

The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents

By Catriona Kennedy Supervised by Dr. Fionnuala Tynan

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Abstract

Background

Recent studies indicate that learners with Down syndrome can become competent bilinguals and biliterates. However, less is known about whether immersion education is a suitable and beneficial education setting for these learners, as previous studies have included participants from bilingual home backgrounds rather than students who acquire additional languages through school programmes.

Aims

This study aimed to investigate whether there were differences in the verbal communication of pupils with Down syndrome who attend English-medium mainstream (EMM), English-medium special setting (EMSS) and Irish-medium mainstream (IMM) primary schools. Additionally, the study aimed to gather the views of these students, and their parents, regarding their experiences of primary school.

Sample

Fifty-four participants took part in Phase One, including children with Down syndrome (n = 5), parents of children with Down syndrome (n = 12), and professionals currently working with children with Down syndrome (n = 37). Phase Two participants included 13 children with Down syndrome attending EMM (n = 4), EMSS (n = 5) and IMM (n = 4) primary schools, and 13 parents linked to child participants.

Methods

Semi-structured interviews were conducted with parent participants to gather information about their experiences and their child's verbal communication development. The Mosaic approach, including use of cameras and picture-story activities, was employed to investigate the experiences of child participants.

Results

Parental interviews highlighted the influence of bioecological factors on verbal communication. There were no significant differences between the verbal communication abilities of child participants attending EMM, EMSS and IMM schools. Themes regarding parental experiences included choosing a primary school, parental responsibilities and fostering inclusion and facilitating success at school. Children's experiences revolved around learning, relationships, places and fun activities at school.

Conclusions

The implications of the findings for professional practice and research are presented, alongside unanticipated ethical dilemmas which arose during the study.

Key Words

Down syndrome, Immersion education, Bilingualism, Cognitive development, Verbal communication development, Inclusive education

Declaration

I hereby declare that this thesis is entirely my own work and has not been submitted for any other awards at Mary Immaculate College or at any other academic establishment. Furthermore, where use has been made of the work of others, it has been fully acknowledged and referenced.

Name: Catriona Kennedy

Catricone Ulenanely_ Signed:

Date: 25/04/2023

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Dedication

This thesis is dedicated to my wonderful father and close friend, Paddy Kennedy. Your brave, resilient, determined and kind nature has always been inspirational to me.

You will live on in our hearts forever.

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Chapter One: Introduction

Chapter One presents an introduction to this study, outlining key concepts, and a structural overview of the thesis. Firstly, the rationale underpinning the choice to undertake research in this area is outlined. Subsequently, the researcher's positionality, including personal interest in, and experience of, the research area, and practice-based factors which influenced the selection of this research topic are explored. Chapter One concludes with an account of the epistemological considerations and theoretical perspectives that informed the research, in addition to an orientation of the overall structure of the thesis. This study utilised a transformative lens and investigated the experiences of Irish-medium and English-medium primary schools for children with Down syndrome and their parents. Furthermore, the research explored whether there are differences in the verbal communication abilities of children with Down syndrome depending on whether they attend Irish-medium or English-medium primary schools.

Rationale

With regards to the history of special education in Ireland, Shevlin (2016) describes the move from segregated provision towards integration and inclusion within mainstream society, for children with disabilities, across time in Irish history. For instance, a culture of institutionalisation, including residential schools and workhouses, existed for children with disabilities across the 19th and 20th century in Ireland. According to Down Syndrome Ireland (DSI, n.d.) (a national organisation providing 'all-through-life' support and services to individuals with Down syndrome), special schools were traditionally the dominant school choice for children with Down syndrome in the late 20th and early 21st century. However, at present, more than 90% of children with Down syndrome now attend their local primary school in Ireland (DSI, n.d.). Shevlin (2016) attests that this fluctuation towards mainstream education for children with Down syndrome and other disabilities in the past three decades, was influenced by human rights movements, the adoption of a social model of disability and important legislation, such as The Education Act (Government of Ireland, 1998), the Equal Status Act (Government of Ireland, 2000) and the Education for Persons with Special Educational Needs (EPSEN) Act (Government of Ireland, 2004). Accordingly, the definition for special educational needs (SEN) used in this study is the definition for SEN which was set out in the EPSEN Act (2004). Specifically, SEN are defined as "a restriction in the capacity of the person to participate in and benefit from education on account of an enduring physical, sensory, mental health or learning disability, or any other condition which results in a person learning differently from a person without that condition..." (Government of Ireland, 2004, Section 1).

Although research highlights the advantages of mainstream schooling (Buckley et al., 2006) and bilingualism for children with SEN (National Council for Special Education, 2011) (NCSE), such as Down syndrome, no research to date has examined the impact of immersion education (IE) for children with Down syndrome in the Irish context. Furthermore, neither of the resources available to parents of children with Down syndrome in Ireland, with regards to choosing a school for their child (NCSE, 2013; DSI, 2018), provide information about Irish-medium schools as options for their children. Thus, further research is necessary to gather information about the impact of Irish-medium education for learners with Down syndrome, to allow parents of children with Down syndrome to make an informed decision about the type of school they wish for their child to attend, in their role as the primary educators of their child (Government of Ireland, 1937).

The United Nations (UN) Convention on the Rights of the Child states that all children have the right to be listened to on matters that affect them (UN, 1989). However,

according to Prunty et al. (2012) "children's views are neither consistently nor reliably incorporated into educational decision making" (p. 29). Although several recent studies have included the voice of children with additional needs in research (Andrews, 2020; Squires et al., 2016), they are of wide-ranging and diverse topics. To date, no study has been undertaken which includes the voices of children with Down syndrome in relation to their school choice or school experience in Irish-medium primary schools. Similarly, no previous research has been undertaken in this research area, which includes the perspectives of parents of children with Down syndrome in the Irish context. Thus, the paucity of information gathered from both children with Down syndrome and their parents in this research area provides a strong rationale for carrying out this research.

Researcher's Positionality

I first became interested in this area through my previous role as a primary school teacher working in an Irish-medium school. I was interested in developing effective teaching approaches for children with additional needs and disabilities, who were learning Irish through the immersion approach. According to anecdotal records, there had never been a student with Down syndrome enrolled in the Irish-medium school I worked in, which was established approximately 40 years ago. Subsequently, when I began my doctorate training, I learned about the theory of language in relation to Down syndrome, during a lecture provided by Dr Margaret Farrelly. For instance, the idea that individuals with Down syndrome may benefit from learning two languages was introduced to me during this lecture, as second language learning may have a positive influence on first language development. However, when I conducted a review of previous studies illustrating this phenomenon, there was a paucity of research in this area, with no previous studies undertaken in the Irish context. For

instance, most studies exploring bilingualism or additional language learning of individuals with Down syndrome have been undertaken in Canada or Wales.

Following this literature review, I wondered about the many students who had attended the Irish-medium school I worked in, who had siblings with Down syndrome, and the rationale underpinning their parent's decision not to send their children with Down syndrome to the Irish-medium school, alongside their siblings. Furthermore, this very issue arose during my first professional placement in my doctorate training, when undertaking an assessment with a 4-year-old child with Down syndrome, whose older sibling was attending an Irish-medium school. The parents of the child with Down syndrome were unsure about sending this child to the Irish-medium school alongside the child's sibling, as Irish was not spoken at home. As a result, I was eager to review previous research in the area of bilingualism, which included participants with Down syndrome who were attending immersion education settings, who were not exposed to the second language in their home environment.

Finally, in 2021, DSI celebrated 50 years in existence and ran a campaign called 'The Upside.' This campaign aimed to demonstrate the value that people with Down syndrome bring to society and the spirit of communities and the nation, whilst also highlighting the gaps and barriers that exist in relation to inclusion for people with Down syndrome (DSI, n.d.). Therefore, owing to my previous experience as a teacher and as a trainee educational psychologist, the limited research in this area and DSI's 'Upside' campaign, it seemed fitting to undertake a study on the experience of children with Down syndrome and their parents in Irish-medium and English-medium primary schools.

Research Funding

Funding was provided for this research by An Chomhairle um Oideachas Gaeltachta agus Gaelscolaíochta (COGG) through the award of a research bursary in May 2021. The roles of COGG relate to three main areas, including the provision of teaching resources, the provision of support services and research, in the Gaeltacht and Irish-medium education sector, and the teaching of Irish in all schools. In addition, a research bursary was awarded for this research in October 2021 under the Irish National Teachers' Organisation's (INTO) Bursary Scheme. This scheme provides grants for six INTO members who are undertaking educational research at masters or doctorate level. Further funding was provided by the National Educational Psychological Service (NEPS) in January 2023, under the Trainee Educational Psychologist Bursary Award Scheme 2022 – 2023. This scheme was established to support trainee educational psychologists in their third year of professional training, as full-time professional doctorate courses in educational and child psychology are not funded in Ireland for the present cohort of final-year trainee educational psychologists.

Research Paradigm and Theoretical Underpinnings

The Transformative Paradigm

It is hoped that the data collected through this study would be used to support parents of children with Down syndrome to make an informed choice when considering an Irishmedium school for their child, and to promote inclusion of learners with a diverse range of strengths and needs. Consequently, as the ultimate goal of the research is to drive change for learners with Down syndrome, their families and supporting education professionals, the transformative paradigm was adopted as a philosophical framework (Mertens, 2007).

The philosophical assumptions which underpin this choice of paradigm include axiological and ontological assumptions. According to Mertens (2007), the axiological assumption of the transformative paradigm is characterised by the view that researchers are presented with opportunities to promote inclusion and address inequalities that may exist for vulnerable populations, such as children with additional needs or disabilities, and their families. Correspondingly, research provides an opportunity to promote human rights and social justice by including individuals who are often "marginalised in school systems" (Mertens, 2007, p. 223) and reporting their views in research. Furthermore, the axiological assumption of the transformative paradigm recognises that research with children can have a transformative impact on both the researcher and the research participants (Mertens, 2021); in this case, bilingual and monolingual children with Down syndrome attending primary schools, and their families. Accordingly, researchers are encouraged to prioritise, or at least give equal weight to, the voices of participants whose voices may not usually be heard amongst relevant stakeholder groups (Mertens, 2007). However, while it is important to capture and understand the experiences of participants when undertaking research that is informed by a transformative lens, the ultimate aim is to empower participants to take an active role in shaping their own future (Mertens, 2007).

Regarding ontology, the transformative paradigm holds the stance that reality is socially constructed, which implies that reality is shaped by interactions between individuals and their environment, and that knowledge is co-created during these interactions. According to Mertens (2007), this ontological assumption indicates that power is unequally distributed, which means that certain individuals occupy a greater stance of power and that other individuals are often excluded from research and decision-making (Mertens, 2007). As a result, individuals with less power are often excluded from research and decision-making, highlighting the need for research to be conducted in an ethical and participatory manner, in

order to challenge unequal power dynamics, in keeping with the transformative paradigm (Mertens, 2021). Consequently, an aim of the present study was to employ a mixed methods approach to data collection that includes learners with Down syndrome and their parents from the beginning of the research process through to the dissemination of the research findings.

The Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006)

In addition to the transformative paradigm, the theoretical framework which underpinned this research was the bioecological model of human development (Bronfenbrenner & Morris, 2006). This model offers an appropriate schema for understanding the wide variety of factors which influence the development of children with Down syndrome and their families, and how factors related to the person, the process, the context and time interact and affect each other (Tudge et al., 2009). For instance, the bioecological model accounts for biological and psychological factors, as well as the various environmental systems that interact with individuals over time, including microsystems, mesosystems, exosystems, macrosystems and chronosystems (Bronfenbrenner & Morris, 2006).

Bronfenbrenner and Morris' framework (2006) is often portrayed as a series of nested circles, as shown in Figure 1. The individual is located in the centre of the circle, surrounded by a series of environmental systems. The first and most immediate level of influence, outside of the individual, is the microsystem. Family members, peers and school staff are usually included in an individual's microsystem (Bronfenbrenner & Morris, 2006). The next level of influence, named the mesosystem, consists of the interconnections between two or more microsystems (Bronfenbrenner & Morris, 2006), such as the relationship between the child's parents and school staff. Subsequent to the mesosystem, is the exosystem, which includes the

social, economic, and political systems that have a secondary influence on the child's development (Bronfenbrenner & Morris, 2006). Examples from an individual's exosystem may include the media or local government policies. The macrosystem is the next level of influence and includes the broader cultural and historical context in which the individual is situated (Bronfenbrenner & Morris, 2006). Bronfenbrenner and Morris (2006) also highlighted the importance of time in the bioecological model. The chronosystem consists of significant life events or changes in the individual's environment across the lifespan.

Figure 1

The Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006)



Research Timeline and Structure of the Thesis

This research was undertaken in order to fulfil partial requirements for the degree of Doctorate of Educational and Child Psychology. Appendix A illustrates the research timeline, which displays the various steps of the research project and outlines when each step was completed. In line with the Mary Immaculate College (2020) 'Doctorate in Educational And Child Psychology Research Guidelines,' the final thesis structure will be presented in three parts including a Review Paper, Empirical Paper and Critical Review and Impact Statement. Therefore, Chapter Two will present the Review Paper. Subsequently, Chapter Three will consist of the Empirical Paper. The thesis will conclude in Chapter Four, where the Critical Review and Impact Statement will be presented.

Chapter Two: Cognitive and Socio-Emotional Outcomes for Students with Down Syndrome Attending Immersion Education Settings: A Systematic Review

Introduction

The present review aims to critically appraise the literature in relation to the impact of immersion education (IE) on school-age learners with Down syndrome using a systematic review process. Accordingly, a systematic approach to reviewing the literature will be undertaken. The aforementioned research topic will be explained in greater detail initially, with the view of providing a clear statement of the review question and addressing relevant key concepts. The rationale underpinning the present review will then be discussed. Next, the search strategy for the selection of studies, including inclusionary and exclusionary criteria, will be illustrated. A review of the selected studies will then be presented using Gough's Weight of Evidence (WoE) (2007) framework. The review will conclude with a summary of the key findings from the selected studies and the implications of these findings for future research.

Down Syndrome

Down syndrome is the most common congenital chromosomal condition and has a research history dating back to the 1800s (Roubertoux & Kerdelhué, 2006). It is caused by the presence of an extra copy of the 21st chromosome in all cells in the body. There are three types of Down syndrome, namely Trisomy 21, Robertsonian translocation and mosaic Down syndrome (Sattler, 2014).

Trisomy 21 accounts for approximately 95% of individuals with Down syndrome and occurs when there are three copies of chromosome 21 found in each cell. Alternatively,

Robertsonian translocation occurs in approximately 3-4% of individuals with Down syndrome and arises when part of the 21st chromosome breaks off and attaches to another chromosome, usually chromosome 14. Research investigating whether there are differences in how Robertsonian translocation Down syndrome affects an individual, in comparison to Trisomy 21 or mosaic Down syndrome, are limited and present inconsistent findings (Karmiloff-Smith et al., 2016; Leung, 2006; Prasher, 1995). For instance, Leung (2006) indicates that the features of Robertsonian translocation Down syndrome are indistinguishable from the features of Trisomy 21. Conversely, a study by Prasher (1995), which included nine individuals with Robertsonian translocation Down syndrome and nine individuals with Trisomy 21, who were matched by age, gender and geographical location, indicated differences between the two types of Down syndrome. For instance, while there were similarities between the stature, experience of ophthalmologic and audiological disorders, and the increased risk of thyroid dysfunction of individuals with Robertsonian translocation Down syndrome and Trisomy 21, Prasher's (1995) findings indicate that individuals with Robertsonian translocation Down syndrome may have milder forms of intellectual disability and a lower risk of obesity than individuals with Trisomy 21. Furthermore, the results of Prasher's (1995) study suggest that individuals with Robertsonian translocation Down syndrome may have an increased risk of experiencing a psychiatric condition across their lifetime in comparison to individuals with Trisomy 21, and the group of individuals with Trisomy 21 attained higher scores on measures of adaptive functioning than the group with Robertsonian translocation Down syndrome.

Finally, approximately 1% of individuals with Down syndrome have mosaic Down syndrome, which occurs when an extra copy of the 21st chromosome is found in some, but not all, cells in the body (Kazemi et al., 2016). Several studies indicate that individuals with mosaic Down syndrome typically attain higher scores on measures of intelligence than

individuals with Trisomy 21 or Robertsonian translocation (Papavassiliou et al., 2015; Zhao et al., 2015). Furthermore, a study in Denmark presented findings which illustrate that a higher proportion of individuals with mosaic Down syndrome attended post-primary school, secured full-time employment, were married or had a child than individuals with Trisomy 21 or Robertsonian translocation (Zhu et al., 2014).

Down syndrome is a lifelong condition, which results in distinct physical features and an increased risk of many medical health concerns, including cardiovascular, hearing and digestive difficulties (Sattler, 2014). While the intellectual abilities of individuals with Down syndrome are diverse (Channell et al., 2021), most individuals with Down syndrome have a moderate intellectual disability (ID) (Chapman & Hesketh, 2001). Worldwide, approximately 1 in 400-1500 infants are born with Down syndrome (Kazemi et al., 2016). Live birth rates vary internationally, depending on prenatal screening methods utilised in different countries and maternal age, as women aged 35 and older are at a higher risk of giving birth to a baby with Down syndrome (Huete-García & Otaola-Barranquero, 2021; Kazemi et al., 2016; Loane et al., 2013).

Although all children with Down syndrome are different and unique in their own way, they often share common characteristics. For instance, many children with Down syndrome exhibit strengths in social interaction (Grieco et al., 2015), gesturing and imitation (Næss et al., 2017), pro-social empathetic behaviours (Kasari et al., 2003), emotion recognition (Pochon & Declercq, 2013), visual learning (Esbensen et al., 2017), visuo-spatial short-term memory (Costa et al., 2015; Gathercole & Alloway, 2006) and reading ability (Snowling et al., 2008). Moreover, research has reported that children with Down syndrome can become skilled readers with early intervention and additional literacy instruction (Loveall & Barton-Hulsey, 2021). Children with Down syndrome may also demonstrate a pattern of relative weaknesses across verbal domains, namely expressive vocabulary, phonology, morphology, syntax and language use (Eggers & Van Eerdenbrugh, 2018; Smith et al., 2020), and in executive functioning (Lanfranchi et al., 2010; Loveall et al., 2017; Tungate & Conners, 2021), including working memory (Doerr et al., 2019; Godfrey & Raitano Lee, 2018), cognitive flexibility (Campbell et al., 2013) and inhibition (Borella et al., 2013).

Accordingly, there are a variety of factors which may impact on the education of learners with Down syndrome. Figure 2 illustrates some of the factors which may influence learning or the education provision of individuals with Down syndrome (Faragher et al., 2020). Taking these factors into account (Faragher et al., 2020), learners with Down syndrome may be educated in mainstream or special education settings, depending on parental choice and access to an inclusive education system, in line with Article 24 (Education) of the UN Convention on the Rights of Persons with Disabilities (UN, 2006).

Figure 2

Factors Influencing the Education of Learners with Down Syndrome (Faragher et al., $2020)^{1}$



¹ Note. From International Guidelines for the Education of Learners with Down Syndrome (p. 2) by R. Faragher,

P. Robertson & G. Bird, 2020, Down Syndrome International. Copyright 2020 by Creative Commons (BY-NC-ND 4.0).

Defining Cognitive and Socio-Emotional Development

The focus of this review is on the cognitive and socio-emotional outcomes of attending an IE setting for students with Down syndrome. Accordingly, definitions for cognitive and socio-emotional development are presented. According to Sattler (2014), cognitions are the mental processes used by individuals to "acquire knowledge, make plans, and solve problems," which include perception, memory and reasoning (p. 10). Cognitive development, therefore, refers to changes in cognitions over time. Gauvain and Richert (2016) differentiate between two important aspects of cognitive development which develop during childhood. For instance, cognitive development in childhood concerns changes in the content of children's knowledge or their knowledge of concepts, and changes in the processes used by children which facilitate cognitive change (Gauvain & Richert, 2016). The processes identified by Gauvain and Richert (2016) are similar to those listed by Sattler (2014), and include memory, reasoning, problem-solving and executive functioning (Gauvain & Richert, 2016). Cognitive abilities also play an important role in academic development, which refers to progress made by students in academic subjects, namely language, literacy, math and science, over time (Zhang et al., 2019). For instance, according to Peng and Kievit (2020), there are two major categories which contribute to academic development, which include foundational domain-specific skills and cognitive abilities, namely working memory, reasoning and executive function. Foundational domain-specific skills which impact academic development include meta-linguistic skills, fluency, comprehension, number sense and number fact retrieval (Peng & Kievit, 2020).

Finally, socio-emotional development is a multifaceted, umbrella term that refers to the skills required by individuals to manage and process their emotions and their behaviour, and to build relationships with others (Jones & Kahn, 2017). Furthermore, Malti and Noam (2016) define socio-emotional development as "understanding, regulating, and expressing emotions in a way that is appropriate for one's age and development, as well as the ability to establish, maintain, and develop healthy relationships with peers and adults" (p. 653). Similar to cognitive development, socio-emotional development plays an integral role in academic development and learning (Jones & Kahn, 2017).

Immersion Education

Bilingualism is a complex and multidimensional construct, which can be difficult to define (Kremin & Byers-Heinlein, 2021). In simple terms, bilingualism can be defined as the use of two languages in everyday life (Grosjean, 2013) or the "simultaneous acquisition of two spoken languages" (Genesee, 2003, p.206). According to Cummins (2009), bilingual education refers to organised education programmes that use two languages of instruction, "where the languages are used to teach subject matter content rather than just the languages themselves" (p. 161). The aims of bilingual education programmes vary across the world. For instance, the aim of some bilingual education programmes is to develop language abilities in two languages simultaneously, whilst the aim of other programmes may be to develop proficiency in the student's second language only or the majority language only (Cummins, 2009). For example, the goal of transitional bilingual education programmes in the USA is to develop students' proficiency in English, the majority language of the country. Two languages are used as languages of instruction (English and the other language spoken by the student) at the beginning, in this type of programme. Subsequently, when it is assumed that sufficient progress has been made in English, the home language (or first language) of the students is discontinued as a language of instruction, and students receive instruction in English only (Cummins, 2009).

Immersion education refers to a form of bilingual education which aims to immerse students in a target language, through the provision of at least half of curricular instruction in

the immersion language (Lyster, 2007). Lyster & Genesee (2019) distinguish between two types of IE, including one-way immersion and two-way immersion. One-way IE settings serve students who speak a common first language (L1), which is usually the dominant, majority or official language of the country, and offer instruction in a second, foreign, heritage or indigenous language (L2, Lyster & Genesee, 2019; Nissilä & Björklund, 2014). Irish immersion for learners whose L1 is English in Ireland, Swedish immersion for learners whose L1 is Finnish in Finland or French immersion for learners whose L1 is English in Canada provide examples of one-way immersion. One-way immersion programmes vary in the proportion of the curriculum provided in L2, the class-level or grade that students begin the immersion programme and the class-levels or grades that the immersion language is used (Lyster & Genesee, 2019). Accordingly, one-way immersion programmes may offer early, middle, late, partial or total immersion (Nissilä & Björklund, 2014).

By contrast, two-way immersion provides instruction in two languages, a community's majority language and a minority language, to learners who are native speakers of both languages (Serafini et al., 2020). In this way, a balanced or equal number of native speakers of the majority language and native speakers of the minority language are accommodated in the same classroom to encourage speakers of both languages to learn from each other through social interaction (Polanco & Baker, 2018). Two-way immersion programmes are predominantly found in the United States of America (USA), utilising English as the majority language and a variety of different minority languages, namely Spanish, German, French, Russian, Italian, Chinese, Japanese and Vietnamese. Further, two-way immersion programmes generally start with equal amounts of instruction time in both languages (50%/50%) or 90% of instruction time provided in the minority language and 10% of instruction time provided in the majority language. However, most two-way immersion programmes eventually provide equal amounts of instruction time in both languages by the

time learners are approximately ten years of age (Lyster & Genesee, 2019).

A Critique of Immersion Education

The advantages and disadvantages of IE for students have been widely documented in research across the globe. While studies have focused primarily on cognitive development, there is also evidence indicating that IE may influence the social and emotional development of students. For instance, many studies indicate that bilingualism, or use of two languages, has a positive impact on children's cognitive development, including working memory (Grundy & Timmer, 2017; McVeigh et al., 2017; Purić et al., 2017), attentional control (Brito et al., 2016; Kapa & Colombo, 2013), conflict resolution (Donnelly et al., 2015), theory of mind (Schroeder, 2018) and metalinguistic awareness (Adesope et al., 2010; Eviatar et al., 2018). Researchers hypothesise that learning more than one language exerts additional demands on the brain, which may underpin the positive effects on the cognitive processes previously mentioned (Barac et al., 2014). Conversely, a recent systematic review and metaanalysis provides little evidence in support of the positive influence of bilingualism on cognitive functions previously reported in research, namely executive functions including inhibition, switching, attention, monitoring, working memory and planning (Gunnerud et al., 2020). Notably, the review, which included 143 comparisons and 583 effect sizes, found substantial heterogeneity between the studies analysed (Gunnerud et al., 2020), with studies including children with higher socioeconomic status, studies from a specific lab in Canada and studies involving switching tasks, attaining larger effect sizes or cognitive advantages for bilingual children. Furthermore, the review highlighted the impact that a child's age of second language acquisition, differences in L1 and L2 fluency and exposure to L2 may have on student outcomes (Gunnerud et al., 2020). These findings provide a rationale for examining the effects of bilingualism in children attending one-way IE settings, owing to the

ability to control for age of second language acquisition and exposure to L2 amongst participants (Purić et al., 2017; Struys et al., 2015).

Regarding cognitive disadvantages associated with bilingualism, many studies demonstrate that bilingual children score lower on receptive vocabulary measures than monolingual children in one or both of their languages (Bialystok et al., 2010; Smithson et al., 2014). In addition, bilingual learners are also more likely to exhibit deficits in lexical access or retrieval, with monolingual learners experiencing fewer 'tip-of-the-tongue' occurrences than learners who use two or more languages (Klassert et al., 2014; Pelham & Abrams, 2014). According to Kim et al. (2020), a 'tip-of-the-tongue' occurrence is a "common type of speech error in which a person has a strong feeling of knowing the target word, but experiences retrieval failure, because of the inability to access phonological information" (p. 2). In other words, individuals who experience a 'tip-of-the-tongue' occurrence cannot quickly verbally recall the name of a word they are thinking about.

In contrast to cognitive development, less research has focused on the potential socioemotional effects of learning a second language for children (Alqarni & Dewaele, 2018), although studies suggest that well-developed language abilities, in general, are associated with better socio-emotional skills and positive behaviour (Shablack et al., 2019; Slot et al., 2020). The limited research examining the impact of bilingualism on socio-emotional development indicates that bilingualism is positively associated with a variety of socioemotional skills, including emotion perception (Alqarni & Dewaele, 2018), self-control (Winsler et al., 2014), self-esteem (Huang, 1995; Licciardello & Damigella, 2013; Lopez & Shen, 2021; Müller et al., 2020; Yazici et al., 2010), attachment (Oades-Sese & Li, 2011; Winsler et al., 2014) and emotional and behavioural well-being (Collins et al., 2011; Han, 2010; Müller et al., 2020; Sun et al., 2018).

However, similar to studies investigating cognitive factors in children who attend IE

settings or who use two languages, there is considerable variation in the definition of socioemotional concepts and bilingualism, and the outcome measures used amongst studies examining the impact of bilingualism on children's socio-emotional development (Müller et al., 2020). Likewise, many studies highlight the need for researchers to pay careful attention to relevant participant demographic characteristics, namely socioeconomic status, L2 language exposure and L1/L2 fluency of participants, when analysing the relationship between bilingualism and socio-emotional outcomes (Nissilä & Björklund, 2014; Sun et al., 2018). Furthermore, studies in this area postulate that the relationship between socioemotional development and bilingualism warrants further research, as early L2 language intervention at preschool may develop children's L2 fluency and competence, which might then contribute to these young children's socio-emotional development. In a similar manner, the implementation of socio-emotional programmes at preschool may have a positive influence on L1 and L2 outcomes for children attending IE settings (Lopez & Shen, 2021; Yazici et al., 2010).

Immersion Education for Students with Special Educational Needs

It is important to note that the studies discussed so far regarding the impact of bilingualism on children's cognitive and socio-emotional development have not included participants with SEN or Down syndrome. Therefore, it is important to highlight research which has included participants with additional needs, as education systems aim to be more inclusive across the world (Azorín & Ainscow, 2020; Vislie, 2003). In 2019, Martínez-Álvarez conducted a narrative review which aimed to review literature related to "the learning of bilingual children with dis/abilities" in bilingual programmes (p. 179). The findings of the review suggest that children with a diagnosis of a SEN or a disability have fewer opportunities than their typically-developing peers to become bilingual. For instance, a theme evident across reviewed studies indicated that upon receiving their child's diagnosis of a SEN, parents were often encouraged to limit language learning to one language only in the home setting, more specifically, to eliminate the minority language during interactions with their child (Kim, 2017; Kremer-Sadlik, 2005). Additional studies, which were not reviewed by Martínez-Álvarez (2019), which included parents of children with autism spectrum disorder (ASD), indicate similar findings regarding advice by professionals to parents to use one language only with their children (Cioè-Peña, 2020; Howard et al., 2021; Kay-Raining Bird et al., 2012; Jegatheesan et al., 2010; Yu, 2013). Cummins (1984, p. 109) indicates that opponents of bilingual education programmes in the USA may also encourage parents of students who speak a minority language to speak English within the home, despite research evidence which refutes the assumption that a "language mismatch" (a mismatch between languages used at home and in school) may explain patterns of underachievement amongst minority language students.

Conversely, a recent study conducted by Sher et al. (2022) found that Jewish educational practitioners in the UK actively encourage students with ASD to learn English and Hebrew in school. However, it is likely that parental and practitioner decision-making regarding Hebrew-English bilingualism in Sher et al.'s study (2022) was influenced by religious beliefs, namely the belief that "Hebrew is essential for Jewish continuity" (p. 4466). For instance, the education practitioners included in Sher et al.'s study (2022) shared the same culture as the parents of the students with ASD, and consequently, may have been more understanding of the significance of bilingualism in home life or culture in Jewish families.

Upon receiving a diagnosis of a disability or SEN, parents are also often recommended by education professionals to transfer their children from IE settings to nonimmersion education settings (Genesee, 2007; Hampton et al., 2017; Martínez-Álvarez, 2019; Nic Aindriú, 2021a). By way of example, a study by de Valenzuela et al. (2016) aimed to investigate the inclusion and exclusion of students with various developmental disabilities in and from bilingual opportunities, by interviewing 79 key informants, namely policy makers, professionals and advocates, across six sites in the UK, the USA, the Netherlands and Canada. Notably, while key informants from all six sites indicated that the institution or system that they worked in adopted an inclusive philosophy, the informants reported reduced access for students with developmental disabilities to non-required language programmes, such as dual-language or immersion programmes (de Valenzuela et al., 2016). Furthermore, the findings of de Valenzuela et al.'s study (2016) signify a link between access to and participation in language programmes, and the SEN of students, as students with more severe disabilities were less likely to have access to language programmes than other students with disabilities. Cummins (1984) also presents findings which concur with the idea that a "pushout phenomenon" (p. 176) has existed for learners attending immersion programmes, who experience learning difficulties, from immersion to non-immersion settings in the USA and Canada. According to Cummins (1984), it is vital that education professionals address this problem in order to prevent the loss of L2 language skills for these learners and to prevent potential negative implications for their self-esteem. Furthermore, Cummins (1984) outlines that encouraging learners with SEN to transfer from immersion to non-immersion settings could also have implications for society, by suggesting that second language learning should be reserved for "an elite group of students" only (p. 176).

Kay-Raining Bird et al. (2016a) assert that there is insufficient evidence to warrant such recommendations to parents of children with specific language difficulties, autism spectrum disorder (ASD) or Down syndrome. Similarly, Uljarevic et al.'s findings (2016) indicate that multilingualism does not have a negative impact on the development of individuals with communication conditions, ASD or intellectual disabilities. In fact, of the 10 studies which explored the effects of multilingualism on children with ASD, all studies indicated that there were either no differences in the performance of multilingual children in comparison to monolingual children, or that the multilingual children outperformed the monolingual children with ASD (Uljarevic et al., 2016). Furthermore, findings from a review by Genesee (2007) presented similar findings. According to Genesee (2007), there is more substantial research evidence available which demonstrates the benefit of attending IE settings for children who experience academic or language-learning difficulties than research evidence which demonstrates that these students may benefit academically, or in relation to language development, if they transfer out of IE settings to non-immersion programmes. In addition, following a review of research data related to the suitability of immersion programmes for minority and majority language students with and without learning difficulties, Cummins (1984) proposes that immersion programmes which are "properly understood and implemented" are suitable for all students.

Moreover, in Ireland, where immersion and non-immersion education settings are required to teach Irish as well as English, many learners with SEN receive exemptions from the study of Irish (O'Duibhir, 2019). Although it is recommended that language exemptions are only provided in rare and exceptional circumstances, it appears that they are provided to learners with SEN "often and routinely" (O'Duibhir, 2019). For instance, findings from a study by Tynan (2018) demonstrated that learners with Williams Syndrome were routinely provided with an exemption from learning Irish, despite relatively strong language abilities and capability for language learning being characteristic of the educational profile of these learners. In addition, Ware et al. (2009) found that Irish is not generally taught in special education settings, including special schools or special classes for students with intellectual disabilities. Similarly, although Welsh is taught in all schools in Wales owing to Welsh legislation and attempts to preserve the Welsh language, it was reported that five out of 20 students with Down syndrome in Ward and Sanoudaki's study (2021a) did not receive Welsh language input in school as a result of reports which exempted them from Welsh language learning. Similar 'opt-out' provisions exist for students with disabilities learning a second or foreign language in certain regions of Canada and the USA (Pesco et al., 2016).

Therefore, it appears that learners with SEN receive fewer opportunities to learn more than one language than their typically-developing peers, owing to the fact they receive language exemptions (Pesco et al., 2016; Tynan, 2018; Ward & Sanoudaki, 2021a), that their parents are advised to speak to them in one language only (Cioè-Peña, 2020; Howard et al., 2021; Jegatheesan et al., 2010; Kay-Raining Bird et al., 2012; Kim, 2017; Kremer-Sadlik, 2005; Yu, 2013), that opportunities to learn a language through immersion may not be available in special education settings (Ware et al., 2009) and that parents are recommended by education professionals to transfer them from IE settings to non-immersion education settings (Genesee, 2007; Hampton et al., 2017; Martínez-Álvarez, 2019; Nic Aindriú, 2021a). Similar to Kay-Raining Bird et al. (2016a), Martínez-Álvarez's review (2019) also indicated that learning two languages or attending a bilingual education setting does not pose additional challenges for children with either speech and language difficulties, specific learning disabilities or ASD. In this way, bilingual exposure does not hinder children's language development (Hambly & Fombonne, 2012). Additionally, Martínez-Álvarez's review (2019) demonstrated that learners with SEN can not only learn two languages, but can become competent bilingual speakers. These findings include children with an intellectual disability and children with Down syndrome, of whom bilingualism has been found to enhance their ability to initiate a response and answer questions during social interactions (Martínez-Álvarez, 2019). However, it must be noted that the studies included in Martínez-Álvarez's review (2019) focused on language outcomes for children with SEN or Down syndrome, rather than cognitive or socio-emotional outcomes as investigated in other studies examining the impact of bilingual education on typically-developing children.

Immersion Education for Students with Down Syndrome

As was previously mentioned, Down syndrome is the most prevalent chromosomal condition and most common genetic cause of intellectual disability across the globe. Consequently, research to enhance understanding of Down syndrome across educational and clinical domains is critical for developing effective interventions to support individuals with Down syndrome across their lifespan (Hendrix et al., 2021). The aforementioned advantages of bilingualism, including cognitive advantages and the positive impact of bilingualism on children's socio-emotional development reported in previous literature, may specifically benefit young children with Down syndrome, as studies indicate that children with Down syndrome exhibit relative weaknesses in executive functioning in comparison to their typically-developing peers (Borella et al., 2013; Campbell et al., 2013; Doerr et al., 2019; Godfrey & Raitano Lee, 2018; Lanfranchi et al., 2010; Loveall et al., 2017; Tungate & Conners, 2021). Furthermore, while researchers have reviewed potential outcomes for bilingual or multilingual children with Down syndrome or intellectual disabilities (Kay-Raining Bird et al., 2016a; Martínez-Álvarez, 2019; Uljarevic et al., 2016; Ware et al., 2015), no study to date has systematically reviewed potential cognitive and socio-emotional outcomes for children with Down syndrome who attend IE settings. Accordingly, the present review aims to fill this gap in Down syndrome and bilingual research.

