2.1 Self-Awareness

Self-awareness was commented on by AEDS whereby participants expressed varying levels of self-awareness that they have in relation to their DS diagnosis (Groves et al., 2018; Cunningham & Glenn, 2004). As one participant described *“I've got Down syndrome, I'm handicapped. I go to special school for people with handicap"* (Cunningham & Glenn, 2004). However, others lacked this insight and awareness of their DS diagnosis (Groves et al., 2018). Furthermore, there was variability regarding how AEDS appraise having a diagnosis of DS, and these appraisals varied from positive to negative (Cunningham & Glenn, 2004). Participants noted various comparisons that they make about themselves in relation to others, including participation in activities as well as a desire to have experiences like others: *“I* *want to go away like him so I can play sport and be with friend [sic] and stuff”* (Nadjari, 2023).

2.4.2.2.2 Personal Qualities related to self-determination

Participants expressed different personal qualities in relation to self-determination which they have or gained through different life experiences. Personal qualities included autonomy, authenticity and perseverance. In addition, advocacy and assertiveness were highlighted, one participant noted: *“I am learning how to Learn and Self Advocacy … I learn how to talk about disabilities. My disability is Down syndrome. I learn to talk for myself”* (Thompson et al., 2020). Through having these personal qualities, some participants described their experience of inspiring others through authenticity: *“I think how I inspire is by standing up for what I believe in, and just being me”* (Chadwick & Fullwood, 2018).

2.4.2.3 Interdependence

AEDS commented upon their experiences of independence and dependence including the feelings attributed to doing things on their own or relying on others. Participants discussed a variety of other people who provide support including family members (for example parents, siblings) and personal assistants. Furthermore, AEDS highlighted some factors which may affect independence and dependence including autonomy and conflict from others.

2.4.2.3.1 Balance between independence and dependence

Experiences of both independence and dependence was a pattern across papers. AEDS expressed a need and motivation for independence. Living independently was an aspect of independence which was noted by participants and narratives were variable: *“I’ve been living independently … I feel really strong about it”* (Faragher et al., 2024). Also, the opposite narrative that living independently comes with responsibilities which they would find difficult (Jevne et al., 2022). The need of family members support was reflected by some AEDS across papers (e.g., Faragher et al., 2024; Jevne et al., 2022; Scott et al., 2014). The experiences of dependency varied, and there was a mixture of both valuing support from others and not seeing it as a barrier (Faragher et al., 2024). One participant stated: *“My mom helped me get job at Sportime she went there with me and drive me all the time before the bus.”* (Nadjari, 2023). There was frustrations from some participants about needing to rely on others: *“If I could drive a car it would be easier. My sister can drive, and she drives me.”* (Scott et al., 2014). For some AEDS, they reflected upon personal assistant support that they receive and how this facilitates them to access the community: *“I like leaving my house and doing things like walk my dog to the Beach Club with my helper”* (Nadjari, 2023).

2.4.2.3.2 Factors which may influence the balance

AEDS acknowledged factors including autonomy, conflict, and control from others. Expressions of the need for autonomy and making decisions was highlighted: *“A good life is being my own boss and living by my own rules”* (Scott et al., 2014). Participants also reflected on issues including control from others; *“It’s too hard for me to control my family.”* (Scott et al., 2014) as well as *“other people telling me things”* (Foley et al., 2012). This suggesting that dependence may be more likely when control from others is present.

2.4.2.4 Contemplating the future

A pattern across papers was participants’ experiences of looking to the future and considering what they want their life to be like, including wanting to experience independence (Segev & Hellman, 2001; Li et al., 2006), desires to have a family (Faragher et al., 2024; Scott et al., 2014) and reaching employment aspirations (Faragher et al., 2024;

Glenn & Cunningham, 2004). One participant stated: *“I would like to become a nursery school teacher”* (Takataya et al., 2022). However, participants were not sure about what is required or needed including education, training, and support to achieve employment aspirations (Glenn & Cunningham, 2004; Segev & Hellman, 2001). Some AEDS shared that they desire to live like their neurotypical peers (Cunningham & Glenn, 2004; Nadjari, 2023): *“Go to University and get a degree. Have a perfect chance to get boyfriend. Get out more, get a better heart, able to do gymnastics. I want a full life."* (Cunningham & Glenn, 2004). In addition to goals and aspirations, participants experience specific fears when thinking about the future including living alone (Takataya et al., 2022) and uncertainties about the future (Segev & Hellman, 2001).

2.5 Discussion

The aim of this research was to build upon the work of Sheridan et al. (2020) who reviewed the limited research focusing on QoL in AEDS and noted the themes of ‘participation’, ‘friendships’, ‘family relationships’ and ‘independence’. By expanding QoL to lived experience, the current review identified four analytical themes: ‘belonging’, ‘self-concept’, ‘interdependence’ and ‘contemplating the future’, to answer the review question: “What are the lived experiences of AEDS?”. Each analytical theme will be discussed further including their links to existing literature and relevant theory.

The theme ‘Belonging’ captures the connections that AEDS have with the network around them (e.g., their friends, family, education, workplace and groups). AEDS noting the set of connections that they have, and how this is reflective of the microsystem in EST (Bronfenbrenner, 1979). In addition, the theme is consistent with existing ID literature whereby the feeling of belonging is gained through connections with others and having places to go to within their communities (Hall, 2010; Sheridan et al., 2020). In contrast, the current review also highlighted disconnect through AEDS experiences of social adversity. Whilst the Equality Act (2010) exists within the UK to prevent discrimination it seems reasonable to suggest that discrimination towards AEDS continues. AEDS within the current review reflected on being different and subsequently discrimination being experienced. In support, the experience of discrimination is found within broader ID research. Buljevac, Milić Babić and Leutar (2022) noted the label of ‘different’ and this being a key cause for discrimination. In addition, the emotional impact from social adversity, for example being bullied was evident from AEDS narratives within this review. Similarly, Hackett, Steptoe, Lang and Jackson (2020) found a link between discrimination related to disability and the negative effect discrimination has to wellbeing. From participants narratives in this review, it suggests that procedures are not necessarily in place to support AEDS, and they are finding their own ways of coping with negative responses or actions from others.

‘Self-concept’ considers aspects of AEDS internal experiences primarily self-awareness and personality qualities related to self-determination. This finding aligns with considering the whole individual (Hodapp & Zigler, 1990). In addition, Bronfenbrenner’s (1979) EST whereby an individual’s internal experiences including personality and beliefs form part of the individual’s microsystem (Crawford, 2020). AEDS vary in relation to the level of insight that they have regarding their DS diagnosis. Furthermore, there is variability in how participants appraise their DS diagnosis, and it seems plausible to suggest there may be an emotional impact to this. AEDS acknowledge the personal qualities that they have including autonomy, perseverance and advocacy. It is important to note that self-concept was not identified within Sheridan et al.’s (2020) scoping review. Therefore, the emergence of the theme self-concept, within the current review, indicates the importance of considering AEDS internal experiences and how integral this is to their lived experience.

The theme ‘Interdependence’ highlights the variability in how independence and dependence are perceived amongst AEDS, as well as the positives and challenges that come with both. Independence was highlighted as one of the key themes which emerged from Sheridan et al. (2020) where they recognised the role of family members in supporting independence. The current review adds to this by highlighting the positive experiences that AEDS have with personal assistant support which facilitates independence. The findings suggest that the influence of others shapes AEDS experiences of interdependence. This reflects Bronfenbrenner’s (1979) EST and more broadly EDT (Hodapp & Zigler, 1990) which emphasises how an individual’s environment is involved in shaping development. Furthermore, there was variability in experiences of living independently, whilst some embrace the opportunity to live independently, others may find this more challenging with additional responsibilities and challenges. Similarly, Bond and Hurst (2010) found mixed feelings and an awareness of practical difficulties that come with independent living from participants with disabilities.

Finally, the theme of ‘contemplating the future’ captures the dreams, aspirations and desires of AEDS. However, this was not found in Sheridan et al. (2020). This important theme derived from being influenced by observing people as well as narratives about wanting to live a ‘normal life’. These dreams, aspirations and desires relate to Arnett’s (2000) ‘possibilities or optimism’ which is a feature of Emerging Adulthood. However, the review demonstrates that contemplating the future is something which adolescents diagnosed with DS are exploring. The review adds that not only are AEDS demonstrating optimism for the future, but they also consider the uncertainty of what the future may look like for them.

Furthermore, the findings suggest that AEDS have hopes but lack insight as to what is needed for example training and skills. These findings highlight the necessity of additional guidance to ensure local authorities are supporting AEDS including providing accessible information detailing what is available in their local area.

2.5.1 Strengths, Limitations and Areas for Future Research

A key strength was the broadness of the research question as it enabled a systematic exploration of existing research regarding the lived experiences of AEDS. In addition, the search strategy was kept broad to provide the most comprehensive search for this review, and in line with Ewald et al. (2022) more than two databases were used in the searches, and this included both published literature and grey literature. The inclusion of grey literature was paramount to locating additional research that had not been published as well as reducing publication bias (Paez, 2017). Therefore, this ensured that all relevant sources were identified. However, the broadness of the review question has meant that the thematic synthesis is not overly specific and provides a much general overview of the lived experiences of AEDS. Thus, enabling a broader understanding of this client group and subsequently contributing to relevant policy and legislation. The limited number of eligible papers included in this study highlights the need for more research. Therefore, future research should aim to explore specific experiences of AEDS, for example experiences of social adversity.

An additional limitation of this review is the lack of consideration of culture and gender difference. This limitation is due to limited demographic reporting in the eligible papers. Furthermore, it is also important to note that the research reviewed in this systematic review did not capture information regarding the specific type of DS that participants have. Therefore, future research should endeavour to capture demographic information (e.g., ethnicity, gender and type of DS) so that a future review could explore experiences of AEDS and examine experiences according to ethnicity, gender and type of DS. It is important to note that most of the eligible studies within this systematic review were conducted in the West. Therefore, it is pertinent that future research considers capturing AEDS experiences from different cultures and ethnicities where there is a paucity of research.

All eligible studies within the review included AEDS who were able to participate within research, which would presume participants were able to verbally communicate with researchers. This suggests the voices of AEDS who could not communicate verbally were missed. Future research should aim to seek the voices from AEDS who have communication difficulties and therefore unable to take part in traditional research which involves standard methodologies (e.g., interviews, focus groups). Therefore, creative data collection methods should be considered to ensure AEDS can participate in research.

2.5.2 Clinical Implications

The findings have shown the importance of AEDS belonging to their communities through having networks and provisions which promote connectedness. It feels plausible to suggest, particularly in accordance with the Down Syndrome Act (2022), that there is a need for local authorities to consider what is currently in place for AEDS (e.g., school placements, work placements, provisions, and activities) that encourage this group to engage with and be part of their local communities. If there is a significant lack of provision, then local authorities should consider ways of introducing inclusive provisions which AEDS can be part of.

In addition, the findings highlight that AEDS may experience social adversity including bullying and discrimination from others around them, and consequently the impact this can have emotionally, psychologically, and socially. McNally, Taggart and Shevlin (2021) found that there is an emerging evidence base for therapeutic interventions for individuals diagnosed with an Intellectual Disability (IID) including Eye movement desensitization and reprocessing (EMDR) and Trauma-Focused Cognitive Behavioural Therapy (TF-CBT). However, McNally et al. (2021) noted that more research including trauma informed care is needed for the ID population. Therefore, services need to consider offering therapeutic interventions for example EMDR or TF-CBT to AEDS who experience trauma following social adversity for example bullying.

As a society, there is a need for more education and teaching which aims to increase awareness and understanding of DS, and more broadly disability, across a range of different settings including education and employment. Additional education and teaching would complement the Equality Act (2010) which is in place to prevent discrimination of individuals who have a disability. The implications of building understanding and awareness related to DS and disability may help to reduce stigma, incidences of bullying and discrimination as well promoting Equity, Diversity and Inclusion (EDI) across all settings.

It should be noted that the DS phenotype gives rise to a broad range of needs that AEDS will have. The review has highlighted this in relation to the variability found across AEDS including insight of their DS diagnosis and their experience of independence and dependence. Therefore, this review highlights the importance of person-centred focused approaches when supporting AEDS.

Finally, the findings highlight that AEDS are considering their future regarding their aspirations and uncertainties. Feeling uncertain about the future is a common experience, and so there is a need for people in the AEDS’ network (e.g., parents and carers, professionals) to offer validation and normalisation of this uncertainty. In addition, there is a need for more timely information and support (e.g., education, employment, independent living), and AEDS and their families are aware of where this support can be accessed from.

2.6 Conclusion

The review has specifically focused upon synthesising existing research related to the lived experiences of AEDS. The synthesis has highlighted the significant amount of insight that AEDS have about their own lives including their experiences of the systems around them, their self-concept and considering their futures. The review has highlighted areas for future research including the need for more research and more specific research. For example, focusing on the experiences of social acceptance and social adversity and uncertainty about the future. Research would also benefit from the integration of more creative methodologies, for example photovoice (Wang & Burris, 1997) and drawings (Bergbom & Lepp, 2022), to seek the voices from AEDS who have communication difficulties. In addition, clinical implications should be considered and implemented to enhance community belonging for AEDS, increasing society’s understanding and awareness of DS to promote acceptance and prevent discrimination towards this population group.

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Chapter 3: *“It's like a Down’s syndrome, but I think it should be Up Syndrome, cause Down syndrome puts you down”:* Exploring the experiences of individuals who have a brother or sister with Down’s Syndrome from Racially or Ethnically Minoritised (REM) communities

This chapter has been written with intent to submit for publication to the journal of Research in Developmental Disabilities

For detailed author guidelines please see appendix A.

3.1 Abstract

Background: Research exploring the experiences of siblings who have a brother or sister diagnosed with Down’s Syndrome is limited and less is known about the sibling experience from racially or ethnically minoritised communities.

Methods: Eight siblings participated to explore, from their own perspectives, what are their experiences of being a sibling to a brother or sister diagnosed with Down’s Syndrome. Interviews were analysed using Interpretative Phenomenological Analysis.

Results: Group Experiential Themes emerged: Relationships and Connections; Understanding; Day-to-Day Life; Responsibilities. Also, there were narratives across the themes as to the interplay of ethnicity and culture including culturally related activities, familial events, and cultural differences in understanding Down’s Syndrome.

Conclusions: Siblings from racially or ethnically minoritised communities are insightful about the experiences that they have as an individual who has a sibling with a diagnosis of Down’s Syndrome. Ethnicity and culture form part of these experiences too.

Keywords: siblings; Down’s Syndrome; racially or ethnically minoritised; sibling experiences; attitudes.

