

Title	Profiling the meaningful reading habits of young people and adults with Down syndrome
Authors	Jolley, Mary
Publication date	2023
Original Citation	Jolley, M. 2023. Profiling the meaningful reading habits of young people and adults with Down syndrome. MRes Thesis, University College Cork.
Type of publication	Masters thesis (Research)
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Download date	2026-10-05 01:53:35
Item downloaded from	https://hdl.handle.net/10468/15934

Ollscoil na hÉireann, Corcaigh

National University of Ireland, Cork



**Profiling the meaningful reading habits of young people and
adults with Down syndrome**

Thesis presented by Mary Jolley BSc (Hons) Speech and Language Therapy for
the degree of Master of Research

University College Cork

School of Speech and Hearing Sciences

Head of School: Prof. Nicole Müller

Supervisors: Dr. Pauline Frizelle, Nicola Hart, and Dr. Ciara O'Toole

October 2023

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Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

A handwritten signature in black ink, reading "Mary Jolley". The script is cursive and fluid, with the first name "Mary" and last name "Jolley" clearly distinguishable.

Date: 05/10/2023

Acknowledgements

Firstly, I would like to thank the Department of Speech and Hearing Sciences in University College Cork for supporting this research.

I'm extremely grateful to my supervisors Dr. Pauline Frizelle, Nicola Hart and Dr. Ciara O'Toole who provided so much support and advice throughout my research. Their insight, words of encouragement and guidance were greatly appreciated.

I would also like to extend my deepest appreciation and admiration to the staff and teachers involved with Down Syndrome Ireland, who continuously and unwaveringly offered guidance and assistance throughout this project. I would particularly like to thank Sinead Flynn and Ross O'Neill who helped me so much.

To all who participated in the current research, thank you for sharing your time, knowledge, and experiences. Without your contribution to the study, there would be no research.

Finally, thank you to my Mam, Dad and brothers who without their love and belief in me, the completion of this thesis would not have been possible. Thanks also to my family, Dylan, and friends (especially my fellow SLTs Sarah, Megan and Niamh) for their endless support and encouragement throughout my studies.

Abstract

Introduction: Given the technological advancements over the last 20 years, the impact of how we use written language in society and therefore the ability to read is particularly pertinent for people with Down syndrome. Adults with Down syndrome are now more than ever, accessing their communities, further education and employment. All of these facets of daily life can require aspects of reading, such as the ability to read street signs, text messages or work contracts. However, to date, no large scale, international study has profiled the reading habits of adults with Down syndrome in everyday contexts, or how they feel about reading. This information is invaluable as it can inform reading interventions which are functional to adults with Down syndrome; thus, having a meaningful impact on their quality of life.

Aim: This study aimed to 1) Explore the reading habits of adults with Down syndrome, informed by the priorities of adults with Down syndrome themselves 2), Gather a large, international profile of meaningful reading for young people and adults with Down syndrome using a valid Meaningful Reading Measure (MRM) (Frizelle et al., 2023) and 3), Investigate whether age, education and place of residence influence meaningful reading for people with Down syndrome.

Method: The research was carried out in two phases. *Phase-1:* Research questions for the study were prioritised and refined following a structured focus group of adults with Down syndrome (n=9). *Phase-2:* Using a combination of online survey and paper forms, data on the meaningful reading habits of people with Down syndrome were gathered using the MRM. The refined research questions were then addressed.

Results: *Phase-1 Results:* The focus group members prioritised research questions such as whether people with Down syndrome liked reading, and what they felt was difficult or the ‘best thing’ about reading. They indicated an interest in those questions that referred to the impact of age and place of residence on meaningful reading. *Phase-2 Results:* Ninety-eight people

with Down syndrome completed the survey. On average, the participants read 34 of the 46 items in the MRM. Scores ranged from 0-46. The most common item read by the sample was cards and food brands and the most common medium for reading was a tablet or computer (45.3%). The most common reason for reading was to pursue personal learning and interests. Many people with Down syndrome felt that reading novel or complex words was difficult and detailed the various challenges they faced with reading. No relationship between age and MRM score was observed. Younger individuals (aged 16-25) read significantly more new media items ($p = .007$) than older individuals (aged 26-37).

Conclusion: Adults with Down syndrome read a variety of different items in everyday contexts, which are not dissimilar to typical populations. The participants in the study provided a unique insight into the challenges they face with reading; such as the accessibility of texts, complex words, and reading comprehension. In addition, it is evident that reading for both functional use and pleasure is focal in the lives of people with Down syndrome. This information can inform future reading interventions which are motivating, functional and meaningful for people with Down syndrome.

Chapter One: Down syndrome

This chapter aims to profile people with Down syndrome; paying particular attention to speech, language and cognitive development. As this study concerns adults and adolescents with Down syndrome, the topics presented are adolescent and adult focused. Although development in childhood is discussed briefly in various sections, the main objective of this chapter is to provide information about adults with Down syndrome which are relevant to this study. Following this, a broad profile of employment, educational and community experiences for people with Down syndrome will be discussed. These experiences are considered significant to this work, as reading and literacy ability have an obvious bi-directional relationship on education, employment and community engagement outcomes. Consequently, meaningful reading experiences will be influenced by these aspects of everyday living for people with Down syndrome.