Rationale and Research Objectives

The need for education settings to become more inclusive is a consensus that exists in educational realms across the globe (Azorín & Ainscow, 2020; Norwich, 2013; Vislie, 2003), in line with the UN Convention on the Rights of Persons with Disabilities (UN, 2006). In many jurisdictions, inclusion is protected and promoted by legislation such as the EPSEN Act (Government of Ireland, 2004) in Ireland or the Special Educational Needs and Disability

(SEND) Code of Practice: 0 to 25 Years (Department for Education and Department of Health, 2015) in the United Kingdom (UK). In short, inclusive education aims to meet the diverse needs of all learners (Fitzgerald & Radford, 2020). In Ireland, inclusive education is defined in the EPSEN Act (Government of Ireland, 2004, Section 1) as an inclusive environment, wherein children with SEN shall be educated alongside their peers, who do not have SEN, "unless the nature or degree of those needs of the child is such that to do so would be inconsistent with (a) the best interests of the child.... [and] (b) the effective provision of education for children with whom the child is to be educated." The SEND Code of Practice (Department for Education and Department of Health, 2015) also refers to the commitment of the UK government to provide inclusive education opportunities for students with disabilities. It asserts that children with SEN should be educated in mainstream education, in line with the Children and Families Act (Department for Education, 2014).

However, previous research demonstrates that learners with Down syndrome or additional needs receive fewer opportunities to learn two languages than their typicallydeveloping peers as a result of recommendations by education professionals to parents of these children to transfer their children from IE programmes and to limit language learning to one language only within the home (Cioè-Peña, 2020; Howard et al., 2021; Jegatheesan et al., 2010; Kay-Raining Bird et al., 2012; Kim, 2017; Kremer-Sadlik, 2005; Martínez- Álvarez, 2019; Yu, 2013). Furthermore, many children with SEN across the globe receive language exemptions from the study of an additional language, which further limits their opportunity to learn a second language (O'Duibhir, 2019; Pesco et al., 2016; Tynan, 2018; Ward & Sanoudaki, 2021b). The present review aims to analyse previous research to investigate the impact that IE settings may have on the cognitive and socio-emotional development of children with Down syndrome. It is hoped that the findings of the review will provide more information about bilingualism for parents of children with Down syndrome, which may
support their decision-making regarding educational placement and language learning for their children (Kay-Raining Bird et al., 2016b). In addition, the review aims to provide education professionals with more information about how bilingualism and IE may impact children with Down syndrome. Subsequently, it is hoped that the findings could inform the recommendations made by education professionals to parents of children with Down syndrome or additional needs, as education settings become more inclusive environments across the world. For instance, a role held by educational and child psychologists is to draw on research and to identify evidence-informed interventions when engaging in consultation with children, parents and other professionals (The British Psychological Society, 2022).

In summary, owing to the focus on bilingual outcomes for bilingual children with Down syndrome in previous research, the potential advantages that IE might offer to learners with Down syndrome in relation to cognitive and socio-emotional development, and the need for education systems to be more inclusive, it is evident that a review of the potential cognitive and socio-emotional outcomes of attending IE settings for children with Down syndrome is necessary. Consequently, the present study aims to address the following research question: What are the cognitive and socio-emotional outcomes of attending IE settings for school-age learners with Down syndrome, in comparison to non-immersion education settings?

Method

Literature Search

A review of previous literature is an essential component of academic research, as knowledge is constructed and advanced from the findings of prior research and academic works (Xiao & Watson, 2019). Literature reviews allow researchers to examine studies to identify gaps and to challenge or extend previous research (Ridley, 2012). However, if literature reviews are not undertaken using a clear and replicable methodology, they may be susceptible to bias, which might produce skewed findings in relation to the research topic under review (Gough et al., 2012). Unless an explicit protocol is utilised during a literature review, researchers may subconsciously select studies for review that support the review question and hypotheses or corroborate particular research findings. Potentially relevant research articles may be left out of a literature review if a thorough search strategy is not employed by reviewers (Winchester & Salji, 2016). Consequently, an unbiased, systematic and rigorous approach to a literature review requires adherence to a coherent methodology, as literature reviews are also pieces of research themselves (Gough et al., 2012).

A comprehensive literature search was undertaken between 26 July, 2021, and 6 August, 2021, using the following databases: PsychInfo, Education Source, Educational Resources Information Centre (ERIC), Communication Source and PubMed®. The search terms presented in Table 1 were used to conduct the search, which produced 71 results across all databases. Next, duplicate results and sources that were not journal articles were removed, resulting in 30 articles. Subsequently, the remaining articles were screened by title and abstract, which excluded a further 14 studies in accordance with the following exclusion criteria: (a) the article was not peer-reviewed or written in the English language; (b) the study did not include bilingual children aged 4 - 18 years with a diagnosis of Down syndrome, who receive the majority of formal instruction through their second language; (c) the study did not examine cognitive and socioemotional outcomes related to the impact of IE and (d) the study did not include quantitative and validated measures of cognitive or socioemotional skills. Consequently, the full-texts of the remaining 16 articles were assessed for eligibility and 5 of these articles, which met the inclusion criteria, were included in the systematic review. The search selection process, following PRISMA protocols (Page et al., 2021), is displayed in Figure 3. A list of excluded studies is included in Appendix B (Tables 2-3), indicating the

various phases of the search process during which studies were excluded, and the exclusion criteria.

Table 1

Database Search Terms

Participants		Intervention
"Down syndrome"	AND	"Immersion Education" OR "Bilingualism" OR "English as a Foreign Language" OR "Second Language"

Figure 3

PRISMA Flow Diagram Demonstrating Search Strategy (Page et al., 2021)



Mapping the Field and Framework for Review

An overview of the five selected studies is represented in Table 4, outlining the research design, country of study, participant characteristics, details of the IE setting, measures used, and the main findings from each study in relation to IE. Gough's Weight of Evidence (WoE) (2007) framework was used to analyse and critique the selected studies in three areas related to study quality. For instance, the initial stage of the framework, WoE A, evaluated the methodological quality of the studies. Subsequently, WoE B determined the relevance of the identified studies' methodologies in relation to the present review question. Thirdly, WoE C assessed the relevance of the evidence presented within the selected studies in relation to the present review. The results of WoE A, B and C were then combined to establish an overall weighting score (WoE D) for each of the six studies to establish the extent to which each study provides evidence to address the current review question.

Table 4

Mapping the Field

	Author and Country of Study	Participants (Included in Review)	Research Design	Immersion Education Setting	Measures of Cognitive or Socio-emotional Development	Findings
1	Author: Burgoyne et al. (2016) <u>Country:</u> England, The UK	 Total Participants (n = 33) <u>Bilingual Down syndrome</u> <u>Participant (MB):</u> 1 child with Down syndrome aged 6 years 11 months (Test Point 1) – 7 years 9 months (Test Point 2) - 9 years 6 months (Test Point 3). L1 of Participant: Russian L2 of Participant: English <u>Comparison Groups:</u> Down syndrome Monolingual English Comparison Group (n = 6), aged between 8 years 1 month – 10 years Typically-Developing (TD) Monolingual English Comparison Group (n = 15) aged between 7 years 2 months – 7 years 10 months Typically-Developing Monolingual Russian Comparison Group (n = 11) aged between 6 years 0 months – 7 years 0 months, living in Moscow, Russia. 	Single case study with comparison groups and longitudinal design 1. Bilingual Down syndrome (Russian/En glish) 2. Monolingual (English) Down syndrome 3. TD Monolingual (English) 4. TD Monolingual (Russian)	Bilingual Down syndrome participant attending an English-medium (L2) mainstream primary school. Bilingual Down syndrome participant had also received a 40-week (40 mins per day, 5 days a week) Reading and Language intervention (Burgoyne et al., 2012), based on 'Reading Intervention' (Hatcher et al., 1994), the multiple context approach (Beck et al., 2002), and target words from parent- completed vocabulary checklists (Down syndrome Education International, 2000)	Literacy skills: YARC Early Word Reading YARC Single Word Reading Syllable deletion English Phoneme deletion Russian Phoneme deletion Russian Phoneme deletion Russian Phoneme deletion Russian Phoneme isolation English Phoneme isolation Russian Letter Knowledge English Letter Knowledge Russian Bespoke Word Reading English Bespoke Word Reading Russian Bespoke Nonword Reading Russian GNWRT Nonword Reading Russian GNWRT Nonword Reading YARC Passage Reading Language skills: British Picture Vocabulary Scale (BPVS-111) BPVS Russian translation CELF-IV Expressive Vocabulary CELF-IV Expressive Vocabulary Russian translation Nonverbal ability: Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III) Block Design and Object Assembly Working Memory Test Battery for Children (WMTBC) Block recall Verbal memory: WMBTC Digit Recall and Word Recall	Cognitive Skills: The bilingual participant with Down syndrome's (MB) cognitive profile is consistent with the level of a child with an intellectual disability, attaining significantly lower scores than her TD peers. On nonverbal ability and verbal memory tests, there was no statistical difference between MB and her monolingual peers with Down syndrome, which indicates that bilingualism/IE did not have a statistically significant impact on her cognitive skills. L1 and L2 Reading Skills Over a 2.5-year period MB consistently performed at age-expected levels (of TD peers reading in L1) on standardised tests. MB performed better than 91% of her monolingual peers in L2 word reading, indicating that children with Down syndrome can display competent levels of word reading in 2 languages. MB's reading comprehension levels in her L2 was similar to her Down syndrome peers, falling in the low to below average range. MB's word reading skills were similar in L1 and L2. In comparison with TD Russian peers, MB demonstrated lower scores on nonword reading and letter-sound knowledge. However, she scored similarly on Russian phonological awareness tasks. Main findings are that IE did not appear to have an impact on MB's cognitive profile, L1 or L2 reading skills are as a result of her excellent home literacy environment rather than from bilingualism or IE.

2	Author: Feltmate & Kay-Raining Bird (2008) Country: Canada	Total Participants $(n = 12)$, matched on nonverbal cognitive abilities. Triad 1 $(n = 3)$: Bilingual Child with Down syndrome TD Bilingual Child Monolingual Child with Down syndrome Triad 2 $(n = 3)$: Bilingual Child with Down syndrome (Attending IE; L1 of Participant: English, L2 of Participant: French) TD Bilingual Child Monolingual Child with Down syndrome Triad 3 $(n = 3)$: Bilingual Child with Down syndrome TD Bilingual Child Monolingual Child with Down syndrome TD Bilingual Child with Down syndrome TD Bilingual Child with Down syndrome	Cross-sectional between triads design	l participant, a bilingual child with Down syndrome, in Triad 2 attended a French immersion primary school prior to data collection.	 English language measures: Peabody Picture Vocabulary Test-Revised (PPVT- R; Dunn & Dunn, 1981) Preschool Language Scale (3rd edition; PLS-3; Zimmerman, Steiner & Pond, 1992) English language measures: Echelle de vocabulaire en images Peabody, Form A (EVIP; Dunn, Theriault-Whelan, & Dunn, 1993) French language sample 	The only finding in relation to IE was that out of all four bilingual children with Down syndrome, the participant who demonstrated the greatest French language ability on French language sample measures was the participant who had attended a French immersion school prior to data collection. This finding indicates that IE may be an effective way for children with Down syndrome to learn a second language, especially when the child is being raised in a bilingual home environment.
		syndrome TD Bilingual Child Monolingual Child with Down syndrome				
3	<u>Author:</u> Martin et al. (2021) <u>Country:</u> Canada	Total Participants $(n = 9)$ <u>Bilingual Participant with Down</u> <u>syndrome $(n = 1)$:</u> Male with pseudonym Jake. Jake was 12 years 2 months at Test Point 1 (T1) and 14 years 3 months at Test Point 2 (T2) L1 of Participant: English L2 of Participant: French <u>Monolingual Participants with</u> <u>Down syndrome $(n = 8)$:</u>	Single case study with comparison group and longitudinal design	1 participant, a bilingual child with Down syndrome (Jake) was attending an early French immersion programme since Grade 3. Between Grade 3 – 5, Jake received 80% of instruction in French (L2). Between Grade 6 – 8, Jake received 70% of	 English language measures: CELF-IV (Wiig et al., 2003) (Three subtests: Concepts and Following Directions, Word Structure and Recalling Sentences) Woodcock Reading Mastery Tests – 3rd edition (WRMT-III, Woodcock, 2011) (Two subtests: Word Identification and Word Attack) <u>French language measures:</u> Évaluation Clinique des Notions Langagières Fondamentales (CELF-IV CDN-FR, Wiig et al., 2009) 	Longitudinal findings: Results from T1 and T2 demonstrated that Jake was becoming bilingual and biliterate in French and English. Jake's L1 abilities were more advanced than his L2 (French) abilities at both T1 and T2. In addition, Jake made progress in his L1 skills but not in his L2 (French) skills between T1 and T2, despite receiving at least 70% of instruction through L2. However, interviews with Jake's mother and teachers indicate that Jake had experienced enormous personal upheaval between T1 and T2, including the death of his father and transition to a new school, which may have impacted his L2 progress.

		Three females and 5 males, aged between 12 years 1 month and 17 years 9 months		instruction through French (L2)	 (Three subtests: Concepts et Exécution de Directives, Morphologie, and Répétition de Phrases) Test de Rendement Individual de Wechsler (WIAT-II FR, Wechsler, 2005). (Two subtests: Lecture de mots and Décodage de Pseudo-mots) <u>Nonverbal ability (Visual memory and reasoning):</u> Stanford-Binet Intelligence Scale, fourth edition (SB-IV; Thorndike et al., 1986) (Two subtests: Bead Memory and Pattern Analysis) <u>Verbal memory:</u> Wechsler Intelligence Scale for Children-IV (WISC-IV; Wechsler, 2003) (Two subtests: Forward Digit Span and Backwards 	<u>Comparative findings:</u> In comparison to the monolingual group with Down syndrome, who were similar to Jake in age, nonverbal mental ability and mother's educational level, Jake outperformed all monolingual participants on all English language measures (language and reading), except for one participant who was the oldest participant (age = 17 years, 1 months; nonverbal mental age = 7 years 11 months). However, the only statistically significant difference was between Jake and the monolingual group's ability to recall sentences in English. It is possible that Jake's more advanced L1 abilities are as a result of bilingualism, as L2 learning enhances metalinguistic awareness,. Alternatively, it is possible that Jake's advanced L1 abilities in comparison to the monolingual group is because of his parent's advocacy and support (Jake's mother was a Franch immarian teacher at his school)
					Digit Span)	was a French immersion teacher at his school).
4	<u>Author:</u> Ward & Sanoudaki (2021b) <u>Country:</u> Wales, UK.	 Total Participants (n = 54) <u>Bilingual Participants with Down</u> <u>syndrome & ASD (n = 4):</u> Dylan (male, age 10 years 5 months, L1 = Welsh, L2 = English) Catrin (female, age 13 years 3 months, L1 = English, L2 = Welsh) Owain (male, age 16 years 8 months, L1 = Welsh, L2 = English) Rhiannon (female, age 6 years, 8 months, L1 = English, L2 = Welsh) **NB: Rhiannon was the only participant attending an immersion setting in her L2** 	Multiple case study design with comparative groups	The study only provided details of the education settings and L1s of the bilingual participants with Down syndrome & ASD. Rhiannon was the only participant receiving the majority of formal instruction through her L2.	 English language measures: Clinical Evaluation of Language Fundamentals – Preschool Second UK Edition (CELF-P; Wiig et al., 2006) Rhyme Identification (Kennedy & Flynn, 2003; Cupples & Iacano, 2000) Rhyme Generation (Boudreau, 2002) Syllable Segmentation (Swank & Catts, 1994; Boudreau, 2002) Syllable Deletion (Verucci et al., 2006) Initial Phoneme Matching (Cupples & Iacano, 2000) Phoneme Segmenting (Cupples & Iacano, 2000) Welsh language measures: Receptive vocabulary subtest of the Prawf Geirfa Cymraeg: Fersiwn 7–11 (The Welsh Vocabulary Test: Version 7–11; Gathercole & Thomas, 2007) Rhyme Identification (Kennedy & Flynn, 2003; Cupples & Iacano, 2000) Rhyme Generation (Boudreau, 2002) Syllable Segmentation (Swank & Catts, 1994; Public Medication (Swank & Catts, 1994; Public Medication) 	As the study only provided details of the L1/L2 and education settings of the 4 case study participants, it is difficult to draw conclusions about the impact of IE in comparison to the control groups. Of the case study participants, only 1 participant (Rhiannon), was receiving the majority of formal instruction through L2. Notably, there were no statistically significant differences between Rhiannon's L1 scores and the English language scores of the Down syndrome comparative groups, which indicates that immersion instruction in L2 did not hamper the development of her L1 skills. Rhiannon's Welsh receptive scores were significantly lower than the bilingual group with Down syndrome only, however, this group were exposed to Welsh, 50% of the time, on average, in comparison to Rhiannon's 20% Welsh exposure. Therefore, the difference in receptive Welsh scores may be as a result of the amount of language exposure in Welsh. Furthermore, there were no statistical differences between Rhiannon and the bilingual Down syndrome group's Welsh
		 Comparison Groups: Bilingual children with Down syndrome (n = 10) TD Bilingual children (n = 25) 			 Boudreau, 2002) Syllable Deletion (Verucci et al., 2006) Initial Phoneme Matching (Cupples & Iacano, 2000) Phoneme Segmenting (Cupples & Iacano, 2000) Nonverbal ability: 	phonological awareness scores, which indicates that while Rhiannon received less Welsh exposure (30%) than the comparison group, she had similar phonological awareness skills, potentially as a result of receiving instruction through Welsh. Rhiannon was also the only participant who had a diagnosis of mosaic Down syndrome rather than

		• Monolingual children with Down syndrome (n = 15)			• <u>Woi</u>	Matrices subtest of the Kaufman's Brief Intelligence Test (KBIT-II; Kaufman & Kaufman, 2004) <u>rking memory:</u> Forwards Digit Span test	Trisomy 21, which means that her results need to be analysed with caution, as children with mosaic Down syndrome do not usually experience impairments in cognitive functioning to the same extent as children with a diagnosis of Trisomy 21 (Papavassiliou et al., 2015; Zhao et al., 2015)
							Regarding the suitability of bilingualism and IE for children with dual diagnosis of Down syndrome and ASD, although substantial variability was found between case study participants and groups, participants with Down syndrome & ASD were able to become bilingual, similar to children with a diagnosis of Down syndrome only, in line with the degree of exposure to each language.
5	<u>Author:</u> Woll & Grove (1996) <u>Country:</u> England, UK	Total Participants (<i>n</i> = 2) Bilingual twin sisters with a diagnosis of mosaic Down syndrome, named Ruthie and Sally, aged 10 years at time of data collection. L1 = British Sign Language (BSL) L2 = English	Case study design	Ruthie and Sally were attending a mainstream English (L2)-medium primary school.	Eng • • BSI • • • • • • • • •	 <u>Rish language measures:</u> The British Picture Vocabulary Scale (BPVS) (Dunn et al., 1981), receptive vocabulary and grammatical structure subtests. Test of Reception of Grammar (TROG) (Bishop, 1989) Edinburgh Articulation Test (EAT) (Anthony, Bogle, Ingram, & McIsaac, 1971) Mean Length Utterance (MLU, Brown, 1973) <u>— measures:</u> Researcher-designed BSL battery of tests MLU (Brown, 1973) <u>mitive skills:</u> The Snijders-Oomen Test of Non-verbal Intelligence (SON, Snijders & SnijdersOomen, 1976) Illinois Test of Psycholinguistic Abilities (ITPA) (Kirk, McCarthy, & Kirk, 1982)	Although research indicates that children with Down syndrome exhibit relative strengths in visuospatial processing, the findings of this study demonstrate that the participants do not find the linguistic system of a sign language (visual) easier to master or develop than a that of a spoken language. In fact, although BSL was the first language of the participants, their dominant language is now English, which might be as a result of the amount of English they are exposed to or as a result of being educated through English. The findings challenge previous hypotheses that a signed language may be easier to acquire by children with Down syndrome than a spoken language, which has implications for visual intervention practice for children with Down syndrome.

Table 5

Methodological Quality Criteria adapted from Nha Hong et al.'s Mixed Methods Appraisal Tool (2018)

		Burgoyne et al. (2016)	Feltmate & Kay- Raining Bird (2008)	Martin et al. (2021)	Ward & Sanoudaki (2021b)	Woll & Grove (1996)
Qu	antitative Non-randomised Design					
1.	Are the participants representative of the target population?	Yes	Yes	Yes	Yes	Х
2.	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Yes	No	Yes	No	Х
3.	Are there complete outcome data?	Yes	Yes	Yes	No	Х
4.	Are the confounders accounted for in the design and analysis?	Yes	Yes	Yes	Yes	Х
5.	During the study period, is the intervention administered (or exposure occurred) as intended?	Yes	Yes	No	Yes	Х
Qu	antitative Descriptive Design					
1.	Is the sampling strategy relevant to address the research question?	Х	Х	Х	Х	Yes
2.	Is the sample representative of the target population?	Х	Х	Х	Х	No
3.	Are the measurements appropriate?	Х	Х	Х	Х	Yes
4.	Are there complete outcome data?	Х	Х	Х	Х	Yes
5.	Is the statistical analysis appropriate to answer the research question?	Х	Х	Х	Х	Yes
Wo	DE Quality Score as a Percentage (% of 'Yes'	100%	80%	80%	60%	80%
Re	sponses)					
Wo	DE A Quality Rating Score	3	3	3	2	3
Wo	DE A Descriptive Quality Rating	High	High	High	Acceptable	High

Weight of Evidence A: Methodological Quality

The WoE A analysed the methodological quality of the studies using Nha Hong et al.'s

(2018) Mixed Methods Appraisal Tool (MMAT), as contrasting research designs were

employed in the five selected studies (Table 5). The MMAT (Nha Hong et al., 2018) indicated

that four of the studies should be assessed using the quantitative non-randomised

methodological quality criteria (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008;

Martin et al., 2021; Ward & Sanoudaki, 2021b). The MMAT (Nha Hong et al., 2018) outlined

that the remaining study should be assessed in accordance with the quantitative descriptive methodological quality criteria (Woll & Grove,1996). As Nha Hong et al. (2018) do not advise computing an overall score from the ratings of each criterion, Gough's WoE Framework (2007) was the principal measure used for the appraisal of selected studies. Consequently, the presence or absence of methodological criterion, depicted in the coding protocol in Table 5, were identified and scored (Yes = 1, No = 0). Next, a quality score was calculated as a percentage [(Number of 'Yes' responses divided by the five relevant criteria) x 100] and converted into WoE Quality Rating Scores and WoE Descriptive Quality Ratings.

Weight of Evidence B: Methodological Relevance

The Muir Gray (1997) matrix, which determines whether the research design of a study offers an appropriate format of answering the research question posed (Petticrew & Roberts, 2003), was used to appraise the methodological relevance, WoE B, of the five studies identified for review. Further, the Muir Gray (1997) matrix was chosen to assess the WoE B of selected studies because of the emerging evidence regarding the wider generalisability or applicability of the "hierarchy of evidence" approach in evaluating the methodological relevance of research (Petticrew & Roberts, 2003). For instance, Muir Gray (1997) assert that randomised controlled trials (RCTs), case-control, quasi-experimental studies and cohort studies are most appropriate for answering research questions addressing the safety or effectiveness of an intervention. In accordance with the "hierarchy of evidence," RCTs are regarded as the most suitable research methodology for investigating effectiveness or safety of an intervention (Petticrew & Roberts, 2003). The present review aimed to examine the impact of IE on the cognitive and socio-emotional development of school-aged children with Down syndrome. Correspondingly, Table 6 and Table 7 (Appendix C) represent the scoring criteria and rationale used to determine the methodological relevance of RCTs, case-control, quasi-

experimental and cohort studies, and single-case design studies in answering this research

question.

Table 6

WoE	WoE B	Study	Rationale
В	Descriptive	-	
Rating	Quality		
Score	Rating		
2	Acceptable	Burgoyne et al. (2016)	A quasi-experimental, case-control or cohort design was used.
2	Acceptable	Feltmate & Kay-	A quasi-experimental, case-control or cohort design was used.
		Raining Bird (2008)	
2	Acceptable	Martin et al. (2021)	A quasi-experimental, case-control or cohort design was used.
2	Acceptable	Ward & Sanoudaki	A quasi-experimental, case-control or cohort design was used.
		(2021b)	
1	Low	Woll & Grove (1996)	A case report design was used

Overall WoE B: Methodological Relevance Scores

Weight of Evidence C: Relevance of Evidence

The WoE C of Gough's WoE Framework (2007) is a review-specific judgement concerning the relevance of evidence described in the five studies selected for review in relation to the review question. As the present review was examining the impact of IE on the cognitive and socio-emotional development of school-aged children with Down syndrome, the following criteria were included in the WoE C: immersion setting of participants, control group participant characteristics and quantitative measures of cognitive and socio-emotional skills. A rubric including coding protocol was developed to score three WoE C criteria (Table 8, Appendix D). By way of example, the IE setting of bilingual participants was scored in accordance with the number of bilingual participants that were attending an IE setting, wherein they were receiving the majority of their formal instruction in their L2, as this would allow for an assessment of the impact of IE. Table 9 illustrates the total WoE C rating scores, produced by calculating the mean score for the three WoE C criteria, and the descriptive quality rating assigned to each study.

Table 9

WoE C Overall Relevance of Evidence Rating Scores and Descriptive Quality Ratings²

	Burgoyne et al. (2016)	Feltmate & Kay-Raining Bird (2008)	Martin et al. (2021)	Ward & Sanoudaki (2021b)	Woll & Grove (1996)
Immersion Setting of Participants	2	2	3	2	3
Research Design	2	2	2	3	1
Quantitative Measures of Cognitive and Socio- emotional Skills	2	2	2	2	2
Total	6	6	7	7	6
Total WoE C Rating Score (Mean score of 3 criteria)	2	2	2.33	2.33	2
Total WoE C Descriptive Quality Rating	Acceptable	Acceptable	High	High	Acceptable

Weight of Evidence D: Overall Weighting

The WoE D of Gough's WoE Framework (2007) provides an overall weighting score for the five included in the present review. Accordingly, the mean score for the WoE A, WoE B and WoE C assigned to each study was calculated to produce an overall weighting score, the WoE D. Table 10 displays a summary of all of the WoE scores appointed to the selected

² *Note.* Scores of 2 and over are allocated a 'high' descriptive quality rating, whilst scores of 1 - 2 are considered 'acceptable' and between 0 - 1 are assigned a 'low' descriptive quality rating.

studies, providing information about the methodological quality, methodological relevance,

relevance of evidence and overall weighting score for each study.

Table 10

	Burgoyne et al. (2016)	Feltmate & Kay-Raining Bird (2008)	Martin et al. (2021)	Ward & Sanoudaki (2021b)	Woll & Grove (1996)
WoE A Score and	3	3	3	2	3
Descriptive Quality	(High)	(High)	(High)	(Acceptable)	(High)
WoE B Score and	2	2	2	2	1
Descriptive Quality	(Acceptable)	(Acceptable)	(Acceptable)	(Acceptable)	(Low)
· · ·	· • •	· •	· • •		
WoE C Score and	2	2	2.33	2.33	2
Descriptive Quality	(Acceptable)	(Acceptable)	(High)	(High)	(Acceptable)
· · ·	· • •				· • •
Total	7	7	7.33	6.33	6
WoE D Rating					
Score					
(Mean Score of	2.33	2.33	2.44	2.11	2
WoE A, B & C)					
WoE D					
Descriptive	Acceptable	Acceptable	High	Acceptable	Acceptable
Quality Rating					

Summary of All WoE Rating Scores and Descriptive Quality Ratings³

Results

Participants

A total of 110 children participated in the five studies included in the current review,

including 55 children with Down syndrome and 55 typically-developing children. The sample

size ranged from n = 2 (Woll & Grove, 1996) to n = 54 (Ward & Sanoudaki, 2021b). The age

³ *Note.* Scores of 2.4 and over are allocated a 'high' descriptive quality rating, whilst scores of 1.5 - 2.4 are considered 'acceptable' and between 0 - 1.5 are assigned a 'low' descriptive quality rating.

of participants was described in all five studies and was an important factor in this review, as the focus of the review was on the impact of IE on school-aged children with Down syndrome. The age of the youngest participants with Down syndrome was 6 years and 8 months (Ward & Sanoudaki, 2021b), the age of the oldest participant with Down syndrome was 17 years and 9 months (Martin et al., 2021).

Fifty-one participants had a diagnosis of Down syndrome alone (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021; Ward & Sanoudaki, 2021b; Woll & Grove, 1996), whilst four participants had a dual diagnosis of Down syndrome and ASD (Ward & Sanoudaki, 2021b). Of the participants who had a diagnosis of Down syndrome, one participant had Robertsonian Translocation Down syndrome (Martin et al., 2021), three participants had mosaic Down syndrome (Ward & Sanoudaki, 2021b; Woll & Grove, 1996), whilst the remaining participants with Down syndrome had a diagnosis of Trisomy 21 (Burgoyne et al., 2016; Feltmate et al., 2008, Martin et al., 2021; Ward & Sanoudaki, 2021b). While findings are inconsistent in relation to the differences between Trisomy 21 and Robertsonian translocation Down syndrome (Karmiloff-Smith et al., 2016; Leung, 2006; Prasher, 1995), research indicates that children with mosaic Down syndrome may not exhibit cognitive functioning difficulties to the same extent as children with Trisomy 21 or Robertsonian translocation Down syndrome (Papavassiliou et al., 2015; Zhao et al., 2015), therefore it is important for researchers to provide data about the type of Down syndrome that participants have when investigating the impact of an intervention on the cognitive development of participants with Down syndrome.

The country of origin of participants varied between studies, including participants from England, Wales, Canada and Russia. The first languages of the bilingual participants with Down syndrome attending IE settings were also different across studies, including English (Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021; Ward & Sanadouki, 2021), Welsh (Ward & Sanadouki, 2021), Russian (Burgoyne et al., 2016) and British Sign Language (Woll & Grove, 1996). Regarding the language of the immersion settings, two studies included French-medium schools (Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021), one study included Welsh-medium schools (Ward & Sanadouki, 2021), whilst the remaining studies included English-medium schools (Burgoyne et al., 2016; Martin et al., 2021; Woll & Grove, 1996). Incomplete outcome data and limited information about procedures used to increase the likelihood that demographic characteristics of participants (age, gender, language exposure, first language, socioeconomic status etc.) were comparable between participants or between groups contributed to a lower WoE A methodological quality score in one study (Ward & Sanoudaki, 2021b).

Research Design

All studies selected for review were non-randomised studies, with two studies employing a case-control design (Burgoyne et al., 2016; Martin et al., 2021), one study employing a multiple case-control design (Ward & Sanoudaki, 2021b), one study employing a bilingual Down syndrome-monolingual Down syndrome-typically-developing bilingual triad design (Feltmate & Kay-Raining Bird, 2008), and one study employing a multiple case study design (Woll & Grove, 1996). In addition, two studies conducted follow-up assessments with the case study participants (Burgoyne et al., 2016; Martin et al., 2021), which provided details about the impact of IE over time. Furthermore, four studies included comparison groups or participants, namely monolingual participants with Down syndrome who were not attending IE settings (Burgoyne et al. 2016; Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021 Ward & Sanoudaki, 2021b), monolingual typically-developing participants, matched with Down syndrome participants on nonverbal mental age, who were not attending IE settings (Burgoyne et al., 2016) and bilingual typically-developing participants, matched with Down syndrome participants on nonverbal mental age (Feltmate & Kay-Raining Bird, 2008). Accordingly, the control groups allowed for greater interpretation of how IE may impact the cognitive and socio-emotional development of children with Down syndrome in comparison to their monolingual peers with Down syndrome, bilingual typically-developing peers and monolingual typically-developing peers, which is reflected in the WoE B scores of these studies (Appendix C).

While Petticrew and Roberts (2003, p. 528) refer to randomised control trials as 'gold standard' when evaluating effectiveness or safety in interventions, in this case random assignment to groups is not possible as the researchers could not control the 'immersion education' or 'bilingual' intervention. Non-randomisation affected the WoE B scores of the case-control studies with comparative groups (Burgoyne et al., 2016; Martin et al., 2021; Ward & Sanoudaki, 2021b) and the study with the triad design (Feltmate & Kay-Raining Bird, 2008), limiting the aforementioned studies to 'acceptable' quality ratings rather than 'high' quality rating scores. Further, Woll and Grove's (1996) study did not include a comparison group, which did not allow for interpretation of how IE may impact cognitive and socio-emotional development in school-aged children with Down syndrome. Three of the five studies had high ecological validity as they were conducted in the natural environment of the participants, such as in the participants' home (Martin et al., 2021; Ward & Sanoudaki, 2021b; Woll & Grove, 1996) or in the participants' school (Ward & Sanoudaki, 2021b; Woll & Grove, 1996).

Immersion Education Settings

Although all studies included at least one participant who had a diagnosis of Down syndrome attending an immersion setting, wherein the majority of formal instruction was provided in L2, only two studies contained the target participants of this review alone in the bilingual group of participants with Down syndrome (Burgoyne et al., 2016; Martin et al., 2021). For instance, Burgoyne et al.'s study (2016) included a school-aged participant with Down syndrome attending an English-medium school whose L1 was Russian and a comparison group of monolingual English-speaking children with Down syndrome, monolingual typically-developing Russian-speaking children and monolingual typically-developing English-speaking children. Further, Martin et al.'s (2021) study included a school-aged participant with Down syndrome attending a French-medium school whose L1 was English and a comparison group of monolingual English-speaking children with Down syndrome syndrome.

Alternatively, in Feltmate and Kay-Raining Bird's study (2008), which employed a triad design, only one participant (from Triad 2) with Down syndrome attended a French immersion primary school prior to data collection. Consequently, only the results of Triad 2 can be analysed in response to the present review's question, as the other triads did not include the target participants of the review: school-aged children with Down syndrome attending IE settings (Feltmate & Kay-Raining Bird, 2008). Furthermore, Ward and Sanoudaki's study (2021b) only provided details of the IE settings and L1 of the bilingual participants with dual diagnosis of Down syndrome & ASD, with only one participant receiving the majority of formal instruction through her L2. Similar to Feltmate & Kay-Raining Bird's study (2008) this means that Rhiannon's results (Ward & Sanoudaki, 2021b) can only be compared to the monolingual participants, as the bilingual participants in the control group may not have been receiving the majority of their formal instruction in their L2. Finally, the two participants in Woll and Grove's study (1996), Ruthie and Sally, were attending a mainstream English, their L2. Conversely, Woll and Grove's study (1996) did not include a comparison group who were

monolingual or who were not attending IE settings, which has implications for how the results of the study can be interpreted in relation to the review question.

Measures of Cognitive and Socio-Emotional Development

All five studies used appropriate measures to gather data regarding the cognitive development of participants through the use of a variety of established and reliable measures, including the York Assessment of Reading for Comprehension (YARC; Hulme et al., 2011), the Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III; Wechsler, 2003), the Working Memory Test Battery for Children (WMTBC; Pickering & Gathercole, 2001), the British Picture Vocabulary Scale (BPVS) (Dunn et al., 1981), the British Picture Vocabulary Scale (BPVS-III; Dunn et al., 2009), the Clinical Evaluation of Language Fundamentals (CELF-IV; Semel et al., 2003), the Graded Nonword Reading Test (GNWRT; Snowling et al., 1996), the Peabody Picture Vocabulary Test-Revised (PPVT-R; Dunn & Dunn, 1981), the Stanford-Binet Intelligence Scale (4th edition; S-B; Thorndike, Hagan, & Sattler, 1986), the Preschool Language Scale (3rd edition; PLS-3; Zimmerman et al., 1992), the Évaluation Clinique des Notions Langagières Fondamentales (CELF-IV CDN-FR, Wiig et al., 2009), the Woodcock Reading Mastery Tests - 3rd edition (WRMT-III, Woodcock, 2011), the Test de Rendement Individual de Wechsler (WIAT-II FR, Wechsler, 2005), the Prawf Geirfa Cymraeg: Fersiwn 7-11 (The Welsh Vocabulary Test: Version 7-11; Gathercole & Thomas, 2007), the Snijders-Oomen Test of Non-verbal Intelligence (SON) (Snijders & Snijders-Oomen, 1976), the Test of Reception of Grammar (TROG) (Bishop, 1989) and the Edinburgh Articulation Test (EAT; Anthony et al., 1971).