3.2 Introduction

Siblings can be key members of a family system, with Conger and Kramer (2010) highlighting that the relationship between siblings is one of the longest relationships that an individual can have with someone. Siblings can be influential in responding to the needs of each other and subsequently become an attachment figure (Whiteman, McHale & Soli, 2011) and can offer emotional support (Jenkins, 1992). Kramer, Conger, Rogers and Ravindran (2019) suggests that siblings also provide support for socialisation and giving advice. In contrast, sibling relationships can also include arguments and conflict (Tucker & Finkelhor, 2015; Wilson, Smith, Ross, & Ross, 2004). Whilst the sibling relationship can be both positive and challenging, when a sibling is diagnosed with a disability (SDD) this can add an additional complexity to the relationship. For example, Giallo, Gavidia-Payne, Minett and Kapoor (2012) explored the mental health of individuals who have a sibling diagnosed with a disability (ISDD) through completion of the Strengths and Difficulties Questionnaire (SDQ), and this was compared to SDQ data obtained from Mellor's (2005) study which set out to establish SDQ norms for children and young people (CYP). Giallo et al. (2012) found that ISDD reported more emotional difficulties and behavioural problems compared to Mellor's (2005) sample. In contrast, Pit-Ten Cate and Loots (2000) highlights how ISDD report both positive experiences and negative experiences when they spend time together.

From a theoretical perspective, Ecological Systems Theory (EST; Bronfenbrenner, 1979) stipulates that different systems will influence and shape an individual using a five systems approach. The closest system to the individual is the microsystem and this relates to the individual's immediate environment including family, friends, and the school environment. The mesosystem considers how different microsystems interact, for example, family and school. The exosystem includes indirect influences that may affect an individual (e.g., parent's workplace). The macrosystem considers broader societal influences including culture (Brim, 1975). Finally, the chronosystem considers the influence of time (Bronfenbrenner, 1994). It is argued by Vélez-Agosto et al. (2017) that culture is inextricably linked to settings within one’s microsystem as opposed to culture(s) operating at only a macrosystem level.

Whilst EST considers the influence of these systems upon an individual, Whiteman et al. (2011) highlights how EST can be applied when thinking about the sibling relationship. Saxena and Adamsons (2013) describes how the EST framework relates to having a SDD including the influence of the individual themselves, their wider social context, and the interconnections between systems. Some of the factors include age and genetic predispositions (individual), conflict and cohesion within family and friendships (microsystem and mesosystem), parent support groups (exosystem), cultural beliefs about disability (macrosystem) and beliefs about disability over time (chronosystem). Meltzer and Muir (2022) highlights that it is the interactions and connections between systems which subsequently influences the individual’s experience of having a SDD. Whilst there is a theoretical basis (Bronfenbrenner, 1979; Saxena & Adamsons, 2013) and research (Giallo et al., 2012; Pit-Ten Cate & Loots, 2000) suggesting the impact that having a SDD has, disability is a broad term for a variety of conditions and so an individual’s experience may vary dependent upon the condition their sibling has.

Down’s Syndrome (DS) is a life-long genetic condition involving a partial or extra copy of chromosome 21 (Down’s Syndrome Scotland, n.d.). The current prevalence of people diagnosed with DS living in the United Kingdom (UK) is estimated to be around 47,000 (Down Syndrome Act, 2022). DS has a unique behavioural phenotype including specific physical features (e.g., short neck, flat nose bridge), associated health conditions (e.g., coeliac disease) as well as varying strengths and difficulties in relation to daily functioning (Daunhauer & Fidler, 2011). In addition, it is likely that individuals diagnosed with Down’s

Syndrome (IDS) will also have an Intellectual Disability (ID; Hodapp, Evans & Gray, 1999). Furthermore, DS has been associated with strengths including visual perceptual abilities (Jarrold, Baddeley & Hewes, 2000) and social engagement skills (Dykens, 2006). Research has found that IDS may experience challenges in relation to working memory (Baddeley & Jarrold, 2007) and motor co-ordination (Daunhauer & Fidler, 2011). Dykens (1995) further highlights how aspects of the phenotype will vary, and each person diagnosed with DS will be different. Therefore, DS and the unique behavioural phenotype for DS will not only influence the lives of IDS but will also have an impact upon family members too, in a myriad of ways.

Research has explored the impact on individuals who have a sibling diagnosed with Down’s Syndrome (ISDS). For example, Skotko, Levine and Goldstein (2011) investigated siblings’ views of having a SDS and found that the majority liked (96%) or loved (97%) their SDS and felt that they had a good relationship. In addition, this study reported that some participants expressed feeling sad, sorry and worried for their SDS. A small proportion also said they felt embarrassed by their SDS and/or annoyed that their sibling needed additional support. Furthermore, other areas identified within the research included finding their siblings’ behaviour personally challenging (Baumann, Dyches & Braddick, 2005; Graff et al., 2012) and a heightened sense of responsibility to support their SDS (Baumann et al., 2005; Skotko et al., 2011). It is important to note that studies (e.g., Baumann et al., 2005; Graff et al., 2012; Gray et al., 2023; Skotko et al., 2011) have primarily included white, western families meaning that the experience of those who identify from racially and culturally diverse backgrounds are missing.

The Office for National Statistics (2022) estimates that there are approximately 2.5 million households where there are people who identify as dual heritage and/or multi-heritage within the UK, an increase from 2 million since the last census (2011) completion. Ethnicity refers to an aspect of an individual’s identity and comprises one’s culture, which may include religion, as well as a sense of community and belonging (Hutchinson & Smith, 1996 as cited by Baumann, 2004). Quintana's (1994) model stipulates that ethnicity develops throughout childhood, adolescence, and into adulthood where one's level of understanding about race and ethnicity becomes more advanced as one gets older. Quintana (1998) summarises and explains four levels of understanding race and ethnicity, and the approximate ages to which CYP develop their understanding of race and ethnicity (see table 6). The model perhaps assumes a universal sequential progression to understanding race and ethnicity. However, the evidence-base which aligns to the model has focused predominantly upon western cultures (e.g., Mexican, American) (Quintana, 1998), and so perhaps cross-cultural utility of this model is unclear. Alongside understanding race and ethnicity, Gainsbury (2017) highlights how both race and ethnicity can influence an individual's perspectives, and so 'Racially or Ethnically Minoritised' (REM) is used to represent these communities and will be used within this paper.

Table 6

Understanding of Race and Ethnicity

Level	Ages (approx.)	Description
Level 0: 'Integration of Affective and Perceptual Understandings of Ethnicity'	3 – 6 years old	CYP at this level learn to differentiate racial/ethnic groups, and their descriptions will be based on external/physical characteristics e.g., skin colour, language spoken etc.
Level 1: 'Literal Understanding of Ethnicity and Race'	6 – 10 years old	There is a move from understanding race and ethnicity in relation to observable aspects to instead understanding race/ethnicity on aspects

		that may not be observable including food, languages, and customs related to the specific ethnic group.
Level 2: 'Social and Nonliteral Perspective of Ethnicity'	10 – 14 years old	Understanding develops beyond the literal understanding of ethnicity to the consideration of social elements including how ethnicity influences relationships (e.g., friendships) and links to other aspects of identity including socioeconomic status. CYP at this level become aware of discrimination and prejudices related to ethnicity.
Level 3: 'Ethnic Group Consciousness and Ethnic Identity'	Adolescence	Understanding considers ethnicity being more integral to an individual's identity as well as awareness of group perspectives related to ethnicity (e.g., shared attitudes and perspectives).

Note: Table adapted from Quintana's (1998) paper and based upon Quintana's model (1994;1998)

More broadly within the ID field, but not the DS field, research has started to consider experiences of individuals who have a sibling diagnosed with an Intellectual Disability (ISID) and who identify from different ethnic backgrounds. Paul et al. (2022) explored participants' experiences of having a sibling diagnosed with an intellectual disability (SID) from Latin America, Africa, and Asia-Pacific backgrounds. They found that ISID expressed a closeness in the relationship with their SID and raised the challenges and issues of stigma that can underpin ID. A UK study by Cooper-Moss et al. (2025) found that carers, including a sibling carer, experience disparities in relation to accessing healthcare for their REM family member. Importantly, it is noted that there is the need for more ethnically and culturally diverse research within the field of SID (Paul et al., 2022), and more specifically SDS (Graff et al., 2012; Sutter, 2016). In addition, Choi and Van Riper (2013) highlighted a need for more qualitative methodologies for exploring ISDS.

The aim of this research is to explore the experiences of having a SDS specifically from REM communities, with the research question "what are the experiences of ISDS from REM communities?" It is hoped that through qualitative interviews and analysis a greater understanding about what it is like to have a SDS from REM communities. This aims to inform future research and recommendations for clinical implications to better support ISDS from REM communities.

3.3 Methods

The research received ethical approval from the University of Southampton Ethics and Research Governance Committee on 25th March 2024 (Submission ID: 91665) (Appendix D).

3.3.1 Design

A qualitative design was used to consider the experiences of ISDS identifying from REM communities. Data was gathered using semi-structured interviews, and qualitative data analysis was completed using Interpretative Phenomenological Analysis (IPA; Smith & Nizza, 2022).

IPA was chosen as it focuses on the exploration of the lived experience of participants and positioning them as experts (Eatough & Smith, 2017). IPA also enables the consideration of how a participant relates to their experience as well as how this shapes their relationships and outlook of their own lives (Smith & Nizza, 2022). IPA is based upon three theoretical standpoints: phenomenology, hermeneutics, and ideography. Phenomenology is concerned with an individual’s lived experience, and Smith, Flowers and Larkin (2009) emphasise that this encapsulates the individual’s own perspective, meaning, and their relationship to the world and others. Hermeneutics is based upon the concept of going beyond what is being said and the process of interpretation (Smith & Nizza, 2022). Within IPA, there is the concept of the ‘double hermeneutic’ (Smith & Osborn, 2003 as cited by Smith et al., 2009), which is a process whereby the participant actively tries to make sense of their own experience whilst the researcher tries to interpret and make sense of the participant’s understanding of their own experience. In consideration of ideography, this is concerned with how researchers are focused upon exploring individual accounts of the lived experience topic area (Love, Vetere & Davis, 2020).

The epistemological approach is interpretivist. An interpretivist position assumes that knowledge is constructed by one’s subjective interpretations of their experiences including the world around them (Hiller, 2016), and that there are multiple realities (Smith, 1983).

3.3.2 Participants

As set out in the inclusion criteria (see table 8), participants were required to be between the ages of 9 and 25 years old. It was felt appropriate to have this age range for several reasons including a consideration of the specific participant demographics (e.g. ISDS and identifying from a REM community) and the age range being broad enough to ensure enough participants took part in the study, previous sibling research included similar ages of participants (e.g., 8 – 25 years old in Paul et al., 2022; 12 – 19 years old in Graff et al., 2012), and consideration of age in relation to participant’s ability to engage in interviews via Microsoft Teams.

Eight participants took part aged between 9 to 24 years old.

Table 7

Participant Demographics

Name*	Age	Gender	Ethnicity **	No. of Siblings	No. of SDS	Age of SDS	Gender of SDS	Additional diagnoses for SDS***	Support accessed ****
James	12	Male	REM	2	1	13	Female	None	None
Tom	12	Male	REM	2	1	13	Female	None	None
Priya	9	Female	REM	1	1	6	Male	None	Yes
Elena	13	Female	REM	3	1	6	Male	None	None
Zara	20	Female	REM	2	1	11	Female	Yes	Yes
Aaliyah	10	Female	REM	4	1	7	Male	None	None
Naomi	9	Female	REM	1	1	14	Female	None	Yes
Nia	24	Female	REM	2	1	27	Male	Yes	Yes

*Note: *Please note all participants have been given pseudonyms to maintain anonymity and protect their confidentiality. ** Ethnicities have been replaced with ‘REM’ to maintain anonymity and protect confidentiality. Ethnicities of participants within this study included:*

*Caribbean, Sri-Lankan, dual/mixed heritage e.g., mixed race, Pakistani, British Asian Indian and Afro-Latina. *** Additional diagnoses and additional health needs include autism, epilepsy, coeliac, hearing impairment, cleft, lip and palate, nystagmus, sleep apnoea, speech difficulties. **** Support accessed included SALT, OT, DS support groups, physical therapy and short break services.*

3.3.3 Interview/material development and involvement of Patient and Public Involvement (PPI)

PPI involvement was sought for the current study. One individual with lived experience of having a SDS and their parent were consulted in the development of a young person user-friendly information sheet and a debriefing form. They also supported in the development of the semi-structured interview schedule, and they were reimbursed for their contribution. Additional consultation was sought from one of the research supervisors whose specialist interest is Equity, Diversity and Inclusion (EDI) to ensure the interview schedule, study, and emphasis took into consideration EDI components. As a result of PPI involvement, participant information, debriefing information, and the semi-structured topic guide was accessible for participants across the age range. For example, the use of both simple sentences and pictorial images in the participant information and debriefing information facilitated understanding of the study for the younger participants. In addition, the topic guide considered the use of language within prompts to ensure comprehension from participants across the entire age range.

3.3.4 Procedure

A purposive sampling method was employed, a poster (see appendix E) detailing information about the study was shared with the Down’s Syndrome Association and DS support groups to advertise via mailing lists and newsletters. Prospective participants (and their parent/carers dependent on participant’s age) contacted the researcher and a virtual meeting was arranged. During this meeting, information was given about the research, and eligibility was ascertained using the inclusion and exclusion criteria (see table 8). The following documentation was sent to eligible participants: information sheets (appendices F, G and H), consent forms and consent with assent form (where applicable) (appendices I, J and K) and demographic questionnaire (see participant demographics table 7).

Following receipt of completed and signed documentation, the researcher arranged a time for the online interview with the participant and their family member (if required). Interviews took place via Microsoft Teams and were facilitated by the researcher, a trainee clinical psychologist, who has experience of working with CYP and their families. For participants under the age of 18 years, their parent/carers were present at the start of the interview. Participants (and their parent/carers) confirmed their consent to participating in the research. Two participants chose to have their parents present for the interview. The researcher used a semi-structured topic guide (appendix L) to facilitate the interviews. The interviews were recorded and transcribed using Microsoft Teams. Interviews ranged from 14 to 59 minutes with a mean time of 33 minutes. At the end of the interview, for participants who were under the age of 18 years, their parent/carer rejoined if they were not already present. Participants were sent debriefing information (appendices M, N and O) and offered a debrief session, although no participants opted for this. All participants received a £15 voucher for their participation.

The transcriptions for each participant were prepared for analysis by the researcher. Each participant was given a pseudonym, and all identifiable information was anonymised or removed from the transcripts to maintain confidentiality.

Table 8

Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Participant is between the ages of 9 – 25 years old.	Participant is outside of the ages of 9 – 25 years old.
Must have a brother or sister with DS.	Does not have a brother or sister with DS.
Capacity to provide assent to participate (where participant is under the age of 18 years old).	Does not have capacity to assent to participate (where participant is under the age of 18 years old)
Must have full informed consent from parent/carers to take part (where participant is under the age of 18 years old).	Does not have full informed consent from parent/carers to take part (where participant is under the age of 18 years old).
Sibling participants must identify from an underrepresented ethnic group (this can include dual heritage and/or mixed race)	Participants must not have an ID and/or DS. Participant must not be receiving or currently on the waiting list for emotional wellbeing support from CAMHS/Mental Health Services.