1.1 Introduction

1.1.1 Overview of Down syndrome

Down Syndrome is a chromosomal disorder which occurs as a result of trisomy of chromosome 21. The condition is recognised by a group of physical and cognitive characteristics impacting bodily systems, in particular the musculoskeletal, neurological and cardiovascular systems (Antonarakis et al., 2020; Grieco et al., 2015; Zigman, 2013). Although people with Down syndrome have been described in different ways before the 1800's, it was in 1866 that John Langdon Down first identified and described the condition clinically (Kazemi et al., 2016). In 1959, full or partial trisomy of chromosome 21 was identified as the genetic cause of Down syndrome (Kazemi et al., 2016). The genetic disorder is in most cases (95%) caused by an extra copy of chromosome 21, although it can manifest as a result of translocation (1%) or mosaicism (4%) (Papavassiliou et al., 2015). Translocation is caused by the attachment of an extra chromosome 21 to another chromosome, whereas mosaicism describes an extra

copy of chromosome 21 appearing in some cells, whilst other cells remain unaffected (Papavassiliou et al., 2015).

Prevalence rates of Down syndrome vary across the world. In the United States, one in every 635 people are born with Down syndrome every year (Mai et al., 2019). However, Ireland has one of the highest rates of Down syndrome in Europe (De Graaf et al., 2021) with the condition occurring in one in every 444 live births (Lagan et al., 2021). Differences in birth rates are influenced by societal and cultural distinctions between populations, such as laws surrounding pregnancy terminations as well as policy or societal norms which impact birth rates in older women (Presson et al., 2013). The most common risk factor for having a baby with Down syndrome is increased maternal age at conception (Coppedè, 2016).

1.1.2 Intellectual functioning across the lifespan

Down syndrome is recognised as the most common genetic cause of intellectual disability (ID), with the condition influencing both cognitive and behavioural functioning across the lifespan (Grieco et al., 2015; Pulsifer, 2021). Individuals with Down syndrome exhibit highly diverse cognitive abilities and can present with profound intellectual disability to borderline/average intellectual functioning (Grieco et al., 2015; Karmiloff-Smith et al., 2016; Roizen, 2012). However, most people with Down syndrome present with a moderate intellectual disability (Bull et al., 2020; Roizen, 2012; Stancliffe et al., 2012; Van Cleve et al., 2006). Whilst the degree of intellectual disability can impact the functioning of individuals with Down syndrome, it is important to acknowledge that other factors also play a role in determining their level of functioning (Grieco et al., 2015). Positive influences such as appropriate school placements, support and interventions received can impact functioning across the lifespan for a person with Down syndrome (McCarron et al., 2017). Similarly, factors which can negatively impact functioning include sensory impairments, endocrine disorders, comorbid conditions such as Autism Spectrum Disorder (ASD), seizures, sleep

disruption, and other medical and psychiatric conditions (McCarron et al., 2017). At various stages of their lives, individuals with Down syndrome can experience unique developmental, behavioural, and cognitive challenges in comparison to other people with ID of other or unknown aetiologies. For example, individuals with Down syndrome can experience increased age-related cognitive decline linked with early onset dementia or more specifically Alzheimer's disease (Bittles & Glasson, 2004; Coppedè, 2016; Pulsifer, 2021; Zigman et al., 2013).

People with Down syndrome have a genetic predisposition to developing dementia relating to Alzheimer's disease due to having three copies, rather than the usual two copies, of the amyloid precursor protein (APP) within their genetic makeup (Hithersay et al., 2017). Furthermore, those with Down syndrome experience accelerated biological ageing in some bodily systems such as the integumentary system, the endocrine system, the sensory system, the musculoskeletal system, the immunological system, and the neurological system (Zigman, 2013). The risk of developing dementia in people with Down syndrome can be 23.4% by age 50, 45% by age 55 and 88% by the age of 65 (McCarron et al., 2017). In general populations, the prevalence rates are much lower. For example, at age 65-74, this rate is roughly 27% and rises to approximately 37% at age 75-84 (Gaugler et al., 2022). In Ireland, the average age for a diagnosis of dementia for a person with Down syndrome is 52.3 years of age in comparison to 65.5 years of age for adults with an intellectual disability of other aetiologies (McCarron et al., 2017).

Ageing and the challenges of adulthood experienced by people with Down syndrome have been increasingly researched within the literature, as people with Down syndrome around the world are living longer and more fulfilled lives (Bittles & Glasson, 2004; McCarron et al., 2017; Santoro et al., 2021). However, little evidence exists for appropriate pharmacological treatment of cognitive impairment and dementia in people with Down syndrome (Lamsal et

al., 2022). This is reported as a significant concern for people with Down syndrome as they progress through adulthood (McCarron et al., 2017).