The use of appropriate measures is reflected in the methodological quality scores for each study. Furthermore, four studies collected data on cognitive abilities through measures designed by the researchers of each study (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Ward & Sanoudaki, 2021b; Woll & Grove, 1996). As recommended by Gersten et al. (2005), multiple measures for the assessment of participants' cognitive abilities were evident in all studies. Conversely, none of the studies included in the review provided information regarding the criterion-related validity and construct validity of the measures used. In addition, none of the five studies included in the review gathered data on the socioemotional development or abilities of participants, which means that the impact of IE on children with Down syndrome's socio-emotional development cannot be analysed in the present review.

The Impact of Immersion Education on the Cognitive and Socio-emotional Development of School-Aged Learners with Down syndrome

The focus of the present review was the impact of IE on the cognitive and socioemotional development of school-aged children with Down syndrome. Gough's WoE Framework (2007) was used to analyse and critique the methodological quality, methodological relevance, and the relevance of evidence of the five studies selected for review. The WoE D (Table 5) component of the framework indicates the overall capability of reviewed studies in answering the research question. In the present review, one study received a 'high' WoE D score of 2.44 (Martin et al., 2021). Alternatively, the remaining four studies obtained 'acceptable' WoE scores of 2.33 (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008), 2.11 (Ward & Sanoudaki, 2021b) and 2 (Woll & Grove, 1996) respectively.

All studies selected for review demonstrated evidence which indicated that immersion may be an effective approach to second language learning for school-aged learners with Down syndrome, as all participants attending IE settings had developed fluency in two languages (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021; Ward & Sanoudaki, 2021b; Woll & Grove, 1996). For instance, although the first and home language of the twin participants in Woll and Grove's study (1996) was British Sign Language, both participants had become fluent English speakers, and predominantly used English without signs or gestures when there were no individuals from the Deaf community in their presence. In addition, a bilingual participant with Down syndrome who had attended an immersion setting previously in Feltmate and Kay-Raining Bird's study (2008) outperformed all other bilingual participants with Down syndrome who had not attended immersion schools on French language measures. Furthermore, Jake, the learner with Down syndrome in Martin et al.'s study (2021) who had had very limited exposure to French prior to being enrolled in a French-immersion programme in Grade 3, attained French language scores in the 4–5-year age range and French reading scores in the 6–7-year age range when he was tested at 12 years 2 months. Jake also demonstrated the ability to code-switch from English to French when appropriate at school and in his community (Martin et al., 2021). Likewise, the bilingual participant with Down syndrome in Burgoyne et al.'s study (2016) also demonstrated competency in both L1 and L2 reading. In addition, the results of Ward and Sanoudaki's study (2021b) indicate that learners with a dual diagnosis of Down syndrome and ASD can also learn a second language successfully through IE.

Aside from language abilities, findings regarding the impact of attendance in IE settings on the cognitive development of school-aged learners with Down syndrome were limited across the five studies selected for review. For instance, Burgoyne et al.'s study (2016) was the only article selected for review that compared the cognitive abilities of a learner with Down syndrome attending an immersion setting and learners with Down syndrome who were not attending IE settings. Notably, on nonverbal ability and verbal memory tests, there was no statistical difference between the cognitive abilities of the participant attending an immersion setting and her peers with Down syndrome who were not attending IE settings, which indicates that bilingualism or IE did not have a statistically significant impact on her cognitive skills (Burgoyne et al., 2016). In addition, none of the five studies selected for review gathered quantitative data in relation to the socio-emotional skills of participants with Down syndrome who were attending IE settings.

Discussion

The aims of this systematic review were twofold. Firstly, the review sought to present a cohesive report of key findings which exist in literature investigating the impact of IE on the cognitive and socio-emotional development of school-aged learners with Down syndrome. Secondly, the review aimed to appraise the strength of the evidence reported in studies examining this research area, through Gough's WoE framework (2007). In summary, all five studies presented findings which indicate that IE is an effective approach to second language learning for school-aged learners with Down syndrome in relation to bilingualism and biliteracy (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021; Ward & Sanoudaki, 2021b; Woll & Grove, 1996), which is similar to previous findings including children with SEN (Martínez-Álvarez, 2019). Furthermore, IE did not have an adverse effect on the cognitive skills of participants with Down syndrome attending IE settings, as there were no statistical differences amongst bilingual and monolingual participants with Down syndrome (Burgoyne et al., 2016), contrary to the findings presented in Adesope et al.'s (2010) large-scale systematic review and meta-analysis on the cognitive correlates of bilingualism.

One study which received a 'high' overall weighting score (Martin et al., 2021), provides evidence which demonstrates that French-immersion did not have a negative impact on the bilingual participant's L1 language or reading skills and that IE allowed the participant to develop L2 oral language fluency and reading skills in French. These findings suggest that IE settings may be a beneficial environment for learners with Down syndrome who are acquiring a second language. However, these findings should be interpreted with caution owing to the case study design of the research, which only includes one bilingual child with Down syndrome, attending an IE setting (Martin et al., 2021). The four remaining studies received 'acceptable' overall weighting scores, which means that their results also need to be analysed with caution owing to limitations in the methodological quality and relevance of these studies, including small sample sizes, unequal samples in comparison groups and case study designs (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Ward & Sanoudaki, 2021b; Woll & Grove, 1996). Notably, none of the five studies selected for review collected data in relation to the socio-emotional development of participants, which prevented an analysis of socio-emotional outcomes for students with Down syndrome attending IE settings.

Limitations of the Research

The search terms used to conduct the literature search may have been too narrow. It is posited that the use of additional search terms, such as 'Trisomy 21,' 'additional language,' 'cognitive,' socio-emotional' and 'development,' may have resulted in the inclusion of more studies in the review. The small sample sizes and research design of all five selected studies were limitations of the current review, as small sample sizes have an impact on the validity of findings and may affect the sample's ability to represent the wider population (Francis, 2012). Four of the five studies employed a case-control or case study design with very few participants with a diagnosis of Down syndrome attending immersion settings, n = 1 (Burgoyne et al., 2016), n = 1 (Martin et al., 2021), n = 1 (Ward & Sanoudaki, 2021b) and n = 2 (Woll & Grove, 1996). Notably, while Martin et al.'s (2021) study only included one

participant with Down syndrome who was attending an immersion setting, it received a 'high' overall WoE score. Furthermore, none of the studies employed a research design with randomisation procedures, which are included in methodological designs with greater rigour, including RCTs (Petticrew and Roberts, 2003). In addition, the English language was either the L1 or L2 described in all five studies, which may impact the generalisability of the reported findings to countries wherein English is not an official language. Similarly, the studies were either carried out in Canada or the UK, which may influence the applicability of the findings to other countries.

Future Research

Future research investigating the impact of IE on the cognitive and socio-emotional development could address the limitations of the studies reviewed, namely the small sample size and nonrandomised research designs utilised across the five studies. None of the studies selected for the present review examined the socio-emotional development of participants. Immersion education programmes often provide the majority of instruction through the second language of learners, which may compound the learning difficulties or overburden children with Down syndrome by exposing them to more than one language (Pesco et al., 2016). Therefore, future research in this area could include socio-emotional measures to evaluate how learning through a second language affects the socio-emotional development of children with Down syndrome, such as whether immersion programmes result in additional stress or enhances the self-esteem of learners with Down syndrome for instance.

In addition, future research could employ a mixed methods approach, gathering qualitative and quantitative data about the cognitive and socio-emotional development of learners with Down syndrome attending IE settings. Furthermore, as the voices of children with intellectual disabilities are rarely included in research (Carroll et al., 2020; Skotko et al., 2011), future research could include the voice of children with Down syndrome and their communication partners about their experience of IE settings. Petticrew and Roberts (2003) assert that RCTs are the most appropriate research design for answering research questions that are evaluating the effectiveness or safety of a variable, and thus, future research examining the impact of IE should employ a RCT design. For instance, participants could be randomly assigned to a full-immersion, partial-immersion or waitlist control group to evaluate the impact of immersion. Furthermore, future studies could also include follow-up measures to evaluate whether the effects of attending IE settings and bilingualism on the cognitive and socio-emotional development of children with Down syndrome are maintained across time.

Previous research indicates that there are a number of confounding variables which need to be considered in research concerning bilingualism, and thus, immersion programmes. For instance, studies demonstrated that family socioeconomic status, home literacy environment, languages spoken by family members and L1 and L2 language exposure may impact findings in second language acquisition research (Burgoyne et al., 2016; Gunnerud et al., 2020; Martin et al., 2021; Naeem et al., 2018; Ward & Sanoudaki, 2021b). Consequently, future research on the impact of IE could gather more detailed participant demographic information to control for the confounding variables previously mentioned.

As was previously stated, all five studies included in the present review were either conducted in Canada or the UK, which may influence the applicability of the findings to other countries. Consequently, future research could investigate the impact of IE on learners with Down syndrome in other countries where opportunities for IE are available, such as Ireland, Finland or the USA.

Chapter Three: Empirical Paper

Introduction

Down syndrome is the most common congenital chromosomal condition, as was previously stated in Chapter Two. Ireland has the highest live birth prevalence and population of individuals with Down syndrome in Europe, with an incidence of approximately 28 in 10,000 live births and around 7,000 individuals with Down syndrome estimated to be living in Ireland (de Graaf et al., 2021). While the intellectual abilities of individuals with Down syndrome are diverse (Channell et al., 2021), most individuals with Down syndrome have a moderate intellectual disability (ID) (Chapman & Hesketh, 2001).

Previous Findings

Although children with Down syndrome typically present with needs across speech, language and communication (Martin et al., 2009), research investigating second language development in children with Down syndrome demonstrates that they are able to acquire and use a second language effectively (Kay-Raining Bird et al., 2016a). Furthermore, studies indicate that the development of a first language in individuals with Down syndrome is not negatively affected as a result of learning a second language (Burgoyne et al., 2016; Cleave et al., 2014; Katsarou & Andreou, 2021; Uljarević et al., 2016; Ward & Sanoudaki, 2021a). Research investigating the impact of bilingualism on the cognitive abilities of individuals with Down syndrome is warranted, particularly in the Irish context, but also owing to the incidence of Alzheimer's disease in older individuals with Down syndrome (Salehi et al., 2016). Findings suggests that bilingualism may serve as a protective factor for the development of the disease in typically-developing populations (Liu & Wu, 2021). Whether this could also be the case in individuals with Down syndrome is not currently known. However, findings from Ward and Sanoudaki's (2021a) study showed that there were no significant differences in the working memory abilities of bilingual children with Down syndrome in comparison to monolingual children with Down syndrome. An additional study indicated that a bilingual student with a dual diagnosis of Down syndrome and Autism Spectrum Disorder (ASD) outperformed bilingual children with Down syndrome and typically-developing children matched with regards to nonverbal mental age on a measure of working memory (Ward & Sanoudaki, 2021b). However, it was posited that these findings were most likely due to age rather than a bilingual advantage for children with a dual diagnosis of Down syndrome and ASD, as the particular student was older than the participants in the typically-developing control group and hence would have received more exposure to literacy interventions owing to the age difference (Ward & Sanoudaki, 2021b). Finally, Edgin et al. (2011) reported that there were no significant differences in the abilities of bilingual children with Down syndrome on a range of cognitive abilities.

While previous findings indicate that there do not appear to be "any detectable costs" associated with bilingualism for children with Down syndrome (Edgin et al., 2011, p. 355), the prevalence of students with Down syndrome who attend IE programmes appears to be quite low (Kay-Raining Bird et al., 2021; Nic Aindriú et al., 2020). Moreover, there is a dearth of research investigating outcomes for students with Down syndrome who attend immersion schools, which prevents inferences being drawn in relation to whether IE settings are suitable and beneficial education placements for students with Down syndrome. It is possible that a bidirectional relationship exists between the low prevalence of students with Down syndrome attending immersion settings and the limited research in this area, as previous findings indicate that the parents of students with disabilities, including intellectual disabilities, are frequently advised to speak to their child in the majority language only or advised against sending their

child to an IE setting (de Valenzuela et al., 2016; Genesee, 2007; Hampton et al., 2017; Martínez-Álvarez, 2019; Nic Aindriú, 2021a; Ware et al., 2015).

The systematic review described in the previous chapter identified only five studies which explored cognitive and socio-emotional outcomes for students with Down syndrome attending IE settings. Despite small sample sizes, the findings imply that IE programmes are an effective intervention for the development of bilingual and biliteracy skills in students with Down syndrome (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021; Ward & Sanoudaki, 2021b; Woll & Grove, 1996). There were no significant differences between the scores of a student with Down syndrome attending an IE setting, on nonverbal ability and verbal memory tests, in comparison to monolingual children with Down syndrome, who were not attending immersion settings (Burgoyne et al., 2016). None of the five studies included in the review investigated socio-emotional outcomes, which highlights a significant gap for educational practitioners. Whilst the views of one parent were explored in one of the five studies (Martin et al., 2021), the voices of students with Down syndrome were not included in any. Notably, only one of the five studies (Martin et al., 2021) received a 'high' overall WoE (Gough, 2007) score. Consequently, the findings of the other studies need to be interpreted with caution, regarding the impact of immersion settings on outcomes for students with Down syndrome (Burgoyne et al., 2016; Feltmate & Kay-Raining Bird, 2008; Martin et al., 2021; Ward & Sanoudaki, 2021b; Woll & Grove, 1996), which is consistent with the methodological quality of studies included in Uljarević et al.'s (2016) review.

Primary School Education in the Irish Context

Prior to commencing primary school, the vast majority of children attend preschool (Organisation for Economic Co-operation and Development, 2017), as children can avail of up to two years free early childhood care and education (ECCE), under the ECCE scheme (Murphy, 2015). In Ireland, children begin primary school in Junior Infants at approximately four or five years of age, progress to Senior Infants and then to first through to sixth class, completing eight years of primary school at approximately 12 to 13 years of age (Department of Education and Science, 2004). It is compulsory for children to begin education in Ireland by six years of age (Gray & Ryan, 2016).

Primary schools in Ireland vary in their language of instruction, their gender of students, the level of needs of students and their school patron, who lays out the school ethos (Department of Education, 2019a). For instance, an Irish-medium primary school or 'Gaelscoil' is a type of school which aims to immerse students in the Irish language, through one-way immersion. Moreover, mainstream schools, special schools and special classes within mainstream schools exist to accommodate learners with a wide variety of educational needs (National Council for Special Education, 2013). As stated in the Irish Constitution/Bunreacht na hÉireann (Government of Ireland, 1937), the family of the child is identified as the "primary and natural educator of the child," which preserves the right of parents to select the school of their choice when enrolling their child at primary school (Article 42).

According to the Department of Education (2019a), "inclusive education is a fundamental principle" of the Irish education system, which aims to meaningfully engage "all learners, including those with special educational needs and learners impacted by disadvantage." In Ireland, IE is typically provided in inclusive settings, namely mainstream primary and post-primary schools. While special classes in Irish-medium schools exist for learners with ASD in Ireland, there are currently no special classes provided in Irish-medium schools which are solely for students with intellectual disabilities (Department of Education, 2022b; NCSE, 2023). Although a map-based application, available on the Irish Department of Education website, indicates that there are no special schools which operate through the medium of Irish in Ireland (Department of Education, 2022a), one special school, operating through the medium of Irish, exists in a Gaeltacht region in Galway (Ní Chuaig et al., 2021). The term 'Gaeltacht' refers to "the regions in Ireland in which the Irish language is, or was until recently, the primary spoken language of the majority of the community" (Údarás na Gaeltachta, 2022, para. 1). Furthermore, while six special schools listed on the Department of Education's website indicate that the languages of instruction of these schools are 'Irish and English,' Irish was not referenced as a language of instruction or as a subject in the school inspection reports of any of these special schools (Department of Education, 2022a). This suggests that Irish is either not used as a language of instruction in these schools or that Irish was not evaluated and reported by the school inspectorate (Department of Education, 2022a). Consequently, the findings are in line with Ware et al.'s (2009) previous study, which indicated that Irish was not typically taught in special schools or special classes for students with intellectual disabilities in Ireland.

As was previously stated, the prevalence of children with Down syndrome in Ireland attending their local school is estimated to be over 90% (DSI, n.d.). This percentage illustrates the movement away from the medical approach that was traditionally applied, in Ireland, when working with children with disabilities or developmental delays in the past (Shevlin, 2016). Furthermore, McConkey et al. (2016) presented findings from a national database which revealed that higher proportions of students with mild and moderate intellectual disabilities now attend mainstream schools than special schools, in Ireland, in comparison to the previous two decades. While there were no significant differences in the daily living and social skills of teenagers with Down syndrome attending mainstream in comparison to special education settings in the UK, the expressive language and literacy skills of teenagers attending mainstream school placements were significantly higher than those of their peers educated in special schools (Buckley et al., 2006). In addition, the results of the study indicated that teenagers with Down syndrome attending mainstream schools were less likely to exhibit behavioural difficulties than teenagers attending special schools (Buckley et al., 2006). Moreover, findings of a review conducted by de Graaf et al. (2012) demonstrated that students with Down syndrome developed better language and academic skills when educated in mainstream schools in comparison to special settings. Similar to Buckley et al.'s findings (2006), there were no significant differences in the self-help skills of children with Down syndrome depending on whether they attended a mainstream or special education setting (de Graaf et al., 2012).

Previous research examining the prevalence of SEN in Irish-medium primary schools have either not included Down syndrome as a category of SEN (Barrett et al., 2019) or have included a category of SEN named 'Assessed Syndromes,' without providing an explicit breakdown of participants with each type of 'Assessed Syndrome' (Nic Aindriú et al., 2020; Nic Gabhann, 2008). There may be implications for students with Down syndrome, their parents and educational practitioners, owing to the paucity of data available in relation to the prevalence of children with Down syndrome attending Irish-medium schools (Barrett et al., 2019; Nic Aindriú et al., 2020; Nic Gabhann, 2008). For instance, if there is no such data available, this may impact parental school choice or the development of SEN interventions in the medium of Irish for learners with Down syndrome. However, while little is known regarding the attendance or inclusion of children with Down syndrome in Irish-medium primary schools, there is evidence to suggest that Irish-medium primary schools are considered and selected as the school of choice by some parents for their children with Down syndrome (Corcoran, 2014).

The Experiences of Primary School-Aged Children with Down Syndrome and their Parents

Article 21 of the UN Convention on the Rights of Persons with Disabilities (UN, 2006) asserts that individuals with disabilities should be supported to employ their right to freedom of expression and opinion. While there appears to be an increase in studies which have included the voices of children with additional needs in research in recent years (Andrews, 2020; Broomhead, 2019; Frizelle & Lyons, 2022; Prunty et al., 2012; Squires et al., 2016; van Bysterveldt & Westerveld, 2017), the views of children with Down syndrome or intellectual disabilities are rarely included in research (Kemps, 2022).

Studies investigating primary school experiences, which included children with Down syndrome or intellectual disabilities in their research sample, presented diverse findings. For instance, a study by Norwich and Kelly (2004) which included primary and secondary schoolaged learners, with general learning disabilities, attending mainstream and special schools indicated that the majority of students were satisfied with their current school setting and happy with their teacher. Maths and literacy were most frequently rated as subjects which are difficult to learn, and the students reported receiving more help from teaching assistants than their class teachers. Notably, there was a strong preference for withdrawal learning support, over in-class support and group work (Norwich & Kelly, 2004). However, it should be noted that the study was undertaken almost two decades ago, which may have influenced the findings. For instance, withdrawal models of learning support were the predominant models of learning support used by SEN teachers, in Ireland, two decades ago (Travers, 2011).

A pivotal study in this research area, conducted by Prunty et al. (2012), reported the perspectives of 38 children with SEN, about their school experiences, as "part of a large and comprehensive study on the role of special schools and special classes in Ireland" (p. 30). The research was commissioned by the NCSE, and the sample included students attending two

special schools for pupils with mild intellectual disabilities and one school for pupils with moderate intellectual disabilities. Themes of friendships and bullying, dual enrolment, views about school, and support available from teachers, Special Needs Assistants (SNAs) and their peers with learning, were identified following analysis of the interviews with students. For instance, when discussing their school experiences, the students described the importance of friendships and how making friends or losing friends impacted the way they felt about their school. In contrast, some students reported previous experiences of bullying at school. Regarding dual enrolment, while some students displayed interest in the idea, other students explained that it would be too difficult for them to attend two different schools. When describing their views about school, the students with SEN, some of whom had transferred from mainstream to special education settings, indicated that they received a greater level of learning support in special classes and special schools than in mainstream settings. One student who was attending an Irish-medium primary school reported that he found it "annoying" speaking Irish (Prunty et al., 2012, p. 31). Two other students who had attended mainstream schools found it difficult, because it was hard to move from one subject to another without finishing work or because the student "was getting older and things got harder" in 5th and 6th class (Prunty et al., 2012, p. 31). Many of the students who participated in the study described the support they received from their peers, teachers, and SNAs or teaching assistants in a positive light. Notably, some students highlighted the need for greater independence from SNAs or teaching assistants on tasks the students perceived to be within their ability level.

An additional study conducted in Ireland (Frizelle & Lyons, 2022), which included children with Down syndrome attending a mainstream school used the Mosaic research approach (Clark, 2005). The study addressed three research questions. It aimed to investigate what signs, from a key word signing system (Lámh), could be recommended to form a core key word signing school-based vocabulary, for use with learners with Down syndrome attending their first year of mainstream primary school. Secondly, to identify which words were recommended for inclusion in the core vocabulary, which did not already exist in the 580word Lámh vocabulary of that time. Finally, the study aimed to investigate how the core key word signing school-based vocabulary would compare to the vocabulary taught in the Lámh Module 1 training course, which is the only funded Lámh training available to teachers teaching students with Down syndrome in Ireland. The outcomes of Frizelle and Lyons' study (2022) led to the development of a core key word signing vocabulary of 140 words that would be appropriate for use with children with Down syndrome who are starting their first year of primary school. Eight of these words were words which did not exist previously in Lámh, including "to line-up, to watch, to be able, outside, yard, favourite, well done, and Duck Duck Goose" [a playground game]. Furthermore, only 55 of the words which met the inclusion criteria for the core key word signing school-based vocabulary are included in the 100-word vocabulary taught in the Lámh Module 1 training, which has important implications for education practitioners.

Finally, a study which included the insights of three female children with Down syndrome, aimed to explore their experiences of using multiple methods to communicate and to identify barriers or facilitating factors for successful communication between these children and their communication partners (Carroll et al., 2020). The participants with Down syndrome were aged between nine and 13 years of age, and used Lámh to support their communication. The communication partners (n = 16) who took part included parents, siblings, teachers, SNAs, a speech and language therapist, and a stuffed animal toy, who was voiced by the nine-year old participant with Down syndrome. Three themes emerged following analysis of the interviews with the children with Down syndrome and their parents, including 'what makes communication work,' 'to be understood' and 'longing for more.' The latter theme refers to the

participants' desire for Lámh to be promoted, in order to increase the awareness and use of Lámh, amongst parents, school staff and the peers of children with Down syndrome at school.

Research exploring the experiences of parents of school-aged children with Down syndrome and intellectual disabilities focus on diverse topics; the school choice made by parents, inclusive educational practices, early intervention, support from education and external professionals, transitions, participation and parent advocacy (Gasteiger-Klicpera et al., 2013; Hargreaves et al., 2021; Kendall, 2017; Lyons et al., 2016; Satherley & Norwich, 2022). It is important to include parents of children with Down syndrome in research regarding their children's experiences, owing to the speech, language and communication needs of children with Down syndrome. Furthermore, studies indicate that the responses of children with additional needs may not be reliable over time, due to the possibility that their views at a given timepoint may be influenced by external factors, such as the research environment or their most recent interactions or activities (Frizelle & Lyons, 2022; Pearlman & Michaels, 2019).

The Present Study

The primary aim of the present study was to promote inclusion and challenge structures that may perpetuate inequality or discriminatory practice within immersion and non-immersion education settings for children with Down syndrome, and their families (Mertens, 2021). As was previously stated, prior research has mainly focused on outcomes for individuals with Down syndrome from bilingual home backgrounds rather than learners with Down syndrome, who acquire a second language through school language programmes. Accordingly, the purpose of the study was to address gaps in previous studies by investigating the experiences and outcomes for children with Down syndrome, attending immersion and non-immersion settings, and their parents. For the purpose of clarity, immersion primary schools will be referred to as Irish-medium mainstream (IMM) schools and non-immersion settings will be referred to as English-medium mainstream (EMM) and English-medium special settings (EMSS) in the present study, as illustrated in Figure 4. It is important to note that EMSS include children who attend the two types of special education setting in Ireland: (1) special classes within mainstream schools and (2) special schools.

Figure 4

Immersion and non-immersion settings in the present study



Methodology

Research Design

A mixed methods research design informed by the transformative paradigm underpinned this research (Mertens, 2003). The study was conducted in two distinct phases, wherein both quantitative and qualitative data was collected and analysed (Creswell, 2020). In accordance with transformative mixed methods research criteria (Mertens, 2003, 2009), the initial research question arose through discussions with parents of children with Down syndrome, concerning their decision-making process regarding the primary school their child would attend, and potential outcomes arising from their school choice. In line with Merten's (2003, 2009) criteria, the aim of Phase One of the present study was to provide members of the Down syndrome community with an opportunity to become actively engaged in the research and to initiate Phase Two of the project, by selecting which developmental outcome would be explored in Phase Two. As a result, the research questions underpinning Phase Two of the research project were not developed until Phase One data collection was completed.

Phase One Design. The research question underpinning Phase One of the study is illustrated in Table 11. Consequently, a mixed methods, online survey methodology was employed to provide participants with the opportunity to choose which aspect or aspects of cognitive and socio-emotional development would be explored in Phase Two and to outline their views in relation to the research area.

Phase Two Design. Phase Two of the project was underpinned by three research questions displayed in Table 11. The first research question was developed in line with data collected by members of the Down syndrome community in Phase One of the research, whilst the second and third research questions were developed in accordance with the transformative lens, aiming to explore the school experiences of children with Down syndrome attending EMSS, EMM and IMM primary schools, and their parents.
Table 11

Research	h q	juesi	tions

Research Phase	Research Questions
Phase One	Which aspect of the cognitive or socio-emotional development of children with Down
	syndrome, in relation to immersion and non-immersion education settings, do members of the
	Down syndrome community wish to have researched?
Phase Two	Are there differences in the verbal communication abilities and of children with Down
	syndrome depending on whether they attend an EMSS, EMM or IMM primary school?
	What are the experiences of parents of children with Down syndrome attending EMSS, EMM
	and IMM primary schools?
	What are the experiences of children with Down syndrome attending EMSS, EMM and IMM
	primary schools?

A mixed methods design with three comparison groups was employed in Phase Two. The primary school setting of the child participants in Phase Two acted as the grouping variable across the three comparison groups (Barker et al., 2016). An online survey methodology was employed to collect quantitative demographic data for matching purposes across the three comparison groups, including the children's chronological age, socioeconomic status and home language and literacy environment. Qualitative data was collected from parent participants through semi-structured interviews, whilst the Mosaic approach (Clark & Moss, 2001) was used to collect data about the school experiences of child participants. The Mosaic approach offers a framework for listening to children which is participatory, reflexive and adaptable, and utilises multiple methods to include the 'voice' of the child, regardless of the style of communication used by the child (Clark & Moss, 2001; Clark, 2017). Furthermore, the Mosaic approach focuses on children's lived experiences and captures these experiences through the use of visual and verbal tools, such as observations, child interviews, children's photographs and book making, child-led tours and map-making (Clark & Moss, 2001; Clark, 2017). Consequently, the Mosaic approach was deemed the most appropriate design for data collection with child participants, owing to the visual strengths in short-term memory and

working memory, and variation in verbal communication abilities, amongst children with Down syndrome (Tungate & Conners, 2021).

Ethical Considerations

This research was conducted in adherence with the Psychology Society of Ireland's (PSI) Professional Code of Ethics (The PSI, 2019) and the Doctorate in Child and Educational Psychology Research Guidelines (Mary Immaculate College, 2020). First, an application for ethical approval (Appendix E) and a 'Child Safeguarding Statement' (Appendix F) were completed and sent to the Mary Immaculate Research Ethics Committee (MIREC) on 14 January, 2022. Subsequently, ethical approval was awarded on 4 April, 2022, 80 days after the initial application was submitted to the MIREC (Appendix G). Owing to potential recruitment difficulties, DSI was contacted in order to assist with recruitment. DSI requested that a 'Research Checklist' was completed by the researcher and submitted to the National Research Coordinator at DSI prior to receiving support from DSI with the research project. This 'Research Checklist' was submitted to DSI by the researcher on 14 April, 2022.

The key ethical principles which guided the study were "Respect for the Rights and Dignity of the Person, Competence, Responsibility, and Integrity" (PSI 2019, pp. 3-4). In addition, the principal ethical considerations arising from this research, included anonymity, confidentiality, consent, and the avoidance of harm to participants. Consequently, a process of informed consent was undertaken prior to data collection with child participants to ensure that the child participants understand who the researcher was and the research activities that they would be engaging in. A visual schedule and easy-read assent form was used with child participants to support their decision-making in the informed consent process. Furthermore, during the informed consent process and all research activities with child participants, an adult known to the child (e.g. parent, class teacher or SNA) accompanied the researcher and each child participant. Pseudonyms were provided to each participant to protect their anonymity and confidentiality. To avoid mixing up the participants, the pseudonyms were applied immediately once data had been collected from the participant (e.g. pseudonyms were used in the researcher's reflective journal, rather than the participants' real names). In addition, data containing personal information (e.g. consent forms) was stored on a password-protected file on the researcher's laptop in order to protect the privacy and confidentiality of participants.

Adult participants were also provided with information sheets in order to obtain informed consent from them regarding their decision to participate. For instance, the information sheets contained information about the data collection procedures and how the research data would be stored and used. At the beginning of online interviews in Phase Two, parent participants were reminded that the interview would be recorded on Microsoft Teams to ensure that the participants understood what their participation would entail. The researcher engaged in the online interviews in a secure room in the researcher's home to prevent other people from entering the room (Maldonado-Castellanos, & Barrios, 2023). Furthermore, the researcher wore earphones during interviews to ensure that nobody, apart from the researcher, could hear what the research participants were saying during interviews (Maldonado-Castellanos, & Barrios, 2023). A discussion regarding unanticipated ethical issues which arose throughout the research process is presented in Chapter Four, the Critical Review and Impact Statement.

Phase One

Participants. The target population for Phase One of the research included members of the Down syndrome community who were associated with primary schools in Ireland,

including children with Down syndrome, parents of children with Down syndrome and relevant professionals. Purposive sampling methods (Barker et al., 2016) were utilised to recruit participants, as participants were selected according to whether they met the following selection criteria: (a) was a child with Down syndrome currently attending primary school in Ireland, (b) was a parent of a child currently attending a primary school in Ireland, or (c) was an individual employed in a professional capacity and currently working with a child with Down syndrome attending primary school in Ireland. Participants were recruited with the support of national organisations for children with Down syndrome and local children's disability network teams in Ireland, through use of newsletters, emails, posters and social media posts.

Fifty-four participants took part in Phase One, including children with Down syndrome attending primary school (n = 5), parents of children with Down syndrome attending primary school (n = 12), and a variety of professionals currently working with children with Down syndrome attending primary schools in Ireland (n = 37). Figure 5 and Figure 6 provide further information about the participants who took part in Phase One.

Figure 5



Phase One child and parent participants

Figure 6





Measures and Materials. Two separate online surveys were created using Qualtrics, an online survey tool that allows researchers to build, distribute and analyse surveys online. One of the online surveys was created for child and parent participants (Appendix H), whilst the other survey was created for professional participants (Appendix I). Both surveys contained an information sheet (Appendix H and Appendix J) for participants to read prior to commencing the survey. In addition, a visual information sheet, containing short sentences, a photo of the researcher and pictures explaining the survey process, was included in the survey for child and parent participants (Appendix H).

The mixed methods survey for child and parent participants (Appendix H) included seven questions in total, six questions for parents and one question for child participants. The questions for parent participants included five quantitative questions and one qualitative question which captured whether parent participants met the inclusion criteria for participation, which research outcome parent participants preferred for exploration in Phase Two and any additional comments parent participants possessed in relation to the research area, in line with the transformative paradigm (Mertens, 2003, 2009). Furthermore, the survey contained a question which invited parents to participate in Phase Two of the research project. The survey for parent and child participants ended with a quantitative picture question for child participants to indicate their preferred outcome for exploration in Phase Two. An overview of the questions contained in the survey for child and parent participants is presented in Table 12. Notably, the pictures used in the visual information sheet and the picture question for child participants were gathered from a database used to store visuals for intervention programmes and resources in a children's disability service in Ireland.

Table 12

Theme	Participant	Survey item
Inclusion	Parents	Does your child have a diagnosis of Down syndrome?
criteria		Is your child with Down syndrome currently attending primary school?
		What age is this child?
Research	Parents	Please rank your preference for learning about the impact of immersion-settings and
preference		non-immersion settings by providing the following skills and abilities with a rating on
		a scale of 1-6:
		(a) executive functioning;
		(b) adaptive functioning;
		(c) verbal communication abilities;
		(d) nonverbal communication abilities;
		(e) social skills, and
		(f) emotional development
	Children	Ask your child to point at the picture they like the best or would most like to learn
		about. Allow your child to select their answer by clicking on the corresponding
		picture:
		(a) brain skills;
		(b) daily skills;
		(c) talking skills;
		(d) body language skills;
		(e) social skills, and
		(f) feelings

Overview of Phase One survey for parents and child participants

Views on	Parents	Do you have any additional comments about this research?
the research		
area		
Invitation	Parents	Are you interested in taking part in Phase Two of this research which will take place
for		across the summer months? This would involve another short questionnaire (10
participation		minutes), a follow-up interview on Microsoft Teams with you (approximately 60
in Phase		minutes) and two visits to your child's school to interview your child?
Two		

Table 13 illustrates the themes included in the survey created for professional participants, which included five questions. Four quantitative questions were provided in the survey for professional participants in order to evaluate whether the participants met the inclusion criteria for participation and to indicate their preferred research outcomes for exploration in Phase Two. Similar to parent participants, a qualitative question was included in the survey for professional participants to provide an opportunity to voice comments regarding the research study (Mertens, 2003, 2009).

Table 13

Overview of Phase One survey for professional participants

Theme	Survey item
Inclusion criteria	Do you currently work with a child with a diagnosis of Down syndrome?
	Is this child currently attending primary school?
	What age is this child?
Research preference	Please rank your preference for learning about the impact of immersion-settings
	and non-immersion settings by providing the following skills and abilities with a
	rating on a scale of 1-6:
	(a) executive functioning;
	(b) adaptive functioning;

	(c) verbal communication abilities;
	(d) nonverbal communication abilities;
	(e) social skills, and
	(f) emotional development
Views on the research area	Do you have any additional comments about this research?

Data Collection Procedures. The survey was piloted with a typically-developing child, a child with Down syndrome, two parents and two doctoral students, known to the researcher, prior to data collection (n = 6). As was previously stated, purposive sampling was used to recruit participants with assistance from national Down syndrome organisations and local children's disability network teams in Ireland, wherein a link to the online survey was included in newsletters, emails, posters and social media posts. In order to address low response rates after three weeks of the survey's publication online, follow-up emails were sent to the relevant organisations and services, and social media posts were posted on the researcher's social media accounts and social media groups relevant to parents and professionals associated with Down syndrome. Data were collected form participants over six weeks from April to May 2022. In accordance with MIREC guidelines, an information sheet (Appendix H and Appendix J) was presented at the beginning of the surveys and completion of the survey implied that participants provided consent for participation. The 'skip logic' function in Qualtrics was used on 'inclusionary criteria' survey items, in order to prevent participants who did not meet the inclusion criteria from participating. According to data from Qualtrics, the completion time for both online surveys was 5–10 minutes.

Data Analysis. Analysis of the quantitative results in Phase One involved identifying the most popular outcome selected by each group of participants: (a) children with Down syndrome, (b) parents of children with Down syndrome, and (c) professionals currently

working with children with Down syndrome attending primary school. For instance, 'talking skills,' or verbal communication abilities, was the most popular outcome selected by child participants, verbal communication abilities was the most popular outcome selected by parent participants and adaptive functioning abilities was the most popular outcome selected by professional participants. Qualitative data collected in Phase One was analysed using the six-phase model in Reflexive Thematic Analysis (Braun & Clarke, 2022).