	Sibling participant does not identify from an underrepresented ethnic group (including dual heritage and/or mixed race)

3.3.5 Analysis

IPA analysis was conducted by the researcher following the process outlined by Smith and Nizza (2022). Each transcript was read, and exploratory notes were made, considering descriptive, linguistic, and conceptual aspects (Smith et al., 2009). Experiential statements were developed, and statements were clustered based upon their meanings. Each cluster formed Personal Experiential Themes (PETs), and a name was assigned to each PET. PETs were analysed for similarities and differences across participants and Group Experiential Themes (GETs) were created and assigned a name. Supervision was sought from the research team to discuss and refine GETs.

3.3.6 Researcher Reflexivity

The positionality of the researcher was important to consider, and the influence that this may have had when drawing interpretations from the qualitative data. The researcher considered aspects of their own identity and how this might have influenced interpretations, including identifying as White-British, a sibling (sibling has no diagnosis), and experience of working with CYP who have additional needs and their families. It was important to notice and reflect upon any influences or assumptions that arose, and so field notes were kept capturing any relevant reflections and discussions were had within research supervision.

3.4 Results

Four GETs emerged from the analysis: ‘Relationships and Connections’; ‘Understanding’; ‘Day-to-day life’, and ‘Responsibilities’. GETs and related sub-themes are outlined in table 9.

Table 9

Group Experiential Themes and Sub-Themes

Group Experiential Theme	Sub-Theme	Participants
Relationships and Connections	1. Sibling relationship	All
	2. Other family members	All
	3. Friendships	Tom, Priya, Elena, Zara, Aaliyah, Naomi, Nia
	4. External support systems	Priya, Zara, Naomi, Nia
Understanding	1. Own Understanding	All
	2. Understanding from others	James, Priya, Elena, Zara, Aaliyah, Naomi
Day-to-day life		James, Priya, Elena, Zara, Aaliyah, Naomi, Nia

Responsibilities	James, Tom, Elena, Zara, Aaliyah, Nia

3.4.1 Group Experiential Theme 1: Relationships and Connections

This theme refers to participants reflecting upon the importance of relationships and connections including their SDS, family, friends, and external support systems. Participants discussed the benefits and challenges of spending time with their SDS. They also shared how spending time with parents is important, but recognised however the limitations (e.g., parents needing to support their SDS). Participants spoke about friendships and the challenges around being able to spend time with their friends. Finally, external systems (e.g., support groups) were highlighted as an opportunity to receive support, including connecting with other siblings/carers, but also the challenges of doing so including cultural/belief systems or a lack of ethnic diversity.

3.4.1.1 Sub-Theme 1: Sibling Relationship

All participants spoke about the opportunities to spend time with their SDS. They shared a variety of different activities (at home, in the community, and activities related to their cultural/ethnic background) that they do with their SDS. In Naomi’s account she reflected proudly on her religion and noted that they “*go to Tabla class together” (Naomi).* This suggests that culture and religion play an important part in the sibling relationship including activities which are done together. Conversely, participants reflected upon how activities which they once did together they no longer do or due to their SDS having additional needs there being limitations on what they can do together. This was demonstrated in Naomi’s account relating to classes which she and her SDS used to attend together: *“Well,* *we used to, but then we got split up into two classes. So ... there's a class on the left ... next door which do the easiest stuff. And then my class do ... bit harder stuff” (Naomi).*

Some participants reflected upon how time spent together is often influenced by their SDS: *“And it’s impossible to get that out of her head. She’s just always in charge” (James).* There was a sense from participants that these factors can lead to challenges with sibling interactions including spending less time with their SDS and pursuing independence. However, Nia’s account suggests there might not be a choice to spend time apart: *“I got tired of being a package deal like we were twins” (Nia).* Nia’s use of ‘tired’ implies the physical and emotional impact that this had on her. Participants discussed independence being a challenge, not only when they wanted to do an activity by themselves, but also just being able to have any time for themselves:

> *Well, I have a bunk bed ... we made a rule that nobody else can go on the top except for me ... so that's like the only place I could stay without someone like going up to my ear and being like can you play with me? (Aaliyah).*

There was equally a strong narrative that many participants saw huge benefits from the sibling relationship including enjoyment that is shared: *“Well, it’s fun. Whenever she plays a game because she always really excited about playing them with us” (Tom).*

3.4.1.2 Sub-Theme 2: Other family members

Participants reflected on the relationships and connections with other family members, both immediate and extended. Participants referred to the busyness of their parents and how this is even more so with a SDS. Participants commented on how their SDS has more contact with their parents: *“Umm just sometimes my parents have to pay more attention to him than to me, and I don't get as much play time as [name of brother]” (Priya)*. Priya’s account highlights the additional allocations (e.g., time with parents) that her SDS gets compared to her. There was a sense from participants that they feel that they miss out on opportunities for quality time with their parents due to having a SDS. Tom extends this narrative by acknowledging that time parents spend with their SDS might also be through attending healthcare appointments.

More broadly, connections with wider family were noted by some participants. Zara reflected upon her REM background, specifically funerals, and commented on how her SDS is unable to tolerate these family occasions: *"Family events, we've had it a few times in the past where main thing funerals. She can't be in that setting" (Zara).* Zara elaborated that she had to stay at home to look after her SDS and was not able to spend time with wider family. This account suggests that participants experience missed opportunities to be with extended family members, and the impact that this may have including difficulties with maintaining close relationships with extended family members and feeling isolated from extended family. In addition, some participants also commented on their dual heritage and how extended family live far away. This suggests that participants may feel less connected and if additional support is needed this may not be easily accessible.

3.4.1.3 Sub-Theme 3: Friendships

Friendships were another important relationship that was reflected on by participants. Zara noted how shared identities (e.g., ethnicity) can foster connections and how friendships become a form of support:

> *…So that's the main thing that she is [REM background]. We are really close friends and she's seen [name of sibling]. I've seen her sister...So, if there ever is anyone that I want to talk about [name of sibling] whatever with she's probably the one that I'd go to first… (Zara).*

Conversely, there was a narrative amongst participants that there are limited opportunities to spend time alone with just their friends. Nia added to this by stating: *"Eventually, some people wouldn't invite me to stuff because [name of sibling] would be there" (Nia).* This suggests that there can be social and emotional consequences in relation to navigating friendships with a SDS.

3.4.1.4 Sub-Theme 4: External Support Systems

Some participants described the value of support systems. Naomi contributed to this narrative by expressing the need for more: "*More of my groups…and meeting like sibling groups" (Naomi).* This suggests that the groups enable siblings to foster connections with others whilst having a space that is for them. Ethnicity and cultural awareness were demonstrated by Zara who stated that there is often a lack of ethnic diversity in these groups: *"I don't think they understand me on the same level because they were all White. Me and my cousin were the only ones who were [REM background]" (Zara)*. Therefore, the value of support groups varies from one participant to another. However, Zara offered an extended perspective whereby mutual understanding and ensuring groups include people from a range of cultures is key to engagement and feeling heard. Furthermore, cultural belief systems that a family holds may be indicative as to whether support is accessed: *"They would be the type of people that would say you're putting your business out there. They like to keep things in house" (Nia).*

3.4.2 Group Experiential Theme 2: Understanding

The second theme encapsulates the understanding that participants have about their SDS diagnosis/es whilst also reflecting upon the impact this can have on their SDS. Participants spoke about the understanding that others have about their SDS diagnosis/es. In addition, how ethnicity and culture may influence understanding around DS and disability.

3.4.2.1 Sub-Theme 1: Own understanding

Participants discussed their own understanding of their SDS's diagnosis including the amount of knowledge that they have. Some participants were insightful and commented on different co-morbidities which their SDS has. They demonstrated compassion and reflected how the diagnosis/es impacts upon their SDS: *"He's non-verbal ... which means he finds it harder to speak… We use sign language. We use Makaton" (Aaliyah).* This suggests that alongside understanding there is also the need to understand the practical day-to-day implications, and how participants need to be adaptable, such as learning sign language to communicate with their SDS.

In addition to varying levels of insight about their SDS diagnosis, Priya reflected upon the 'Down's Syndrome' label and the negative connotations it brings: *"It's like a Down's syndrome, but I think it should be Up Syndrome, cause Down syndrome puts you down" (Priya)*. There was a sense that these negative connotations can have an impact upon how people perceive IDS as well as what it means to have DS. Finally, Priya spoke positively about *"a TV presenter on CBeebies called George and he's got Down syndrome" (Priya).* It appeared important to Priya to have DS represented within wider society, lending support to people's understanding and acceptance of people with DS as meaningful members of society.

3.4.2.2 Sub-Theme 2: Understanding from others

Many of the participants referred to their experiences of the understanding from others around them in relation to their SDS. Zara commented on the experience of her family and extended family's understanding: *"my mum was born in England, and my dad was born in [name of country], so his understanding already is very different to my mum's" (Zara).* Zara highlighted how different understandings about DS and disability can vary according to cultural heritage. To add, she highlighted the impact of different upbringings and intergenerational understandings of DS and disability: *"They don't understand what they don't* *even know what the name of it is" (Zara).* Participants shared acceptance that comes with the understanding that others have for their SDS. Aaliyah joyfully portrays this: *"... he's always like around, like so much love and stuff…like he's like a superstar. Like famous and stuff" (Aaliyah).* Aaliyah's use of *'superstar'* and *'famous'* emphasises the degree of fondness and admiration from others. Some participants spoke specifically about their friendships and how friends were aware of and accepting of their SDS. In contrast, some participants spoke about how only some of their friends knew about their SDS's diagnosis, *"Um…some of them" (Naomi).* There was a sense that there might be reasons for sharing and not sharing this with friends with Zara explaining that when she feels *"comfortable"* in her friendships she is more likely to talk about her SDS. This appeared to be linked to participants wanting people to understand and not wanting peers to have negative assumptions about their SDS.

3.4.3 Group Experiential Theme 3: Day-to-day life

The third theme represents participants day-to-day life. Participants reflected upon the challenges as well as the positives about daily life with their SDS and the impact that this has upon them. Most participants reflected upon how the support needs of their SDS could influence aspects of their daily life, particularly in terms of their SDS's behavior impacting on activities and engagement: *"We could be going on a walk, and she will see a bench and just sit down there for 2 minutes and not go" (James).* There was a sense that some participants felt apprehensive about going out with their SDS. For instance, one participant reflected upon not taking their SDS to certain places (e.g. cinema) due to worries about what they might do. In addition, Priya added that there can be home life challenges: *"Well, it's really hard because umm like if I have to go to school in the morning and if I'm late it sometimes will mostly be because of him" (Priya).* The accounts suggest that there are missed opportunities for engaging in activities that are important to them or the need to manage difficult conversations with others (e.g., teachers). In addition, Aaliyah shared how things can be 'hard' and at times difficult, and having a personal impact: *“Yeah, with him, there's definitely some hard things because, I said he calls you names, takes your seat ... sometimes he just shouts at you” (Aaliyah).* The emotional impact of these experiences was shared including feeling “*angry” (Naomi)* with Aaliyah stating how their SDS *“gets on my nerves quite a lot” (Aaliyah)*.

Conversely, participants referred to the different qualities and personality traits that their SDS has, and which present in day-to-day life. Participants described their SDS as *“stubborn” (James), “cheekiest” (Priya)* and *“loving” (Elena).* There was a strong narrative that their SDS could positively influence their mood: *“He really helps your day ... Like if you're upset ... and you see him, you're instantly happy” (Elena).* Furthermore, having a SDS brought out qualities for participants that support them in daily life including understanding and patience.

3.4.4 Group Experiential Theme 4: Responsibilities

The final theme represents participants discussing responsibilities that they have and the impact that this has upon them. Participants spoke about different responsibilities and roles that they have including *“watching” (Zara), “helped” (Tom),* and *“teach” (Elena).* Some participants added to this narrative by sharing the amount of responsibility that they have as a sibling: *“It comes with a lot of responsibilities” (Aaliyah)*. Aaliyah’s use of ‘a lot’ indicates the degree of responsibility that she has. This is similar in Nia’s account where she shared that *“a lot was thrown on me” (Nia).* This suggests that responsibilities appear to be intertwined and come as part of having a SDS. In addition, they feel the weight of these responsibilities and perhaps not feeling able to ‘voice’ the impact this has.

For some participants, a narrative that responsibilities may resemble roles of other family members. As Elena stated positively: “... *I'm a second mum to him” (Elena).* Whilst some embrace these responsibilities, others may feel apprehensive about having these roles and this would be understandable given the amount of responsibility that a parent has, and how this would be a lot for an ISDS. The impact that this has is how to successfully navigate these responsibilities whilst continuing to be a sibling.

It was apparent that responsibilities may change and evolve over time: *“... I didn't help much because I was in year 4 when she was born, so I only started helping when I kind of got to high school” (Zara).* In addition, Nia discussed advocating for her SDS during health appointments, and it appeared that Nia was worried about this: *“how do I advocate for him without looking like the angry black woman” (Nia).* This suggests that whilst ISDS hold positions of advocacy for their siblings, they are also trying to navigate the psychological impact of worries that they have around being judged by professionals, and how these worries are connected to their REM identity.

3.5 Discussion

Through IPA, four GETs emerged with the aim of capturing the experiences of ISDS from REM communities. Each theme will be discussed in more detail including their links to existing literature and theory.

The GET of ‘relationships and connections’ the various associations that participants have with their SDS, family, friends, and support systems. This finding aligns with the microsystem proposed by Bronfenbrenner’s (1979) EST. Furthermore, participants identified the limited time they spend with their parents due to parents needing to support their SDS. In addition, limited time to spend with friends due to their SDS being present also. In support, Gray et al. (2023) found that from a parent perspective of the sibling experience, parents often gave more attention to the SDS and therefore little time was allocated to the sibling. In addition, parents acknowledged how the sibling’s friendships were impacted including the limited interactions with friends (Gray et al., 2023). Within this GET, participants reflected upon the varying degree of value in attending support groups for siblings including wanting more sibling groups. The potential need for more sibling support, and opportunities to connect with other siblings, was also found with individuals of siblings diagnosed with developmental disabilities (Arnold, Heller & Kramer, 2012). Importantly, this study found that ISDS from REM communities observe a lack of ethnic diversity in the support groups which in turn impacts on ability to form connections and relate with other group members. It seems fair to propose that this may lead to non-attendance which further contributes to marginalisation. Also, it was highlighted how cultural beliefs of a family may influence whether support is accessed for an ISDS. These findings are in line with wider literature for accessing services (Jacobs & Pentaris, 2021; Memon et al., 2016) which indicates the influence of cultural beliefs on seeking help and accessing support.

The GET of ‘understanding’ features the experiences of the participants’ varying levels of insight into their SDS’s diagnosis (and additional needs), as well as the varying degree of understanding and acceptance they experience others having for their SDS. In consideration of cultural factors, Paul et al. (2022) highlighted how there is a lack of understanding about disability within African and Asia-Pacific communities. In support, one participant reflected upon the varying degrees of understanding about DS, both intergenerationally and according to the country in which family members are born and subsequently raised in. However, it is important to note that this was the only participant to discuss this. Whilst EST (Bronfenbrenner, 1979) takes into consideration the systems around the individual including broader systemic influences (e.g., culture). The model gives rise to individual differences, due to the recognition of context and variation in systems which are experienced differently by individuals (Darling, 2007). Therefore, it seems reasonable to suggest that participants and their families may be more aware of western understandings surrounding DS and disability. An alternative explanation may be that participants might not be aware of the intergenerational understanding of DS and disability within their REM communities. Subsequently, this understanding has been shaped by the context of systems surrounding participants and their families.

The GET of ‘day-to-day life’ introduces the daily challenges and positives of having a SDS. For example, the participants spoke about experiencing disruptions in their daily life due to having a SDS. In contrast, participants also spoke of the positive day-to-day influences including personality traits (e.g., loving, sense of humour) that their SDS has. To add, participants noting how their SDS’s presence and determination to make them laugh has a positive impact on their own emotional wellbeing. These findings are supported by Graff et al. (2012) where participants noted challenges including their SDS’s behaviour which had a negative impact. In addition, identification of personality traits including ‘loving’ and their SDS being able to make others laugh was found within Graff et al. (2012). Participants also highlighted various emotions that arise from these experiences including anger which is consistent with previous research (Giallo et al., 2012; Skotko et al., 2011). It seems fair to propose that ISDS experience a range of daily events that influence emotion, and there may be a need for proactive support in consideration of the ISDS’s emotional wellbeing.

The final theme ‘responsibilities’ involved participants reporting adopting a carer role for their SDS, and with some suggesting that such responsibilities can be burdensome. This is consistent with existing literature on ISDS having responsibilities to support their sibling (Graff et al., 2012; Sutter, 2016), and how the weight of this responsibility can be experienced by some participants (Skotko et al., 2011). Advocacy was noted within the current study (for example attending healthcare appointments). Individuals participating in advocacy roles on behalf of their sibling are consistent with wider ID literature (Burke, Arnold & Owen, 2015). Importantly, the current study highlighted apprehensions around advocating and these apprehensions being connected with one’s REM identity.

3.5.1 Strengths, Limitations and Areas for Future Research

Previous research (Baumann et al., 2005; Graff et al., 2012; Skotko et al., 2011) has highlighted the lack of ethnic diversity with their samples, and so seeking the experiences of participants who identify from REM backgrounds is a strength of this study. It is important to note that this research highlights that some of the identified themes from ISDS from REM communities are similar when compared to previous research (Graff et al., 2012; Skotko et al., 2011; Sutter, 2016).

In consideration of the influence of ethnicity and culture, there was an overall lack of responses focusing on this area. One potential reason for this could be the ages of participants in the current study. Based upon Quintana’s (1994; 1998) model, most participants (n=6) could be categorised across the ‘literal understanding of ethnicity and race’ and ‘social and non-literal perspective of ethnicity’. Therefore, participants’ ability to discuss ethnicity and culture is dependent upon their level of understanding. It seems plausible to suggest that for younger participants their level of understanding ethnicity and race may have limited their responses in discussing aspects related to ethnicity alongside their experiences of being a sibling. A further reason could be attributed to acculturation and enculturation. Acculturation refers to the movement of people, meeting people from different cultural backgrounds, and subsequently change occurring in relation to the meeting of cultures (Sam & Berry, 2006). Enculturation refers to the process whereby whilst an individual is adapting to a new culture they will also hold on to the values of their culture of origin (Calzada et al., 2012). In addition, Parke et al. (2004) suggests that the degree of acculturation influences parenting. For participants within the current study, it seems plausible that in relation to acculturation they could be at least second generation, possibly third or fourth generation. Therefore, participants could be more assimilated to the dominant culture, and subsequently their experiences and narratives are reflective of this. A useful area for future research could be capturing additional contextual information regarding participants including length of residence in the country, and their generational background (for example the exploration of generations within the family, e.g., parents and grandparents, noting their birthplaces and length of residence in the country) to consider acculturation further. Acquiring this additional contextual information would enable a much greater understanding of how race, culture and ethnicity influences participants’ experiences. Furthermore, as the researcher identifies as White British, it seems probable that participants may have been answering in a culturally appropriate way that aligns with the dominant cultural group in the National Health Service (NHS; NHS England, 2023). Finally, considering the intersectionality of two aspects of identity ‘ethnicity’ and ‘disability’, and how perhaps the experiences of ISDS within the current study the bigger focus was sharing their experiences of their sibling and their DS diagnosis.

Whilst a homogenous sample is preferential for conducting IPA (Alase, 2017), it is acknowledged that there was a lack of homogeneity in the study’s sample, and this included age (ranged from 9-24 years old), gender (75% female), and ethnic diversity. Furthermore, there is a likelihood that experiences will be different for younger and older participants, with older participants having more to reflect upon. In addition, four participants have a younger SDS, and four participants have an older SDS, and so it is likely that their experiences may differ also. A strength of the current study was the qualitative methodology which enabled participants to be heard, and the richness of the data gathered (Howitt, 2010). Future research should continue to explore ISDS experiences using qualitative methodologies whilst also considering aspects of identity (e.g., gender, age, race/ethnicity) which would enable samples to be more homogenous. In addition, future research should consider talking to older siblings and gathering retrospective experiences to add to the sibling experience.

The current study highlighted that ISDS from REM communities may engage in advocacy roles for their sibling and that there may be fears and worries, including fears and worries in relation to their REM identity around doing so. Within Burke et al.’s (2015) study there was a lack of REM representation within ISDD participants (diagnoses included ID, Cerebral Palsy and DS). Therefore, future research may wish to explore the experiences of ISDS, or more broadly ISDD, from REM communities, to consider what are their experiences of advocating across settings including whether there are any enablers or barriers to advocating.

Finally, it is important to provide a theoretical critique on EST. Whilst the findings are supportive of the interactions that occur between the individual and their microsystem (e.g., parents, SDS, friends, support groups). In contrast, the findings appeared to be more in line with Vélez-Agosto et al. (2017) whereby culture is much more integrated. For example, ethnic-related activities which siblings do together and ethnic identities of group members in support groups, and the influences this has upon building mutual understanding. In addition, there was no links to the influence of other systems within the EST model (e.g., mesosystem, exosystem, and chronosystem) in responses. To add, Saxena and Adamsons (2013) highlights how there is a lack of research in relation to systems including the macrosystem and exosystem at explaining the role that these systems play in influencing the experiences of ISDD. Therefore, it could suggest that these systems are difficult to measure or explore. Future research should look to consider how to explore these broader systems and gain a more thorough understanding as to how these systems influence ISDS experiences, more broadly ISDD, and to build a greater evidence base for applying EST in sibling research.

3.5.2 Clinical Implications

The clinical implications include the impact of being a young carer including the psychological, emotional, and social impact from having a SDS, which may go unrecognised by parents perhaps due to assumed expectations of ISDS having a caring role or the needs of the SDS outweighing the needs of other CYP within the home. Therefore, it feels important for ISDS to have opportunities to feel heard and listened to, and for there to be encouragement of open dialogue within families. Carers Trust (2016) highlights the importance of professionals taking a whole family approach and including the timely identification of young carers so that mental health support can be sought early, and so for ISDS this feels particularly pertinent. In addition, accessing different forms of support outside of the family home. The findings have shown the potential need for sibling support, and the importance of support groups comprising ethnically diverse members including representation from a range of ethnic and cultural backgrounds in support groups and clinical settings. Also, it may be beneficial for professionals to consider other therapeutic interventions including systemic interventions (e.g., Family Therapy; Carr, 2012) to support ISDS and their families navigate the possible complexities.

In consideration of EDI, the Department for Education (DfE; 2024) advocates for elements of diversity (e.g., understanding of different cultural communities) to be taught within the early years. However, the DfE (2024) framework does not appear to extend to awareness of disability. Therefore, education and teaching which incorporates understanding of disability is crucial, and how EDI should be taught as one ages and develops. The significance of this would be that CYP have an understanding and awareness of aspects related to EDI (including race, ethnicity, and disability) much earlier, which in turn may help to increase understanding and reduce stigma and discrimination.

Finally, there is the need for NHS professionals, teams, and services to ensure they have the cultural understanding, awareness, and sensitivity to support families who identity from REM backgrounds. One way of doing this is to gain a greater understanding about the community in which services serve (Stubbe, 2020). The implications of building cultural humility, within the NHS, may help to reduce health disparities in which people experience

(Schiavo, 2023) as well as encourage and support engagement of families who identify from REM communities.

3.6 Conclusion

This study has highlighted the perspectives of ISDS from REM communities including how their needs are similar to other ISDS across different ethnic and cultural backgrounds. However, ethnicity and cultural influences can also form part of these experiences including culturally related activities, familial events, and cultural differences in understanding DS. There were also the experiences of a lack of ethnic diversity in support groups and difficulties in advocating for their SDS. Due to the novel nature of this study, future research is needed to explore the perspectives of ISDS from REM communities to build the research-base and to have a much greater understanding and awareness of how being a sibling is experienced by ISDS across life stages and across REM communities. Furthermore, clinical implications should be considered and implemented to raise understanding of DS, increase support for ISDS from REM communities, as well as the need for cultural humility training to be delivered across the NHS.

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Appendices

Appendix A: Submission Guidelines ‘Research in Developmental Disabilities’

- **About the journal**
- **Aims and scope**

Research In Developmental Disabilities is an international journal aimed at publishing original research of an interdisciplinary nature that has a direct bearing on the understanding or remediation of problems associated with developmental disabilities. Articles will be primarily empirical studies, although an occasional position paper or review will be accepted. The aim of the journal will be to publish articles on all aspects of developmental difficulties using rigorous research methods. Our aim is to publish the best available and most current research possible.

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3. Final approval of the version to be submitted.

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- Statement: During the preparation of this work the author(s) used [NAME TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the published article.

The declaration does not apply to the use of basic tools, such as tools used to check grammar, spelling and references. If you have nothing to disclose, you do not need to add a statement.

Please read Elsevier’s author policy on the use of generative AI and AI-assisted technologies, which can be found in our GenAI Policies for journals.

Please note: to protect authors’ rights and the confidentiality of their research, this journal does not currently allow the use of generative AI or AI-assisted technologies such as ChatGPT or similar services by reviewers or editors in the peer review and manuscript evaluation process, as is stated in our GenAI Policies for journals. We are actively evaluating compliant AI tools and may revise this policy in the future.

- **Preprints**
- **Preprint sharing**

Authors may share preprints in line with Elsevier's article sharing policy. Sharing preprints, such as on a preprint server, will not count as prior publication.

We advise you to read our policy on multiple, redundant or concurrent publication.

- **Free preprint posting on SSRN**

In support of open science this journal offers authors a free preprint posting service on SSRN to ensure early registration and dissemination of research and facilitate early citations and collaboration. Posting to SSRN is subject to SSRN's standard checks.

You will be provided with the option to release your manuscript on SSRN during the submission process. Agreeing to this option will have no effect on the editorial process or outcome, and your manuscript will remain publicly available and free to read on SSRN whether our editors accept or reject your manuscript.

You will receive an email when your preprint is posted online on SSRN and a Digital Object Identifier (DOI) is assigned.

Corresponding authors must seek approval from all co-authors before agreeing to release a manuscript publicly on SSRN.

We advise you to read about SSRN, including the SSRN Terms of Use and SSRN FAQs before selecting this option.

- **Use of inclusive language**

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Authors should ensure their work uses inclusive language throughout and contains nothing which might imply one individual is superior to another on the grounds of:

- age
- gender
- race
- ethnicity
- culture
- sexual orientation
- disability or health condition

We recommend avoiding the use of descriptors about personal attributes unless they are relevant and valid. Write for gender neutrality with the use of plural nouns ("clinicians, patients/clients") as default. Wherever possible, avoid using "he, she," or "he/she."

No assumptions should be made about the beliefs of readers and writing should be free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions.

These guidelines are meant as a point of reference to help you identify appropriate language but are by no means exhaustive or definitive.

- **Reporting sex- and gender-based analyses**

There is no single, universally agreed-upon set of guidelines for defining sex and gender. We offer the following guidance:

- Sex and gender-based analyses (SGBA) should be integrated into research design when research involves or pertains to humans, animals or eukaryotic cells. This should be done in accordance with any requirements set by funders or sponsors and best practices within a field.
- Sex and/or gender dimensions of the research should be addressed within the article or declared as a limitation to the generalizability of the research.
- Definitions of sex and/or gender applied should be explicitly stated to enhance the precision, rigor and reproducibility of the research and to avoid ambiguity or conflation of terms and the constructs to which they refer.

We advise you to read the Sex and Gender Equity in Research (SAGER) guidelines and the SAGER checklist (PDF) on the EASE website, which offer systematic approaches to the use of sex and gender information in study design, data analysis, outcome reporting and research interpretation.

For further information we suggest reading the rationale behind and recommended use of the SAGER guidelines.

Definitions of sex and/or gender

We ask authors to define how sex and gender have been used in their research and publication. Some guidance:

- Sex generally refers to a set of biological attributes that are associated with physical and physiological features such as chromosomal genotype, hormonal levels, internal and external anatomy. A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth") and is in most cases based solely on the visible external anatomy of a newborn. In reality, sex categorizations include people who are intersex/have differences of sex development (DSD).
- Gender generally refers to socially constructed roles, behaviors and identities of women, men and gender-diverse people that occur in a historical and cultural context and may vary across societies and over time. Gender influences how people view themselves and each other, how they behave and interact and how power is distributed in society.
- **Jurisdictional claims**

Elsevier respects the decisions taken by its authors as to how they choose to designate territories and identify their affiliations in their published content. Elsevier's policy is to take a neutral position with respect to territorial disputes or jurisdictional claims, including, but not limited to, maps and institutional affiliations. For journals that Elsevier publishes on behalf of a third party owner, the owner may set its own policy on these issues.