Phase Two

Participants. The target population for Phase Two of the research included children with Down syndrome in primary education (attending EMSS, EMM and IMM primary schools), and their parents. Owing to time constraints, professional participants (included in Phase One), who were currently working with a child with Down syndrome attending a primary school, were not invited to participate in Phase Two of the research project. Similar to Phase One, purposive sampling methods (Barker et al., 2016) were used to recruit participants and the recruitment process was conducted with the support of national organisations for children with Down syndrome and local children's disability network teams in Ireland, through use of newsletters, emails, posters and social media posts.

Twenty-six participants took part in Phase Two, including children with Down syndrome attending primary school (n = 13) and an individual parent linked to each child participant (n = 13). Table 14 provides further detail and demographic information about the participants who took part in Phase Two. The information provided in Table 14 regarding Phase Two participants was presented carefully to ensure that identifiable information was not included.

Table 14

Phase Two Participants

Child Participant	Linked parent participant	Child's age at time of school visits (SVs)	Type of primary school at time of parent interviews and SVs	Primary caregiver's level of education	Child's first language is the same as the language medium of their school	No. of langua ges spoken in the child's home	Use of Lámh currently or in the past	Attends speech and language therapy	Irish language exemption	Time spent reading with the child on a typical school day	Time spent reading with the child on a weekend	Number of children's books in the child's home	Number of adult's books in the child's home
Anna	Maria	6 years	Irish-medium mainstream school (PI, SVs)	Completed a Level 8 Honours Degree or Higher Diploma	No	2	Yes, currently	Yes	Not applicable	16-30 minutes	5-15 minutes	60+	200+
Brendan	Liam	6 years	English- medium mainstream school (PI) Special class within an English- medium mainstream school (SVs)	Completed a post- graduate Level 9 Degree or higher	No	2	Not reported	Not reported	Not reported	5-15 minutes	5-15 minutes	60+	1-50
Ciara	Kevin	7 years	English- medium mainstream school (PI, SVs)	Completed a Level 6 or Level 7 Certificate or Diploma	Yes	1	Not reported	Yes	Not reported	5-15 minutes	0-5 minutes	41-60	1-50

Daniel	Jean	8 years	English- medium mainstream school (PI, SVs)	Completed a post- graduate Level 9 Degree or higher	Yes	2	No.	Yes	No	30-60 minutes	5-15 minutes	60+	1-50
Enda	Irene	10 years	English- medium special school (PI, SVs)	Completed post- primary (secondary) school	Yes	1	Yes, currently.	Yes	Not reported	5-15 minutes	5-15 minutes	1-20	1-50
Ferdia	Helen	10 years	Irish-medium mainstream school (PI, SVs)	Completed a post- graduate Level 9 Degree or higher	Yes	2	Yes, in the past.	Yes	Not applicable	0-5 minutes	5-15 minutes	41-60	51-99
Gary	Gráinne	10 years	Irish-medium mainstream school (PI, SVs)	Completed a Level 6 or Level 7 Certificate or Diploma	No	1	Yes, in the past.	Not reported	Not applicable	5-15 minutes	0-5 minutes	21-40	1-50
Harry	Fiona	11 years	Special class within an English- medium mainstream school (PI, SVs)	Completed a Level 6 or Level 7 Certificate or Diploma	Yes	1	Yes, in the past.	Not reported	No	16-30 minutes	16-30 minutes	21-40	1-50
Isobel	Eimear	11 years	Special class within an English- medium mainstream school (PI, SVs)	Completed a post- graduate Level 9 Degree or higher	Yes	2	Not reported.	Yes	No	5-15 minutes	5-15 minutes	60+	200+
			*attended an Irish-medium										

mainstream school from Junior Infants to 5th Class

Jack	Doireann	11 years	English- medium special school (PI, SVs)	Completed post- primary (secondary) school	Yes	1	Not reported.	Yes	Not reported	0-5 minutes	0-5 minutes	1-20	0
Kate	Carla	12 years	Irish-medium mainstream school (PI, SVs)	Completed a post- graduate Level 9 Degree or higher	No	1	No.	Yes	Not applicable	16-30 minutes	5-15 minutes	41-60	1-50
Laura	Bernadette	12 years	English- medium mainstream school (PI, SVs)	Completed a post- graduate Level 9 Degree or higher	Yes	1	Yes, in the past.	Yes	Yes	16-30 minutes	5-15 minutes	21-40	51-99
Michael	Aileen	13 years	English- medium mainstream school (PI, SVs)	Completed a Level 6 or Level 7 Certificate or Diploma	Yes	1	Yes, in the past.	Yes	Yes	16-30 minutes	16-30 minutes	41-60	1-50

Measures and Materials. As child participants were either attending Irish-medium or English-medium primary schools, Phase Two information sheets (Appendix K), consent forms (Appendix L) and assent forms (Appendix M) were developed in both English and Irish languages. Irish language materials were translated from the English-language materials by the researcher, prior to being edited by a certified Irish language translator, known to the researcher.

Findings from the systematic literature review (Chapter Two) indicated that the socioeconomic status, home literacy environment and languages spoken by family members of participants may impact findings in second language acquisition research (Burgoyne et al., 2016; Gunnerud et al., 2020; Martin et al., 2021; Naeem et al., 2018; Ward & Sanoudaki, 2021b). Consequently, Phase Two parent participants completed an online survey (Appendix N) in order to collect demographic information about the child participants. Similar to Phase One, Qualtrics was used to develop the online survey in order to collect demographic information from parent participants, including their child's chronological age, socioeconomic status, and home language and literacy environment. Table 15 provides an overview of the survey items. The primary caregiver's level of education was used as a measure of socioeconomic status, as this variable is one of the most commonly used methods of measuring socioeconomic status in research investigating children's development (Luo et al., 2021). Furthermore, the educational level of primary caregivers is highly correlated with other measures of socioeconomic status, such as income or occupation (Bornstein et al., 2003). The survey items based on the home language and literacy environment were developed in line with previous studies which included multilingual child participants (Inoue et al., 2020; Luo et al., 2021).

Table 15

Theme	Survey item
Chronological age	What is your child's date of birth?
School type	What type of primary school does your child attend?
Socio-economic status	What level of education has your child's primary caregiver attained?
Home language	Please select all languages spoken in your child's home on a regular basis. If your child
environment	speaks more than one language, what was your child's first language?
	If your child speaks more than one language, which language is most commonly spoken
	in your child's home?
	How often do you (or someone else at home) speak an additional language (a language
	other than your child's first language) to your child at home?
Home literacy	During the school year, approximately how much time do you (or someone else at home)
environment	spend reading to your child on a typical school day (Monday - Friday)?
	During the current school year, how much time do you (or someone else at home) spend
	reading to your child on a typical weekend day (Saturday or Sunday)?
	Approximately how many children's books do you have in your child's home?
	Approximately how many adult's books do you have in your child's home?

Overview of Phase Two online survey collecting demographic information

Phase Two parent participants also participated in a semi-structured interview in order to collect data regarding their child's verbal communication abilities, their child's school experiences and their own experiences, as a parent, of their child's school. The interview schedule is illustrated in Appendix O and all items were adapted from Sattler's (2014) guidelines.

A bilingual visual assent form (English and Irish) was created in order to attain consent from child participants, which contained short sentences, a photo of the researcher and pictures explaining the data collection process (Appendix M), as research indicates that there are differences between the verbal working memory and visual working memory abilities of children with Down syndrome, in favour of visual working memory (Costa et al., 2015; Gathercole & Alloway, 2006; Jarrold & Baddeley, 1997). Similar to materials used with child participants in Phase One, the pictures included in the visual assent form were gathered from a database of visuals used for intervention programmes and resources in a children's disability service in Ireland. This visual assent form was then laminated and used as a visual schedule to prepare child participants for data collection on the dates that data collection was conducted. Visual 'break cards' were also created and provided to child participants during data collection to ensure that participants understood that they could withdraw from data collection or take a break from data collection as necessary (Figure 7). As part of the Mosaic approach (Clark & Moss, 2001, 2003; Clark, 2017), the children were invited to take photographs of various objects and areas in their school. An 'Alcatel 10 1T Quad-Core 1.3 GHz' tablet was used by child participants for this purpose. Scrapbooks, in either A3 or A4 size, were used to record the photographs during the book making exercise with child participants.

Figure 7

Example of visual 'break card' used during data collection with child participants



Data Collection Procedures. The interview schedule and selected tools from the Mosaic approach were piloted with two typically-developing children and one parent known to

the researcher, and a child with Down syndrome and linked parent, prior to data collection (n = 5). Furthermore, written consent was obtained from child and parent participants prior to data collection in line with MIREC guidelines using the consent and assent forms in Appendix L and Appendix M. As data collection for child participants was taking place in the children's schools, owing to the Mosaic approach utilised (Clark & Moss, 2001, 2003; Clark, 2017), written consent was also obtained from the school principals. Furthermore, consent was obtained from the SNA or teacher, who accompanied each child participant during the childled tours.

First, parents who expressed interest in participating in Phase Two were screened by email to determine whether they met the inclusion criteria for participation: that they had a child with Down syndrome who was currently attending a primary school in Ireland. Next, parents who expressed interest were invited to complete the online survey on Qualtrics via email in order to collect demographic information about their child. Qualtrics data indicated that participants completed the online survey in approximately 5-10 minutes, across the months July 2022 – January 2023. Subsequently, semi-structured online interviews were conducted with parent participants using the Microsoft Teams online platform, which allowed for recordings of each interview to take place. Interviews took place at a date and time convenient to the parent in accordance with family-centred practices (McCarthy & Guerin, 2021), across the months July 2022 – January 2023. Each interview lasted between 60 and 120 minutes.

A range of verbal and visual tools developed in line with the Mosaic approach (Clark & Moss, 2001, 2003; Clark, 2017), including observations, child-led tours, children's photographs, book-making and child interviews, were used to collect data from child participants regarding their experiences of primary school. Data was collected in the children's schools. Prior to beginning data collection, the researcher showed each child participant the visual schedule to explain how data would be collected and how to use the 'break card' (Figure

7). Test photographs were taken by child participants, using the tablet, in order to ensure that the child could manage the tablet independently. In addition, verbal assent was obtained from each child participant prior to conducting data collection. An adult, known to the child, accompanied the researcher during this informed consent process and all research activities with child participants, and remained in the room whilst data was being collected. The rationale underpinning this ethical decision was to ensure that each child participant felt safe during data collection, in line with child protection procedures. An additional aim of this action was to prevent potential frustration for the child participants, in the event that their verbal communication could not be understood by the researcher during data collection, owing to the speech, language and communication needs of children with Down syndrome.

First, the child participants brought the researcher on a child-led tour of their primary school. The child-led tour was completed with each child participant in approximately 20-30 minutes. During the tour of the school, the child was prompted to show and photograph the following areas and objects, in line with previous research (Andrews, 2020; Clark, 2017; Nic Aindriú, 2021b):

- (i) various places around the school where activities take place (e.g., school hall, computer rooms, school yard, school garden, basketball courts, pitches, school stage etc.);
- (ii) the child's favourite place in the school;
- (iii) the child's least favourite place in the school;
- (iv) the child's favourite book;
- (v) the child's favourite learning activity at school.

Following the child-led tour, the child's photos were printed from the tablet. The photos were then utilised as visual stimuli to generate discussion with the child participants during an interview and a book making exercise which also took place in each participant's school. The interview with each child was recorded using a voice recorder. A book was created using a scrapbook, wherein the photos taken by the child participants were selected and glued into the

scrapbook by the child participants. Sentences based on the verbal responses and nonverbal behaviours of each child participants were constructed by the researcher and recorded in the scrapbook. When the book making exercise was complete, the book was read to the child by the researcher and the children were invited to evaluate the book. Subsequently, the researcher took photographs of each participant's book before allowing each participant to take the book home with them. An example of a page from a child's book is illustrated in Figure 8 in order to illustrate the process of the book making exercise. The photo in Figure 8 was taken by a child participant during the child-led tour, whilst the handwriting was written by the researcher and was based on the verbal and nonverbal responses of this child, during the child-led tour, the interview and book making exercise. This child's pseudonym is not provided here in order to protect the anonymity of the participant and their parent.

Figure 8

Example of a page from a child's book to illustrate the book making exercise

Here is the ball pit. favourite my schoo my in to jump ball pit when

Data Analysis. A variety of data analysis procedures were implemented in Phase Two, depending on the research question, in line with Braun and Clarke's (2021) thinking that it is important that the method of analysis used "'fits' the project's purpose, that theoretical assumptions, research question and methods are in alignment, and that the overall research design is coherent" (p.38).

For instance, a mixed methods approach was employed in order to analyse data related to RQ1. As the research question aimed to explore differences in the verbal communication abilities amongst three groups of children, an IMM group (n = 4), EMM group (n = 4) and an EMSS group (n = 5), data related to the children's chronological age, developmental age, socioeconomic status, and home language and literacy environment was analysed quantitatively for matching purposes initially, as previous research indicates that the impact of learning a second language may be mediated by socioeconomic status (Luo et al., 2021). First, this quantitative data was prepared for analysis, which involved converting categorical variables into continuous variables. Table 16 illustrates this conversion process. Next, Microsoft Excel was used to record and analyse the data, through a series of one-way Analysis of Variance tests (ANOVA).

Table 16

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Continuous value provided	Level of education of primary care- giver	Time spent reading with child at home daily	Number of children's books in child's home	Number of adult's books in child's home
1	Lower post-primary (secondary) school or less	Less than 5 minutes a day	0	0
2	Completed post-primary (secondary) school	Between 5 – 15 minutes a day	1 - 20	1-49

3	Completed a Level 6 or Level 7 Certificate or Diploma	Between 15 – 30 minutes a day	21 - 40	51 – 99
4	Completed a Level 8 Honours Degree or Higher Diploma	Between 30 - 60 minutes a day	41 - 60	100 - 199
5	Completed a post-graduate Level 9 Degree or higher	More than an hour a day	60+	200+

Subsequently, a deductive approach to Braun and Clarke's (2022) reflexive thematic analysis was adopted when analysing qualitative data collected from parents in relation to RQ1, as codes were produced related to verbal communication, across three areas including expressive language, receptive language and writing. Firstly, data related to the verbal communication abilities of child participants were analysed across the entire sample of child participants (n = 13). Next the data related to the verbal communication abilities was analysed between each of the three groups, EMM, EMSS and IMM, in order to explore whether there were differences in the verbal communication abilities of the child participants depending on their school setting.

Contrastingly, an inductive approach to reflexive thematic analysis (Braun & Clarke, 2022) was utilised when analysing Phase Two data relevant to RQ2, regarding parental experiences, as an open-ended approach to coding was employed "in order to best represent meaning as communicated by the participants" (Byrne, 2022, p. 1397).

Braun and Clarke's (2022) six-phase process of reflexive thematic analysis was used to analyse qualitative data for RQ1 and RQ2, which included an iterative approach, moving back and forth through the six phases. The six phases of reflective data analysis are: (1) data familiarisation, (2) generating initial codes, (3) generating themes, (4) reviewing potential themes, (5) defining and naming themes, and (6) producing the report (Braun & Clarke, 2022). Data familiarisation was conducted by transcribing the parent interviews, printing each transcript and reading each transcript three times, whilst making notes in a reflective journal (Byrne, 2021). Figure 9 presents an illustration of notes which were written in the reflective journal during the data familiarisation phase analysis of RQ2. Questions which were considered during the data familiarisation phase and ongoing reflection included (Kriukow, 2022):

- 1. How does the participant make sense of what they're discussing?
- Why might they be making sense of things in this way? (and not in another way?)
- 3. In what different ways do they make sense of the topic?
- 4. How 'common-sense or social normative is this depiction or story?
- 5. How would I feel if I was in that situation? (Is that different from or similar to how the participant feels, and why might that be?)
- 6. Why might I be reacting this way to the data?
- 7. What ideas does my interpretation rely on?
- 8. What different ways could I make sense of the data?

Figure 9

Notes from researcher's reflective journal during data familiarisation phase of analysis

- Parents highlight the importance of intrinsic factors, mainly personality traits, on the children's learning and the experience of children at school.
- Parents emphasise the importance of a positive school culture and how the implementation of inclusive methodologies has a positive impact on their children.
- Parents vary in their attitude towards their own role in their children's development. Some
 parents appear to exhibit a high locus of control with regards to their ability to have a
 positive impact on their child's development, whilst others appear to display an external locus
 of control, where they believe that their actions do not have a significant impact on their
 child's development, and strongly believe that their child's progress or lack of development is
 a result of factors outside their control (e.g. school staff, access to disability services etc.).
- In many interviews, I sense that parents are experiencing strong emotions, such as anger or disappointment, when discussing their experiences, especially when the parents/reference early hospitalisation experiences, their children's medical needs and having to fight for resources or extra support. It must be so draining being in a state of hyper-arousal frequently and also trying to anticipate when the next battle for resources or support may be around the corner.

Following the transcription of parental interviews, NVivo 12® was used to code the data. Initially, a data-driven approach was utilised to code the data in Phase Two, which meant that the researcher generated initial codes based on the content of the data rather than on the basis of "any pre-conceived theory or conceptual framework" (Byrne, 2021, p. 1396). This approach resulted in the production of an abundance of codes. Figure 10 illustrates an example of the initial codes which were generated based on the content of the data. Consequently, the codes were reviewed and interpreted in relation to the research question, and were condensed into larger codes. For instance, the initial code "stress at home due to disorganisation" was later condensed into a larger code entitled "the impact of children's needs on the family," whilst the initial code "success in school associated with student's attitude and personality" was later condensed into "child intrinsic factors conducive to success at school." The researcher's reflective journal was imperative in tracking the progression of codes, following the repetition of the coding phase in attempts to evolve the codes, with regards to the entire dataset and the

research question (Braun & Clark, 2022; Byrne, 2021). Appendix P presents a worked example

of the coding process from the generation of initial codes to the evolution of larger codes with

regards to the subtheme "Advocating for Inclusion."

Figure 10

Initial coding as part of the thematic analysis

Positive teacher attitude towards the learning of all students And that there's, you know, hope for all their learning and desire for all their learning. Impact of positive teacher attitudes on students Student's positive attitude toward immersion school So that's been a significant thing for Kate. Now Kate has embraced it fully, which we're Children's ability to adapt differs from child-to-child very lucky with, do you know? Because not every child does that and can do that. So I Impact of student's positive attitude on learning mean, I think she has been an integral part of her learning. And her success in the Success in school associated with student's attitude and personality Gaelscoil, is a huge credit to her. I think she in all fairness to her she's quite Adaptable personality Tendency to engage in rigid thinking adaptable as well, you know? Sometimes in her thinking it's hard. You know in the Attendance at school despite difficulties Need for consistent routine Missing school due to illness routine thing, but she has managed it and she has like she hasn't missed much school in the sickness. She is always...there might be kind of Sometimes in the Difficulties getting organised in the morning Stress at home due to disorganisation morning, the stress of kind of getting organized, it might be a bit overwhelming. But the Ability to adapt and move on following transition Ability to persist despite personal difficulties minute we're in the car and she's running into school, and she takes it on like she takes it on and she's.... Yeah, and I'm, I'm sure it's been very challenging for her, I'm sure it's Ability to persist despite personal difficulties been hard. She picks herself up every morning and goes and does it.

Phase three of reflexive thematic analysis involved generating potential themes following a review of the larger codes generated. The aim was to analyse the coded data in order to review and interpret how different codes could be connected or combined to form subthemes and themes, in accordance with shared meaning across the entire data set (Braun & Clark, 2022; Byrne, 2021).

The next phase involved reviewing potential themes in relation to the entire dataset to ensure that each theme would serve to meaningfully represent the data set as a whole and would also address the research question. This phase of the analysis involved moving back and forth between the phases of reflexive thematic analysis frequently, following consideration of the following questions (Braun & Clark, 2022, p. 99):

- Can I identify boundaries of this theme?
- Are there enough (meaningful) data to evidence this theme?
- Are the data contained within each theme too diverse and wide-ranging?
- Does this theme convey something important?

The fifth phase of the reflexive thematic analysis involved defining and naming each theme. In accordance with Braun and Clarke (2022), definitions were written for each theme in order to evaluate the quality and richness of each theme. Figure 11 presents an example of the definition written by the researcher for the RQ2 theme entitled "The Hardest Decision of All."

Finally, phase six of the process involved producing a report of the findings by mapping the outcomes of the data into a coherent and flowing story (Braun & Clark, 2022).

Figure 11

Definition of the theme "The Hardest Decision of All"

The theme 'The Hardest Decision of All' explores participants' experience of choosing a school for their child. The core ideas underpinning this theme, and which were expressed in different ways across the whole dataset, were the notion that parents are often isolated and left on their own when making this difficult decision, and that parental experiences of choosing a school were ultimately influenced by the ethos of the school; whether the school was ready and prepared to include their child and meet their child's needs, or not. 'Settling into Preschool' explores the parents first experience of education for their child, and how parents first learned about the suitability of a school setting through a trial-and-error approach (e.g. child's preschool readiness, support needed etc.). These early experiences of preschool would shape how parents later decided on a primary school for their child. 'Key Considerations' explores the learnings of parents from their children's experiences of preschool and from their sole (and often isolated) mission of figuring out which school would best meet their children's needs, by visiting schools and speaking with other parents. The quantity of factors which parents felt were important in considering before choosing their child's school conveys the complexity of this decision-making for parents. Additionally, as parents felt alone when making this decision, the importance of sharing these considerations with other parents became more apparent, through parent reflections such as "if only I had known this then." Finally, 'First Impressions Matter' describes the experiences of parents when visiting potential primary schools. Parents described the pressure of finding an appropriate school (often by yourself), which was compounded by the feeling of being on the clock, as September looms. As a result, the vulnerability of walking into a school and meeting staff who would potentially support their children was conveyed, and these first impressions (which would often influence the parent's judgement of the inclusive nature of the school) played a vital role in choosing which school the children would attend.

Thematic analysis of the children's photos, scrapbooks and interview transcripts was also conducted in a similar way. However, in addition to reflexive thematic analysis (Braun & Clarke, 2022), the analysis of children's data was also conducted in accordance with Clark's (2017) Mosaic approach, which involved returning to the children's photographs and their responses during the book making exercise, in addition to notes made by the researcher during data collection with children, to ensure that the themes generated represented the entire dataset (Braun & Clarke, 2022; Clark, 2017).

Trustworthiness. Research journals are recommended in previous research in order to avoid research bias and to increase trustworthiness in qualitative data analysis (Braun & Clarke, 2022; Houghton & Houghton, 2018; Nowell et al., 2017). A research journal was used in the present study to document reflections and informal notes throughout data collection and analysis to track changes and to support the analytical process. For instance, when analysing the data related to the experiences of parent participants, twelve themes were initially generated. Examples of these initial themes included 'parent attitudes' and 'recommendations for other parents.' While the twelve themes initially generated assisted the researcher in understanding the data, there were too many themes, and the themes were more like 'topic summaries' than themes (Braun & Clarke, 2022). Consequently, these initial themes were abandoned, and the researcher moved from the fourth phase back to the second phase of the reflective thematic analysis process. Subsequently, the reflective journal was used to reflect on the ensuing themes that were generated to ensure that the themes were based on meaning rather than categories or summaries of the codes.

In addition to a research journal, Nowell et al.'s (2017) step-by-step approach was utilised in order to establish trustworthiness during each phase of the reflexive thematic analysis. A checklist which indicates the actions taken to promote trustworthiness at each phase of the analysis is included in Appendix Q.

Results

Are there differences in the verbal communication abilities of children with Down syndrome depending on whether they attend an EMSS, EMM or IMM primary school?

Preliminary Analysis. Descriptive statistics were obtained to examine the characteristics of the categorical and continuous variables analysed regarding this research question. Table 17 demonstrates descriptive statistics for relevant demographic information of child participants in the entire sample and across groups. Notably, a series of one-way Analysis of Variance tests (ANOVA) indicated that there were no statistical differences between the three groups (IMM, EMM & EMSS) in relation to the children's chronological age (p = 0.99), primary caregiver's level of education (p = 0.60), time spent reading at home (p = 0.49), quantity of children's books within the home (p = 0.67) and quantity of adult's books within the home (p = 0.70). These results allow for matching across groups and may serve to decrease the likelihood that differences in the verbal communication abilities across groups are due to variables which have previously been found to have a confounding impact on the verbal communication abilities of this sample.

Table 17

Descriptive statistics

	Entire group	IMM group	EMM group	EMSS group				
Children's age in months								
Mean	122.6923077	120.75	123	124				
Minimum value	75	75	85	79				
Maximum value	156	152	156	141				
Child's gender								
Female	38.5%	50%	50%	20%				
Male	61.5%	50%	50%	80%				
Primary caregiver's level of	Primary caregiver's level of education according to converted continuous variables							
Mode	5	5	3, 5	2, 5				
Minimum value	2	3	3	2				
Maximum value	5	5	5	5				
Time reading with child at 1	home on weekdays							
Minimum value	0-5 minutes	0-5 minutes	5 - 15 minutes	0-5 minutes				
Maximum value	30 - 60 minutes	16 – 30 minutes	30 – 60 minutes	16 – 30 minutes				
0-5 minutes	15%	25%	0%	20%				
5 – 15 minutes a day	38.5%	25%	25%	60%				
16 – 30 minutes a day	38.5%	50%	50%	20%				
31 - 60 minutes a day	8%	0%	25%	0%				
+60 minutes	0%	0%	0%	0%				
Time reading with child at 1	home on weekends							
Minimum value	0-5 minutes	0-5 minutes	0-5 minutes	0-5 minutes				
Maximum value	16 – 30 minutes	5 – 15 minutes	16 - 30 minutes	16 - 30 minutes				
0-5 minutes (%)	23%	25%	25%	20%				
5 – 15 minutes a day (%)	62%	75%	50%	60%				
15 – 30 minutes a day (%)	15%	0%	25%	20%				
30 - 60 minutes a day (%)	0%	0%	0%	0%				
+60 minutes (%)	0%	0%	0%	0%				
Number of children's books at home								
Minimum value	1 - 20	21 - 40	21 - 40	1 - 20				
Maximum value	60+	60+	60+	60+				
0 (%)	0%	0%	0%	0%				
1 - 20 (%)	15%	0%	0%	40%				
21 - 40 (%)	23%	25%	25%	20%				
41 - 60 (%)	31%	50%	50%	0%				
+60 (%)	31%	25%	25%	40%				
Number of adult's books at home								
Minimum value	0	1 - 49	1 - 49	0				
Maximum value	+200	+200	50 - 99	200+				
0 (%)	8%	0%	0%	20%				
1 - 49 (%)	62%	50%	75%	60%				
50 - 99 (%)	15%	25%	25%	0%				
100 - 199 (%)	0%	0%	0%	0%				
+200 (%)	15%	25%	0%	20%				

Mixed Methods Analysis. Two key areas were explored in relation to the verbal communication abilities of children with Down syndrome attending EMSS, EMM and IMM primary schools, namely 'Expressive Oral Language' and 'Receptive Oral Language.'

Expressive oral language. Parent participants discussed their children's expressive oral language abilities by describing their 'Speech,' 'Vocabulary' and 'Grammar.' For instance, parents described their children's speech in terms of pace and the typical number of words spoken per utterance. According to parental report, the differences in the length of utterances between children attending EMM, EMSS and IMM primary schools were not statistically significant, as indicated by an ANOVA test (p = 0.60). For instance, the number of words per utterance spoken by children attending EMM schools ranged from one-word utterances to more than five words per utterance. Similarly, the number of words per utterance spoken by children attending EMSS and IMM primary schools also ranged from two-word utterances to more than five words per utterance.

Across the three groups, parents reported that, while their children experienced difficulties with clarity of speech, they could generally make themselves understood to their family members, adults known to them and their peers. Furthermore, parents noted that pace of speech also impacted clarity and articulation. For instance, when talking about her 8-year-old son, Aileen stated "while his language is not clear, like he can make himself understood. And he talks very fast as well, which probably doesn't help the situation."

While there were no apparent differences, amongst children's expressive vocabulary and grammar across groups, a similar pattern between expressive vocabulary and grammar, and chronological age was evident. For instance, regarding 7-year-old Ciara's vocabulary, her father, Kevin, stated "she would have a small number of words" and Maria noted that her 6year-old child Anna's use of grammar was "pretty much non-existent." Contrastingly, the older children within the sample were described as having "lots of vocabulary" (Laura, 12-year-old) and "she really has a very good vocabulary and kind of good grammatical kind of, you know, structures and that kind of thing" (Isobel, 11-year-old). When discussing the type of vocabulary used by their children, many parents referenced the variety or the amount of question words used, namely the question words 'who,' 'what,' 'where,' 'when' and 'why.' For example, when explaining the vocabulary used by her 8-year-old son, Daniel, Jean reported that he often asked questions like "where are we going? What is going to happen now?" and "Where were you?" and "I was wondering where you were?"

Most parents reflected on the changes in their children's expressive language abilities over time. For instance, regarding 11-year-old Harry's expressive language skills, his mother, Fiona outlined "now his speech has really progressed massively. There's a lot of work in that. The fewer words Harry uses, the better.... But he started to bring slang into his conversation and it's really cute, you know, listening to others around." Parents attributed improvements in expressive language abilities to age, access to speech and language therapy, language interventions in school, exposure to rich language and reading. Notably, the ten parents, who reported that their child receives speech and language therapy, represented different levels of socioeconomic status, as quantified by the primary caregiver's level of education. In addition, some parents referred to within-child factors, such as their child's muscle tone, motivation to speak, and personality, when discussing their expressive language abilities. On this topic, Gráinne commented that her 10-year-old son, Gary, is "very competitive and so you know he always wants to do things... You know, he's motivated... I think his personality would stand to him in that sense of learning."

Receptive oral language. Parent participants discussed their children's receptive oral language abilities by describing their 'Vocabulary,' Understanding Questions' and 'Following Instructions.' Regarding receptive vocabulary, across the three groups, parents outlined that there were differences between their children's expressive and receptive

vocabulary, in favour of the latter. For instance, Maria noted that her 6-year-old daughter, Anna, is "taking in more information accurately. Much more than she would communicate back. Much, much more than what should communicate back." Similarly, when discussing her 10-year-old son, Enda, Irene highlighted "it's the comprehension... He has it all in here [points at head]... And it will come out and whether it's body language, whether it's modelling or whether it's, you know, a three-word sentence..." Regarding understanding of questions, parents across groups discussed children's understanding of question words, such as 'who,' 'what,' 'where,' 'when' and 'why.' Notably, there was a pattern across all three groups regarding questions beginning with 'when,' as parents reported that children may use this word in the correct context but would not fully understand it's meaning, owing to their concept of time. For instance, Eimear stated "in a way things happen today or tomorrow for Isobel [11year-old], you know? Or you know, OK, three sleeps away or whatever, you know. But talking about, "when?" "oh next March!" No, that means nothing, you know?" With regards to following instructions, parents differentiated between their children's ability to understand instructions and their ability to follow through. Ciara's father, Kevin, explained,

"I don't know if it's not understanding the instruction or just not willing to follow it? ... if you're just in the shops or whatever, and I'd say "stop" or "stay beside me" and, you know, she'll just want to go off and look and explore and do her own thing... [if I] say "stop," give a bit of eye contact and make her stay and she'll do it then. Yeah, so she understands she's just not always willing to oblige."

Similar to expressive oral language abilities, there were no differences apparent between groups in relation to the children's receptive vocabulary and understanding of questions. Parents in each group attributed their children's receptive vocabulary and understanding of questions to their age, speech and language interventions, exposure to rich language and understanding of abstract concepts, such as time. For instance, 8-year-old Daniel's mother, Jean, described the efforts put in by parents to develop receptive language abilities, commenting,

"See, that's the thing I'm working on. "How? Where? Why?" He does [understand] but then sometimes he confuses them... Like I was going "why is this?" and "how is this?" and "where is this?" and "what?" Yeah, that's something that he still needs to work on... in the context of the whole sentence, he understands what you're talking about..."

According to parental report, the differences in the complexity of instructions understood by children attending EMSS, EMM and IMM primary schools (Table 18) were not statistically significant, as indicated by a ANOVA test (p = 0.88). While there were no differences between the groups in relation to the children's ability to follow instructions, there was variability amongst each group in terms of the quantity of instructions the children could follow, and the prompts required. For instance, in each group, the ability to follow instructions ranged in quantity and prompting, including one-step instructions, first-then instructions, twostep related instructions, two-step unrelated instructions and three-step instructions.

Table 18

Instruction	IMM (<i>n</i> = 4)	EMM (<i>n</i> = 4)	EMSS $(n = 5)$
One-step	2	3	1
Two-step (including first-then)	1	0	2
Three-step or more	0	1	0
Not reported	1	0	2
Mode	One-step	One-step	Two-step

Complexity of instructions understood by child participants

What are the experiences of parents of children with Down syndrome attending EMSS, EMM and IMM primary schools?

Figure 12 presents a thematic map of the experiences of parents of children with Down syndrome attending EMSS, EMM and IMM primary schools. As illustrated in Figure 12, three themes were identified which represent the experiences of parents of children with Down syndrome attending EMSS, EMM and IMM primary schools. In Figure 12, the three themes are coloured grey: 'The Hardest Decision of All,' 'Keeping All the Balls in the Air' and 'Fostering Inclusion and Facilitating Success at School.' The subthemes are coloured light blue.

Figure 12

Thematic map of parents' experiences



The Hardest Decision of All. This theme describes participants' experience of choosing a school for their child and comprises three subthemes: 'Settling into Preschool,' 'Key Considerations' and 'First Impressions Matter.'

Settling into Preschool. All child participants attended preschool prior to commencing primary school and this transition offered parents an opportunity to reflect on their child's preschool readiness. Reflecting on her child, Anna's age, Maria stated "we had to start her at preschool, and it felt very wrong because she still felt very much so like a baby. She did not feel ready to go to preschool," while Fiona noted that her child, Harry, "didn't have any language at that stage... He had no independent skills... He would be so overwhelmed." Parents attributed small class sizes in preschools and support received from preschool staff, as factors which supported their child to settle in. Notably, children's access to support workers varied across participants, with Michael's mother, Aileen, stating that she had to pay for a support worker, as Michael was finding the transition to preschool challenging.

He didn't take change well at the start... I was paying someone kind of to be an SNA, but there was one stage where I think they [preschool] were asking him to leave because he had bit somebody and then it was going to be really hard for me to get another place.

Key Considerations. For some parents the process of selecting a school for their child was straightforward. For instance, Jean, who decided to send her child, Daniel, to a local EMM school, stated "he was born and a week later, I rang them up and enrolled him. That's it. That was the process." Contrastingly, many other parents experienced significant difficulties when choosing a school. Harry's mother, Fiona, stated "that was the most difficult journey of all, finding the school... At that stage you're still quite vulnerable… you've no idea where to go or what to do. You don't really know what you're looking for." Parents reflected on a variety of factors, which they had to consider when deciding on a school. Figure 13 presents a list of

the various factors considered by parent participants in the present sample when choosing a primary school for their child. For instance, some parents were concerned about the level of access to a SNA their child would receive in their chosen school, owing to their child's care needs. When deliberating between choosing a mainstream or special school, Irene felt that "if Enda was toilet-trained, he would not get all the hours," whilst Michael's mother, Aileen, stated that she was toilet-training him prior to starting school but realised that " it was better to have a few extra care needs, so he'd get an SNA in school. So I was kind of actively trying to toilet him and then I stopped."

Figure 13

Key considerations in school choice

Inclusion in the local community	Sibling's school	School ethos	Class size
Resources and supports available in the school	Child's strengths and needs	Mainstream or special setting	School's expectations for the child
Location of the school	Down syndrome research	Languge medium of the school	School's knowledge and experience with children with Down syndrome

First Impressions Matter. Many parents visited a number of schools to support their decision-making and referenced the impact of an inclusive enrolment experience on their school choice. Brendan's father, Liam, remembered feeling anxious when dropping the
enrolment form into Brendan's EMM school, stating "it said on it that he had Down syndrome and I was just hoping that that wasn't going to be like a red flag," but felt relieved when the secretary accepted the form and "didn't have to go and ask anyone... it was just a really obvious thing that he was going to be accepted and welcomed." Furthermore, parents placed high value on their interactions with school leaders during enrolment. For instance, whilst visiting different schools, Kate's mother, Carla, noticed that across schools "the principal's approach and their receptiveness was very different... we had one principal that we certainly felt that Kate would not be welcome there. Certainly was not welcome. Very obvious, very clear." Conversely, in the IMM school that Carla eventually selected, she noted that the principal "opened the door for Kate, for her learning... they said that they were going to challenge themselves and how they wanted it to work." Similarly, when describing her initial contact with Harry's principal in an EMSS, Fiona stated,

So I sat in front of him, this was ten schools later and I was expecting nothing. His first question was "what does Harry like? What makes him happy? And what does he have difficulty with?" And I explained that he wasn't at all ready for school and he just turned around and looked at me smiling, and he goes, "You know what? Most of our kids in that side of the house aren't, so how do we make him happy?"