- Maps: Readers should be able to locate any study areas shown within maps using common mapping platforms. Maps should only show the area actually studied and authors should not include a location map which displays a larger area than the bounding box of the study area. Authors should add a note clearly stating that "*map lines delineate study areas and do not necessarily depict accepted national boundaries*”. During the review process, Elsevier’s editors may request authors to change maps if these guidelines are not followed.
- Institutional affiliations: Authors should use either the full, standard title of their institution or the standard abbreviation of the institutional name so that the institutional name can be independently verified for research integrity purposes.
- **Writing and formatting**
- **File format**

We ask you to provide editable source files for your entire submission (including figures, tables and text graphics). Some guidelines:

- Save files in an editable format, using the extension .doc/.docx for Word files and .tex for LaTeX files. A PDF is not an acceptable source file.
- Lay out text in a single-column format.
- Remove any strikethrough and underlined text from your manuscript, unless it has scientific significance related to your article.
- Use spell-check and grammar-check functions to avoid errors.

We advise you to read our Step-by-step guide to publishing with Elsevier.

- **Double anonymized peer review**

This journal follows a double anonymized review process which means author identities are concealed from reviewers and vice versa.To facilitate the double anonymized review process, we ask that you provide your title page (including author details) and anonymized manuscript (excluding author details) separately in your submission.

The title page should include:

- Article title
- Author name(s)

- Affiliation(s)
- Acknowledgements
- Declaration of Interest statement
- Corresponding author address (full address is required)
- Corresponding author email address

The anonymized manuscript should contain the main body of your paper including:

- References
- Figures
- Tables

It is important that your anonymized manuscript does not contain any identifying information such as author names or affiliations.

Read more about peer review.

- **Title page**

You are required to include the following details in the title page information:

- Article title. Article titles should be concise and informative. Please avoid abbreviations and formulae, where possible, unless they are established and widely understood, e.g. DNA.
- Author names. Provide the given name(s) and family name(s) of each author. The order of authors should match the order in the submission system. Carefully check that all names are accurately spelled. If needed, you can add your name between parentheses in your own script after the English transliteration.
- Affiliations. Add affiliation addresses, referring to where the work was carried out, below the author names. Indicate affiliations using a lower-case superscript letter immediately after the author's name and in front of the corresponding address. Ensure that you provide the full postal address of each affiliation, including the country name and, if available, the email address of each author.
- Corresponding author. Clearly indicate who will handle correspondence for your article at all stages of the refereeing and publication process and also post-publication. This responsibility includes answering any future queries about your results, data, methodology and materials. It is important that the email address and contact details of your corresponding author are kept up to date during the submission and publication process.

- Present/permanent address. If an author has moved since the work described in your article was carried out, or the author was visiting during that time, a "present address" (or "permanent address") can be indicated by a footnote to the author's name. The address where the author carried out the work must be retained as their main affiliation address. Use superscript Arabic numerals for such footnotes.

- **Abstract**

You are required to provide a concise and factual abstract which does not exceed 250 words. The abstract should briefly state the purpose of your research, principal results and major conclusions. Some guidelines:

- Abstracts must be able to stand alone as abstracts are often presented separately from the article.
- Avoid references. If any are essential to include, ensure that you cite the author(s) and year(s).
- Avoid non-standard or uncommon abbreviations. If any are essential to include, ensure they are defined within your abstract at first mention.

- **Structured abstract**

A structured abstract, by means of appropriate headings, should provide the context or background for your research. Some guidelines:

- State the purpose of your research.
- Outline basic procedures followed such as the selection of study subjects or laboratory animals and observational and analytical methods.
- Include your main findings, providing specific effect sizes and their statistical significance, if possible, and your principal conclusions.
- Emphasize new and important aspects of your study or observations.

- **Keywords**

You are required to provide 1 to 7 keywords for indexing purposes. Keywords should be written in English. Please try to avoid keywords consisting of multiple words (using "and" or "of").

We recommend that you only use abbreviations in keywords if they are firmly established in the field.

- **Highlights**

You are required to provide article highlights at submission.

Highlights are a short collection of bullet points that should capture the novel results of your research as well as any new methods used during your study. Highlights will help increase the discoverability of your article via search engines. Some guidelines:

- Submit highlights as a separate editable file in the online submission system with the word "highlights" included in the file name.
- Highlights should consist of 3 to 5 bullet points, each a maximum of 85 characters, including spaces.

We encourage you to view example article highlights and read about the benefits of their inclusion.

- **Graphical abstract**

You are encouraged to provide a graphical abstract at submission.

The graphical abstract should summarize the contents of your article in a concise, pictorial form which is designed to capture the attention of a wide readership. A graphical abstract will help draw more attention to your online article and support readers in digesting your research. Some guidelines:

- Submit your graphical abstract as a separate file in the online submission system.
- Ensure the image is a minimum of 531 x 1328 pixels (h x w) or proportionally more and is readable at a size of 5 x 13 cm using a regular screen resolution of 96 dpi.
- Our preferred file types for graphical abstracts are TIFF, EPS, PDF or MS Office files.

We encourage you to view example graphical abstracts and read about the benefits of including them.

- **Math formulae**
- Submit math equations as editable text, not as images.
- Present simple formulae in line with normal text, where possible.
- Use the solidus (/) instead of a horizontal line for small fractional terms such as X/Y.
- Present variables in italics.
- Denote powers of e by exp.

- Display equations separately from your text, numbering them consecutively in the order they are referred to within your text.
- **Tables**

Tables must be submitted as editable text, not as images. Some guidelines:

- Place tables next to the relevant text or on a separate page(s) at the end of your article.
- Cite all tables in the manuscript text.
- Number tables consecutively according to their appearance in the text.
- Please provide captions along with the tables.
- Place any table notes below the table body.
- Avoid vertical rules and shading within table cells.

We recommend that you use tables sparingly, ensuring that any data presented in tables is not duplicating results described elsewhere in the article.

- **Figures, images and artwork**

Figures, images, artwork, diagrams and other graphical media must be supplied as separate files along with the manuscript. We recommend that you read our detailed artwork and media instructions. Some excerpts:

When submitting artwork:

- Cite all images in the manuscript text.
- Number images according to the sequence they appear within your article.
- Submit each image as a separate file using a logical naming convention for your files (for example, Figure_1, Figure_2 etc).
- Please provide captions for all figures, images, and artwork.
- Text graphics may be embedded in the text at the appropriate position. If you are working with LaTeX, text graphics may also be embedded in the file.
- **Artwork formats**

When your artwork is finalized, "save as" or convert your electronic artwork to the formats listed below taking into account the given resolution requirements for line drawings, halftones, and line/halftone combinations:

- Vector drawings: Save as EPS or PDF files embedding the font or saving the text as "graphics."

- Color or grayscale photographs (halftones): Save as TIFF, JPG or PNG files using a minimum of 300 dpi (for single column: min. 1063 pixels, full page width: 2244 pixels).
- Bitmapped line drawings: Save as TIFF, JPG or PNG files using a minimum of 1000 dpi (for single column: min. 3543 pixels, full page width: 7480 pixels).
- Combinations bitmapped line/halftones (color or grayscale): Save as TIFF, JPG or PNG files using a minimum of 500 dpi (for single column: min. 1772 pixels, full page width: 3740 pixels).

Please do not submit:

- files that are too low in resolution (for example, files optimized for screen use such as GIF, BMP, PICT or WPG files).
- disproportionally large images compared to font size, as text may become unreadable.
- **Figure captions**

All images must have a caption. A caption should consist of a brief title (not displayed on the figure itself) and a description of the image. We advise you to keep the amount of text in any image to a minimum, though any symbols and abbreviations used should be explained.

Provide captions in a separate file.

- **Color artwork**

If you submit usable color figures with your accepted article, we will ensure that they appear in color online.

Please ensure that color images are accessible to all, including those with impaired color vision. Learn more about color and web accessibility.

- **Generative AI and Figures, images and artwork**

Please read our policy on the use of generative AI and AI-assisted tools in figures, images and artwork, which can be found in Elsevier's GenAI Policies for Journals. This policy states:

- We do not permit the use of Generative AI or AI-assisted tools to create or alter images in submitted manuscripts.
- The only exception is if the use of AI or AI-assisted tools is part of the research design or methods (for example, in the field of biomedical imaging). If this is the case, such use must be described in a reproducible manner in the methods section, including the name of the model or tool, version and extension numbers, and manufacturer.

- The use of generative AI or AI-assisted tools in the production of artwork such as for graphical abstracts is not permitted. The use of generative AI in the production of cover art may in some cases be allowed, if the author obtains prior permission from the journal editor and publisher, can demonstrate that all necessary rights have been cleared for the use of the relevant material, and ensures that there is correct content attribution.

- **Supplementary material**

We encourage the use of supplementary materials such as applications, images and sound clips to enhance research. Some guidelines:

- Supplementary material should be accurate and relevant to the research.
- Cite all supplementary files in the manuscript text.
- Submit supplementary materials at the same time as your article. Be aware that all supplementary materials provided will appear online in the exact same file type as received. These files will not be formatted or typeset by the production team.
- Include a concise, descriptive caption for each supplementary file describing its content.
- Provide updated files if at any stage of the publication process you wish to make changes to submitted supplementary materials.
- Do not make annotations or corrections to a previous version of a supplementary file.
- Switch off the option to track changes in Microsoft Office files. If tracked changes are left on, they will appear in your published version.

- **Video**

This journal accepts video material and animation sequences to support and enhance your scientific research. We encourage you to include links to video or animation files within articles. Some guidelines:

- When including video or animation file links within your article, refer to the video or animation content by adding a note in your text where the file should be placed.
- Clearly label files ensuring the given file name is directly related to the file content.
- Provide files in one of our recommended file formats. Files should be within our preferred maximum file size of 150 MB per file, 1 GB in total.

- Provide "stills" for each of your files. These will be used as standard icons to personalize the link to your video data. You can choose any frame from your video or animation or make a separate image.
- Provide text (for both the electronic and the print version) to be placed in the portions of your article that refer to the video content. This is essential text, as video and animation files cannot be embedded in the print version of the journal.

We publish all video and animation files supplied in the electronic version of your article.

For more detailed instructions, we recommend that you read our guidelines on submitting video content to be included in the body of an article.

- **Research data**

We are committed to supporting the storage of, access to and discovery of research data, and our research data policy sets out the principles guiding how we work with the research community to support a more efficient and transparent research process.

Research data refers to the results of observations or experimentation that validate research findings, which may also include software, code, models, algorithms, protocols, methods and other useful materials related to the project.

Please read our guidelines on sharing research data for more information on depositing, sharing and using research data and other relevant research materials.

Research data deposit, citation and linkin

For this journal **Option C** instructions from our research data guidelines apply. This means you are **required** to:

- Deposit your research data in a relevant data repository.
- Cite and link to this dataset in your article.
- If this is not possible, make a statement explaining why research data cannot be shared.
- **Data statement**

To foster transparency, you are required to state the availability of any data at submission.

Ensuring data is available may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you can state the reason why (e.g., your research data includes sensitive or confidential information such as patient data) during the submission process. This statement will appear with your published article on ScienceDirect.

Read more about the importance and benefits of providing a data statement.

- **Data linking**

Linking to the data underlying your work increases your exposure and may lead to new collaborations. It also provides readers with a better understanding of the described research.

If your research data has been made available in a data repository there are a number of ways your article can be linked directly to the dataset:

- Provide a link to your dataset when prompted during the online submission process.
- For some data repositories, a repository banner will automatically appear next to your published article on ScienceDirect.
- You can also link relevant data or entities within the text of your article through the use of identifiers. Use the following format: Database: 12345 (e.g. TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

Learn more about linking research data and research articles in ScienceDirect.

- **Research Elements**

This journal enables the publication of research objects (e.g. data, methods, protocols, software and hardware) related to original research in Elsevier's Research Elements journals.

Research Elements are peer-reviewed, open access journals which make research objects findable, accessible and reusable. By providing detailed descriptions of objects and their application with links to the original research article, your research objects can be placed into context within your article.

You will be alerted during submission to the opportunity to submit a manuscript to one of the Research Elements journals. Your Research Elements article can be prepared by you, or by one of your collaborators.

- **Article structure**
- **Article sections**
- Divide your article into clearly defined and numbered sections. Number subsections 1.1 (then 1.1.1, 1.1.2, ...), then 1.2, etc.
- Use the numbering format when cross-referencing within your article. Do not just refer to "the text."
- You may give subsections a brief heading. Headings should appear on a separate line.

- Do not include the article abstract within section numbering.

- **Theory and calculation**

The theory section should lay the foundation for further work by extending the background you provided in the introduction to your article. The calculation section should represent a practical development from a theoretical basis.

- **Glossary**

Please provide definitions of field-specific terms used in your article, in a separate list.

- **Footnotes**

We advise you to use footnotes sparingly. If you include footnotes in your article, ensure that they are numbered consecutively.

You may use system features that automatically build footnotes into text. Alternatively, you can indicate the position of footnotes within the text and present them in a separate section at the end of your article.

- **Acknowledgements**

Include any individuals who provided you with help during your research, such as help with language, writing or proof reading, in the acknowledgements section. Include acknowledgements **only** in the **title page** since this journal follows a double anonymized peer review process. Do not add it as a footnote to your title.

- **Author contributions: CRediT**

Corresponding authors are required to acknowledge co-author contributions using CRediT (Contributor Roles Taxonomy) roles:

- Conceptualization
- Data curation
- Formal analysis
- Funding acquisition
- Investigation
- Methodology
- Project administration
- Resources

- Software
- Supervision
- Validation
- Visualization
- Writing – original draft
- Writing – review and editing

Not all CRediT roles will apply to every manuscript and some authors may contribute through multiple roles.

We advise you to read more about CRediT and view an example of a CRediT author statement.

- **Funding sources**

Authors must disclose any funding sources who provided financial support for the conduct of the research and/or preparation of the article. The role of sponsors, if any, should be declared in relation to the study design, collection, analysis and interpretation of data, writing of the report and decision to submit the article for publication. If funding sources had no such involvement this should be stated in your submission.

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants, scholarships and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

- **Appendices**

We ask you to use the following format for appendices:

- Identify individual appendices within your article using the format: A, B, etc.
- Give separate numbering to formulae and equations within appendices using formats such as Eq. (A.1), Eq. (A.2), etc. and in subsequent appendices, Eq. (B.1), Eq. (B. 2) etc. In a similar way, give separate numbering to tables and figures using formats such as Table A.1; Fig. A.1, etc.
- **References**
- **References within text**

Any references cited within your article should also be present in your reference list and vice versa. Some guidelines:

- References cited in your abstract must be given in full.
- We recommend that you do not include unpublished results and personal communications in your reference list, though you may mention them in the text of your article.
- Any unpublished results and personal communications included in your reference list must follow the standard reference style of the journal. In substitution of the publication date add "unpublished results" or "personal communication."
- References cited as "in press" imply that the item has been accepted for publication.

Linking to cited sources will increase the discoverability of your research.

Before submission, check that all data provided in your reference list are correct, including any references which have been copied. Providing correct reference data allows us to link to abstracting and indexing services such as Scopus, Crossref and PubMed. Any incorrect surnames, journal or book titles, publication years or pagination within your references may prevent link creation.

We encourage the use of Digital Object Identifiers (DOIs) as reference links as they provide a permanent link to the electronic article referenced.

- **Reference style**

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the *Publication Manual of the American Psychological Association, Seventh Edition (2020)* ISBN 978-1-4338-3215-4.

The reference list should be arranged alphabetically and then chronologically. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Examples:

Reference to a journal publication:

Van der Geer, J., Handgraaf T., & Lupton, R. A. (2020). The art of writing a scientific article. J*ournal of Scientific Communications, 163*, 51–59. https://doi.org/10.1016/j.sc.2020.00372.

Reference to a journal publication with an article number:

Van der Geer, J., Handgraaf, T., & Lupton, R. A. (2022). The art of writing a scientific article. *Heliyon, 19,* Article e00205. https://doi.org/10.1016/j.heliyon.2022.e00205.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style (4th ed.)*. Longman (Chapter 4).

Reference to a chapter in a book:

Mettam, G. R., & Adams, L. B. (2020). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). E-Publishing Inc.

Reference to a website:

Powertech Systems. (2022). Lithium-ion vs lead-acid cost analysis. Retrieved from *http://www.powertechsystems.eu/home/tech-corner/lithium-ion-vs-lead-acid-cost-analysis/.* Accessed January 6, 2022.

Reference to a dataset:

Oguro, M., Imahiro, S., Saito, S., & Nakashizuka, T. (2015). Mortality data for Japanese oak wilt disease and surrounding forest compositions [dataset]. *Mendeley Data, v1.* https://doi.org/10.17632/xwj98nb39r.1.

Reference to a conference paper or poster presentation:

Engle, E.K., Cash, T.F., & Jarry, J.L. (2019, November). *The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales.* Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.

Reference to software:

Coon, E., Berndt, M., Jan, A., Svyatsky, D., Atchley, A., Kikinzon, E., Harp, D., Manzini, G., Shelef, E., Lipnikov, K., Garimella, R., Xu, C., Moulton, D., Karra, S., Painter, S., Jafarov, E., & Molins, S. (2020). *Advanced Terrestrial Simulator (ATS) (Version 0.88) [Computer software].* Zenodo. https://doi.org/10.5281/zenodo.3727209.

- **Web references**

When listing web references, as a minimum you should provide the full URL and the date when the reference was last accessed. Additional information (e.g. DOI, author names, dates or reference to a source publication) should also be provided, if known.

You can list web references separately under a new heading directly after your reference list or include them in your reference list.

- **Data references**

We encourage you to cite underlying or relevant datasets within article text and to list data references in the reference list.

When citing data references, you should include:

- author name(s)
- dataset title
- data repository
- version (where available)
- year
- global persistent identifier

Add [dataset] immediately before your reference. This will help us to properly identify the dataset. The [dataset] identifier will not appear in your published article.

- **Preprint references**

We ask you to mark preprints clearly. You should include the word "preprint" or the name of the preprint server as part of your reference and provide the preprint DOI.

Where a preprint has subsequently become available as a peer-reviewed publication, use the formal publication as your reference.

If there are preprints that are central to your work or that cover crucial developments in the topic, but they are not yet formally published, you may reference the preprint.

- **Reference management software**

Most Elsevier journals have their reference template available in popular reference management software products. These include products that support Citation Style Language (CSL) such as Mendeley Reference Manager.

If you use a citation plug-in from these products, select the relevant journal template and all your citations and bibliographies will automatically be formatted in the journal style. We advise you to remove all field codes before submitting your manuscript to any reference management software product.

If a template is not available for this journal, follow the format given in examples in the reference style section of this Guide for Authors.

- **Submitting your manuscript**
- **Submission checklist**

Before completing the submission of your manuscript, we advise you to read our submission checklist:

- One author has been designated as the corresponding author and their full contact details (email address, full postal address and phone numbers) have been provided.
- All files have been uploaded, including keywords, figure captions and tables (including a title, description and footnotes) included.
- Spelling and grammar checks have been carried out.
- All references in the article text are cited in the reference list and vice versa.
- Permission has been obtained for the use of any copyrighted material from other sources, including the Web.
- For open access articles, all authors understand that they are responsible for payment of the article publishing charge (APC) if the manuscript is accepted. Payment of the APC may be covered by the corresponding author's institution, or the research funder.

- **After receiving a final decision**
- **Article Transfer Service**

If your manuscript is more suitable for an alternative Elsevier journal, you may receive an email asking you to consider transferring your manuscript via the Elsevier Article Transfer Service.

The recommendation could come from the journal editor, a dedicated in-house scientific managing editor, a tool-assisted recommendation or a combination.

If you agree with the recommendation, your manuscript will be transferred and independently reviewed by the editors of the new journal. You will have the opportunity to make revisions, if necessary, before the submission is complete at the destination journal.

- **Publishing agreement**

Authors will be asked to complete a publishing agreement after acceptance. The corresponding author will receive a link to the online agreement by email. We advise you to read Elsevier's policies related to copyright to learn more about our copyright policies and your, and your employer’s/institution’s, additional rights for subscription and open access articles.

- **License options**

Authors will be offered open access user license options which will determine how you, and third parties, can reuse your open access article. We advise that you review these options and any funding body license requirements before selecting a license option.

- **Open access**

We refer you to our open access information page to learn about open access options for this journal.

- **Permission for copyrighted works**

If excerpts from other copyrighted works are included in your article, you must obtain written permission from the copyright owners and credit the source(s) within your article using Elsevier’s permission request and license form (Word).

- **Proof correction**

To ensure a fast publication process we will ask you to provide proof corrections within two days.

Corresponding authors will be sent an email which includes a link to our online proofing system, allowing annotation and correction of proofs online. The environment is similar to Word. You can edit text, comment on figures and tables and answer questions raised by our copy editor. Our web-based proofing service ensures a faster and less error-prone process.

You can choose to annotate and upload your edits on the PDF version of your article, if preferred. We will provide you with proofing instructions and available alternative proofing methods in our email.

The purpose of the proof is to check the typesetting, editing, completeness and correctness of your article text, tables and figures. Significant changes to your article at the proofing stage will only be considered with approval of the journal editor.

- **Share Link**

A customized Share Link, providing 50 days free access to the final published version of your article on ScienceDirect, will be sent by email to the corresponding author. The Share Link can be used to share your article on any communication channel, such as by email or on social media.

A Share Link will not be provided if your article is published open access. The final published version of your open access article will be openly available on ScienceDirect and can be shared through the article DOI link.

- **Responsible sharing**

We encourage you to share and promote your article to give additional visibility to your work, enabling your paper to contribute to scientific progress and foster the exchange of scientific developments within your field. Read more about how to responsibly share and promote your article.

- **Resources for authors**
- **Elsevier Researcher Academy**

If you would like help to improve your submission or navigate the publication process, support is available via Elsevier Researcher Academy.

Elsevier Researcher Academy offers free e-learning modules, webinars, downloadable guides and research writing and peer review process resources.

- **Language and editing services**

We recommend that you write in American or British English but not a combination of both.

If you feel the English language in your manuscript requires editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English, you may wish to use the English Language Editing service provided by Elsevier's Author Services.

- **Getting help and support**
- **Author support**

We recommend that you visit our Journal Article Publishing Support Center if you have questions about the editorial process or require technical support for your submission. Some popular FAQs:

- How can I track the status of my submitted article?
- When will my article be published?

Appendix B: Quality Checklists (AACODS & MMAT)

AACODS Checklist:

https://fac.flinders.edu.au/dspace/api/core/bitstreams/e94a96eb-0334-4300-8880-c836d4d9a676/content

MMAT:

http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT__criteria-manual_2018-08-01_ENG.pdf

Appendix C: Quality Assessment Tables

AACODS Checklist

Author/Year/ Country	Authority	Accuracy	Coverage	Objectivity	Date	Significance	Comments
Hunter (2005)	Yes	Yes	Yes	Yes	Yes	Yes	The study had clear aims and methodology. In addition, the study considered the researcher, their role and identity within the research process. Acknowledgement to bias.
Nadjari (2023)	Yes	Yes	Yes	Can't tell	Yes	Yes	Clear aims, rationale and methodology. Transparency around limitations of methodology. Some information given about objectivity including reflexive log however no additional information the researcher's identity/role.
Segev & Hellman (2001)	Yes	Yes	Yes	Yes	Yes	Yes	Indication of educational level and establishment. Citation from one other. Clear purpose of study and rationale for methodology. Limitations and parameters of study identified. Researcher identity partially highlighted as well as procedures to manage biases e.g., participant checks of analysis.

Mixed Methods Assessment Tool (MMAT):

Qualitative Studies:

Screening Items: S1. Are there clear research questions S2. Do the collected data allow to address the research questions?

Qualitative items: 1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3 Are the findings adequately derived from the data? 1.4 Is the interpretation of results sufficiently substantiated by the data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

Author/Year	**S1.**	**S2.**	**1.1.**	**1.2.**	**1.3**	**1.4**	**1.5.**	**Comments**
Adenan et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study satisfied all qualitative criteria within the MMAT. Authors stipulated their epistemological positioning as well as rationale for using qualitative methodology. Detailed descriptions of data collection and data analysis. Quotes utilised within themes generated and relevancy of these. There appeared to be coherence throughout process.
Chadwick & Fullwood (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study met all qualitative criteria within the MMAT. Authors defined their epistemological positioning. Description was given as to how data was collected included method of data collection and analysis. Quotes related to themes and these typically were captured within figures within the paper. Coherence appeared to be apparent throughout.
Dolva et al. (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	All qualitative criteria was met. Authors outlined their approach and rationale behind their chosen approach which fits the nature of the research question. Data collection was justified and explained

								within the paper. Quotes were used to support the categories identified and reference to data sources. There appeared to be a logical coherence throughout the paper.
Downs et al. (2013)	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	The study met 4/5 qualitative criteria. Whilst author discussed process for analysing data it was not clear as to ‘exact’ analytic method used. Participant quotes were used and these related to themes.
Faragher et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study satisfied all qualitative criteria. Epistemological positioning was referred to. Authors gave a detailed description as to how data was collected and analysis with reference to methods used. Interpretation of themes including participant quotes and links to data source included. There appeared to be coherence throughout.
Foley et al. (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study met all the qualitative criteria. Whilst an epistemological position was not outlined by the authors, authors discussed rationale to why qualitative data collection include specific method type was chosen. The authors highlighted modifications that were made to support the needs of the participants and how qualitative data was collected.
Geiger (2023)	Yes	Yes	Yes	Yes	Yes	Can’t tell	Can’t tell	The study met 3/5 qualitative criteria. The author discussed modifications within the methodology to support the participants. When discussing themes, the author used more interpretation as opposed to specific quotes from participants.

Groves, Rayner & Muncer (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study met all the qualitative criteria. The authors highlighted qualitative approach taken within the research. When discussing themes, authors utilised quotes and interpretations when describing themes derived. It appeared that there was coherence between data, analysis and interpretation.
Jevne, Kollstad & Dolva (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study met all the qualitative criteria. The authors discussed how data was collected and the analysis method chosen. In addition, modifications made during the data collection process e.g., interviews taking place in preferred settings for participants. The authors referred to, with example of extract of analysis, how analysis was completed. Quotes were utilised when discussing the themes.
Li et al (2006)	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	The study satisfied 4/5 of the qualitative criteria. The authors discussed qualitative methods used in regard to data collection and data analysis used. Participant quotes were more than adequately used when discussing themes. There was perhaps a lack of author interpretation when discuss themes.
Santoro et al. (2023a)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study met all the qualitative criteria. Authors discussed data collection and data analysis methods used. Authors discussed modifications that were made within the data collection method also. Authors used an adequate amount of participant quotes to justify themes, and this was balanced with author interpretation/discussion.
Scott et al. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The study satisfied all qualitative criteria. Authors discussed methods for data collection and data analysis. Transparency was made around modifications made in data collection. There appeared to be

								coherence from data sources to interpretation with authors making links to existing theory and research.
Takataya et al (2022)	Yes	Yes	Yes	Can’t tell	Can’t tell	Yes	Can’t tell	The study met 2/5 qualitative criteria. There was limited information as to how data was collected and subsequently analyzed, and so more discussion regarding analytical method would have been beneficial and this is linked to understanding how themes emerged.
Thompson et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	The authors provided a rationale for the qualitative approach within the study and how this links to the research aims. There was comprehensive commentary from the authors as to how data was collected and analysed. Authors provided a table of quotes from participants which supported themes derived.

Mixed Methods Studies:

Screening Items: S1. Are there clear research questions S2. Do the collected data allow to address the research questions?

Qualitative items: 1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3 Are the findings adequately derived from the data? 1.4 Is the interpretation of results sufficiently substantiated by the data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

Quantitative Descriptive: 4.1 Is the sampling strategy relevant to address the research question? 4.2 Is the sample representative of the target population? 4.3 Are the measurements appropriate? 4.4 Is the risk of nonresponse bias low 4.5 Is the statistical analysis appropriate to answer the research question?