Keeping All the Balls in the Air. This theme focuses on the responsibilities of parents who have a child with Down syndrome. The theme contains three subthemes: 'Safety First,' 'Accessing Community Supports' and 'Advocating for Inclusion.'

Safety First. Parents highlighted their concerns regarding the medical needs of their children and noted that these needs often took priority over other areas of their children's development and learning. For instance, 10-year-old Ferdia's mother, Helen, asserted "that the fact that he has Down syndrome and any challenge that comes with that is way down the list for us." Similarly, 11-year-old Harry's mother, Fiona, noted that Down syndrome is "not the

difficult bit. It's the easiest bit." Some parents expressed feelings of isolation when describing the challenge of meeting their children's needs, whilst also managing other family responsibilities, such as shopping or attending family events. Eleven-year-old Jack's mother, Doireann, expressed her desire to explain to others "how hard it is and what it's like to have a child with Down syndrome... your heightened awareness is, like, I won't say doubled. Quadrupled?" Moreover, parents shared a sense of fear regarding their children's tendency to flee from supervision and described the impact that this can have on family life. On this topic, 7-year-old Ciara's father, Kevin, outlined,

We have to keep the front door locked all the time. It's actually alarmed. So as soon as the front door opens, it beeps, and we can hear it throughout the house.... We'd be too anxious just to bring her into a crowd like and not have full control of her. You know, because she would just go off and you'd lose her.

Accessing Community Supports. An additional responsibility referenced by many parents was in relation to accessing supports for their child in their local community, including extracurricular activities, social groups and therapeutic services. For instance, parents were in consensus regarding the importance of encouraging their child's involvement in their communities. Maria noted that her 6-year-old child, Anna, "moves in mainstream circles," with regards to extracurricular activities, stating that the local ballet teacher "has gotten trained in Lámh so that she can be more inclusive of Anna." Furthermore, when describing her efforts to involve her 13-year-old son in activities, enjoyed by her son's typically-developing peers in the local community, Aileen stated,

I send him to tennis, I send him to the piano, he goes to gymnastics, he goes swimming. Like I'm sending him off out to things all the time, you know, to have him mixing with different people. I don't want him pigeonholed. Contrastingly, some parents highlighted the lack of supports available within the community and how this impacted on inclusion. For instance, 11-year-old Jack's mother, Doireann, outlined "I can't take him to any clubs or sports or camps or anything like that because they want someone qualified and vetted and everything to be with him one-to-one."

Moreover, parents shared a sense of frustration regarding the support they received from children's disability services, which have recently been reconfigured into local disability teams in Ireland. Bernadette commented that since moving to her 12-year-old child Laura's new disability team, the level of services available "deteriorated terribly." Similarly, 7-year-old Ciara's father, Kevin, reported "very poor engagement and communication, very lacking in services, never forthcoming with anything," as his experience of the local disability service. As a result, many parents described taking matters into their own hands. For instance, in reference to the limited services her 12-year-old daughter, Kate, has received from her local children's disability team, Carla stated "I can't guarantee that she's going to get support regularly... I feel I've taken full responsibility for my kids... Physio? I bring her to the playground!" Whilst another parent outlined that they had set up their own support group for siblings of children with Down syndrome. Additionally, many parents outlined that they pay for private therapy for their children or receive subsidised therapy from Down syndrome organisations. For instance, 13-year-old Michael's mother, Aileen, reported "you need to have plenty of money... and you have to try and prioritise... I've made that choice that he needs it. He's going to get it."

Advocating for Inclusion. Parents also highlighted the role they play in advocating for their children. Since 11-year-old Jack's birth, his mother, Doireann, explained "I have developed a lot about speaking up for Jack." While Michael's mother, Aileen summarised,

You actually see the world in a totally different way once you have your own child, because you have to look at things differently and you have to get used to maybe having to fight for stuff or not being able to get the right start or get the right extra thing. Consequently, in addition to other parental responsibilities, parents reported raising their children's human right for inclusion to boards of management, human rights organisations and local politicians.

Fostering Inclusion and Facilitating Success at School. This theme describes parents' reflections on the key components which are conducive to positive school experiences for their children attending primary schools. The theme consists of three subthemes, namely 'Communication and Collaboration,' 'Inclusion From the Top Down,' and 'Provision of Appropriate Supports.'

Communication and Collaboration. The quality of home-school communication and collaboration were frequently referenced when parents described their satisfaction with their child's school and learning. For instance, parents valued daily communication from their child's SNA or class teacher regarding their child's needs, with 12-year-old Kate's mother, Carla, stating "what I have with the SNA is, I have a daily handover... sometimes I text in the morning... just brief descriptions so that the teacher and the SNA is aware of what that morning has been like." Other parents referenced home-school communication diaries to promote daily communication. Home-school communication and collaboration were also described by parents as essential for developing trust with school staff and maintaining consistency between teaching and learning approaches used at home and in school. For instance, Jack's mother, Doireann, explained that "it's all down to communication... basically I just want to be told how I can help him... how can we teach them if we don't know how to do it ourselves?" Parents also outlined the role that good home-school communication plays in their children's verbal communication development, as communication from school staff provides conversation starters for parents at home. Regarding her 10-year-old son's teacher, Irene stated,

Very quickly at the end of the day, she'd send a quick WhatsApp message, "Enda had a great day in school..." We'll just say they had PE today. So at least when Enda got off the bus I was able to go into the conversation of the day... because Enda likes conversation. He hates being asked questions.

Inclusion From the Top Down. Parents highlighted the impact that an inclusive school ethos had on their child's experiences of success at school, with many parents citing the importance of fostering inclusion through a top-down approach. For instance, Fiona noted that the inclusive school culture in 10-year-old son's school is "not a big deal to them... I think that's why it works. It's completely natural... It's fostered from the top down." Furthermore, Carla described the school principal's approach in her 12-year-old daughter's school "was to include and do their best to look at Kate's learning styles and to figure out from there...and this fed down to all the teachers." Further, with regards to inclusion, Carla noted that a child with Down syndrome and their parent cannot "really instil that [inclusion] in someone, but a leader can inspire the teacher... and then that filters down to the children." Eimear described an inclusive school ethos as a school where her child is "going to be looked after here. She's going to be welcomed here. She's going to be cherished, celebrated, etcetera here." Parents reflected on a variety of methods which school leaders and management could implement to foster an inclusive school ethos, such as organising meetings between parents and principals, involvement from principals in support planning, provision of support from principals to teachers in implementing inclusive teaching practices, organising training for school staff, allocating resources with children's needs in mind and including the voices of parents of children with additional needs in policies and decision-making.

Provision of Appropriate Supports. Access to a SNA and the dynamic between the SNA and the child were frequently cited by parents as critical factors in their child's experience of success at school. For instance, Helen commented "it's very, very important to

match, as far as possible, the SNA to the needs of the child," with Enda's mother, Irene, highlighting that the SNA's knowledge of the child's personality was as important as their knowledge of Down syndrome, stating that many SNAs have "done the training, but do not necessarily know the personality...You have to read them [children with Down syndrome] ... You have to know their personality." Furthermore, parents valued when SNAs encouraged their child's development of independence skills. For example, 10-year-old Gary's mother, Gráinne, mentioned "she's my kind of SNA. She wouldn't do things for him necessarily. Or, you know, she'd have him doing a lot for himself. And, you know, he's come on in leaps and bounds with Eithne [SNA] being there." Further to appropriate support from SNAs, parents valued the use of evidence-based inclusive strategies by teachers, such as differentiation, use of Lámh, use of positive behaviour support strategies, access to a support teacher, access to sensory rooms and the implementation of evidence-based literacy and numeracy programmes, such as See and Learn and Touch-type Read and Spell (TTRS).

What are the experiences of children with Down syndrome attending EMSS, EMM and IMM primary schools?

Figure 14 displays a thematic map of the experiences of children with Down syndrome attending EMSS, EMM and IMM primary schools. Three themes were identified which represent the school experiences of the child participants. As displayed in Figure 14, these themes are shown in grey, including 'Love of Learning,' 'People and Places' and 'Amazing Activities.'

Figure 14



Thematic map of children's experiences

Love of Learning. Many of the children indicated that they liked coming to school and enjoyed learning, which was also reflected in parental interviews. Literacy or more specifically, reading, was a popular subject reported by many children in all three types of school setting. For instance, when provided with the camera, the first photograph taken by 6year-old Anna, the youngest child participant, was of a book in her classroom called "Ainmhithe Feirme" [Farm Animals]. Similarly, 8-year-old Daniel captured a photo of a book in his classroom and stated "I like reading this book about Floppy." Contrastingly, 11-year-old Isobel commented "sometimes I don't like reading." Two children named their "favourite" subjects, with 10-year-old Gary outlining that Gaeilge [Irish] and Art were his favourite subjects at school, and 8-year-old Daniel describing Irish as his favourite subject, as he enjoys engaging with the games, songs and activities included in the Irish programme 'Bua na Cainte.' Physical Education and Maths were also frequently reported by child participants as learning areas that they enjoyed in school. Figure 15 demonstrates all of the subject areas photographed or referenced by children during child-led tours and interviews, highlighting the heterogeneity of this group of children.

Figure 15

School subjects enjoyed by child participants



Four children outlined that they felt proud about their learning. For example, 13-yearold Michael commented that he was proud of his Maths work, stating "look at all my ticks! I like to do Maths at school. I like to correct my work myself!" In addition, three children discussed class projects and 'Show and Tell' presentations when asked about learning activities that they enjoyed at school, with one child showing the researcher a recent Geography project that he had completed about 'Serbia' during data collection. Contrastingly, 10-year-old Enda indicated that he did not like doing "matching" activities at school.

People and Places. Overall, most children were very capable of leading the child-led tours and demonstrated good knowledge of how to navigate around their schools. Similarly,

many children recognised school staff whilst engaging in the child-led tour and appeared to enjoy greeting school staff and introducing them to the researcher. When photographing or discussing areas around the school, children tended to relate the area to the person or people they engaged with in that area. For instance, 12-year-old Kate stated "I don't like doing work in the classroom" but later mentioned "I like to work in here with Áine [learning support teacher]" when taking a photograph of the learning support room. Furthermore, 10-year-old Gary described the principal giving out prizes during assembly, when queried about the photograph he captured of the school hall. Ten-year-old Ferdia also explained that he liked the yard because his teacher sometimes plays football there with him and his best friends.

Positive relationships at school were built up between the children, their friends, their classmates, SNAs, teachers, school principals and other school staff. For instance, many children indicated that they had a best friend at school. By way of example, 12-year-old Laura frequently referenced playing with her friends and also mentioned playing games with her learning support teacher when discussing what she enjoyed at school. Three children indicated that they enjoyed helping others at school, with 7-year-old Ciara selecting a photo of the key card system and demonstrating that she enjoyed helping the SNA open doors around the school, while Daniel (8-year-old) and Ferdia (10-year-old) mentioned helping the secretary and the school principal.

Photographs of outdoor areas were most commonly photographed by children, including the school yard, the school playground, football fields, basketball courts, an outdoor classroom and the school garden. The sensory room was the most common indoor area discussed or photographed by children, followed by the classroom, the school library and learning support classrooms. Three children named their "favourite" places at school, with 11year-old Jack highlighting an area that contained a gymnastics ladder and mattress, as his favourite area in the school, stating "I like to climb and jump." Similarly, 13-year-old Michael indicated that an area containing a ball pit and the school library were his favourite places, whilst 11-year-old Isobel mentioned that the school hall was her favourite place at school because she liked to sing "on the stage." Only one child responded to a question regarding a place that they didn't like at school, with Michael outlining that he did not like the area where the bin is kept in his classroom, referencing the smell and stating "I don't like a mess!"

Amazing Activities. In relation to what they liked about school, children described a range of different activities, which mainly revolved around play. Figure 16 illustrates all of the activities the child participants referenced when identifying activities, they enjoy engaging in at school. For instance, many children indicated that they enjoyed playing games with friends on the yard, such as chasing, football and basketball. Twelve-year-old Kate noted that her "favourite" outdoor game was called "The Floor is Lava," while 8-year-old Daniel indicated that he enjoyed collecting leaves and conkers around the school fields. Sensory activities which included water play, sand, bubbles and balloons were frequently described by children. Furthermore, regarding the sensory room, 11-year-old Isobel noted "I like to go to the sensory room to play and to relax." Some children referenced being allowed to engage in enjoyable activities, as a reward, following the completion of schoolwork. For instance, during the childled tour, 6-year-old Brendan pointed at and photographed a balloon that he was allowed to play with as a reward for his engagement with learning activities.

Sports were also frequently recorded by children. In fact, basketball was referenced by seven children with regards to enjoyable activities at school. During the child-led tour, 10-year-old Enda was very eager to demonstrate his basketball skills and stated "I scored!" when discussing a photo he captured of a basketball hoop. Artwork and construction activities were also popular amongst children. Gary (10-year-old), Harry (11-year-old) and Laura (12-year-old) displayed two pieces of artwork each during the child-led tour, while Enda indicated that he made a "shoebox" in the Woodwork room.

Figure 16

Outdoor play	Sensory play	Construction play	Playing games
Playing with toys	Playing computer games	Art	Singing and listening to music
Reading	Playing sports	Nature play	Trampoline exercises
Relaxing during movement breaks	Engaging with animals at school	Gymnastics	Pretend play

Activities enjoyed by child participants at school

Discussion

In line with the transformative paradigm, the ultimate goal of this study was to promote inclusion and drive change for children with Down syndrome attending EMSS, EMM and IMM primary schools in Ireland, and their families. Consequently, online surveys, parental interviews and a variety of verbal and visual tools from the Mosaic approach (Clark, 2017) were employed in order to include children with Down syndrome and their parents in the research process from the formation of research questions through to data collection. The findings provide novel insights into the impact of immersion and non-immersion primary school settings on the verbal communication abilities of children with Down syndrome, the experiences of parents of children with Down syndrome attending primary schools, and the school experiences of children with Down syndrome attending EMM, EMSS and IMM primary schools.

Verbal communication abilities of children with Down syndrome attending EMSS, EMM and IMM primary schools

This is the first study examining bilingualism in children with Down syndrome in the Irish context. Furthermore, it is the first study to compare a group of children with Down syndrome attending immersion settings to a group of children attending non-immersion settings. Two themes were identified from parental interviews in relation to verbal communication abilities, including expressive and receptive oral language. For instance, expressive oral language subthemes included speech, vocabulary and grammar, whilst receptive oral language subthemes included vocabulary, understanding questions and following instructions. Findings from the present study indicate that there were no significant differences amongst the expressive and receptive oral language abilities, of children with Down syndrome who were attending IE settings (IMM) in comparison to non-immersion settings (EMM & EMSS), through quantitative analysis of the child participants' typical length of utterance and the complexity of instructions understood by child participants. These findings are in line with the limited previous research conducted in this area (Martin et al., 2021; Ward & Sanoudaki, 2021b). For instance, Martin et al.'s (2021) findings indicate that there were no significant differences between the English expressive and receptive oral language abilities of a student with Down syndrome attending a French immersion school in comparison to eight agematched children with Down syndrome attending a non-immersion, English-medium school.

Findings from the present study contribute to the research field in the area of IE for students with Down syndrome by addressing the small sample size used in Martin et al.'s

(2021) study. For instance, a larger overall sample size, with similar sample sizes across the three comparison groups (IMM: n = 4, EMM: n = 4, EMSS: n = 5), was used in the present study, whilst only one student attending an immersion setting was compared to a group of students attending non-immersion settings in Martin et al.'s (2021) study, and only one participant attending an immersion setting in Ward & Sanoudaki's study (2021b) was identified. However, findings from the present study in relation to verbal communication abilities should be interpreted with caution owing to the use of non-standardised measures of expressive and receptive oral language.

Notably, rather than type of school, a relationship between the length of children's utterances and chronological age was evident, with younger children producing fewer words per utterance in comparison to older children within the sample. The relationship between length of utterance and chronological age in this sample is consistent with Chapman et al.'s (1992) findings, which indicated that the length of utterances produced by children with Down syndrome aged between 5 and 20 years increased with age, with the oldest participants (20year-olds) continuing to develop their expressive syntax. By contrast, a study by Buckley et al. (2006) indicated that the communication skills of adolescents with Down syndrome attending special education settings in the UK did not continue to develop with age. It is likely that children's length of utterances are influenced by access to speech and language therapy, as the children who were reported to produce more words per utterance were also the children who were reported to attend regular speech and language therapy. This is consistent with previous findings demonstrating the impact of the duration and frequency of sessions of speech and language therapy on the language outcomes of children with Down syndrome (Neil & Jones, 2019; O'Toole et al., 2018; Yoder et al., 2014). Furthermore, according to the parent participants, verbal communication development could be attributed to language interventions in school, exposure to rich language, time reading, muscle tone, motivation for communication, and personality. These factors can be interpreted within the context of Bronfenbrenner's bioecological theory (Bronfenbrenner & Morris, 2006). Figure 17 displays the various individual, microsystem, mesosystem, exosystem, macrosystem and chronosystem factors which were referenced by parent participants as factors influencing their children's verbal communication development.

Figure 17

Influence of bioecological factors on verbal communication development



The experiences of parents of children with Down syndrome attending EMSS, EMM and IMM primary schools

Three themes were identified from parental interviews in relation to their experiences as parents of children with Down syndrome attending EMSS, EMM and IMM schools, namely 'The Hardest Decision of All,' 'Keeping All the Balls in the Air' and 'Fostering Inclusion and Facilitating Success at School.' For instance, parents reflected on the challenging experience of choosing a school for their child, their first impressions during the enrolment process and important factors that were considered during their school decision-making process. In the present study, some parents faced a real dilemma when choosing a school, which was similar to the parents of children with intellectual disabilities in the UK, who also referenced high levels of parental distress when making this important decision (Satherley & Norwich, 2022). Whilst alternative school types were considered by parents in the present study, none of the parent participants reported considering home education, which is in contrast to the 19.3% of UK parents who considered home-schooling their child (Satherley & Norwich, 2022).

Parents in the present study contemplated their many responsibilities as parents, namely keeping their child healthy and safe, accessing community supports and advocating for inclusion on behalf of their child. Parents who took part in Lyons et al.'s (2016) study reported similar views regarding the balancing act of promoting participation, whilst keeping their child safe and well, which is similar to the 'Safety First' theme in the present study. In addition, definitions for inclusion provided by parents in the present study were in congruence with those reported by over half of the participants in Satherley & Norwich's study (2022), who prescribed to the idea that " a sense of belonging to class and school, and social acceptance by peers" underpin high-quality inclusive education provision. Furthermore, two out of three of the advocacy strategies used by Latina mothers in the United States of America (Rios & Aleman-Tovar, 2022) were reportedly used by parents included in the present study whilst

advocating on behalf of their children with Down syndrome, including knowledge of special education law and requests for data.

Finally, parents identified factors which foster inclusion and facilitate success for their children with Down syndrome attending primary school, namely communication and collaboration, a top-down approach to inclusion and providing appropriate supports at primary school to children with Down syndrome. While the sample described in Mullan et al.'s (2018) study included parents of children with Down syndrome who were attending post-primary schools, the views of these parents were similar to the views of the parents of primary school children with Down syndrome included in this study, who also highlighted the importance of regular, open communication between parents and school staff.

The experiences of children with Down syndrome attending EMSS, EMM and IMM primary schools

The experiences of children with Down syndrome attending EMSS, EMM and IMM revolved around learning, relationships, important places and fun activities at school. Contrary to Norwich and Kelly's (2004) findings, which indicated that learners with intellectual disabilities rated Maths and literacy as challenging learning areas, the present sample rated Maths, and in particular literacy, as subjects they enjoyed at school. Additionally, one child included in the present study indicated that she preferred to complete her work in the learning support room, which is similar to the preference for withdrawal support by participants from Norwich and Kelly's (2004) study. Moreover, the many references to friends and positive relationships developed between children who participated in this study and school staff conforms with Prunty et al.'s (2012) findings, who suggests that the quality of social relationships in school may mediate the views of children with additional needs with regards to

school. In contrast to Prunty et al.'s findings, none of the participants in the present study reported negative experiences with their peers, such as bullying. Furthermore, Gaeilge (Irish) was highlighted as one of the favourite subjects of a 10-year-old student attending an IMM in the present study, which is contrary to the student with SEN who was attending an Irishmedium school and found Irish "annoying" in Prunty et al.'s study (2012, p. 31).

Conclusion

This chapter of the thesis provided novel insights into the impact of IE on the verbal communication abilities of children with Down syndrome, in comparison to children with Down syndrome attending non-immersion settings, in addition to the experiences of children with Down syndrome and their parents. In summary, there were no significant differences in the verbal communication abilities of children with Down syndrome who were attending EMSS, EMM and IMM primary schools, which is in line with previous research. Similar to previous findings, parent participants highlighted the difficulties they experienced choosing a school for their child, their many parental responsibilities and the importance of top-down inclusion, appropriate supports and regular home-school communication. In contrast to previous findings, the parents in the present study did not consider home-schooling as an option for their child. The experiences of children related to their learning, relationships, important places and fun activities at school. The important role played by friendship and relationships with school staff, reported by child participants, is in line with previous findings. Contrary to previous research, the children in the present study identified literacy (English and Irish) and Maths as subjects they enjoyed at school. In addition, the participants did not report experiences of bullying, which is in contrast to previous findings. In line with the transformative paradigm which informed this study, parents and children attending Irishmedium and English-medium primary schools were included in the research from the formulation of research questions through to data collection.

The next chapter of the thesis presents a critical reflection of the research process, which will include a detailed discussion regarding the epistemological position and theoretical perspectives that were adopted, a rationale for the research design employed, strengths and weaknesses of the research, ethical considerations and dilemmas that were encountered during the research process, and the implications of the research for professional practice in educational psychology, schools, services for children and adolescents, and future research.

Chapter Four: Critical Review and Impact Statement

Introduction

The final chapter in this thesis presents a critical review and reflection on the research process adopted across the project. An outline of the research paradigm employed in the study is outlined initially, alongside a review of and rationale for the research design utilised, and the strengths and weaknesses of the research. Subsequently, an account of the ethical considerations which were identified prior to beginning the research and ethical dilemmas which arose throughout the research process is provided. Next, the implications of the research for personal professional practice, professional practice in the field of educational psychology, child development, schools, services for children and young people, and for future research, is presented. Finally, the chapter concludes with an impact statement, which describes the contribution made by this thesis both inside and outside of academia.

Research Paradigm and Theoretical Underpinnings

The Transformative Paradigm

As was previously stated, the primary aims of this research were to promote inclusion and to drive change for learners with Down syndrome their families and supporting education professionals. Accordingly, the transformative paradigm was adopted as a philosophical framework (Mertens, 2007), and guided all decision-making related to the research from the development of a research proposal, to attaining ethical approval, to the development of research questions and data collection. Additionally, every effort was made to ensure that the study's findings were presented in a manner which enhances social justice and the human rights of children with Down syndrome, and their families (Mertens, 2021). Once this thesis has been approved and formally accepted by Mary Immaculate College, feedback will be provided to child-participants through the use of a child-friendly, easy-read research report. A brief summary of the findings, in addition to a link indicating where participants can find the full thesis, will be sent via email to parent participants. Furthermore, it is hoped that the participants in the present study will be included in the dissemination of the research findings at a later date (Mertens, 2021). For instance, parent participants will be invited to make decisions about which medium they prefer with regards to communicating the results. As was previously highlighted, there are currently no resources available for parents of children with Down syndrome, who are choosing a school for their child, which provides information about Irish-medium schools as an option or school choice (NCSE, 2013; DSI, 2018). Consequently, the findings from the present study may also be shared as an information booklet for parents. As many of the child participants in the present study highlighted that they enjoyed artwork and looking at photographs, the child participants will be invited to offer their own artwork or to select photographs to be included in this information booklet.

The research design of the present study was developed carefully to ensure that the overall design would promote inclusion and human rights for children with Down syndrome and their families, and empower both child and adult participants to take an active role in shaping the future of their lives, through decision-making and participation. In accordance with the aforementioned axiological assumptions (Mertens, 2007), the present study was grounded in the idea that children with Down syndrome are active agents in their own lives, with their own unique perspectives, experiences, and contributions to society. From the outset of the study, children with Down syndrome were regarded as important and competent stakeholders in the research project, who were capable of contributing to research and decision-making processes, just the same as other stakeholders, namely parents and professionals working in a professional capacity with children with Down syndrome. Similar to adult participants,

children with Down syndrome were invited to participate in Phase One of the research project, which involved selecting the variable or variables that would be researched in Phase Two of the research project. This meant that children with Down syndrome, their parents and professionals acted as decision-makers, whose views held equal weight, with regards to the direction of Phase Two of the project, in alignment with transformative axiological and ontological assumptions (Mertens, 2007).

Furthermore, the unique cognitive profile of children with Down syndrome was considered when designing the surveys and child assent forms, and selecting the tools that were used to collect data from the child participants. The aim was to address potential power imbalances between the researcher and the children with Down syndrome by providing research materials and offering data collection opportunities that would incorporate the relative strengths in visual-spatial working memory abilities of children with Down syndrome (Costa et al., 2015; Gathercole & Alloway, 2006). As a result, visual tools, such as online visual surveys, monolingual and bilingual (English-Irish) assent forms, visual schedules and photographs, were used to empower the child participants and to include their voices in decision-making and the research process. Additionally, as there is evidence to suggest that memory of spatial positions is another relative strength in the unique cognitive profile of children with Down syndrome (Costa et al., 2015), a tour of the child's school, led by the child and an adult known to the child, was conducted with the researcher, as an additional data collection measure. It is hoped that the range of data collection procedures, employed in the study, presented the children with Down syndrome with a variety of participatory methods that engaged them in the research process in a meaningful way, in accordance with the transformative paradigm (Mertens, 2021).

The Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006)

The findings of this study can also be contextualised within the bioecological model of human development (Bronfenbrenner & Morris, 2006). For instance, the influence of factors within an individual's microsystem were evident in the experiences of children with Down syndrome and their parents in this study. By way of example, friendships and social support structures were frequently reported by children with Down syndrome and their parents. Furthermore, parents frequently referenced the important influence of siblings, the children's peers, school staff and speech and language therapists had on the development of the verbal communication skills of child participants. Notably, parents who took part in the study highlighted the impact of mesosystem factors on their child's development. For instance, communication and collaboration, between home and school, were cited as components within the child's mesosytem, which influence the children's experiences of inclusion at school. Furthermore, local services and community resources available to children with Down syndrome were highlighted by parents as important factors within the exosystems of the child participants. Regarding macrosystem factors, parents in this study referenced the influence of the economy, human rights legislation and the educational policies developed for students with additional needs in Ireland, on the development and experiences of the child participants. Furthermore, parents in the present study repeatedly described the considerable impact of the COVID-19 pandemic and school closures, the recent reconfiguration of child disability services in Ireland and school transitions had on the development of the child participants, particularly in relation to learning and verbal communication.

Strengths of the Study

This study addressed gaps in previous research by comparing the verbal communication abilities of a sample of bilingual children with Down syndrome attending immersion primary schools to samples of children with Down syndrome who attended two types of non-immersion settings, namely special education and mainstream primary schools in Ireland. The population of children with Down syndrome attending immersion settings is likely very low in Ireland (Nic Gabhann, 2008; Nic Aindriú et al., 2020). While the sample size included in this study was small, it was larger than sample sizes included in previous studies in this research area. In contrast to previous literature in this area, the study included the voices of children with Down syndrome regarding their experiences of immersion and non-immersion settings, and the voices of their parents. Notably, the child and parent participants were involved in the research design of the study by choosing which area of development would be included as a variable in Phase Two of the research, consistent with the transformative paradigm. It is posited that this is the first study to include children with Down syndrome and their parents from the outset of the study through to data collection in the Irish context.

This research was informed by the bioecological model of human development (Bronfenbrenner & Morris, 2006). Bronfenbrenner highlighted the importance of undertaking research with children in settings that are familiar to the children in order to increase the ecological validity of the findings. A strength of the present study was that all data collection with child participants was conducted in their natural settings. For instance, owing to the online nature of the survey used in Phase One, the child participants were facilitated to take part in their own homes. In addition, Phase Two data collection took place in the children's primary schools. Notably, there was a good geographical spread across the study's participants, as the participants who took part resided in rural and urban areas, across three out of the four provinces in Ireland, including Leinster, Munster and Connaught. The data analysis methodology employed in the empirical paper was also a strength of this research. For instance, variables that were identified as having a confounding impact on the language abilities of children in previous research were controlled for across the three groups of participants (EMSS, EMM and IMM) in the present study. Namely, the differences in chronological age, socioeconomic status and home literacy environments of the child participants across the three groups were not statistically significant.

Limitations of the Study

As was previously stated, the sample size included in the present study was small. While the prevalence of children with Down syndrome attending Irish-medium primary schools is unknown, previous research indicates that the population of children that were defined as having a diagnosis of an 'assessed syndrome' and who were attending Irish-medium primary schools was very low (Nic Aindriú et al., 2020), constituting 4.53% of the research sample (n = 705). Thus, the number of children with Down syndrome attending Irish-medium primary schools, who participated in the present study, may provide a representative subset of this population of students in Ireland, Furthermore, there was variability in the demographic characteristics of the present sample and the participants were located across three provinces in Ireland. Limitations of the present study also included the use of non-standardised measures of verbal communication and missing data from parent participants. Furthermore, there were problems with the use of the school setting as an independent variable in this study, as two children moved schools during the duration of the research process. Furthermore, two students who were not attending immersion settings were exposed to two languages at home, which influences the interpretation of the findings across the three groups.

Owing to time constraints, professionals who participated in Phase One of the study were not invited to take part in Phase Two. In accordance with the bioecological model of human development, it is posited that the inclusion of these participants would have offered further insight into the interplay between factors at the microsystem and mesosystem levels of the framework (Bronfenbrenner & Morris, 2006). Furthermore, of the 13 parent participants included in the study, only two fathers took part, which may have influenced the findings related to parent participants' experiences of juggling many responsibilities as a parent of a child with Down syndrome (Keeping All the Balls in the Air).

Ethical Considerations

As was referenced in the Chapter Three, this research was planned and undertaken under the guidance of the PSI's Professional Code of Ethics (2019) and the 'Doctorate in Child and Educational Psychology Research Guidelines' (Mary Immaculate College, 2020). Accordingly, "Respect for the Rights and Dignity of the Person, Competence, Responsibility, and Integrity" (PSI 2019, pp. 3-4) were the dominant ethical principles which underpinned the planning, data collection and data analysis processes. The principal ethical considerations which arose during the planning phase of the research project included anonymity, confidentiality, consent, and the avoidance of harm to participants.

Challenges with Ethical Approval Process

As was previously stated, ethical approval for this research project was granted on 4 April 2022, 80 days after the initial application was submitted to the MIREC. Consequently, the proposed timeline of the research project was delayed, which had a significant impact on recruitment and data collection procedures, owing to the primary school summer holiday dates. While the transformative approach is widely recognised as a major research paradigm in educational and psychological research (Avramidis & Smith, 1999; Kivunja & Kuyini, 2017; Mertens, 2015), it is likely that the delay in attaining ethical approval was, in fact, due to the study's transformative underpinnings. Hence, the challenges associated with obtaining ethical approval for research which includes the voices of participants, who are often "marginalised in school systems" (Mertens, 2007, p. 223), may discourage postgraduate researchers, who are imposed by the time constraints of a full-time professional training course, from conducting research in accordance with the transformative paradigm. The present study was conducted in adherence with the PSI Professional Code of Ethics (2019), which indicates that researchers shall "ensure that they maintain the highest standards of scientific integrity in their research" (p. 12). Thus, the challenge of attaining ethical approval in a timely manner raises a fundamental issue with ethical approval processes for research which includes children or vulnerable populations, underpinned by the transformative paradigm (Mertens & Ginsberg, 2008; Mertens, 2018).

Unanticipated Ethical Dilemmas

According to Taquette et al. (2022), "research is a dynamic process and unpredictable events can occur; thus, it is crucial that the researcher is able to foresee possible hindrances and prevent them from happening" (p. 1). However, Taquette et al. (2022) assert that despite preparation in light of ethical research considerations, unanticipated ethical dilemmas often arise in research which require "situational solutions, always keeping in mind primarily the participants' needs" (p. 2). Accordingly, an outline of unanticipated ethical dilemmas which transpired during this study is presented.

Recruitment. The second unanticipated ethical dilemma which transpired during this study relates to the recruitment of Phase Two participants. Owing to the delay in attaining ethical approval, the timing of the recruitment phase and the nature of the sample, there were challenges recruiting participants for Phase Two of the present study. For instance, as ethical approval was not attained until April 2022, recruitment and initial data collection in Phase Two occurred during the summer holidays. It is likely that the timing affected recruitment because participants, who initially expressed interest in participating in the research, dropped out during the summer months. Furthermore, while two Down syndrome organisations in Ireland provided enormous support with the recruitment of participants, some branches of both organisations did not respond to numerous requests for support with recruitment, from the researcher, during the summer months. In addition, it is likely that there were challenges recruiting participants because of the nature of the sample included in the study. For instance, while the aim was to recruit five children and five linked parents or caregivers, as part of the IMM group, only four children and four of their parents could be recruited. However, it is worth noting that a recent study conducted by Andrews (2020) highlighted similar challenges, regarding the recruitment of children with intellectual disabilities, who attend Irish-medium schools. Correspondingly, in an Iranian study, Alemi and Bahramipour (2019) reported that they decided to recruit adults with Down syndrome, who were learning English as a second language, because they could not find volunteer children with Down syndrome, who were learning English as a second language, and who would make up a homogeneous group.

Owing to the low recruitment rate subsequent to advertising the research project through Down syndrome and Irish language organisations and on social media sites, school principals in Irish-medium primary schools were contacted in order to recruit additional participants for the IMM group. Two child participants and two linked parents, in the IMM group, were recruited through this approach. It is possible that these participants may have felt pressure to participate, owing to being informed about the research project and invited to participate through their school principal. Hence, this potential power differential between children, parents and school principals, presented an additional ethical dilemma that was not anticipated. For instance, the idea that participants may have felt pressure to participate runs counter to the ontological assumptions which underpin the transformative paradigm of the present study, namely that power is often unequally distributed in research (Mertens, 2007).

Informed Consent. An additional example of an unanticipated ethical issue which arose during the present study pertains to informed consent procedures with participants. To ensure that informed consent could be provided by child and adult participants, information sheets were created, in both English and Irish languages, and provided to participants to explain the research process. As was previously mentioned, a visual information sheet, containing short sentences, a photo of the researcher and pictures explaining the survey process, was included before the survey question for child participants in the Phase One survey. A similar visual assent form was created for child participants taking part in Phase Two of the research, and was posted to the child's house prior to undertaking data collection, alongside information sheets and consent forms for parents. It is important to note that inclusive colours and a child-friendly font (Comic Sans) were utilised in the design of children's research materials and the images used in the materials were sourced from the database of a children's disability service. Parents were asked to return the forms prior to undertaking data collection. During the visits to children's schools for the purpose of data collection, a laminated version of the visual information sheet and assent form for child participants was used to attain verbal assent from the children for participation in the study.

Despite careful consideration about how informed consent would be obtained from child and parent participants, it became apparent, during data collection, that some parent participants provided written consent to participate without fully understanding what data collection would involve or what would happen to the data collected. For instance, more than one parent asked the researcher not to relay information they had provided during interviews to school staff, during the researcher's visits to the children's schools. Hence, it is possible that the parents, who were concerned that the researcher may share data collected with school staff, were not aware of the researcher's commitment to confidentiality, as stated in the information sheet. By way of example, one parent stated "how honest can I be?" in response to questions about what was going well and what was not going so well for their child at school. In addition, after providing written consent about their children's participation in the study, two parent participants asked the researcher what their child would be doing with the researcher during the school visits. The unanticipated ethical dilemmas related to informed consent were resolved by providing the parents, who were unsure about the data collection and analysis procedures, with further information to ensure that they could provide informed consent for participation. Furthermore, subsequent parent participants were provided with a brief verbal overview about data collection and analysis procedures, during the interviews, for the purpose of informed consent.

Photos Taken by Child Participants. Additional unanticipated ethical issues, which transpired during the present study, concern the photos taken by child participants. Firstly, while the child participants were informed by the researcher and the adult accompanying them, prior to the child-led tour, not to take photos of other children in their school, some children took photos of other children. Similar to what Ciara's father, Kevin, mentioned during the interview, it's difficult to "know if it's not understanding the instruction or just not willing to follow it?" As in, it was hard to ascertain whether some of the children either did not understand the instruction not to take photos of other children, which raises questions about the informed consent materials used with children, or they did understand, but were not willing to follow the instruction. Consequently, photographs that were taken by child participants, which

included another child or identified the school location were deleted prior to leaving the school during data collection. Additionally, while it was very tempting to include the beautiful images captured by the child participants in this thesis, the photos were not included as it was posited that they could potentially reveal the location of a school or the identity of a child or parent participant.

Language and Terminology. The preferred language of parent participants regarding Down syndrome was another unanticipated ethical issue that arose during the present study. For instance, prior to undertaking this research, the researcher was aware that person-first language is encouraged by many organisations promoting supports and services for individuals with Down syndrome (DSI, n.d.; National Down Syndrome Congress, 2023). Consequently, person-first language was used during interactions with participants and in materials created for the purpose of this research. Notably, one parent highlighted a preference for using the language 'Trisomy 21,' 'T21,' or 'has an additional chromosome,' rather than 'Down syndrome,' when discussing her child's abilities and needs. The researcher resolved this ethical dilemma, posed by differences in parental preference for language regarding Down syndrome, by following the lead of each parent participant and mirroring the language they used. It is also worth noting that the importance of using respectful language, including person-first language, in relation to Down syndrome, was referenced by some parents during interviews. For instance, parents reported that they had experienced meetings or appointments with professionals, such as school staff and medical practitioners, where identity-first language was used (e.g. "Downs child") when discussing an individual or a child with Down syndrome. Consequently, parental reports draw attention to the need for researchers and professional practitioners to practice what is preached in graduate or training programmes, as part of continuous professional development (Crocker & Smith, 2019). Additionally, these parental experiences highlight the need for researchers and professional practitioners to ask individuals with disabilities, and their

families, about their language preferences during the informed consent process, in accordance with the "nothing about us without us" slogan used by advocacy groups (Dunn & Andrews, 2015, p. 263).

Voice of Child Participants. Finally, an additional unanticipated ethical dilemma which occurred during the present study relates to the voice of the child participants during data collection in the children's schools. To ensure that the children's voices could be heard by the researcher, bilingual and visual research materials were utilised and provided to the child participants, and an adult known to the child accompanied the child and the researcher, during all of the data collection activities. As was previously stated, the purpose of the latter was to ensure that the child felt safe and also to prevent potential frustration if the researcher could not understand what was communicated by the child. Furthermore, the researcher completed Lámh Module 1 training. Notably, despite planning for potential difficulties understanding the child participants prior to conducting the study, there were two occasions, with two child participants, where the researcher did not notice that a child was responding to a question by using Lámh. The Lámh signs in question were "yes" and "mother." On both occasions, the researcher repeated the question and the adult accompanying the child was able to indicate what the child was communicating. Consequently, the researcher revised the Lámh Module 1 signs (including 'yes' and 'mother') and altered the seating position during subsequent research activities to ensure that all hand movements and signs made by child participants could be seen by the researcher. Furthermore, while there were other instances where the speech of child participants may not have been initially understood by the researcher, the children were usually able to support their communication skills, independently, by using Lámh or hand gestures to ensure that they were understood.

Implications of the Research

Personal Practice

The learning gained from creating the section of the online survey and information sheets for child participants has had important implications for the researcher's practice as a trainee educational psychologist. The resources that the researcher will create and use going forward, when preparing children for a psychological assessment, such as a cognitive assessment, which may be querying a diagnosis of an intellectual disability, could be essential scaffolds. Furthermore, working with the child participants in the present study has increased my awareness of the importance of using culturally and linguistically responsive assessment processes in my work as a trainee and qualified educational and child psychologist going forward (Ding et al., 2019; Vega et al., 2015). Use of the visual and verbal tools from the Mosaic approach (Clark & Moss, 2001, 2003; Clark, 2017), with children with Down syndrome has also had important implications for the researcher's professional practice. For instance, the child-led school tour provides deeper insight into a child's visuo-spatial abilities, whether or not they can provide verbal instructions, the style of communication they prefer and information about their social skills when meeting their peers or different members of school staff around the school. Using a camera also presents children with speech and language difficulties the opportunity to communicate without using language. Furthermore, the use of photos whilst interviewing child participants has been useful, as it provides children with a visual aid to support their understanding of the questions asked. These methodologies may support children with Down syndrome or SEN in voicing their views and experiences, and are approaches that will be brought forward in the researcher's assessment work as a trainee and as a qualified educational psychologist. The researcher will also continue to use Lámh in assessment and intervention work to ensure that individuals, who use Lámh to support their

communication skills, are understood and can also understand what the researcher is communicating.

The findings from data collected from parent participants have also had important implications for the researcher's professional practice, as the interviews provided insight into their experiences of choosing a school for their child with Down syndrome, their opinions on the advantages and disadvantages of different primary school settings, and the impact that different primary school settings may have on their child's development. Going forward, the researcher will ensure to ask children and young people with Down syndrome or SEN, and their families, about their language preferences when discussing Down syndrome or SEN. Finally, owing to the online nature of the parental interviews, the researcher was also able to personally reflect on consultation and communication skills, whilst listening back or watching the recorded videos of parental interviews, which provided a unique opportunity to engage in continuous professional development through the use of Video Enhanced Reflective Practice strategies (Murray & Leadbetter, 2018).

Professional Practice in Education Settings and the Field of Educational and Child Psychology

The findings of the present study have important implications for professional practitioners who work in the field of education or educational and child psychology, namely teachers, SNAs, principals, school boards of management, special educational needs officers (SENOs), psychologists and clinicians working in children's disability services or primary care settings. Owing to the influence of exosystem and macrosystem factors on the findings of the present study (Bronfenbrenner & Morris, 2006), there are also important implications for policymakers in various governmental departments in Ireland, namely the Department of

Children, Equality, Disability, Integration & Youth, the Department of Education, the Department of Health and the Department of Social Protection in Ireland.

School Choice. Many parents who took part in the present study referenced the difficulties they experienced when choosing a primary school for their child with Down syndrome. This finding has important implications for SENOs. For instance the role of SENOs is to support parents of children with SEN about educational supports and special education settings, and to provide advice to parents about their child's transition from preschool to school from primary school (NCSE, n.d.). Furthermore, SENOs, educational and child psychologists, and clinicians from children's disability services could signpost the key considerations, identified by parents in the present study, in order to support parents of children with Down syndrome, who are deciding on a school for their child. Furthermore, the findings of the systematic review (Chapter Two) and the Empirical Paper (Chapter Three) are in line with previous research, regarding the impact of bilingualism or IE settings on the language development of children with Down syndrome (Martin et al., 2021; Ward & Sanoudaki, 2021b). Thus, owing to the findings of the present research, it is recommended that SENOs, education and child psychologists, and clinicians from children's disability services, support parents of children with Down syndrome, who are interested in sending their child to a IMM primary school.

Primary School Enrolment. The finding that 'first impressions matter' for parents of children with Down syndrome, when visiting a school, has significant implications for school staff. For instance, it is important to parents that inclusion is fostered 'from the top down' by school principals and boards of management. Accordingly, parents value when school principals are welcoming and promote inclusion, when they are enrolling their children at primary school. By way of example, one parent in the present study referenced the positive impact a school principal made on her during an initial visit to the school. For instance, the

parent appreciated when the school principal asked her how school staff could make her child happy, rather than asking the parent problem-oriented questions about her child's school readiness or needs. In addition, a parent in the present study referenced the neutral reaction of a school secretary upon receiving the child's enrolment form. For instance, the parent interpreted this neutral reaction as an indication that the school was an inclusive environment, that was welcoming of children with Down syndrome. Educational and child psychologists may also play a role in supporting school staff to implement inclusive practices. For instance, the British Psychological Society's (2022) core competencies for educational and child psychologists include, applying "equality and diversity principles" (p. 19) and "challenging views and actions judged potentially harmful to the child/young person" (p. 19), such as the use of identity-first language when describing a child with Down syndrome.

Irish Language Exemptions. As was previously stated, there were no significant differences between the expressive and receptive oral language abilities, of children with Down syndrome who were attending IE settings in comparison to non-immersion settings, including mainstream and special education settings. This finding also has implications for authorities who grant exemptions from the study of Irish. By way of example, although the findings of the systematic review (Chapter 2) indicate that children with Down syndrome can become competent bilingual speakers and biliterates, two out of five of the child participants attending EMM schools had received Irish exemptions. These findings call into question why access to second language learning opportunities, for students with Down syndrome who attend EMM schools, are being denied. Furthermore, one student, attending an EMM primary school, referenced that Irish was his favourite subject at school. While this student had not been granted an Irish exemption at the time of data collection, this child's view raises questions about how the voices of children with Down syndrome are included in decision-making regarding Irish exemptions, especially if it is a subject that some students with Down syndrome may enjoy.

Learning Irish in Special Education Settings. The principles of Circular 0054/2022 (Department of Education, 2019b) outline that children who attend special classes or special schools in Ireland are "automatically entitled to an exemption from the study of Irish without an application" (p. 6). As a result, children with Down syndrome may be denied opportunities to learn Irish, and to potentially become bilingual, if they attend a special education setting, namely a special school or a special class within a mainstream school. This principle is contrary to the findings of the present study and previous research, which has significant implications for psychologists, boards of management in special education settings and authorities who grant Irish exemptions. Furthermore, the findings regarding differences in the verbal communication abilities of learners with Down syndrome, also have implications for SENOs. According to the NCSE (2016), SENOs may "approach a school directly where they are aware that a special class is or will be required in the near future" (p. 5). Consequently, SENOs and school boards of management could increase opportunities for second language learning for children with Down syndrome, who attend special classes, by establishing special classes for pupils with intellectual disabilities in Irish-medium schools. As was previously stated, there are currently no special classes available for students with intellectual disabilities in Irish-medium primary schools in Ireland. Notably, one participant in the present study transferred from an IMM to a EMSS (special class within a mainstream school) in 6th class. While this student is bilingual, she may no longer have opportunities to learn or speak Irish at school, owing to the transfer to her new school.

The Impact of Bioecological Factors on Verbal Communication Abilities. Parents in the present study referenced the impact of a wide variety of bioecological factors on the development of their children's verbal communication abilities. For instance, many parents
referenced the significant impact that access to speech and language therapy has on their children's verbal communication abilities. However, the majority of parents highlighted that they were paying for speech and language therapy privately or receiving concessions from various Down syndrome organisations for speech and language therapy, as they could not access speech and language therapy through their local children's disability network team. This finding has significant implications for government policymakers, who hold responsibility for the provision of appropriate services for individuals with disabilities, in line with the Disability Act (Government of Ireland, 2005). In addition to speech and language therapy, parents referenced the impact that exposure to rich language learning opportunities within the home has on their children's verbal communication abilities. However, many parents highlighted the number of responsibilities they hold as a parent, whilst also working in full-time employment. As a result, there are significant implications for policymakers in the Department of Social Protection, who design and deliver financial supports for individuals with disabilities and their families.

Supporting Children with Down Syndrome in Primary School. The views of parent participants in the present study, about how to support learning and foster inclusion at school, have significant implications for practitioners who are employed in primary school settings. For instance, parents highlighted the significant role that regular communication with school staff plays in their child's learning and development. In the present study, parents appreciated when teachers and SNAs engaged in daily communication about their child's progress through home-school communication diaries, texts or emails. Furthermore, parents in the present study valued when school principals attended meetings with SEN teachers, class teachers and SNAs, regarding the child's learning progress. Additionally, parents highlighted the crucial role played by SNAs in supporting their children's needs and appreciated when SNAs promoted the development of the children's independence skills. These findings may also have implications for educational and child psychologists, when making recommendations in assessment reports for children with Down syndrome.

The views of children, regarding their love of learning, and the places and activities they enjoy at school, have important implications for practitioners in education settings. For instance, the school subjects enjoyed by the children with Down syndrome were very diverse, which underpins the need for teachers to implement appropriate teaching and learning strategies that will allow children with Down syndrome to access a varied curriculum at school. Notably, one child in the present study indicated that they do not like 'matching' activities at school, which may have implications for teachers. For instance, it is possible that teachers engage children with Down syndrome in matching activities frequently, as the 'match, select, name' strategy is often recommended for learners with Down syndrome (Buckley & Bird, 1993; Copeland & Keefe, 2007).

In addition, teachers could use the visual methodologies utilised with children with Down syndrome, in the present study, to identify the learning preferences of children with Down syndrome, such as subject choice or the location of learning support (e.g. in-class or withdrawal support), and adapt their teaching methodologies as necessary. Educational and child psychologists could also employ these visual methodologies in order to include the voice of the child in psychological assessment and intervention. While children with Down syndrome often exhibit speech and language difficulties, three children in the present study indicated that they enjoyed undertaking projects and 'show and tell' activities, where they had opportunities to present their learning in front of their peers. Accordingly, teachers may offer learners with Down syndrome in primary school with further opportunities to engage in inquiry-based learning and classroom presentations, as a result of the present findings. Finally, many children in the present study highlighted various 'play' activities, as the activities they enjoy the most at school. Consequently, teachers and SNAs could implement more play-based learning

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methodologies, such as strategies from Aistear, the Early Childhood Curriculum Framework (National Council for Curriculum and Assessment, 2009), to incorporate the interests of children with Down syndrome in primary school learning activities, across all class levels in primary school.

Future Research

Future research could expand on the findings of the present research. For instance, while professional practitioners currently working with children with Down syndrome were included in Phase One, these participants were not included in the Phase Two sample, owing to time constraints. Consequently, future research could build on the current findings by including professional practitioners who work in immersion and non-immersion primary education settings, in order to explore their experiences of supporting learners with Down syndrome, in line with the bioecological model of human development (Bronfenbrenner & Morris, 2006). Furthermore, future research could include siblings of children with Down syndrome to investigate their experiences of attending the same or different primary education settings, as their sibling with Down syndrome. Finally, future research could include students with Down syndrome you post-primary schools, to explore the transition from primary to post-primary school in immersion and non-immersion education settings, and the school experiences of post-primary students with Down syndrome.

As there is currently no information available regarding the number of children with Down syndrome, who attend immersion primary schools in Ireland, future research could gather information about this cohort of learners. Accordingly, future research could aim to increase the sample size used in the present study to ensure that a representative sample is utilised, when information becomes available regarding the number of children with Down syndrome attending immersion education settings in Ireland. Furthermore, three of the children with Down syndrome attending IMM settings in the present study used Lámh. Future research could explore how Lámh, or indeed other key word signing systems, are applied and adapted for bilingual learners with Down syndrome attending immersion education settings in Ireland. While it was beyond the scope of the current study, three children in the present study changed schools from mainstream to special education settings, and from immersion to non-immersion education settings. Consequently, future research could investigate why parents choose to transfer their children with Down syndrome from their current school to a new education setting.

Owing to the small sample size, non-standardised measures of verbal communication were utilised to gather information about the verbal communication abilities of the child participants in the present study. Future research could address this limitation by recruiting a larger sample size and using standardised tests to collect data regarding the verbal communication abilities of children with Down syndrome. Furthermore, the findings of the systematic review (Chapter Two) indicated that none of the five selected studies investigated the impact of attending immersion education settings on the socio-emotional development of pupils with Down syndrome. Accordingly, future research could address this gap in research. Finally, one parent in the present study highlighted that a follow-up study, including the present sample of participants, could build on the current findings. Accordingly, future research could employ a longitudinal design to investigate the effects of immersion and nonimmersion settings on the verbal communication abilities of children with Down syndrome, and the experiences of these children, and their parents, over time.

Impact Statement

This thesis aimed to investigate whether there were differences in the verbal communication of pupils with Down syndrome who attend immersion and non-immersion primary schools in Ireland, including mainstream and special education settings. Furthermore, the study aimed to gather the views of these learners, and their parents, regarding their experiences of primary school. The findings of the study add to the limited existing research in this area, which examines outcomes for bilingual children with Down syndrome, who attend immersion programmes at school. Future research could build on the findings of the present study by examining cognitive and socio-emotional outcomes, using the school setting as an independent variable, as was utilised in this study. Ireland offers a unique context to conduct future research in this area, owing to the presence of over 200 Irish-medium schools providing immersion education, across the country. It is posited that this thesis presents the first study, undertaken in the Irish context, which includes the voices of children with Down syndrome, and their parents, about their experiences of immersion and non-immersion primary schools, from the beginning of the research process. The novel approach to including the voices of children with Down syndrome, utilised in this study, could inform future research studies which aim to explore the perspectives of children, including typically-developing children and children with special educational needs.

The impact of this research also extends beyond academia. For instance, the findings of this study have significant implications for individuals with Down syndrome, their families and their communities. This research can support parents of children with Down syndrome to make informed decisions about the type of school they would like for their child to attend. As one parent in the present study stated, "this was exactly the kind of research I would have loved to read, or to have read, when I was making my decision years ago, you know? Because I did search high and low, and there was nothing!"

The research findings also have important implications for clinical practice, particularly for those who work in the field of education or educational and child psychology. For instance, clinicians can use the key considerations identified by parents in the present study to support parents of children with Down syndrome or SEN regarding their school choice and decision-making. Furthermore, the views of child and parent participants can support education professionals who wish to implement inclusive practices in education settings. Additionally, the research design utilised in this study, to elicit the views of children with Down syndrome, could be used in other community or public health settings in order to include their voices in decision-making and service delivery. Finally, the findings of the present study have implications for government policymakers. For instance, the aim of the Progressing Disability Services model (Health Service Executive, 2020) was to provide more equal access to services for children with disabilities. However, many of the parents in the present study indicated that their children were not accessing appropriate services in their community, leading to parents paying for therapies privately.

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Appendices

Appendix A: Timeline of the Research Project



Appendix B: Tables Representing Excluded Studies

Table 2

Studies Excluded after Title and Abstract Screening

	Reference	Criteria for Exclusion
	Alami M. & Dohnominoun S. (2010) An innovative	2 Douticinants
1	approach of incorporating a humanoid robot	2. Farucipants
	into teaching EEL learners with intellectual	bilingual children aged 4 18
	disabilities. Asian Pasifis Journal of Second	veges with a diagnosis of Down
	and Excision Language Education $A(10)$ 1.22	Syndrome, who receive the
	https://doi.org/10.1186/s40862.010.0075.5	maiority of formal instruction
	https://doi.org/10.1180/\$40802-019-0073-3	through their second language
		through their second language.
2	Baker-Ramos, L. K. (2017). Gesture and signing in	2. Participants
	support of expressive language development.	The study did not include
	Le.: Inauiry in Education, 9(2), 1-42.	bilingual children aged 4 - 18
	https://digitalcommons.nl.edu/ie/vol9/iss2/2	vears with a diagnosis of Down
		Syndrome, who receive the
		majority of formal instruction
		through their second language
3	Burgoyne, K., Kelly, J. M., Whiteley, H. E., &	2. Participants
	Spooner, A. (2009). The comprehension skills	The study did not include
	of children learning English as an additional	children with a diagnosis of
	language. The British Journal of Educational	Down Syndrome.
	Psychology, 79(4), 735–747.	
	https://doi.org/10.1348/000709909X422530	
4	Burgoyne, K., Whiteley, H. E., & Hutchinson, J. M.	2. Participants
	(2011). The development of comprehension	The study did not include
	and reading-related skills in children learning	children with a diagnosis of
	English as an additional language and their	Down Syndrome.
	monolingual, English-speaking peers. The	

	British Journal of Educational	
	Psychology, 81(2), 344–354.	
	https://doi.org/10.1348/000709910X504122	
5	Burgoyne, K., Whiteley, H. E., & Hutchinson, J. M.	2. Participants
	(2013). The role of background knowledge in	The study did not include
	text comprehension for children learning	children with a diagnosis of
	English as an additional language. Journal of	Down Syndrome.
	Research in Reading, 36(2), 132–148.	
	https://doi.org/10.1111/j.1467-	
	9817.2011.01493.x	
6	Caselli, M. C., Lucioli, T., & Recchia, M. (2010). Lo	2. Participants
	sviluppo lessicale di una bambina con	The study did not include
	sindrome di Down: Parole e segni = The	bilingual children aged 4 - 18
	lexical development of a little girl with Down	years with a diagnosis of Down
	syndrome: Words and signs. Rivista Di	Syndrome, who receive the
	Psicolinguistica Applicata, 10(1–2), 27–60.	majority of formal instruction
		through their second language.
7	Doctoral School Summer Conference 2012 Institute of	1. Type of Article
	Education, (2012), <i>Educate</i> ~, 12(2), 54–80.	
		The research article was not
		peer-reviewed or written in the
		English language.
8	Ellis, J., Logan, S., Pumphrey, R., Tan, H. K., Henley,	3. Outcome
	W., Edwards, V., Moy, R., & Gilbert, R.	The study did not examine
	(2008). Inequalities in provision of the	cognitive and socioemotional
	Disability Living Allowance for Down	outcomes related to the impact
	syndrome. Archives of Disease in	of immersion education.
	Childhood, 93(1), 14–16.	
	https://doi.org/10.1136/adc.2006.112839	

9	Homolková, K. (2020). Bilingvismus u dítěte s	1. Type of Article
	Downovým syndromem. Studies in Applied	
	Linguistics / Studie z Aplikované Lingvistiky,	The research article's full-text
	11(2), 7–15.	was not written in the English
		language.
10	Kay-Raining Bird, E., Genesee, F., & Verhoeven, L.	1. Type of Article
	(2016). Bilingualism in children with	The study was not a research
	developmental disorders: A narrative	article, but a review paper.
	review. Journal of Communication	Review papers are excluded
	Disorders, 63, 1–14.	from the present review.
	https://doi.org/10.1016/j.jcomdis.2016.07.003	
11	Kunze, M., Drew, C., Machalicek, W., Safer-	3. Outcome
	Lichtenstein, J., & Crowe, B. (2019).	The study did not examine
	Language preference of a multilingual	cognitive and socioemotional
	individual with disabilities using a speech	outcomes related to the impact
	generating device. Behavior Analysis in	of immersion education.
	Practice, 12(4), 777–781.	
	https://doi.org/10.1007/s40617-019-00379-w	
12	Lee, A., Nyland, J., & Peppé, S. (2021). Irish English	4. Participants
	PEPS-C (2015 edition) and learners of	The study did not include
	ESL. Folia Phoniatrica et Logopaedica:	children with a diagnosis of
	Official organ of the International Association	Down Syndrome.
	of Logopedics and Phoniatrics (IALP), 1–10.	
	https://doi.org/10.1159/000513082	
13	Lim, L., Arciuli, J., Rickard Liow, S., & Munro, N.	4. Participants
	(2014). Predictors of spelling ability in	The study did not include
	children with Down syndrome. Scientific	bilingual children aged 4 - 18
	Studies of Reading, 18(3), 173–191.	years with a diagnosis of Down
	https://doi.org/10.1080/10888438.2013.862247	Syndrome, who receive the

majority of formal instruction through their second language.

14	Seung, HK., & Chapman, R. S. (2003). The effect of	4. Participants
	story presentations rates on story retelling by	The study did not include
	individuals with Down syndrome. Applied	bilingual children aged 4 - 18
	Psycholinguistics, 24(4), 603–620.	years with a diagnosis of Down
	https://doi.org/10.1017/S0142716403000304	Syndrome, who receive the
		majority of formal instruction
		through their second language.

Table 3

Studies Excluded after Full-Text Review

	Reference	Criteria for Exclusion
1	Abbasian, G., & Ebrahimi, F. (2020). Assessing Down	4. Participants
	syndrome EFL learner's language ability:	The participants included in
	Incorporating learners-teachers'	the study were not all between
	perspectives. English Language	4-18 years of age.
	Teaching, 13(3), 45–67.	
	https://doi.org/10.5539/elt.v13n3p45	
2	Cleave, P. L., Kay-Raining Bird, E., Trudeau, N., &	4. Participants
	Sutton, A. (2014). Syntactic bootstrapping in	The study did not include a
	children with Down syndrome: The impact of	distinct group of bilingual
	bilingualism. Journal of Communication	children aged 4 - 18 years with
	Disorders, 49, 42–54.	a diagnosis of Down
	https://doi.org/10.1016/j.jcomdis.2014.02.006	Syndrome, who receive the
		majority of formal instruction
		through their second language.

	(2011). Neuropsychological effects of second language exposure in Down syndrome. <i>Journal</i> <i>of Intellectual Disability Research</i> , 55(3), 351– 356. https://doi.org/10.1111/j.1365- 2788.2010.01362.x	The study did not include a distinct group of bilingual children aged 4 - 18 years with a diagnosis of Down Syndrome, who receive the majority of formal instruction through their second language.
4	Goral, M., & Conner, P. S. (2013). Language	1. Type of Article
	disorders in multilingual and multicultural	The study was not a research
	populations. Annual Review of Applied	article, but a review paper.
	Linguistics, 33, 128–161.	Review papers are excluded
	https://doi.org/10.1017/S026719051300010X	from the present review.
5	Katsarou, D., & Andreou, G. (2021). Bilingualism in	4. Participants
	Down syndrome: A Greek study. International	The study did not include
	Journal of Disability, Development &	sufficient information to
	Education, 68(3), 376–382.	indicate that the participants
	https://doi.org/10.1080/1034912X.2019.16844	were receiving the majority of
	58	formal instruction through their
		second language.
6	Kay-Raining Bird, E., Cleave, P., Trudeau, N.,	4. Participants
	Thordardottir, E., Sutton, A., & Thorpe, A.	The study did not include a
	(2005). The Language Abilities of Bilingual	distinct group of bilingual
	Children With Down Syndrome. American	children aged 4 - 18 years with
	Journal of Speech-Language Pathology, 14(3),	a diagnosis of Down
	187-199. https://doi.org/10.1044/1058-	Syndrome, who receive the
	0360(2005/019)	majority of formal instruction
		through their second language.

3

Edgin, J. O., Kumar, A., Spano, G., & Nadel, L.

4. Participants

7	Nelson, R. L., Damico, J. S., & Smith, S. K. (2008).	3. Outcome
	Applying eye movement miscue analysis to the	The study did not examine
	reading patterns of children with language	cognitive and socioemotional
	impairment. Clinical Linguistics &	outcomes related the impact of
	Phonetics, 22(4/5), 293–303.	immersion education.
	https://doi.org/10.1080/02699200801919265	
8	Trudeau, N., Bird, E. KR., Sutton, A., & Cleave, P.	1. Type of Article
	L. (2011). Développement lexical chez les	The research article's full-text
	enfants bilingues avec Trisomie 21 = Lexical	was not written in the English
	development in bilingual children with Down	language.
	syndrome. <i>Enfance</i> , 63(3), 383–404.	
	https://doi.org/10.4074/S0013754511003089	
9	Ward, R., & Sanoudaki, E. (2021a). Language profiles	4. Participants
	of Welsh-English bilingual children with	The study did not include
	Down syndrome. Journal of Communication	sufficient information to
	Disorders, 93, 106126.	indicate that the bilingual
	https://doi.org/10.1016/j.jcomdis.2021.106126	participants with Down
		Syndrome were all receiving
		the majority of formal
		instruction through their
		second language.
10	Woll, B., & Morgan, G. (2012). Language	3. Outcome
	impairments in the development of sign: Do	The study did not examine
	they reside in a specific modality or are they	cognitive and socioemotional
	modality-independent deficits? Bilingualism:	outcomes related the impact of
	Language & Cognition, 15(1), 75–87.	immersion education.
	https://doi.org/10.1017/S1366728911000459	
11	Wong, B., Brebner, C., McCormack, P., & Butcher, A.	4. Participants
	(2015). Word production inconsistency of	The study did not include
	Singaporean-English-speaking adolescents	sufficient information to

with Down Syndrome. International Journal ofindicate that the bilingualLanguage & Communication Disorders, 50(5),participants with Down629-645. https://doi.org/10.1111/1460-Syndrome were all receiving6984.12164the majority of formalinstruction through their

second language.

Appendix C: Weight of Evidence B

Table 7

WoE B Scoring Criteria and Rationale

WoE B Methodological Relevance Rating Score	WoE B Descriptive Relevance Rating	Research Design	Rationale
1	Low	Case Reports	Case reports were not recommended by researchers as suitable research methodologies when investigating research questions involving the impact or safety of an intervention e.g., whether immersion education will do more good than harm for children with DS? (Gray, 1997; (Petticrew & Roberts, 2003)
2	Acceptable	Quasi-Experimental, Case-Control, & Cohort Studies	Quasi-experimental, case-control and cohort studies are regarded as appropriate research methodologies for evaluating the impact or safety of an intervention (Gray, 1997).
3	High	Randomised Controlled Trials	RCTs are deemed 'gold standard' when examining research questions related to the impact, effectiveness or safety of an intervention (Petticrew & Roberts, 2003)

Appendix D: Weight of Evidence C

Table 8

WoE C Scoring Criteria and Rationale

WoE C	WoE C	Description	Rationale
Criteria	Scoring		
Immersion	1	No participants were receiving the majority of formal	The impact of immersion education on the cognitive and
Setting of		instruction in L2 through immersion education.	socioemotional development of school-aged children with DS
Participants	2	Some bilingual participants were receiving the majority of	is the focus of the present review.
		formal instruction in L2 through immersion education.	
	3	All bilingual participants were receiving the majority of	
		formal instruction in L2 through immersion education.	
Research Design	1	The research design did not include a comparative or control	Variability in socioeconomic status between participants has
		group, who were not receiving the majority of formal	been identified in previous research as a contributory factor in
	_	instruction in L2 through immersion education.	studies examining differences in cognitive ability between
	2	The research design included a comparative or control group,	bilingual and monolingual participants (Naeem et al., 2018).
		who were not receiving the majority of formal instruction in	Furthermore, research investigating the language or cognitive
		L2 through immersion education, who were not matched to	abilities of children with DS usually ensures that control
	2	the bilingual group on mental age and socioeconomic status.	groups are matched on nonverbal mental or cognitive ability to
	3	The research design included a comparative or control group,	allow for comparison of the language abilities that are typically
		who were not receiving the majority of formal instruction in	seen within population (Feitmate et al., 2008). Finally, control
		L2 through immersion education, who were matched to the	groups anow for comparison between participants allending
		bilingual group on mental age and socioeconomic status.	attending immersion education settings
Quantitativa	1	Quantitative measures of cognitive or socioemotional skills	Measures of cognitive or socioemotional skills allow for
Measures of	1	were not collected	comparison between participants attending immersion
Cognitive and	2	Quantitative measures of cognitive or socioemotional	education receiving the majority of formal instruction through
Socioemotional	2	dualitative incasures of cognitive of socioemotional	L2 and participants who do not attend immersion education
Skills	2	Skills were collected.	settings
GAIII 5	3	Quantitative measures of cognitive and socioemotional	Settings.
		skills were collected.	

Appendix E: MIREC Ethical Approval Application



MIREC-3 Research Ethics Committee

Research Ethics Application Form

FOR C	FFICE USE ONLY: APPLICATION REFERE	
Pleas	e read <u>RGS SOP114</u> before comple	eting this form. A guide to completing this form can be
found	1 <u>here</u> IIDEC 2 is served it Windows service As	debe Asselect. Compatibility with Apple Map is not everyteed
1. N 2. T	his form must be completed using Adobe Acrol	bat Reader DC. For instructions on installing Adobe Acrobat Reader DC and
а	dding Adobe Digital Signatures, please click he	re.
3. C	omplete all sections. Information provided must ttach a copy of all relevant documentation to the	t be comprehensible to non-experts. e application. All appendices should be submitted in one PDF with your
N	IREC 3 application form as a seperate PDF. PI	ease submit Safeguarding forms and/or DPIAs as an additional separate PDF
5. F	ocument or Postgraduate Research Students (PGRs), th	e Supervisor must sign Section 1.16 of this form.
SEC	TION ONE: APPLICATION DETAILS	
		Eaculty/Staff V DCD
1.1		
1.2	APPLICATION TYPE:	New Application Resubmission
1.3	If this application is a resubmission, please reference number: (e.g. A16-023)	e quote original application A22-003
1.4	PROJECT DURATION: Prop	osed Start Date (Month, Year) February 2022
	Antic	ipated Completion Date (Month, Year) May 2023
1.5	PROJECT TITLE: The Experience of Irish-	Medium and English-Medium Primary Schools for Children with Down
	Syndrome and their Pare	nts.
16		Research bursaries of €20450 and €3000 were awarded for this research project
1.0	PONDING BODT (ir any).	by An Chomhairle um Oideachas Gaeltachta & Gaelscolaíochta and the Írish
1.7	NAME OF PRINCIPAL INVESTIGATOR:	Catriona Kennedy
1.8	OTHER INVESTIGATORS	
	and AFFLIATIONS:	
		20109214@miastudent micul in
1.9	MIC EMAIL ADDRESS:	20108214@micstudent.mic.ui.ie
1.10	POSITION, DEPARTMENT & FACULTY	Postgraduate Researcher, Department of Educational Psychology, Inclusive and
	(PGRs should add Supervisor's Position, Department & Faculty):	Dr. Fionnuala Tynan, Academic Staff Member, Department of Reflective
1.11	ID NUMBER (PGRs only):	Dadagone & Early Childhood Studies Ecoulty of Education 20108214
1.12	PROGRAMME OF STUDY (PGRs only):	Professional Doctorate in Educational & Child Psychology
1 1 2	NAME OF SUPERVISOR(e)	Dr. Fionnuala Tynan
1.13	(PGRs only):	
		1

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NOTE: PGR Supervisors are responsible for reading this application fully in advance of its submission to MIREC.

They must ensure the form is filled in correctly and completely, and that all ethical considerations have been included.

1.14 This application form is accurate to the best of my knowledge and I take full responsibility for it. I undertake to abide by the ethical principles set out in the MIREC guidelines. If approved, I undertake to adhere to the study protocols without deviation, and to comply with any conditions set out by MIREC. I undertake to request MIREC to sanction any changes in the protocol that may be required subsequent to this application receiving ethical clearance.

I accept without reservation that it is my responsibility to ensure the implementation of the guidance of MIREC as described in MIREC-6.

	Ves No		
1.15	SIGNATURE OF PRINCIPAL INVESTIGATOR:		DATE:
	Carine Kennely	22/03/2022	
1.16	SIGNATURE OF CO-INVESTIGATOR(s):		DATE:
	Fionnuala Typan	22/03/2022	
1.17	SIGNATURE OF PGR SUPERVISOR(s) (required if relevant):		DATE:
1.18	SIGNATURE OF HEAD OF DEPARTMENT OF DEAN OF FACULTY (as appropriate	n):	DATE:

SECTION TWO: DESCRIPTION OF RESEARCH STUDY

2.1 Purpose of research (300 words maximum).

The area I am researching is additional language learning in children with Down Syndrome. While recent research demonstrates that individuals with Down Syndrome can become competent bilinguals, little is known about whether immersion education is a suitable and beneficial education setting for these learners in Ireland, as previous research in this area has included participants with Down Syndrome from bilingual home backgrounds rather than children who acquire an additional language through school programmes. Furthermore, a systematic literature review conducted by the principal investigator identified a number of gaps in previous research in this area. For instance, most research has focused on the impact of additional language learning on children with Down Syndrome's language and literacy development rather than their socio-emotional or broader cognitive development. Therefore, the first aim of the study is to investigate the impact of immersion and non-immersion settings on the cognitive and socio-emotional skills of children with Down Syndrome in relation to their school placement, experience of immersion education or learning additional languages. As this research is designed through a formative lens, the second aim of the current study is to include the voices of children with Down Syndrome and their parents from the onset of the study through a survey methodology, in line with the transformative paradigm. Finally a third aim of the study is to gather information from children with Down Syndrome and their parents about their experience of immersion education the mersion education the immersion education is a studied the woices of children with Down Syndrome and their parents from the onset of the study through a survey methodology, in line with the transformative paradigm. Finally a third aim of the study is to gather information from children with Down Syndrome and their parents about their experience of immersion education through semi-structured interviews and a child-friendly methodology called the

2.2 Research methodology (300 words maximum). This must describe in detail all interactions with research participants (focus groups / interviews / online surveys etc.)