Mixed Methods: 5.1 Is there an adequate rationale for using a mixed methods design to address the research question? 5.2 Are the different components of the study effectively integrated to answer the research question? 5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted? 5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? 5.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Key: Yes

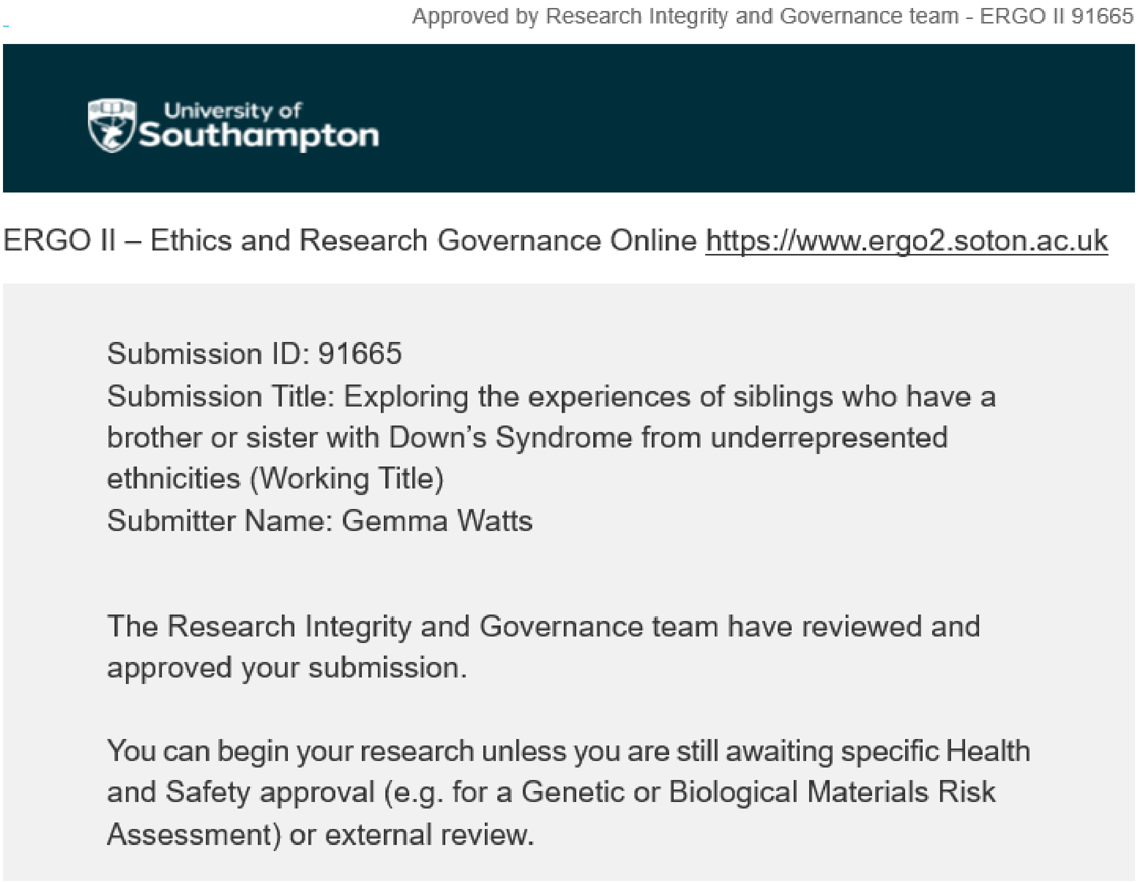
Can’t tell

No

Author/Year	*1*	*2*	*1.1.*	*1.2*	*1.3*	*1.4*	*1.5*	*4.1*	*4.2*	*4.3*	*4.4*	*4.5*	*5.1*	*5.2*	*5.3*	*5.4*	*5.5*	**Comments**
Cunningham & Glenn (2004)	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟥	🟩	🟨	🟨	🟨	There appeared to be no clear rationale as to why this study was mixed methods. Whilst there was integration of qualitative and quantitative data, it was perhaps unclear at times how they were interpreted together, possibly loosely through categories identified within the study e.g., awareness categories.
Glenn & Cunningham (2004)	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟥	🟩	🟨	🟨	🟨	Similar appraisal as paper above. Both studies were part of a much larger study. No indication of a rationale. There was integration of qualitative and quantitative data however it was

	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟥	🟩	🟨	🟨	🟨	unclear at times as to how they linked and are interpreted together.
Santoro et al. (2023b)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟩	🟩	🟩	🟨	🟨	🟨	The authors highlighted a clear rationale as to why this study was mixed methods. The study satisfied all qualitative criteria. Whilst the authors brought qualitative and quantitative results together, there was perhaps a lack of integrated interpretation.

Appendix D: ERGO Ethical Approval



Approved by Research Integrity and Governance team - ERGO II 91665

University of Southampton

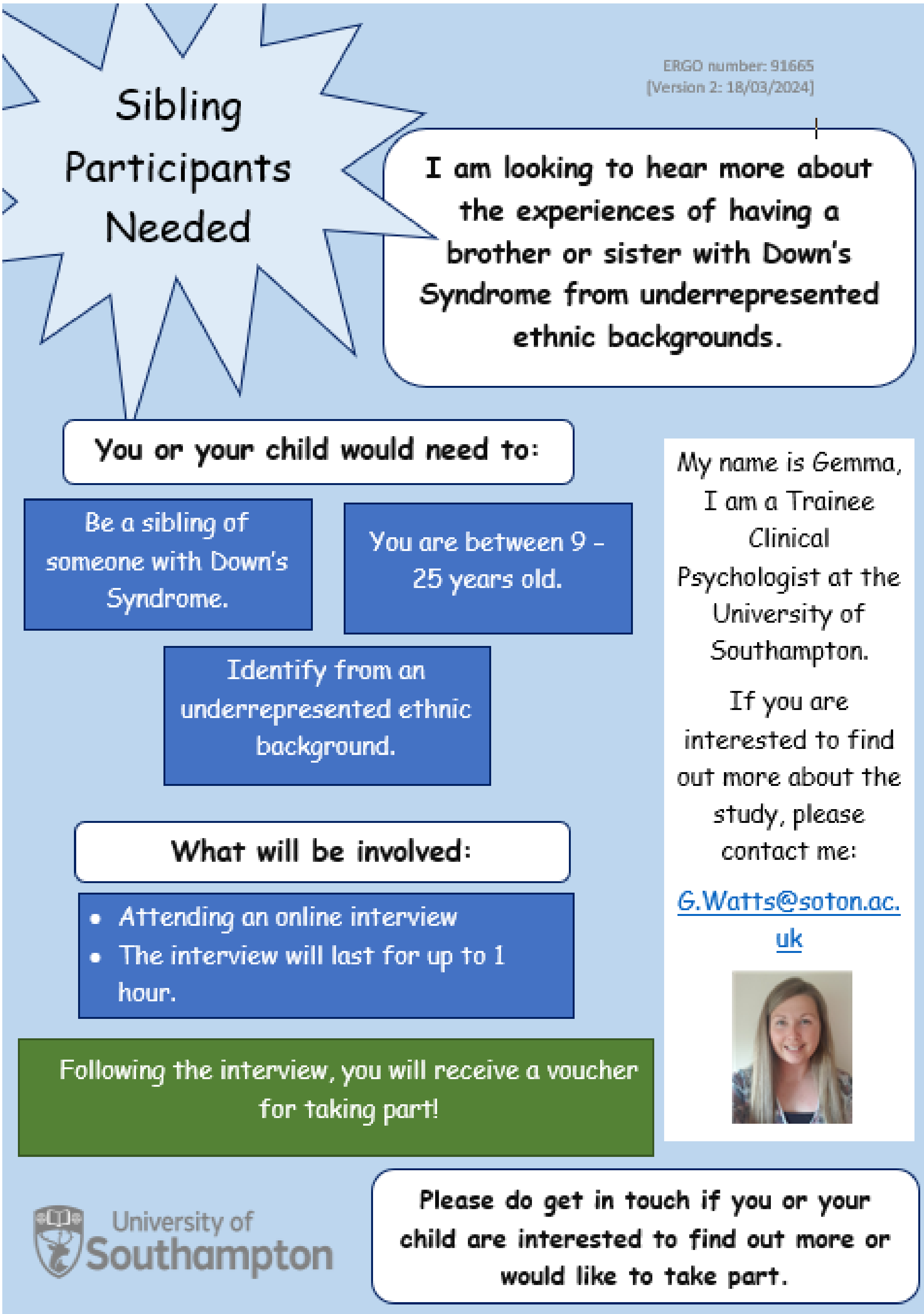
ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 91665
Submission Title: Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnicities (Working Title)
Submitter Name: Gemma Watts

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

Appendix E: Recruitment Poster



ERGO number: 91665
[Version 2: 18/03/2024]

Sibling Participants Needed

I am looking to hear more about the experiences of having a brother or sister with Down’s Syndrome from underrepresented ethnic backgrounds.

You or your child would need to:

Be a sibling of someone with Down’s Syndrome.

You are between 9 – 25 years old.

Identify from an underrepresented ethnic background.

What will be involved:

- Attending an online interview
- The interview will last for up to 1 hour.

Following the interview, you will receive a voucher for taking part!

My name is Gemma, I am a Trainee Clinical Psychologist at the University of Southampton.

If you are interested to find out more about the study, please contact me:

G.Watts@soton.ac.uk

University of Southampton

Please do get in touch if you or your child are interested to find out more or would like to take part.

Appendix F: Participant information Sheet (Parent/Carers)

Participant Information Sheet

Study Title: Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnicities (Working Title)

Researcher: Gemma Watts

ERGO number: 91665

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

What is the research about?

My name is Gemma, I am a trainee clinical psychologist at the University of Southampton.

The research project is looking to explore the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnic groups. The project aims to explore what are sibling’s experiences of having a brother or sister with Down’s Syndrome as well as gaining a greater understanding from siblings as to what services could do to support and/or changes that could be made to services to ensure siblings are supported within family systems.

Why would the research like your child’s participation?

The research would like your child’s participation because:

- They are a sibling of someone with a diagnosis of Down’s Syndrome.
- They are between the ages of 9 – 25 years old.
- They identify from an underrepresented ethnic background.

I am looking to recruit around 6 – 8 sibling participants for this research project.

What will happen to your child if they take part?

The research would like to invite your child to take part in an interview. The interview will take place online via Microsoft teams.

There will only be one interview for your child to attend and they will meet with Gemma Watts (researcher).

As a parent/carer you are invited to also be present during your child’s interview

Within the interview, your child will be asked some questions. Your child can choose to share and discuss as little or as much as they want to.

The interview will last no longer than 1 hour.

The interviews will be audio/video recorded, this will enable the researcher to listen to the interview after it has taken place and type up what was said during the interview. This is called transcription. The transcript will then enable the researcher to look at and analyse the data collected. There is a consent form which will require specific consent from you for this audio/video recording to take place.

Your child will not be required to take part in any further follow-up.

Are there any benefits in taking part?

There is no direct benefit to your child taking part however, your child's participation will help us to have a greater understanding as to what are the unique experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnic groups and what could services do to ensure sibling needs are being considered.

Following completion of the interview, your child will receive a £15 gift voucher for taking part.

Are there any risks involved?

There are no risks to your child taking part. However, you can speak to Gemma Watts (researcher) to discuss the research and/or if you want to make a complaint.

Following the study, you may find the following support services helpful:

- **Down's Syndrome Association**: Telephone: +44 (0)333 1212 300 Email: info@Down'ss-syndrome.org.uk
- **Sibs:** https://www.sibs.org.uk/

What data will be collected?

You will be asked to read, understand, and sign the consent form if you are happy for your child to take part in the research. Your child will also be asked to give their assent (consent) to taking part also. Completed forms will be collected by the researcher and these will be handled securely.

The interviews will be recorded via Microsoft Teams. Transcription of the recording will be done either via the researcher or through using a university approved transcription company called Page Six (https://www.pagesix.co.uk/). The audio/video recording of the interview in Teams will be destroyed upon completion and checking of the transcription document.

Transcription documents will be stored on University of Southampton laptops. These laptops require log-in and password access. The transcription document will also be backed up onto a secure Onedrive account, just in case the laptop breaks.

Once the study has been completed, the University of Southampton will keep identifiable information about your child for 10 years after the study has finished after which time your child's information will be destroyed.

Will my participation be confidential?

Your child's participation and the information we collect about your child and your family during the research will be kept strictly confidential.

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

Does your child have to take part?

No, it is entirely up to you and your child to decide whether to part or not. If you decide you want your child to take part, you will need to sign a consent form to show you have agreed for your child to take part. Your child also needs to give their consent (assent) to take part also.

What happens if my child or I change our minds?

You and your child have the right to change your mind and withdraw at any time without giving a reason and without participant rights being affected.

If you and/or your child decide to withdraw from the study after the interview has been transcribed and anonymised, you will not be able to withdraw the information that has been contributed so far.

What will happen to the results of the research?

Your child's personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify your child.

Where can I get more information?

If you have any concerns or questions about this project, please contact Gemma Watts at G.Watts@soton.ac.uk.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher, Gemma Watts, G.Watts@soton.ac.uk who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

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

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

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

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

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

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

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

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

Thank you.

Thank you for taking the time to read the information sheet and considering your child's involvement in the research.

Appendix G: Participant information Sheet (18 – 25 years old)

Participant Information Sheet

Study Title: Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnicities (Working Title)

Researcher: Gemma Watts

ERGO number: 91665

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

What is the research about?

My name is Gemma, I am a trainee clinical psychologist at the University of Southampton.

The research project is looking to explore the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnic groups. The project aims to explore what are sibling’s experiences of having a brother or sister with Down’s Syndrome as well as gaining a greater understanding from siblings at what services could do to support and/or changes that could be made to services to ensure siblings are supported within family systems.

Why have I been asked to participate?

The research would like your participation because:

- You are a sibling of someone with a diagnosis of Down’s Syndrome.
- You are between the ages of 9 – 25 years old.
- You identify from an underrepresented ethnic background.

I am looking to recruit around 6 – 8 sibling participants for this research project.

What will happen to me if I take part?

The research would like to invite you to take part in an interview. The interview will take place online via Microsoft teams.

There will only be one interview to attend and you will meet with Gemma Watts (researcher).

Within the interview, you will be asked some questions. You can choose to share and discuss as little or as much as you want to.

The interview will last no longer than 1 hour.

The interviews will be recorded, this will enable the researcher to listen to the interview after it has taken place and type up what was said during the interview. This is called transcription. The transcript will then enable the researcher to look at and analyse the data collected. There is a consent form which will require specific consent for this recording to take place.

You will not be required to take part in any further follow-up.

Are there any benefits in taking part?

There is no direct benefit to taking part however, your participation will help us have a greater understanding as to what are the unique experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnic groups and what could services do to ensure sibling needs are being considered.

Following completion of the interview, you will receive a £15 gift voucher for taking part.

Are there any risks involved?

There are no risks to you taking part. However, you can speak to Gemma Watts (researcher) to discuss the research and/or if you want to make a complaint.

Following the study you may find the following support services helpful:

- **Down's Syndrome Association**: Telephone: +44 (0)333 1212 300 Email: info@downs-syndrome.org.uk
- **Sibs:** https://www.sibs.org.uk/

What data will be collected?

You will be asked to read, understand, and sign the consent form if you are happy to take part in the research. Completed forms will be collected by the researcher and these will be handled securely.

The interviews will be recorded via Microsoft Teams. Transcription of the recording will be done either via the researcher or through using a university approved transcription company called Page Six (https://www.pagesix.co.uk/). The audio/video recording of the interview in Teams will be destroyed upon completion and checking of the transcription document.

Transcription documents will be stored on University of Southampton laptops. These laptops require log-in and password access. The transcription document will also be backed up onto a secure Onedrive account, just in case the laptop breaks.

Once the study has been completed, the University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time your information will be destroyed.

Will my participation be confidential?

Your participation and the information we collect about you and your family during the research will be kept strictly confidential.

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

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without participant rights being affected.

If you decide to withdraw from the study after the interview has been transcribed and anonymised you will not be able to withdraw the information that has been contributed so far.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you.

Where can I get more information?

If you have any concerns or questions about this project, please contact Gemma Watts at G.Watts@soton.ac.uk.

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher, Gemma Watts, G.Watts@soton.ac.uk who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

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

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

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

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

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

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

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

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

Thank you.

Thank you for taking the time to read the information sheet and considering your involvement in the research.