A transformative mixed methods research design will underpin this study. In Phase 1, a mixed methods, online survey methodology will be employed to provide participants with the opportunity to choose which aspect/aspects of cognitive and socio-emotional development will be explored in Phase 2. The most popular outcome selected will be chosen for further analysis. In the event of a tie, a maximum of 3 outcomes will be selected. Ten children with Down Syndrome, 10 parents of children with Down Syndome, and 10 professionals currently working with children with Down Syndrome will be included in Phase 1. A qualitative case-study design will be employed in Phase 2 of the study to investigate whether there are differences in the experiences and outcomes (selected in Phase 1) for children with Down Syndrome and their parents depending on whether they attend an Irish-medium, English-medium mainstream or special primary school. Participants in Phase 2 will include 30 participants who will be divided into 3 groups. Group 1 will include 5 children with Down Syndrome attending Irish-medium primary schools and 5 parents/caregivers linked to each child participant. Group 2 will include 5 children with Down Syndrome attending English-medium mainstream primary schools and 5 linked parents/caregivers. Group 3 will include 5 children with Down Syndrome attending special primary schools and 5 linked parents/caregivers. Groups will be matched according to the childrens' chronological age, socioeconomic status, home language and literacy environment. This data will be collected through a Qualtrics questionnaire (Appendix 6). Qualitative data will be collected in Phase 2 through the Mosaic approach with child participants, which aims to gather children's views through a school tour, photos and story-writing interview in their schools, and through semi-structured interviews via Microsoft Team video calls with linked caregivers. Piloting will be conducted with a DECPsy student, a typically developing child, a child with Down Syndrome and a linked caregiver to assess the feasability and to refine the instruments used in both phases (e.g. survey, interview questions, children's materials). Data from the child with Down Syndrome and linked caregiver will be included in final analysis of both phases if significant refinements are not made to the instruments following piloting

2.3 Sample questions.

Sample questions for interviews / focus groups should be included. You may attach a separate document as part of your appendices file if necessary.

I have included a separate document (Appendix 7) as part of my appendices file, which includes sample questions for parental interviews which will be used in the Pilot Phase and Phase 2 of the study.

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2.4	Research Ethics from another Research Performing Organisation
	Are there ethical guidelines (other than MIREC) to which Ves No you must adhere in your field of study?
	Do you require ethical clearance from another source? Yes V
	If you answered YES to either of these questions, please specify the ethical guidelines / ethical clearance that is required.
As this re also com	esearch project is being conducted as part of the Principal Investigator's Doctorate in Educational and Child Psychology, it must ply with the Psychological Society of Ireland's (PSI) Code of Professional Ethics (2019).
Psycholo	gical Society of Ireland. (2019). Code of Professional Ethics. Dublin: Psychological Society of Ireland.

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SECTION THREE: RESEARCH PARTICIPANTS

3.1 Explain why the use of human participants is essential to your research project.

As this study aims to explore the experience of immersion and non-immersion settings for children with Down Syndrome and their parents, the use of human participants is essential as the design involves interviewing participants to gather their views.

3.2 How many participants will be recruited? How will potential research participants be identified and selected?

Phase One of the study will involve the recruitment of 30 participants, including 10 children with Down Syndrome, 10 parents of children with Down Syndrome and 10 professionals currently working with a child with Down Syndrome. Inclusionary criteria for children will be having a diagnosis of Down Syndrome and attending primary school, whilst criteria for parents will be having a child with Down Syndrome who attends a primary school, and inclusionary criteria for professionals will require current professional practice with a child with Down Syndrome attending primary school. Phase Two will involve the recruitment of 30 participants, who will be divided into 3 groups. Group 1 will include 5 children with Down Syndrome attending English-medium primary schools and 5 parents/caregivers linked to each child participant. Group 2 will include 5 children with Down Syndrome attending English-medium primary schools and 5 parents/caregivers linked to each child participant. Group 3 will include 5 children with Down Syndrome attending english-medium primary schools and 5 parents/caregivers linked to each child participant. Group 3 will include 5 children with Down Syndrome attending special primary schools and 5 parents/caregivers linked to each child participant. Group 3 will include 5 children with Down Syndrome attending special primary schools and 5 parents/caregivers linked to each child participant. Groups will be matched according to the children's chronological age, socioeconomic status, home language and literacy environment. This data will be collected via an online questionnaire using Qualtrics (Appendix 6). Inclusionary criteria for child participants in Phase Two will include having a diagnosis of Down Syndrome and current attendance at an Irish-medium, English-medium mainstream or special primary school. Adult participants in Phase Two will be parents or caregivers who are linked to each child participant who meets the inclusionary criteria previously outlined.

3.3 Does the proposed research necessitate the participation of your current students?

Yes 🖌 No

If you have indicated that the proposed research necessitates the participation of students that you teach, please provide:

- A rationale as to why it is necessary that students that you teach participate in the research.
- Details of the steps you will take to ensure that participation is voluntary and that participants may withdraw at any time without consequence or fear of consequence.

You must answer this question if you intend to recruit students that you teach as research participants

N/A		

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3.4 How do you plan to gain access to / contact / approach your potential participant(s)? Please also indicate the location(s) of the project

I plan to gain access to potential participants by emailing the secretary and/or chairperson of the following Down Syndrome Ireland Appendix 11) local branches (local branches selected due to geographical locations convenient to the principal investigator), Louth/Meath, Dublin, Athlone, Cavan, Cork, Donegal, Galway East, Galway West, Kerry, Kildare, Longford/Westmeath, Mayo, Waterford and Wicklow, and the Down Syndrome Association Northern Ireland, and asking if it would be possible to present a short presentation (Appendix 16) about the proposed research at various branch meetings. After the presentations, I will share the link to participate in the online survey in Phase One and my student email address for anyone who is interested in participating in Phase Two. Phase One participants will also have the option of leaving their contact details at the end of the online survey if they wish to participate in Phase Two of the study. Furthermore, I will ask Down Syndrome Ireland, Gaeloideachas and Comhairle na Gaelscolaíochta (Appendix 12) if they will advertise a recruitment poster (Appendix 14) for my research on their websites and social media sites which will include information which guides participants who are interested in taking part on how they can participate in the research. In the event that the sample for Phase One or Phase Two of the study is not obtained through advertising the recuitment poster with branches of Down Syndrome Ireland, through Down Syndrome Ireland, Gaeloideachas and Comhairle na Gaelscolaíochta's websites and social media sites, a recruitment email (Appendix 13) will be sent to principals of all Irish-medium primary schools and special schools in the Republic of Ireland and Northern Ireland (N = 290), and an equal random sample of English-medium primary schools and special schools, asking them to share the recruitment poster with their school community. The Department of Education and the Education Authority's (organisation responsible for delivering education services across Northern Ireland) websites will be used to obtain lists of primary schools and a random number generator will be used to attain a random sample of English-medium schools. Personal data of Phase Two participants (e.g. contact details and consent forms) will be stored on a password-protected file on the principal investigator's laptop. All participants will receive an Information Sheet (Appendix 1, Appendix 4 & Appendix 9).

Phase One of the study will take place remotely through an online survey using Qualtrics. Demographic characteristics of child participants for grouping purposes in Phase Two of the study will be collected from parents of each child participant online through a questionnaire using Qualtrics. Data collection with child participants in Phase Two of the research will take place in the participants' schools. Qualitative data collection with parent participants in Phase Two will take place remotely via video call on Microsoft Teams, unless otherwise requested by parents. In this event, data collection will be arranged to take place at the parent's home or at their child's school.

SECTION FOUR: ETHICAL ISSUES AND IMPLICATIONS

4.1	HUMAN PARTICIPANTS		
	Does the research proposal involve:	Yes	No
	Children? (any person under the age of 18)	~	
	Vulnerable persons? (as defined in Section 7.3)		~

4.1a If you have ticked YES to any question in the Human Participants section above how will you ensure that vulnerable research participants are protected?

Child participants will be protected through adherance to the PSI's Code of Professional Ethics and the DECPsy Research Guidelines. The principal ethical considerations arising from this research, include anonymity, confidentiality, consent, and the avoidance of harm to participants. Children will be provided with pseudonyms to protect their anonymity and confidentiality. In addition, data containing personal information (e.g. consent forms) will be stored on a password-protected file on the principal investigator's laptop. Additionally, a process of informed consent will be undertaken with child participants to ensure that they understand who the researcher is and the research activities that the child will be engaging in should they wish to participate. A visual schedule and easy-read assent form (Appendix 8) will be used with child participants to support their decision-making in the informed consent process, as all children will have an intellectual disability arising from Down Syndrome. During the informed consent process and all research activities with child will accompany the researcher and remain in the room (e.g.parent, class teacher or SNA). Piloting will be conducted with a DECPsy student, a typically developing child, a child with Down Syndrome and a linked caregiver to assess the feasability and to refine the instruments used in both phases (e.g. survey, interview questions, children's materials).

4.2 SUBJECT MATTER

Does the research proposal involve:	Yes	No
Sensitive personal issues? (e.g. suicide, bereavement, gender identity, sexuality, fertility, abortion, gambling)	~	
Illegal activities, illicit drug taking, substance abuse or the self- reporting of criminal behaviour?		~
Any act that might diminish self-respect or cause shame, embarrassment or regret?		~
Research into politically and/or racially and/or ethnically and/		~

4.2a If you have ticked YES to any question in the Subject Matter section above, how will you protect participants when dealing with sensitive issues in your research?

It is possible that during interviews with parents that they might discuss the time they received their child's diagnosis of Down Syndrome, which could be considered a sensitive personal issue and a distressing topic for adult participants. Research in this area recommends for researchers to engage in training to manage psychological distress during interviews (Fahie, 2014). I have already engaged in continuous professional development through attending a HSE training called 'Making Difficult Conversations Easier' and plan on following Drauker et al.'s (2009) distress protocols during qualitative data collection with parents. This will involve consistent monitoring of participants' emotional reactions, providing frequent breaks if a stressful topic arises during interviews, offering to engage in the interview at a different time, debriefing participants, and providing information on available psychological or social services if necessary.

Draucker, C. B., Martsolf, D. S., & Poole, C. (2009). Developing distress protocols for research on sensitive topics. Archives of Psychiatric Nursing, 23(5), 343 – 350. https://doi.org/10.1016/j.apnu.2008.10.008

Fahie, D. (2014). Doing Sensitive Research Sensitively: Ethical and Methodological Issues in Researching Workplace Bullying. International Journal of Qualitative Methods, 19 – 36. https://doi.org/10.1177/160940691401300108

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4.3 RESEARCH PROCEDURES

Does the research proposal involve:	Yes	No
Use of personal records without consent?		~
Deception of participants?		~
The offer of inducements or incentives to participate?		~
Audio or visual recording without consent?		~
Invasive physical interventions or treatments?		~
Research that might put researchers or participants at risk?		~
Reimbursement of participants?		~

4.3a If you have ticked **YES** to any question in the Research Procedures section above, how will you protect participants when dealing with sensitive procedures in your research?



4.4 AREAS OTHER THAN HUMAN

Does the research proposal involve:	Yes	No
Use of animals?		~
Military technology?		~
Hazardous biological materials?		~
Genetic modification?		
Nuclear reaction?		
Any field that may bring the College adverse attention?		~

4.4a If you answered **YES** to any of the questions in AREAS OTHER THAN HUMAN above, please specify why:

IN	1	А	
μ.,		-	

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4.5 If you have ticked **YES** to any question in 4.3 (Research Procedures) and/or 4.4 (Areas Other Than Human), describe how you intend to comply with any established procedures which have been approved by MIREC for your research.

4.6 Foresight

N/A

The principal investigator is undertaking this research as part of a doctoral degree (Doctorate in Educational and Child Psychology), therefore the principal investigator will not be changing institutional affiliation until the study is complete. In the unlikely event that the research supervisor changes institutional affiliation during the course of the research process, supervision will be provided to the principal investigator by the DECPsy Supervisory Committee.

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SECTION SIX: MANAGEMENT OF RESEARCH MATERIALS

6.1 COMPLIANCE WITH THE GENERAL DATA PROTECTION REGULATION (GDPR)

If your proposed research will entail collection (and retention, whether temporary* or permanent) of third-party personal data as a primary source, you are required to adhere to the GDPR and the data protection legislation of any state within the European Economic Area (EEA) where the data is collected and/or stored (e.g. the Irish Data Protection Act, 2018). Adherence to the GDPR will continue to obtain if data collected within the EEA is transferred to external jurisdictions and made accessible there.

Please confirm whether or not your proposed research will require you to comply with the GDPR and Data Protection Act (2018)



*Note: Once your research activity results in the anonymisation of raw data and/or secure and complete destruction of raw data sets that contain sensitive personal information, the GDPR and Data Protection Act (2018) will cease to pertain. A definition of anonymisation & pseudonymisation under the GDPR can be found <u>here</u>.

6.2 DATA PROTECTION IMPACT ASSESSMENT (DPIA)

In some circumstances, collection and retention of third-party personal information legally requires prior completion of a DPIA.

According to Article 35 of the GDPR, "(w)here a type of processing, in particular using new technologies, and taking into account the nature, scope, context and purposes of the processing, is likely to result in a high risk to the rights and freedoms of natural persons, the controller shall, prior to the processing, carry out an assessment of the impact of the envisaged processing operations on the protection of personal data."

As a rule of thumb, this applies to research where collection and retention of sensitive personal information, especially where collection methodologies include usage of media where risk of data loss are comparatively high. While personal information includes units of data such as name, address or gender, sensitive personal information may include health or economic status, stated value preferences, political opinions, personal data revealing racial or ethnic origin etc., which can be readily associated with identifiable individuals. The important thing to remember is that identifiable personal information belongs to the data subject (research subject / respondent / informant) and not to the researcher or research funder. For this reason, it is advisable to conduct a DPIA for any research project involving the collection of personal data and this should be strongly considered in the case of research with children (those under 18 years) and/ or vulnerable people.

In order to gather data for your proposed research, are you required to carry out a DPIA? Yes 🗸

5.3 HOW WILL YOU ENSURE THAT INFORMED CONSENT IS FREELY GIVEN BY PARTICIPANTS?

I will ensure that informed consent is provided freely by participants by providing every participant with an information sheet which contains information about the details of involvement, and potential benefits and risks involved through participation in the research. Adult and child participants in Phase Two of the research will sign consent and assent forms before they can participate. The information sheets, consent forms and assent forms will be sent to the participants approximately one month before data collection, to ensure that adult participants have time to read and process what is involved in participating in the research to their child prior to their signing of the assent forms. Participant's right to withdraw from the research without consequence will be communicated in writing in the information sheet and again verbally prior to conducting parental interviews. The final two pages of the child assent forms will be re-explained to all child participants at the beginning of their school visits to ensure that they understand that they can withdraw from the research without consequence at any time during the school visits.

5.4 ANONYMITY AND CONFIDENTIALITY

What arrangements have you made for anonymity or confidentiality (where appropriate)?

In Phase One of the study, no personal details will be collected from participants of the online survey. In Phase Two, parent and child participants will be provided with pseudonyms to protect their anonymity. In order to protect participant confidentiality, data collected from all phases, including signed consent forms, will be stored in a secure, locked location. Furthermore, electronic data will be protected by passwords.

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No

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SECTION SEVEN: SAFEGUARDING

7.1 GARDA VETTING

I give consent to the Garda Vetting office to confirm that I have been the subject	t of
a satisfactory vetting disclosure	

N	0

No

Yes

Yes

7.2 CHILDREN

According to <u>Children First: National Guidance for the Protection and Welfare of Children (2017)</u> it is a requirement for any researcher working with children to complete a Child Safeguarding Statement to assess any potential harm to children.

The Guidance on conducting Research with Children and Child Safeguarding Statement template can be found <u>here</u>. Please include this completed document when submitting your application.

I have conducted an assessment of potential harm to children	~	
I have developed a child safeguarding statement which describes mitigating factors to prevent such harm	~	
I will comply with the MIC Safeguarding Policies and the Children First Act 2015.	~	

7.3 VULNERABLE PERSONS

"Vulnerable Person" means a person, other than a child, who-

- (a) is suffering from a disorder of the mind, whether as a result of mental illness or dementia,
- (b) has an intellectual disability,
- (c) is suffering from a physical impairment, whether as a result of injury, illness or age,
- or
- (d) has a physical disability, which is of such a nature or degree-

(i) as to restrict the capacity of the person to guard himself or herself against harm by another person, or
 (ii) that results in the person requiring assistance with the activities of daily living including dressing, eating, walking, washing and bathing

The Safeguarding Guidance on Conducting Research with Vulnerable Persons document can be found <u>here</u>. Please include this completed document when submitting your application.

	Yes	No
Does your research involve people who may be vulnerable and in respect of whom a question of capacity to give consent may arise?		~
I have done an assessment of potential harm to vulnerable persons		~
I have developed a safeguarding statement which outlines mitigating factors to prevent such harm		~
I will comply with the MIC Vulnerable Persons Safeguarding Policy		~

SECTION EIGHT: DOCUMENT CHECKLIST

NOTE: Applicants must create a single electronic PDF document of all appendices. Multiple appendix files will not be accepted. Safeguarding forms & DPIAs should be submitted as separate PDF attachments.

Whick	n documents are attached? Please tick N/A if not applicable:	Yes	N/A
		~	
8.1	Information Sheet for Participants		
8.2	Consent form for participants	~	
8.3	Information sheet for parents / guardians	~	
8.4	Consent form for parents / guardians	~	
8.5	Institutional Permission Request to conduct research		•
8.6	Questions / survey for interviewees / focus groups etc.	~	
8.7	Recruitment letter / email / poster	~	
8.8	Child Safeguarding Statement	~	
8.9	Vulnerable Persons Safeguarding Statement	~	
8.10	Data Privacy Impact Assessment (DPIA)		~
8.11	Other document(s) - please specify below:		~

WHERE TO SUBMIT

All applications including appendices MUST be submitted in electronic copy to the MIREC Administrator at mirec@mic.ul.ie

The deadline for MIREC applications is 5pm on the first Friday of each month.

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Appendix F: Child Safeguarding Statement



Child Safeguarding Statement

As Principal Investigator in a research exercise to explore the experiences of Irish-medium and English-medium primary schools for children with Down Syndrome by means of a school tour, photography exercise and recorded story-writing activity.

This research will engage with children (those under 18 years of age). My academic institution, Mary Immaculate College (MIC) has a formal Safeguarding Policy, including provision for Child Safeguarding. The fundamental tenet of this policy is that the safety and welfare of children is paramount and is the primary consideration of all members of the MIC community, including those engaged in research.

I have undertaken a comprehensive risk assessment (attached) in order to form this Safeguarding Statement and this risk assessment fully informs my research design, my research plan and my data collection methodologies. This risk assessment is fully consistent with statutory provision for safeguarding (including the Children First Act) and with MIC policies and procedures which the Governing Authority of the College has deemed to be fit for purpose. My research design is also informed by best practice in the engagement of data subjects who are children as set out in the relevant academic literature and codes of practice for research integrity. I have received Garda Vetting through my academic institution which extends to my activities as PI in research activities.

A duly constituted College research ethics screening group has reviewed and approved by research proposal and my intended methodology, inclusive of my safeguarding risk assessment and this Safeguarding Statement.

1

A. The Research	A. The Research Project		
Research Project Title:	Research Project Title: The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents.		
Timescale for delivery:			
 January 2022: Ethical Approval Application to MIREC. March – June 2022: Data Collection with Child Participants on Fridays at their schools. June 2022 – June 2023: Write-up of the research findings and thesis submission. 			
Are you in the process of completing an ethics application? Yes \square No \square			
Please provide your MIREC Application Number: A22-003			

B. Child Safeguarding Statement Specific to this Research

- The general requirements of MIC's Safeguarding Children Policy and Procedures will be complied with.
- In undertaking this research, the welfare of the children involved will be the paramount consideration. The principle of non-maleficence will be respected.
- Appropriate consent from a parent/guardian will be obtained and respect for children will be demonstrated by obtaining and maintaining their informed consent during the research.
- Attention will be paid to the power differences inherent in the adult/child relationship and the views of participating children will be obtained and listened to.
- Particular attention will be paid to children's understanding of the research and outcome.

2

C. Risk Assessment

I have carried out an assessment of any potential *harm to a child while engaged in this research. The table below lists the areas of risk identified and the procedures for managing these risks. In undertaking this risk assessment, every effort has been made to identify as far as possible the risks of harm that are relevant to the research project and to ensure that adequate procedures are in place to manage all risks identified. While it is not possible to foresee and remove all risk of harm, the procedures in this risk assessment have been put in place to manage and reduce risk to the greatest possible extent.

*harm means in relation to a child -

(a) Assault, ill-treatment or neglect of the child in a manner that seriously affects or is likely to seriously affect the child's health, development or welfare, or

(b) Sexual abuse of the child, Whether caused by a single act, omission or circumstance or a series or combination of acts, omissions or circumstances or otherwise.' (Section 2 of the Children First Act 2015)

Risk identified:	Measures in place to manage this risk	
 The child is harmed by another child or adult during school visits, or the child makes a disclosure of their experience of a recognised and substantive form of abuse to the principal investigator during school visits. 	 The principal investigator has been Garda vetted and has completed HSE's Children First programme. The principal investigator will be accompanied by a school employee (teacher of SNA) known to the child at all times during school visits. All school employees are Garda Vetted and are Mandated Persons. The principal investigator has prepared for engagement with child participants by familiarising herself with provisions of: (i) Child Safeguarding Policy of principal investigator's academic institution (ii) Child Safeguarding Policy of school setting. The principal investigator is not a Mandated Person but has recorded and retained the emergency contact number of: (a) the Designated Liaison Persons of the principal investigator's academic institution (b) the Designated Liaison Person and Deputy Designated Liaison Person of the school setting. The principal investigator understands the strictly detailed procedures for engaging appropriately with a child in the event of a sudden / impromptu disclosure by the child or observing harm to the child during school visits, including the importance of engaging immediately and appropriately with a Designated Liaison Person or Deputy Designated Liaison Person of the school. On arrival to each school setting, the Designated Liaison Person or Deputy Designated Liaison Person by a school. The principal investigator understands that her role is limited to reporting the details of a disclosure to the Designated Liaison Person person person but is available for requests for supplementary information in the event of a duly constituted investigator understands that her cole is limited to reporting the details of a disclosure to the Designated Liaison Person or Deputy Designated Liaison Person but is available for requests for supplementary information in the event of a duly constituted investigator understands that she cannot act as a counsellor to a child in the	

	 and that contact with such other persons will be made, as appropriate, by designated authorities (including TUSLA and/or An Garda Siochána) should the Designated Liaison Person deem it necessary to report the details of the disclosure in line with proper procedures. The principal investigator understands that disclosure of a form
	 of abuse, including affective, sexual or physical abuse or neglect, may refer to a child or vulnerable person other than the child making disclosure and that in such an event the same safeguarding procedures apply as above. In line with the Mary Immaculate College Safeguarding Policy, the principal investigator has formulated a plan for managing a disclosure that is not made privately by a child but openly, in group setting, that preserves the right to privacy and dignity of the child, that is based on the paramount importance of the safety of children and not the continuation of the data collection exercise as a priority of the principal investigator.
Parent participants disclose during	 The principal investigator has been Garda vetted for purpose of research engagement
interactions with the researcher that their child is being harmed at home or at school by another individual.	 The principal investigator has had formal training in Child Safeguarding, including the provisions of the Children First Act. The principal investigator is not a Mandated Person but has recorded and retained the emergency contact number of the Designated Liaison Persons of the principal investigator's academic institution. The principal investigator understands the strictly detailed procedures in the event of a sudden / impromptu disclosure by the parent or observing harm to the child during video calls on Microsoft Teams with parent participants, including the importance of engaging immediately and appropriately with the Designated Liaison Person of the principal investigator's
	academic institution.
	 The principal investigator understands that her role is limited to reporting the details of a disclosure by a parent to the Designated Liaison Person of her academic institution, but is available for requests for supplementary information in the event of a duly constituted investigation being launched by the proper authorities (i.e. TUSLA and/or An Garda Siochána).
	 The principal investigator understands that she cannot act as a
	counsellor to a child or parent in the event of disclosure and cannot suggest or make referrals on behalf of the child to any third party.
	 The principal investigator understands that while a guarantee of confidentiality cannot be provided to a parent making a disclosure, the next line of communication must be with the Designated Liaison Person and not with any other person (including a parent, Guardian, After School Club supervisor etc.), and that contact with such other persons will be made, as appropriate, by designated authorities (including TUSLA and/or An Garda Siochána) should the Designated Liaison Person of the principal investigator's academic institution deem it necessary to report the details of the disclosure in line with proper procedures. The principal investigator understands that disclosure of a form of abuse, including affective, sexual or physical abuse or neglect, may refer to a child or vulnerable person other than the child whose parent is making the disclosure, and that in such an event the same safeguarding procedures apply as above. In line with the Mary Immaculate College Safeguarding Policy, the principal investigator has formulated a plan for magnetic procedures a plan and that the same safeguarding procedures and the same safeguarding procedures and the same safeguarding procedures and that in such an event the same safeguarding procedures apply as above.

		that is based on the paramount importance of the safety of children and not the continuation of the data collection exercise as a priority of the principal investigator.
3.	The child does not understand what they will be doing during the school visits or story-writing activity.	 Child-friendly, visual assent forms and information sheets have been created by the primary investigator to support the child's understanding of what they will be doing during the school visits and story-writing activity. Parents will be encouraged to explain the research process using communication strategies that will support the child's understanding of the study. An adult known to the child, such as a SNA or teacher, will accompany the child during all research activities the child engages in with the primary investigator.
4.	The child decides that they do not want to take part in the research.	 Visual cards for 'stop,' 'go' and 'I need a break' have been created to support the child to stop their participation in the research if they decide not to participate further. The visual cards are part of the child assent forms that the child will sign at the beginning of the research process to ensure that they are familiar with their right to 'stop' or withdraw from the research at any point. An adult known to the child, such as a SNA or teacher, will accompany the child during all research activities the child engages in with the primary investigator.
5.	The researcher may not understand the speech of the child.	 An adult known to the child, such as a SNA or teacher, will accompany the child during all research activities the child engages in with the primary investigator and will be asked in advance to repeat what the child says only when a pre-agreed signal is given by the researcher.

D. Procedures

This Child Safeguarding Statement has been developed in line with the requirements under the Children First Act 2015, the Children First: National Guidance and Tusla's Child Safeguarding: A Guide for Policy, Procedure and Practice. In addition to this Child Safeguarding Statement, the research project will be bound by and abide by all other existing and forthcoming policies and procedures for the protection of children in research contexts, notably MIC's Safeguarding Children Policy and Procedures and Safeguarding Statement 2019 and the provisions of the Mary Immaculate College Research Ethics Committee (MIREC). In particular MIC's arrangements for the management of child protection or welfare concerns will be followed.

E. The Principal Investigator

The Principal Investigator (PI) is the person in overall charge of the project and who bears final responsibility for all aspects of the project including this Child Safeguarding Statement.

Name:	Catriona Kennedy	Department:	EPISE				
Telephone	085 153 7303	Position:	Postgraduate				
& Email	20108214@micstudent.mic.ul.ie		Researcher (Year 2)				

5
F. The Principal Investigator's Signature		
PI Name:	Catriona Kennedy	
PI Signature:	Catinione Kennely_	
Date:	14/03/2022	

G. Supervisor's Signature		
MIC Supervisor Name:	Fionnuala Tynan	
MIC Supervisor Signature:	Fronce Jynan	
Date:	21/03/2022	

H. MIC Sign-off			
I confirm that appropriate risk assessment and risk management arrangements are in place.			
In addition to the procedures detailed above the College's Safeguarding Children Policy and			
Procedure will be complied with in the activity or programme.			
Signed:			
	RESPONSIBLE PERSON - Professor Gary O'Brien, Vice President (Governance & Strategy)		
Date:			

The data provided in this statement will be managed in compliance with the provisions of GDPR (2018) and linked MIC policies and protocols.

Appendix G: MIREC Ethical Approval Final Decision Form

MIREC-5, Created November 2021



MIREC-5

Research Ethics Committee

MIREC Final Decision Form

APPLICATION NUMBER:

A22-003

PROJECT TITLE

The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents.

2. APPLICANT

1

Name:	Catriona Kennedy
Department / Centre / Other:	EPISE
Position:	Postgraduate Researcher

3. DECISION OF MIREC CHAIR (✓)

	Ethical clearance through MIREC is not required and therefore the applicant need take no further action in this regard.
*	Ethical clearance is required and is hereby granted by the Chair without need for referral to the MIREC committee.
	Ethical clearance for a funding application or a similar purpose is granted by the Chair pro tem without need for referral to the MIREC committee. However, the applicant must subsequently seek ethical clearance from MIREC prior to embarking on any related project work involving human participants or their data.
	Ethical clearance is granted following review of the application by the MIREC committee.
	Ethical clearance is not granted following review of the application by the MIREC committee.

REASON(S) FOR DECISION

I have reviewed this application and I am satisfied that it meets with MIREC requirements.

Safeguarding Statement and Risk Assessment are now fully fit-for purpose.

The application is, therefore, approved.

5. SIGNATURE OF MIREC CHAIR

Name (Print):	Dr Marie Griffin
Signature:	1 D. Gmff.
Date:	4 th April 2022

Appendix H: Phase One Parent and Child Online Survey

Phase One Parent and Child Questionnaire

Part of the inclusion criteria for participation in this study is that your child has been identified as having a diagnosis of Down syndrome and is of primary school-going age. Please confirm this by completing the following questions before starting the survey:

Does your child have a diagnosis of Down syndrome?

- Yes
- No 🗌

Is your child with Down syndrome currently attending primary school (mainstream or special school)?

- Yes, my child attends a mainstream English-medium primary school.
- Yes, my child attends a mainstream Irish-medium school.
- Yes, my child attends a special school.
- No

What age is this child?



years old.

The aim of this research is to investigate the impact of immersion-settings (e.g., Gaelscoil) and non-immersion settings (e.g. mainstream English-medium school or special school) on the development of children with Down syndrome. I am interested in your views and what you, as a parent, would prefer to find out about the impact of immersion/non-immersion settings on children with Down syndrome's development.

Please rank your preference for learning about the impact of immersion-settings and non-immersion settings on the following skills and abilities on a scale of 1-6. A rating of 6 is the skill or ability you are <u>most</u> interested in and a rating of 1 is the skill or ability you are <u>least</u> interested in. If you cannot decide between two choices you are permitted to give them the same score (e.g. giving two skills/abilities a score of 1 if you cannot decide which you are most interested in learning about).



Executive functioning abilities

Executive function is a set of mental skills that include working memory, flexible thinking, and selfcontrol. Children use these skills every day to learn and manage daily life activities. Difficulties with executive function can make it hard to focus, follow directions, and handle emotions, amongst other things.

Ad

Adaptive functioning abilities

Adaptive functioning skills are the skills required for daily living and to function safely and appropriately in everyday life. They are those day-to-day activities that are necessary for a person to get along with others and to take care of themselves. Adaptive functioning skills might include feeding, dressing, going to the toilet, making friends, social skills, playing and safety awareness.

Verbal communication abilities

Verbal communication is the use of words to convey a message. Some forms of verbal communication are written and oral communication.



Nonverbal communication abilities

Non-verbal communication is communication that does not involve words, such as body language, tone of voice, and gestures.



Social skills

Social skills are the skills that we use every day to interact and communicate with others. They include verbal and non-verbal communication, such as speech, gesture, facial expression and body language. Social skills facilitate interactions with others and help people to build relationships.



Emotional development

Emotional development refers to the ability to recognise, express, and manage feelings at different stages of life and to have empathy for the feelings of others.

Do you have any additional comments about this research?

Are you interested in taking part in Phase Two of this research which would involve another questionnaire, a follow-up interview with you and a visit to your child's school to interview your child?

- Yes (click on this link to send your email address)
- No

The next section involves your child who has a diagnosis of Down Syndrome. As I am eager to include your child's voice, please do not try to influence their choice in any way. Please show and read these sections to your child to help them to make a choice about they would most like to learn about.

Hi! My name is Catriona.
I am a research student.
I am learning about children and their learning at home and at school.
I want to find out what you would like to learn about children's learning at home and school.
What would you like to learn about?

Ask your child to point at the picture they like the best or would most like to learn about. Write the number corresponding to the picture chosen by your child in the box below.



Appendix I: Phase One Professional Online Survey

Phase One Professional Questionnaire

Part of the inclusion criteria for participation in this study is that you work with a child that has been identified as having a diagnosis of Down Syndrome and is of primary school-going age. Please confirm this by completing the following questions before starting the survey:

Do you currently work with a child with a diagnosis of Down Syndrome?

- Yes, please state your job title _____
- No

Is this child currently attending primary school (mainstream or special school)?

Yes No

What age is this child?



years old.

The aim of this research is to investigate the impact of immersion-settings (e.g., Gaelscoil) and non-immersion settings (e.g. mainstream English-medium primary school or special primary school) on the development of children with Down Syndrome. I am interested in your views and what you, as a professional, would prefer to find out about the impact of immersion education on children with Down Syndrome's development.

Please rank your preference for learning about the impact of immersion-settings and nonimmersion settings on the following skills and abilities on a scale of 1-6. A rating of 6 is the skill or ability you are <u>most</u> interested in and a rating of 1 is the skill or ability you are <u>least</u> interested in. If you cannot decide between two choices you are permitted to give them the same score (e.g. giving two skills/abilities a score of 1 if you cannot decide which you are most interested in learning about).



Executive functioning abilities

Executive function is a set of mental skills that include working memory, flexible thinking, and selfcontrol. Children use these skills every day to learn and manage daily life activities. Difficulties with executive function can make it hard to focus, follow directions, and handle emotions, amongst other things.

Adaptive functioning abilities

Adaptive functioning skills are the skills required for daily living and to function safely and appropriately in everyday life. They are those day-to-day activities that are necessary for a person to get along with others and to take care of themselves. Adaptive functioning skills might include feeding, dressing, going to the toilet, making friends, social skills, playing and safety awareness.

Verbal communication abilities

Verbal communication is the use of words to convey a message. Some forms of verbal communication are written and oral communication.



Nonverbal communication abilities

Non-verbal communication is communication that does not involve words, such as body language, tone of voice, and gestures.



Social skills

Social skills are the skills that we use every day to interact and communicate with others. They include verbal and non-verbal communication, such as speech, gesture, facial expression and body language. Social skills facilitate interactions with others and help people to build relationships.



Emotional development

Emotional development refers to the ability to recognise, express, and manage feelings at different stages of life and to have empathy for the feelings of others.

Do you have any additional comments about this research?

Appendix J: Phase One Information Sheet



Phase One Information Sheet

My name is Catriona Kennedy, and I am a student undertaking a Doctorate in Educational and Child Psychology at Mary Immaculate College, under the supervision of Dr. Fionnuala Tynan. I am undertaking a study which has been funded by An Chomhairle um Gaeltachta agus Gaelscolaíochta (COGG) about 'The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents'. The study will be conducted in two phases.

Who Can Take Part in Phase One of the Research?

- Parents of children with Down Syndrome who attend an English-medium **primary school** (e.g., national school or special school) or an Irish-medium **primary school** (e.g., a Gaelscoil or Scoil Ghaeltachta), and their child.
- Professionals who are **currently working** with a primary-school child with Down Syndrome (e.g., primary-school teacher, primary-school SNA, primary-school principal, educational psychologist, speech and language therapist, occupational therapist etc.).

Aims of Phase One of the Research

The aims of Phase One of this research project are to:

- Collect information from participants about their preference for learning about the impact of immersion and non-immersion settings on different areas of children with Down Syndrome's cognitive and socio-emotional development (e.g., executive functioning, social skills etc.).
- Provide participants with the opportunity to offer comments or thoughts they may have about the research, which may guide Phase Two of the research.

Details of Involvement in the Research

- Involvement in Phase One of the research will consist of participation in an anonymous online survey on Qualtrics which takes approximately 10 minutes to complete. The end of the surveys completed by parents will contain a question for their child with Down Syndrome to complete alongside their parent.
- Participation in this research is entirely voluntary. If you do decide to take part in the study, you and/or your child can change your mind about your decisions to take part and withdraw from the research at any time until the point of data analysis.

Potential Benefits and Risks to Participants arising from Involvement in this Research

• This research will address gaps in previous studies in this area, as no previous research has investigated the impact of immersion education on the cognitive and/or socio-emotional development of children with Down Syndrome.

- This will also be the first study in Ireland to include the voices of children with Down Syndrome and their parents about child development and different types of education settings from the beginning of the research process.
- It is not envisaged that there are any major risks to participants arising from involvement in Phase One of the study. However, should participants experience distress arising from participating in the research, the contact details for support services provided on page 3 of this information sheet may be of assistance to participants.

Confidentiality Procedures, Data Storage and Destruction

- If you decide to participate in this research **your participation will be completely anonymous**, as you will not be asked to provide any identifiable information during the online survey, such as your name or your child's name or school.
- All electronic data (data stored on a computer) generated from the online surveys will be protected by passwords.