Appendix H: Participant information Sheet (Children and Young People)

PARTICIPANT INFORMATION SHEET

FOR CHILDREN

To be read by parent/carer if required

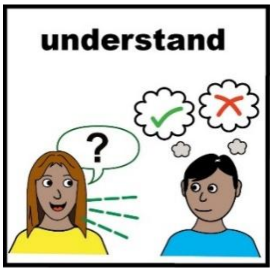
Exploring the experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnicities *(Working Title)*

What is research?

Research helps us to explore questions that we would like to find out more about.

Why is the research being done?

The research would like to speak to siblings with a brother or sister who has Down's Syndrome. Also, siblings who are from ethnic backgrounds where we do not have much research currently. Speaking to these siblings will help us to understand what it is like to have a brother or sister with Down's Syndrome.



Why me?

You have been chosen because you have a sibling with Down’s Syndrome.

You are between the ages of 9 and 25 years old.

You are from an ethnic background where we do not have much research currently.

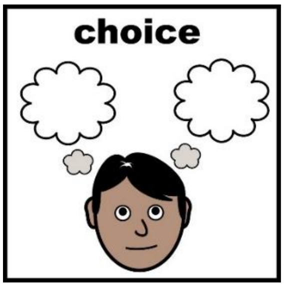
Do I have to take part?

You do not have to take part. It is your choice.

There will be lots of time to read this information sheet.

If you would like to take part, we would like you to complete a consent form with your parent/carers.

If you change your mind later that is ok, your parent/carers will just need to let Gemma the researcher know.



What will happen?

You will meet with Gemma the researcher via Microsoft Teams.

Gemma will ask you some questions about what it is like to have a brother or sister with Down's Syndrome.

Your parent/carers can stay with you during the interview if you would like them to.

The interview will last no more than 1 hour.

The Microsoft Teams call will be recorded so that the conversation can be typed up.

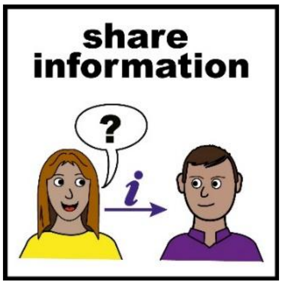
After meeting with Gemma, the researcher, you will receive a £15 voucher for taking part in the research.

What happens when the research stops?

All of the conversations will be explored using a process called analysis.

The analysis will help us understand what it is like to have a brother or sister with Down's Syndrome.

We can also share our results with different services who support your family.



What else might happen?

There are no risks to you taking part in this study. However, if you would like to speak to someone following the study there will be some information given to you and your parent/carers about who you could speak to for further support.

What if I don't want to do the research anymore?

If you change your mind later that is ok, your parent/carers will just need to let Gemma the researcher know.

What if I wish to complain about the study?

If you want to complain you and your parent/carers can talk to Gemma, the researcher.

Will anyone else know I'm doing this?

Gemma and her research team will know you are taking part. Your parent/carers will also know that you have taken part. However, no one else will know that you have taken part. We will not use any personal information that we have about you. Your personal information will be kept safe.

Once the research has finished, the University of Southampton will keep identifiable information about you for 10 years. After this time your information will be destroyed.

What happens to the research?

All your information will be kept in a safe place and will only be accessed by Gemma and people in the research team. The research will be written up into a report. The report may be shared with services so that they can think about what they might need to do to support siblings.

Did anyone else check the study is OK to do?

The study has been checked by the University of Southampton to make sure it is OK to do.

How can I find out more about this study?

Your parent/carers may be able to help in answering your questions. If it is something that they are not able to answer, then your parent/carers can contact Gemma the researcher who will be happy to answer any questions that you have about the study.

Thank you for taking the time to read this. Please ask any questions about the research if you need to.

Appendix I: Consent Form (Parent/Carers)

CONSENT FORM

Study Title: Exploring the experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnicities (Working Title)

Ethics/ERGO number: 91665

Version and date: Version 2: 18/03/2024

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

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

I confirm that I read the Participant Information Sheet [Version 2], dated 18/03/2024 explaining the study above and I understand what is expected of my child.	
I was given the opportunity to consider the information, ask questions about the study, and all my questions and my child's questions have been answered to my satisfaction.	
I agree for my child to take part in this study and understand that data collected during this research project will be used for the purpose of this study.	
I understand that my child's participation is voluntary and that my child and/or I am free to withdraw consent at any time without giving a reason.	
I understand that I am giving consent on behalf of my child, as they are under 18 years old.	

I understand my child will be asked to sign an assent form to confirm they would like to participate in the study.	
I understand that all personal information collected about my child (e.g., name and contact details) will be kept confidential (i.e., will not be shared beyond the study team) unless required by law or relevant regulations (e.g., for the purpose of monitoring the safety of this study).	
I understand that taking part in this study involves audio/video recording. I am happy for my child’s interview to be audio/video recorded and understand that the audio/video recording will be deleted immediately once transcription is completed.	
I understand that my child may be quoted directly in the research reports but that they will not be directly identified (e.g. that their name will not be used).	
I understand that if my child withdraws from the study, it may not be possible to remove their data once personal information is no longer linked to the study data.	
I understand that my child will receive a £15 gift voucher after finishing the interview.	

Name of Participant (print name) …………………………………………..

Name of consenting adult ……………………………………………..
Signature ……………………………..

Relationship to child…………………………………………………
Date ……………………………………

Signature of researcher………………………………………………..
Date……………………………………

*Once this Consent Form has been signed by all parties, a copy of the signed and dated form should be provided to the study participant. Original signed copy should be stored in the study site file (If applicable).

Appendix J: Consent Form (18 + years old)

CONSENT FORM

(Sibling Participants who are 18 years and older)

Study Title: Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnicities (Working Title)

Ethics/ERGO number: 91665

Version and date: Version 2: 18/03/2024

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

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

I confirm that I read the Participant Information Sheet [Version 2], dated 18/03/2024, explaining the study above and I understand what is expected of me.	
I was given the opportunity to consider the information, ask questions about the study, and all my questions have been answered to my satisfaction.	
I agree to take part in this study and understand that data collected during this research project will be used for the purpose of this study.	
I understand that my participation is voluntary and that I am free to withdraw consent at any time without giving a reason.	
I understand that all personal information collected about me (e.g., my name and contact details) will be kept confidential (i.e., will not be shared beyond the study team) unless required by law or relevant regulations (e.g., for the purpose of monitoring the safety of this study).	

I understand that taking part in this study involves audio/video recording. I am happy for my interview to be audio/video recorded and understand that the audio/video recording will be deleted immediately once transcription is completed.	
I understand that I may be quoted directly in the research reports but that I will not be directly identified (e.g. that my name will not be used).	
I understand that if I withdraw from the study, it may not be possible to remove my data once my personal information is no longer linked to the study data.	
I understand that I will receive a £15 gift voucher after finishing the interview.	

Name of Participant (print name) ……………………………
Signature …………………………………...

Signature of researcher……………………………………………..
Date……………………………………

*Once this Consent Form has been signed by all parties, a copy of the signed and dated form should be provided to the study participant. Original signed copy should be stored in the study site file (If applicable).

Appendix K: Consent/Assent Form (Children and Young People)

CONSENT/ASSENT FORM

Study Title: Exploring the experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnicities (Working Title)

Ethics/ERGO number: 91665

Version and date: Version 2: 18/03/2024

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

The researcher has explained the project to me.	
I have read and understood the participant information sheet [Version 2], dated 18/03/2024 and have had the opportunity to ask any questions.	
I understand the researcher will ask me questions and the answers will be recorded using Microsoft Teams.	
I understand that the researcher is a student, and my interview will help her complete a piece of coursework.	
I understand my name, or any other information which could identify me will be removed.	
I understand that I can tell the researcher if I do not want to take part. I can do this at any point, and this is completely OK.	
I would like to take part in the interview.	
I understand I will receive a £15 gift voucher after finishing the interview.	

If you want to take part, you can write your name below:

Your name …………………………………………………………………..

Your signature……………………………………………………………

Date…………………………………

The person who explained the study to you needs to sign here:

Signature………………………………………………….……

Date……………………………………

Appendix L: Topic Guide

- “Hello, lovely to see you again _________. It has been a couple of months since we last met for our initial meeting for you to find out more about the research. Just to remind you in case you have forgotten. My name is Gemma, and I am trainee clinical psychologist at the University of Southampton”.
- “I have received all the signed and completed paperwork. I just wanted to check that you both (parent/carer present if needed) have understood the information about the research?”
- “I just wanted to ask whether you have any questions for me before we start?”

- “The interview will last up to an hour depending on how chatty we are. If you would like to take a break at any time you can.”
- “Would you like your parent to stay with you during the interview?”
- “The interview will be being recorded today and just to remind you that you have the right to change your mind about taking part at any time prior to the transcription taking place, this is where the video recording is turned into a script of everything we talk about today.”
- To the parent: “Are you happy for ________ to take part?”
- To the child: “Are you still happy to take part?”

**** Start Recording *****

- Thank you for taking part. We are going to be talking about you and your brother/sister (_________) we would really love to hear from you.
- How old are you?
- How old is (___________)?
- Can you tell me about (____________)? *(Prompts: Their favourite things, what do they like to do etc.)*
- What is like growing up with ______________?
- What things do you enjoy doing with _____________? *(Prompts; Things that you do together e.g., games/activities that you play together?)*
- What do you know about ________ diagnosis of Down’s Syndrome?
- Are there any tricky things about having a brother/sister with Down’s Syndrome? (*Prompts: Relationships e.g., friendships, family relationships, Health, Day-to-Day, Feelings, School*)

Prompt (if participant comments on theirs or their sibling’s ethnicity during responses); “Can you tell me more about _______”

- So, you told me that you are (ethnicity), are there any ways that this affects you, or your sibling, or your family? (*Prompts: Can you tell me more about this).*
- What do you like most about having a brother/sister with Down's Syndrome?
- Are there any things that you would like (or would have liked) to have as a brother/sister of someone who has Down's Syndrome? (*Prompt: When your sibling was born? When your parents told you about their diagnosis of Down's Syndrome?*).

Prompt (if participant comments on theirs or their sibling's ethnicity during responses); "Can you tell me more about _______"

- Is there anything that you would say to someone else who has a sibling that has Down's Syndrome?

- "That's the end of my questions for you today. Thank you very much for taking part. It has been lovely to meet you today and hear about you and _________. Do you have any questions for me before we finish? (If child is on own for interview) I wonder if we could get Mum/Dad back please so that I can say goodbye to them too."

End of Interview. Stop Recording.

Offer debrief session and/or debriefing information sheet to sibling participant and parent/carers.

Appendix M: Debrief Form (Parent/Carers)

Debriefing Form

Study Title: Exploring the experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnicities (Working Title)

Ethics/ERGO number: 91665

Researcher(s): Gemma Watts

University email(s): G.Watts@soton.ac.uk

Version and date: Version 1: 23/02/2024

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

Purpose of the study

The aim of this research was to explore what are the experiences of siblings who have a brother or sister with Down's Syndrome from underrepresented ethnic groups.

It is expected that your child's experiences along with other sibling's experiences will enable us to have a greater understanding into the unique experiences of having a brother or sister with Down's Syndrome from underrepresented ethnic groups. Your child's experiences will help us to understand more about the opportunities and challenges of being a sibling of an individual with Down's Syndrome. Also, an insight from siblings into what services could do to support and/or changes needed within services to ensure siblings are being supported.

Confidentiality

Results of this study will not include your child's name or any other identifying characteristics.

Study results

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

Further support

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

Down's Syndrome Association: Telephone: +44 (0)333 1212 300 Email: info@downs-syndrome.org.uk

Sibs: https://www.sibs.org.uk/

Further reading

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

Paul, A. M., Hussey, M. M., Woodman, A. C., Smith, A. L., & Shriver, T. P. (2022).

Experiences of siblings of people with intellectual disabilities: Multiregional

perspectives. *Family Relations*, 71(2), 671-685.

Further information

If you have any concerns or questions about this research, please contact Gemma Watts at G.Watts@soton.ac.uk who will do their best to help.

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

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

Appendix N: Debrief Form (18+)

Debriefing Form

Study Title: Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnicities *(Working Title)*

Ethics/ERGO number: 91665

Researcher(s): Gemma Watts

University email(s): G.Watts@soton.ac.uk

Version and date: Version 1: 23/02/2024

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

Purpose of the study

The aim of this research was to explore what are the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnic groups.

It is expected that your experiences along with other sibling’s experiences will enable us to have a greater understanding into the unique experiences of having a brother or sister with Down’s Syndrome from underrepresented ethnic groups. Your experiences will help us to understand more about the opportunities and challenges of being a sibling of an individual with Down’s Syndrome. Also, an insight from siblings into what services could do to support and/or changes needed within services to ensure siblings are being supported.

Confidentiality

Results of this study will not include your name or any other identifying characteristics.

Study results

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

Further support

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

Down’s Syndrome Association: Telephone: +44 (0)333 1212 300 Email: info@downs-syndrome.org.uk

Sibs: https://www.sibs.org.uk/

Further reading

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

Paul, A. M., Hussey, M. M., Woodman, A. C., Smith, A. L., & Shriver, T. P. (2022). Experiences of siblings of people with intellectual disabilities: Multiregional perspectives. *Family Relations*, 71(2), 671-685.

Further information

If you have any concerns or questions about this research, please contact Gemma Watts at G.Watts@soton.ac.uk who will do their best to help.

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

Thank you again for your participation in this research.

Appendix O: Debrief Form (Children and Young People)

DEBRIEF FORM

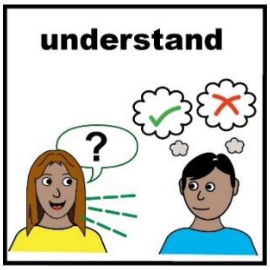
To be read by parent/carer if required

Exploring the experiences of siblings who have a brother or sister with Down’s Syndrome from underrepresented ethnicities (Working Title)

Thank you for taking part in our research. Your responses to the questions asked during the interview are important.

Why we did the research?

We wanted to explore what it is like to have a brother or sister who has Down’s Syndrome from ethnic backgrounds where we do not have much research currently.



Information we have about you.

No one else will know that you have taken part. We will not use any personal information that we have about you. Your information will be kept safe.

The research report

If you would like to have a copy of the research report, your parent/carers can contact Gemma the researcher.

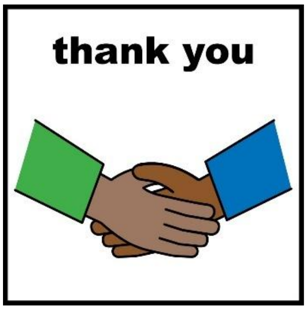
Further support

You might like to contact the following for further support:

- Down's Syndrome Association: Telephone: 0333 1212 300 Email: info@downs-syndrome.org.uk
- Sibs: https://www.sibs.org.uk/

Your parent/carers can also contact Gemma who will do her best to help with any questions.

Thank you again for taking part in this research.


thank you