If you have any questions, please do not hesitate to contact me or my research supervisor at any stage, using the contact details below. Alternatively, you may wish to contact an independent person about this research. If so, please contact the Mary Immaculate College Research Ethics Committee (MIREC) Administrator using the details below. I sincerely thank you for your time reading this information letter and for considering your participation in this study.

Le dea-ghuí,

Catriona Kennedy (Principal Researcher)

20108214@micstudent.mic.ul.ie

Research SupervisorIndependent Contact DetailsDr. Fionnuala TynanMary CollinsResearch SupervisorMIREC Administratorfionnuala.tynan@mic.ul.iemirec@mic.ul.ie+35361 204 980

Support Services

Visit www.mentalhealthireland.ie or www.aware.ie for more information.

Freephone Aware on 1800 80 48 48 or email supportmail@aware.ie

You could also contact your GP.

LEAGÁN GAEILGE



Céim 1: Bileog Eolais

Is mise Caitríona Ní Chinnéide, táim ag tabhairt faoi thionscadal taighde mar chuid de mo chéim dochtúra i gColáiste Mhuire Gan Smál, faoi stiúir an Dochtúra Fionnuala Tynan. 'The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents' an teideal atá ar an tionscadal taighde agus tá sé urraithe ag An Chomhairle um Oideachas Gaeltachta agus Gaelscolaíochta (COGG). Beidh dhá chéim sa thionscadal taighde.

Cé atá Ábalta Páirt a Ghlacadh i gCéim 1 don Staidéar Seo?

• Tuismitheoirí a bhfuil páiste acu a bhfuil Siondróm Down orthu agus atá ag freastal ar **bhunscoil** lán-Béarla (m.sh. scoil príomhshrutha nó scoil speisialta srl.) nó **bunscoil** lán-Ghaeilge (m.sh. Gaelscoil nó scoil Ghaeltachta srl.) agus an páiste é/í féin.

• Gairmithe atá ag obair **i láthair na huaire** le páiste a bhfuil Siondróm Down orthu atá ag freastal ar bhunscoil (m.sh. múinteoir bunscoile, cúntóir riachtanais speisialta atá ag obair i mbunscoil, teiripeoir urlabhra, teiripeoir saothair, síceolaí oideachais srl.).

Cuspóirí do Chéim 1 den Staidéar Seo:

Is iad cuspóirí an taighde ná:

- Eolas a bhailiú ó rannpháirtithe faoi na roghanna foghlama atá acu faoin tionchar atá ag tumoideachas ar ghnéithe áirithe do fhorbairt cumais chognaíoch agus sochmhothúchánach páistí a bhfuil Siondróm Down orthu (m.sh. feidhm feidhmiúcháin, scileanna sóisialta, scileanna cumarsáide srl.).
- Deis a thabhairt do rannpháirtithe a gcuid smaointe nó faoin staidéar a roinnt leis an taighdeoir, a d'fhéadfadh a bheith mar threoir ag Céim 2 den taighde.

Cad a Bheidh i gCeist le Rannpháirtíocht sa Taighde?

- Tógfaidh sé thart ar 10 nóiméad an ceistneoir se ar Qualtrics a líonadh ar líne agus ní gá d'ainm a thabhairt leis an gceistneoir. Beidh ceist amháin ag deireadh an cheistneora le líonadh amach ag tuismitheoirí i gcomhar lena bpáiste a bhfuil siondróm Down orthu.
- Is ar do chonlán féin a ghlacann tú páirt sa taighde seo. Má dhéanann tú cinneadh páirt a ghlacadh sa staidéar, is féidir leatsa nó do pháiste tarraingt siar ón tionscadal taighde ag pointe ar bith suas go dtí an chéim anailísithe sonraí gan míniú a thabhairt.

Na Buntaistí agus na Baoil a Bhaineann le Rannpháirtíocht sa Staidéar

• Déanfar iarracht leis an taighde na bearnaí i dtorthaí taighde roimhe seo a líonadh mar níor thug aon duine faoi thaighde ar an tionchar atá ag tumoideachas ar fhorbairt cumais chognaíoch agus shochmhothúchánaigh páistí a bhfuil Siondróm Down orthu.

• Beidh an tionscadal taighde seo ar an gcéad phíosa taighde in Éirinn a chuimsíonn guthanna páistí a bhfuil Siondróm Down orthu agus a dtuismitheoirí faoin taithí agus faoi na tuairimí atá acu faoi fhorbairt an linbh agus suíomhanna oideachais éagsúla ó thus go deireadh an taighde. Baileofar do roghanna agus do thuairimí má ghlacann tú páirt i gCéim 1 a thabharfaidh treoir do Chéim 2 den tionscadal taighde.

• Ní mheastar go bhfuil baoil ag gabháil le rannpháirtíocht páirt i gCéim 1 den staidéar seo. Ar an gcaolseans go gcuirfeadh rannpháirtíocht sa staidéar seo as go mór do rannpháirtithe, is féidir leo dul i dteagmháil leis na seirbhísí tacaíochta atá ar fáil ag bun an leathanaigh.

Nósanna Imeachta Rúndachta, Stóráil agus Scriosadh Sonraí

- Má ghlacann tú páirt sa staidéar, ní gá d'ainm a thabhairt leis an gceistneoir. Beidh gach freagra a thabharfar faoi rún. Ní ainmneofar tú féin, do pháiste nó do scoil/shuíomh oibre ainmnithe i dtorthaí an taighde.
- Úsáidfear pasfhocal chun sonraí leictreonacha (sonraí a stóráiltear ar ríomhaire) a chosaint.

Má tá sé i gceist agat tabhairt faoin tionscadal taighde seo, is féidir leat dul i dteagmháil leis an bpríomhtaighdeoir Caitríona Ní Chinnéide nó leis an Dochtúir Fionnuala Tynan ar na sonraí atá luaite thíos. Chomh maith leis sin is féidir leat dul i dteagmháil leis an gCoiste Eitice Taighde, i gColáiste Mhuire Gan Smál maidir leis an taighde seo ar na sonraí atá luaite thíos. Tá mé fíorbhuíoch as an suim atá agat sa tionscadal taighde seo agus as do chomhoibriú leis.

Le gach dea-ghuí,

Caitríona Ní Chinnéide (Príomhthaighdeoir)

20108214@micstudent.mic.ul.ie

Maoirseoir Taighde

An Dr. Fionnuala Tynan (Maoirseoir Taighde) fionnuala.tynan@mic.ul.ie

Sonraí Teagmhála an Duine Neamhspléach Mary Collins (Riarthóir MIREC) mirec@mic.ul.ie +35361 204 980

Seirbhísí Tacaíochta

ar www.mentalhealthireland.ie nó ar www.aware.ie.

Is féidir glaoch gutháin saor in aisce a chur ar Aware ar **1800 80 48 48** nó ríomphost a sheoladh chucu ar **supportmail@aware.ie.**

Is féidir dul i dteagmháil le do dhochtúir fosta.

Appendix K: Phase Two Parent Information Sheet



Phase Two Parent Information Sheet

My name is Catriona Kennedy, and I am a student who is currently pursuing a Doctorate in Educational and Child Psychology at Mary Immaculate College, under the supervision of Dr. Fionnuala Tynan. I am undertaking a research study which has been funded by An Chomhairle um Gaeltachta agus Gaelscolaíochta (COGG) about 'The experience of Irish-medium and English-medium primary schools for children with Down Syndrome and their parents.'

Who Can Take Part in Phase Two of the Research?

 Parents of a child with Down Syndrome who attend an English-medium primary school (e.g., mainstream school or special school) OR an Irish-medium primary school (e.g., a Gaelscoil) and their child.

Aims of Phase Two of the Research

- To investigate whether there are differences in the verbal abilities, adaptive behaviours, emotional development and school experiences of primary-school children with Down Syndrome depending on whether they attend an Irish-medium, English-medium mainstream or special school.
- To explore whether there are differences in the experiences of parents based on whether their child with Down Syndrome attends an Irish-medium, English-medium mainstream or special school.

Details of Involvement in the Research

- 1. Parents will complete an online questionnaire to provide demographic characteristics to the researcher for each child participant. The questionnaire will take approximately 10 minutes.
- 2. Parents will take part in an interview on Microsoft Teams at a time and date convenient to the parent, that will last for approximately 60 90 minutes.
- 3. Your child, accompanied by an adult that they trust, will bring the researcher on a tour of their school which will last approximately 20 minutes. It is hoped that the school visits will take place on Fridays between June December 2022. On the tour of the school, your child will use a camera to take photos of the following place and objects. Please note that photos taken by the child which contain identifiable information (e.g., a person or the school's name etc.) will be deleted to protect your child, your child's classmates and children and the school's confidentiality:

- (i) various places around the school where activities take place (e.g., school hall, computer rooms, school yard, school garden, basketball courts, pitches, school stage etc.)
- (ii) your child's favourite place in the school
- (iii) your child's least favourite place in the school
- (iv) your child's favourite book
- (v) your child's favourite learning activity at school
- 4. On the second visit to your child's school, your child, accompanied by an adult they trust, will participate in a story-writing activity with me. We will discuss the photos your child took during the previous school visit. This discussion with your child will be recorded and transcribed by me. Next, your child and I will stick the photos into a scrap book and write a simple story. This activity will take approx. 20 minutes and your child can take the scrap book home with them when we are finished.

Voluntary Nature of Participation in this Research

• Participation in this research is entirely voluntary, as you can decide against participating in the research if you so wish. Additionally, you and/or your child can change your mind about your decisions to take part and withdraw from the research at any time until the point of data analysis.

Potential Benefits and Risks to Participants arising from Involvement in this Research

- This research will address gaps in previous studies in this area, as no previous research has
 investigated the impact of immersion education on the cognitive and/or socio-emotional
 development of children with Down Syndrome. It will also be the first study in Ireland to
 include the voices of children with Down Syndrome and their parents about child development
 and experiences of Irish-medium, English-medium mainstream and special primary schools
 from the beginning of the research process.
- It is not envisaged that there are any major risks to participants arising from involvement in Phase One of the study. However, should participants experience distress arising from participating in the research, the contact details for support services provided on page 3 of this information sheet may be of assistance to participants.

Confidentiality Procedures and Data Storage

- In order to protect your confidentiality, pseudonyms (fake names) will be generated for you
 and your child and any identifiable information, such as your child's school's name or your
 location will not be included in any of the written results.
- All of your responses, including questionnaires and signed consent forms, will be stored in a secure, locked location. Electronic data (data stored on a computer), including recordings, transcriptions of interviews and photographs, will be protected by passwords.

If you have any questions or concerns, please do not hesitate to contact me or my research supervisor at any stage, using the contact details below. Alternatively, you may wish to contact an independent person about this research. If so, please contact the Mary Immaculate College Research Ethics Committee (MIREC) Administrator using the details below. I sincerely thank you for your time reading this information letter and for considering your participation in this study.

Le dea-ghuí,

Carnina Vennez

Catriona Kennedy Principal Researcher 20108214@micstudent.mic.ul.ie

Research SupervisorIndependent Contact DetailsDr. Fionnuala TynanMary CollinsResearch SupervisorMIREC Administratorfionnuala.tynan@mic.ul.iemirec@mic.ul.ie+35361 204 980

Support Services

Visit www.mentalhealthireland.ie or www.aware.ie for more information. Freephone Aware on 1800 80 48 48 or email supportmail@aware.ie You can also contact your GP.

Leagán Gaeilge



Bileog Eolais do Thuismitheoirí

Is mise Caitríona Ní Chinnéide, táim ag tabhairt faoi thionscadal taighde mar chuid de mo chéim dochtúra i gColáiste Mhuire Gan Smál, faoi stiúir an Dochtúra Fionnuala Tynan. 'The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents' an teideal atá ar an tionscadal taighde agus tá sé urraithe ag An Chomhairle um Oideachas Gaeltachta agus Gaelscolaíochta (COGG).

Cé atá Ábalta Páirt a Ghlacadh i gCéim 2 den Staidéar Seo?

 Tuismitheoirí a bhfuil páiste acu a bhfuil siondróm Down orthu agus atá ag freastal ar bhunscoil lán-Béarla (m.sh. scoil príomhshrutha nó scoil speisialta srl.) NÓ scoil lán-Gaeilge (m.sh. Gaelscoil nó scoil Ghaeltachta srl.) agus an páiste é/í féin.

Cuspóirí do Chéim 2 den Staidéar Seo:

- Fiosrú a dhéanamh ar na difríochtaí sna scileanna cainte, san iompraíocht oiriúnaitheach, san fhorbairt mhothúchánach agus sna taithí scoile do pháistí a bhfuil siondróm Down orthu ag brath ar an suíomh scoile (bunscoil lán-Ghaeilge, bunscoil lán-Béarla príomhshrutha nó bunscoil lán-Béarla speisialta) ar a bhfreastalaíonn siad.
- Fiosrú a dhéanamh ar na difríochtaí sa taithí atá ag tuismitheoirí ag a bhfuil páistí a bhfuil siondróm Down orthu ag brath ar an scoil (scoil lán-Ghaeilge, scoil lán-Béarla príomhshrutha nó scoil lán-Béarla speisialta) ar a bhfreastalaíonn a bpáistí.

Céard a bheidh i gCeist le Rannpháirtíocht sa Taighde?

- Líonfaidh tuismitheoirí ceistneoir bunaithe ar phróifíl dhéimeagrafach a bpáiste a bhfuil siondróm Down orthu. Tógfaidh sé thart ar 10 nóiméad an ceistneoir seo a líonadh amach.
- Glacfaidh tuismitheoirí páirt in agallamh ar Microsoft Teams faoi fhorbairt a bpáiste. Mairfidh an t-agallamh thart ar 60 - 90 nóiméad agus tarlóidh sé ar dáta agus ag am a oireann don tuismitheoir.
- 3. Tógfaidh do pháiste mé (in éineacht le duine fásta ón scoil a bhfuil aithne ag an bpáiste air) ar thuras timpeall na scoile. Mairfidh an turas scoile thart ar 20 nóiméad agus meastar go dtarlóidh an turas ar Aoine áirithe idir Meitheamh Nollaig 2022. I rith an turais scoile glacfaidh do pháiste roinnt grianghraf le ceamara bunaithe ar na háiteanna timpeall na scoile atá luaite thíos. Scriosfar grianghraif a ghlacann do páiste ina bhfuil faisnéis inaitheanta phearsanta (m.sh. aghaidh páiste eile, ainm na scoile srl.) ón gceamara chun rúndacht an pháiste, a bpáirtithe ranga agus an scoil a chosaint.

- Na háiteanna ina mbíonn na gníomhaíochtaí éagsúla ar fad ar súil sa scoil (mar shampla, an halla scoile, seomra ríomhaire srl.).
- (ii) An áit is fearr leis an bpáiste sa scoil.
- (iii) An áit is lú a thaitníonn leis na bpáiste sa scoil.
- (iv) An leabhar is fearr leis an bpáiste.
- (v) An gníomh foghlama is fearr leis an bpáiste ar scoil.
- 4. Ar an dara cuairt chuig scoil do pháiste, glacfaidh do pháiste (in éineacht le duine fásta ón scoil a bhfuil aithne ag an bpáiste air) páirt i ngníomh scríbhneoireachta scéalta liomsa. Déanfaidh muid plé orthu ar na grianghraif. Déanfaidh mé taifead ar an bplé seo leis an bpáiste agus déanfaidh mé an t-agallamh ar fad a thras-scríofa. I rith an phlé, greamóidh mé fhéin agus do pháiste na grianghraif isteach i leabhar gearrthóg agus scríobhfaidh muid scéal simplí le chéile. Mairfidh an gníomh scríbhneoireachta thart ar 20 nóiméad agus beidh cead ag do pháiste an leabhar gearrthóg a thabhairt abhaile leo nuair a bheidh muid críochnaithe.

Rannpháirtíocht ar do Chonlán féin sa Stáidear

 Is ar do chonlán féin a ghlacann tú páirt sa taighde seo. Is féidir leatsa nó le do pháiste cinneadh a dhéanamh gan páirt a ghlacadh sa staidéar seo. Má dhéanann tú cinneadh páirt a ghlacadh sa staidéar, is féidir leatsa nó do pháiste tarraingt siar ón tionscadal taighde ag pointe ar bith suas go dtí an chéim anailísithe sonraí gan míniú a thabhairt.

Na Buntaistí agus Na Baoil a Bhaineann le Rannpháirtíocht sa Staidéar

• Déanfar iarracht leis an taighde na bearnaí i dtorthaí taighde roimhe seo a líonadh mar níor thug aon duine faoi thaighde ar an tionchar atá ag tumoideachas ar fhorbairt cumais chognaíoch agus shochmhothúchánaigh páistí a bhfuil siondróm Down orthu. Beidh an tionscadal taighde seo ar an gcéad phíosa taighde in Éirinn a chuimsíonn guthanna páistí a bhfuil siondróm Down orthu agus a dtuismitheoirí faoin taithí agus faoi na tuairimí atá acu faoi fhorbairt an linbh agus suíomhanna oideachais (bunscoil lán-Ghaeilge, bunscoil lán-Béarla príomhshrutha nó bunscoil lán-Béarla speisialta) éagsúla ó thus go deireadh an taighde. Baileofar do roghanna agus do thuairimí má ghlacann tú páirt i gCéim 1 a thabharfaidh treoir do Chéim 2 den tionscadal taighde.

• Ní mheastar go bhfuil baoil ag gabháil le rannpháirtíocht páirt i gCéim 1 den staidéar seo. Ar an gcaolseans go gcuirfeadh rannpháirtíocht sa staidéar seo as go mór do rannpháirtithe, is féidir leo dul i dteagmháil leis na seirbhísí tacaíochta atá ar fáil ag bun an leathanaigh.

Nósanna Imeachta Rúndachta, Stóráil agus Scriosadh Sonraí

 Chun rúndacht d'fhaisnéise pearsanta a chosaint, tugtar ainmneacha bréige do rannpháirtithe agus d'fhaisnéis phearsanta eile cosúil le hainm na scoile nó a suíomh. Úsáidfear na hainmneacha bréige i dtorthaí scríofa an tionscadail taighde. Coimeádfar freagaraí agus sonraí a bhaileofar i rith an phróisis taighde i suíomh slán sábhailte, faoi ghlas. Úsáidfear pasfhocal chun sonraí leictreonacha (sonraí a stóráiltear ar ríomhaire) a chosaint.

Má tá sé i gceist agat tabhairt faoin tionscadal taighde seo, is féidir leat dul i dteagmháil leis an bpríomhthaighdeoir Caitríona Ní Chinnéide nó leis an Dochtúir Fionnuala Tynan ar na sonraí atá luaite thíos. Chomh maith leis sin is féidir leat dul i dteagmháil leis an gCoiste Eitice Taighde i gColáiste Mhuire Gan Smál maidir leis an taighde seo ar na sonraí atá luaite thíos. Tá mé fíorbhuíoch as an suim atá agat sa tionscadal taighde seo agus as do chomhoibriú leis.

Le gach dea-ghuí,

Carmione Venney

Caitríona Ní Chinnéide Príomhthaighdeoir 20108214@micstudent.mic.ul.ie

Maoirseoir Taighde	Sonraí Teagmhála an Duine Neamhspléach
An Dr. Fionnuala Tynan	Mary Collins (Riarthóir MIREC)
Maoirseoir Taighde	mirec@mic.ul.ie
fionnuala.tynan@mic.ul.ie	+35361 204 980

Seirbhísí Tacaíochta

Is féidir eolas breise a fháil ar **www.mentalhealthireland.ie** nó ar **www.aware.ie.** Is féidir glaoch gutháin saor in aisce a chur ar Aware ar **1800 80 48 48** nó ríomphost a sheoladh chucu ar supportmail@aware.ie. Is féidir dul i dteagmháil le do dhochtúir fosta.

Appendix L: Phase Two Parent Consent Forms



'The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents.'

Dear _____,

As outlined in the Information Sheet provided to you, this study aims to explore primary-school children with Down syndrome and their parents' experience of immersion and non-immersion education settings. Furthermore, the study aims to investigate the impact that immersion and non-immersion education settings have on aspects of children with Down syndrome's development. Please read the Information Sheet carefully before you provide consent for you and your child's participation in the study.

Please read the following statements before signing the consent form.

- I have read and understand the participant information sheet.
- I understand what the aims of the research are.
- I am aware that my participation will involve the completion of an online questionnaire and an interview via video call on Microsoft Teams that will take place between April December 2022.
- I am aware that my child's participation in the study will involve two school visits, including a school tour and an interview with my child in the company of an adult from school that he/she trusts.
- I am aware of the benefits and risks associated with participation in the study.
- I understand that my participation is entirely voluntary and that I can withdraw from the study at any stage without giving a reason and without consequence.
- I am aware that any information given by me, will be treated with the utmost confidentiality, and that pseudonyms will be applied to the data to maintain anonymity.
- I am aware that the findings from my interview will form part of the primary researcher's doctoral thesis.
- I am 18 years of age or older and agree to participate in this study.

Child's Name (PRINTED):

Parent's Name (PRINTED):

Parent's Name (Signature):

Date:



Α_____,

Mar is eol duit ón mbileog eolais, is iad cuspóirí an tionscadail taighde seo ná fiosrú a dhéanamh ar na difríochtaí sa taithí agus sna torthaí forbartha do pháistí a bhfuil siondróm Down orthu ag brath ar an suíomh scoile ar a bhfreastalaíonn siad agus fiosrú a dhéanamh ar na difríochtaí sa taithí atá ag tuismitheoirí ag a bhfuil páistí a bhfuil siondróm Down orthu ag brath ar an sucial a bhfuil siondróm Down orthu ag brath ar an scoil ar a bhfreastalaíonn a bpáistí. Léigh an Bileog Eolais go cúramach sula dtugann tú cead páirt a ghlacadh sa staidéar nó sula dtugann tú cead do do pháiste páirt a ghlacadh sa staidéar.

Léigh na ráitis seo a leanas sula síníonn tú an fhoirm thoilithe seo:

- Tá an Bhileog Eolais léite agam agus tuigim an t-eolas atá tugtha dom.
- Tuigim cuspóirí taighde an tionscadail taighde.
- Tuigim go bhfuil ceistneoir le líonadh ar line agus agallamh trí fhísghlao ar Microsoft Teams le déanamh leis an taighdeoir idir Aibreán Nollaig 2022 má ghlacaim páirt sa staidéar.
- Tuigim go mbeidh an taighdeoir ag tabhairt cuairt ar scoil mo pháiste faoi dhó, ina ndéanfar turas scoile agus agallamh le mo pháiste, in éineacht le duine fásta ón scoil a bhfuil aithne ag do pháiste air, má ghlacaim fhéin agus mo pháiste páirt sa staidéar.
- Tuigim na buntáistí agus na baoil a bhaineann le rannpháirtíocht sa staidéar seo.
- Tuigim gur ar mo chonlán féin atá mé ag glacadh páirt sa staidéar seo agus go bhfuil cead agam tarraingt siar ón tionscadal taighde ag pointe ar bith suas go dtí an chéim anailísithe sonraí gan míniú a thabhairt.
- Tuigim go ndéanfaidh an taighdeoir iarracht eolas ar bith a thugaim di a choinneáil faoi rún agus go núsáidfidh an taighdeoir ainmneacha bréige chun m'fhaisnéis phearsanta a chosaint.
- Tuigim go mbeidh torthaí ón gceistneoir agus m'agallamh san áireamh i dtráchtas dochtúireachta an phríomhthaighdeora.
- Tá mé 18 bliain d'aois nó níos sine agus ba mhaith liom páirt a ghlacadh sa staidéar seo.

Ainm an Pháiste (BLOCLITREACHA):

Ainm an Tuismitheora (BLOCLITREACHA):

Ainm an Tuismitheora (Síniú):

Dáta:

Appendix M: Phase Two Child Assent Form



'The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents.'

What is this project about?

This project is going to try and find out all about you, your school and what you are learning.





What will you do?

You will bring Catriona on a tour of your school with _____ (name of teacher or SNA).







You will show Catriona where your classroom is and take her to different places all around the school.



You will use a camera to take photos of different places around the school.



You and Catriona will look at the photos.



You and Catriona will talk about the photos.



You and Catriona will write a story and make a book with the photos.





You will take the book home with you.





I can stop when I want.

I can take a break if I want.

I can keep going when I want.

I can say 'Yes.'

I can say 'No.'









I can ask for help if I want.





I would like to take part in the project.

I would not like to take part in the project.



Yes



My name: _____



Leagán Gaeilge



'The Experience of Irish-Medium and English-Medium Primary Schools for Children with Down Syndrome and their Parents.'

Cad a bheidh i gceist leis an staidéar?

Déanfar iarracht fáil amach faoi do scoil agus na rudaí atá á fhoghlaim agat i rith an staidéar seo.





Cad a dhéanfaidh tú?

Tabharfaidh tú Caitríona ar thuras timpeall do scoil le _____ (ainm an mhúinteoira nó an CRS).







Taispeánfaidh tú do Chaitríona cá háit atá do sheomra ranga agus tabharfar í go dtí áiteanna difriúla timpeall na scoile.



Bainfidh tú úsáid as ceamara chun grianghraif a ghlacadh d'áiteanna difriúla timpeall na scoile.



Féachfaidh tú fhéin agus Caitríona ar na grianghraif.



Labhróidh tusa agus Caitríona faoi na grianghraif.





Scríobhfaidh tú fhéin agus Caitríona scéal agus déanfaidh sibh leabhar leis na grianghraif a ghlac tú.





Tógfaidh tú an leabhar abhaile leat.





Ba mhaith liom an gníomh a stopadh.

Ba mhaith liom sos a ghlacadh.

Ba mhaith liom leanúint ar aghaidh.

Is féidir liom 'Is ea' a rá.

Is féidir liom 'Níl' a rá.









Is féidir liom cabhair a lorg.





Tá mé ag iarraidh páirt a ghlacadh sa staidéar.

Níl mé ag iarraidh páirt a ghlacadh sa staidéar.







M'ainm:
Appendix N: Phase Two Demographic Characteristics Online Questionnaire

What is your child's name?

What is your child's date of birth?

What type of school does your child attend?

- Special school (primary)
- English-medium mainstream primary school
- Irish-medium mainstream primary school

A child's primary caregiver is defined as the person who provides most care to the child on a day-to-day basis and who knows most about him or her.

What level of education has your child's primary caregiver attained?

•	Lower post-primary (secondary) school or less.	
•	Completed post-primary (secondary) school.	
•	Completed a Level 6 or Level 7 Certificate or Diploma.	
•	Completed a Level 8 Honours Degree or Higher Diploma.	
•	Completed a Post-Graduate Level 9 Degree or higher.	

Please list all languages spoken in your child's home:

1.	 	 	 	
2.	 	 	 	
3.	 	 	 	
4.	 	 	 	
5.				

If your child speaks more than one language, what was your <u>child's first</u> <u>language</u>?

Please answer N/A if your child does not speak more than one language.

If your child speaks more than one language, which language is most commonly spoken in your child's home?

Please answer N/A if your child does not speak more than one language.

How often do you (or someone else at home) speak an additional language (a language other than your child's first language) to your child at home?

Please answer N/A if your child does not speak more than one language.

•	N/A	
•	Never, my child speaks two languages, but only their first	
	language is spoken at home.	
•	Sometimes an additional language is spoken to my child at home. Two (or more) languages are spoken <u>equally</u> to my child at home.	
•	An additional language is the majority language spoken	
	to my child at home.	

During the current school year, how much time do you (or someone else at home) spend reading to your child on a typical school day (Monday - Friday)?

- Less than 5 minutes a day.
- Between 5 15 minutes a day.
- Between 15 30 minutes a day.
- Between 30 60 minutes a day.
- More than an hour a day.

During the current school year, how much time do you (or someone else at home) spend reading to your child on a typical weekend day (Saturday or Sunday)?

- Less than 5 minutes a day.
- Between 5 15 minutes a day.
- Between 16 30 minutes a day.
- Between 31 60 minutes a day.
- An hour a day or more.

Approximately how many <u>children's books</u> do you have in your child's home?

- None.
- Between 1 20 children's books.
- Between 21 40 children's books.
- Between 41 60 children's books.
- More than 60 children's books.



Γ	

Approximately how many adult's books do you have in your child's home?

- None.
- Less than 50 adult's books.
- Between 51 99 adult's books.
- Between 100 199 adult's books.
- More than 200 adult's books.

Γ	

Appendix O: Interview Schedule

- Tell me about your child with Down syndrome.
- Did your child attend preschool? If yes, what kind of preschool?
- When did you make the decision to send your child to their current school?
- Why did you decide to send your child to a Gaelscoil/mainstream school/special school?
- Did anything else influence your decision to send your child to a Gaelscoil/mainstream school/special school?
- Tell me about the school your child currently attends.
- What is going well/not so well for your child at school?
- What does your child like/dislike about their school?
- Tell me about your child's stand out (best) experiences of school so far.
- What languages does your child speak? Tell me about your child's experiences of learning and additional language (e.g. Irish, French, Polish etc.)?
- Do you think that the school your child attends is a good fit for your child's needs? Why?
- What, in your opinion, are the benefits of sending a child with Down syndrome to a Gaelscoil/mainstream school/special school?
- Do you think there are any disadvantages to sending a child with Down Syndrome to a Gaelscoil/mainstream school/special school?
- What do you, as a parent of a child with Down syndrome, think that members of a school community can do to support you and your child?
- Is there anything you would recommend to parents of children with Down syndrome who are thinking about sending their child to a Gaelscoil/mainstream school/ special school?
- Have you any other comments you wish to make regarding you or your child's experiences of primary school?

Verbal Communication Skills

- Verbal communication is the use of words to convey a message. Some forms of verbal communication are written and oral communication. Now I am going to ask you some questions about your child's verbal communication skills.
- Describe your child's ability to use oral communication.
- Describe your child's spoken vocabulary. Approximately how many words do you estimate he/she uses in spoken language?
- Describe your child's use of grammar in his/her spoken language.
- How does your child respond to questions or conversations?
- Does your child ask questions? If yes, describe the types of questions your child usually asks.
- Describe your child's ability to understand spoken language.
- Describe your child's ability to follow verbal instructions.
- Describe your child's reading skills.
- Tell me about your child's written communication skills. What written communication skills is your child able to use?

Appendix P: Worked Example of the Coding Process

Initial coding	Second coding	Illustrative quotes
Accessing research about child's needs	Keeping up to date with Down syndrome	"I'm kind of I've got to a point where by I've become an expert patient, to mean
	research	an expert parent in having a child with Down syndrome, cause I've dabbled in
Attending parent training courses		And Down Syndrome Education I found probably better than anything. And then
		there's a body a medical interest group, which is brilliant, actually for
Discussing decisions with other		information, it's across UK and Ireland, a medical interest group, which just keeps
parents of children with Down		me in touch with what's going on."
syndrome		
		"When he was born and I think I must have done her courses early on because I
		remember people saying to us like 'make sure it's OK to do the two languages.
		Won't you confuse him?'"
		"But those two parents, who I amn't in touch with anymore anyhow, we would have
		just been bouncing ideas 'should we?' 'will we?' 'won't we?' kind of you know?"

Responding to judgement from others	Responding to non-inclusive	"Other parents will raise an eyebrow and say, "ohh, you're making it very hard for your
based on school choice	behaviours by other parents	child" And be prepared with an answer for that. You shouldn't have to defend it because you
		know essentially it's discriminating against your child to say that your child can't do it, but
Responding to judgement from others		you will have to, to a point, and you will have to demonstrate that you're going to do the hard,
about child's abilities		hard, miles, hard yards to make it work."
Not being believed about child's		"And it would be nice if he got invited on play dates and people didn't make an issue of it.
behaviour		People see an awful lot of issues where there are none."
Child not being treated the same as		"There's a lot of judgment from other parents "why are you not sending him to mainstream?
other children because of disability		You know, we fought so hard for our kids to be included."
Responding to others who believe that		
children with disabilities should not		
attend Irish-medium schools		
Child not invited on play dates		
Responding to child being	Responding to non-inclusive	"Because I mean, I worked with people with disabilities, and I just thought it was really
mollycoddled by hospital staff	behaviours from family	important for him to be challenged and to be integrated into the community and the local
	members or members of the	community and that was that! I just wasn't accepting any pity party, any sort of "oh poor
Judgement from others about speaking	community	child with Down syndrome, he won't be able to do anything." So I was just going to challenge
two languages to the child		him and push him on."
Pity from others		

		"I've been very selective of the people she's around and also my other daughters for them to
Experiencing others staring at the child		witness, do you know? That's not easy, you know. So I'm very selective, even with family
		members or, you know friends we haven't there's friends that we that we are no longer as
Family members using disability-first		close because You know? And even like, you know, things like staring and you know? But
labels		the community that she's now in, that she's established is very, very nurturing and very
		supportive."
Child not being welcomed at extra-		
curricular activities		
Protecting the child from bullying in		
the community		
Responding to child being	Responding to non-inclusive	"I think because they understand children with special needs rather than send him into a
mollycoddled at school	behaviours by school staff	mainstream and they 'awwwhh he's so cute, Oh my God.' You know I've been sick of him
		being mollycoddled for you know You know 'ohh look at him, he's gorgeous.'"
Teachers using disability-first labels		
		"We have encountered at our school on multiple occasions Anna being referred to as 'a
		Downs' and also on one particular occasion two teachers talking to each other with me in the
		room and them saying 'did you have one of them in when you were at school?' Which
		absolutely Wow! It floored me and these are young people!"
Political campaigning for access to	Campaigning for better	"I'm on a big campaign about the whole thing anyway. I met with the minister, there a few
disability services	disability services	weeks ago outlining how appalling things are, as if she didn't already know?"
Requests for data from disability		"Like I went down the road of trying to find out how much money was being paid to services
services		on behalf of my child."

Having to justify school choice to	Advocating for children's	"But nobody knows what it's like to have a child with special needs until you actually have
school staff	educational and medical rights	one. And you can think you can imagine what it would be like. But you actually see the world
		in a totally different way once you have your own child, because you have to look at things
Child being sent home from school		differently and you have to get used to maybe having to fight for stuff or not being able to get
		the right start or get the right extra thing."
Exclusion from learning in the		
mainstream classroom		"Don't be afraid to read all the school policies and make sure they're living up to them."
Child not being welcomed to join		"I have developed a lot about speaking up for Jack."
school		
Fighting for extra supports or		"Our school had sent Anna home on 4 occasions, as a sanction for bad behaviour. And I think
resources at school		that the school didn't realise it they didn't realise that actually what they were doing was
		not legal and I think that that kind of identified to me as well that there may be a culture of
Political campaigning for summer		that in schools and the schools don't know that actually now there are, you know, rights in
educational programme		law now, to protect children from having their school day reduced and whether that's with
		parental consent or without parental consent, it doesn't matter."
Knowledge of disability rights		

Phase of	Means of establishing trustworthiness	Criteria	Rationale for
reflexive		met?	criteria not being
thematic analysis			met.
(Braun &			
Clarke, 2022)			
1. Data familiarisation	 Prolong engagement with data Triangulate different data collection modes Document theoretical and reflective thoughts Document thoughts about potential codes/themes Store raw data in well-organised archives Keep records of all data field notes, transcripts, and reflexive journals 	✓ ✓ ✓ ✓	N/A
2. Generating initial codes	 Peer debriefing Researcher triangulation Reflexive journaling Use of a coding framework Audit trail of code generation Documentation of all team meeting and peer debriefings 	✓ ✓ ✓ ✓ ✓ ✓	Researcher triangulation was not achieved. According to Braun and Clark (2022, p. 55) "having only one person coding – usually the researcher – is normal practice, and indeed good practice, for reflexive thematic analysis."
3. Generating themes	 Researcher triangulation Diagramming to make sense of theme connections Keep detailed notes about development 	X ✓	While researcher triangulation was not achieved, potential themes

Appendix Q: Nowell et al. (2017) Quality Assurance Checklist

4. Reviewing potential themes	 and hierarchies of concepts and themes Researcher triangulation Themes and subthemes vetted by team 	X X	 were discussed and reviewed with the research supervisor during supervisory meetings. While researcher triangulation was
	 Test for referential adequacy by returning to raw data 	✓	not achieved, potential themes were discussed and reviewed with the research supervisor during supervisory meetings.
5. Defining and naming themes	 Researcher triangulation Peer debriefing Team consensus on themes Documentation of team meetings regarding themes Documentation of theme naming 	X √ √ √	While researcher triangulation was not achieved, potential themes were discussed and reviewed with the research supervisor during supervisory meetings.
6. Producing the report	 Peer debriefing Describing process of coding and analysis in sufficient details Thick descriptions of context Description of the audit trail Report on reasons for theoretical, methodological, and analytical choices throughout the entire study 		N/A