1.1.3 Cognition

Although a broad profile of abilities will be presented in this section, it is imperative to acknowledge that people with Down syndrome are a heterogeneous population who present with a wide profile of cognitive abilities (Karmiloff-Smith et al., 2016). However, most people with Down syndrome experience some cognitive difficulties (Fidler et al., 2019), with specific deficits in verbal processing skills and relative strengths in non-verbal skills such as visual processing (Godfrey & Lee, 2018; Laws, 2004). Individuals with Down syndrome can present with a relatively specific verbal short-term memory deficit in comparison to typical controls, matched for verbal ability (Jarrold et al., 2002). This is significantly more impaired in people with Down syndrome relative to other groups of people with ID (Kittler et al., 2008). For example, when compared against mental-age matched controls in both verbal and non-verbal abilities, young adults with Down syndrome present with lower scores on tasks such as word and digit recall (Godfrey & Lee, 2018; Raitano-Lee et al., 2010). Nevertheless, verbal abilities do still continue to develop into young adulthood for this population, while non-verbal development continues past this stage (Carr, 2005; Grieco et al., 2015). Visuo-spatial memory is a relative strength in comparison to other memory functions (Laws, 2004). For instance, adolescents with Down syndrome have shown to perform better than other groups with ID in visual memory tasks (Godfrey & Lee, 2018). In a study by Jarrold and colleagues (2002) visual support was also shown to partially alleviate the impact of verbal short-term memory deficits during digit recall tasks for their sample of 19 people with Down syndrome. Lastly, people with Down syndrome can experience general long term memory issues, in comparison to other ID populations (Godfrey & Lee, 2018) and the ability to cognitively inhibit has also been found to be challenging for adolescents with Down syndrome, compared to typically

developing peers (Kristensen et al., 2022). These cognitive challenges, among others, can manifest as difficulties with maintaining attention, long and short-term memory issues such as retrieving, storing, and processing visual and particularly auditory information, and completing tasks of increasing complexity (Grieco et al., 2015; Jarrold et al., 2002). Specifically, this profile with respect to verbal and visual abilities is particularly relevant to the work reported on here, given that verbal and visual short-term memory are reported as predictors of overall reading abilities (Boudreau, 2002), especially reading comprehension in people with Down syndrome (Kalaycı & Diken, 2022). Furthermore, a study by Næss and colleagues (2021) showed that there were significant differences in nonverbal mental ability between six-year-old readers and non-readers with Down syndrome ($n=42$); with those who developed early reading skills showing better nonverbal mental functioning. Therefore, it is important to note the bi-directional impact of reading and cognitive functioning for children with Down syndrome, similar to typical populations (see Hayiou-Thomas et al., 2006).

1.1.4 Language

People with Down syndrome can present as a highly heterogenous group in terms of their language profiles (Abbeduto et al., 2007). Thus, it is imperative to acknowledge variabilities and individual differences in this population. Moreover, individuals with Down syndrome can have language disorders independently and often disproportionately to their intellectual disability (Frizelle et al., 2018). Language profiles of children with Down syndrome have been extensively investigated and reported on throughout the literature (Abbeduto et al., 2007; Burgoyne et al., 2013; Frizelle et al., 2018; Laws & Bishop, 2003). Inconsistencies have been observed across various domains of language in children with Down syndrome, with their expressive language abilities exhibiting more pronounced deficits when compared to their receptive language abilities (Abbeduto et al., 2007; Martin et al., 2009; Roberts et al., 2007). This uneven language profile is characteristic of the syndrome (Cleland et al., 2010). In specific

terms, receptive vocabulary is stronger than receptive syntax ability (Abbeduto et al., 2007; Laws & Bishop, 2003; Martin et al., 2009). With regards to expressive language, difficulties in areas of phonology, grammar and syntax have all been documented (Chapman et al., 1998; Connors et al., 2018; Laws & Bishop, 2003). Intentional uses of gestures and social use of communication in line with mental age, are relative strengths (Onnivello et al., 2022). Although well documented in children with Down syndrome, the language profiles of adolescents and adults have received less attention throughout the literature (Kristensen et al., 2022).

Overall, aspects of receptive and expressive language ability continue to develop (to varying degrees) into early adulthood for people with Down syndrome (Chapman & Hesketh, 2001; Connors et al., 2018). With respect to receptive language, in comparison to their typical peers, progression in understanding complex-syntax is an area of difficulty for young adults with Down syndrome (Chapman, 2006; Loveall & Barton-Hulsey, 2021). However, they show relative stability in development of their single word receptive vocabulary (Connors et al., 2018; Kristensen et al., 2022; Nelson et al., 2001). Life experience appears to positively influence said receptive vocabulary development, as comprehension of event-based or experienced vocabulary has been shown to exceed non-verbal cognitive levels in young adults with Down syndrome (Roberts et al., 2007). However, language development is not immune to age-related cognitive decline (Startin, et al., 2020). For example, in a study of the receptive language of 58 individuals with Down syndrome (aged 4-40), Witczy and Penke (2017) noted a plateau in grammar comprehension abilities in adulthood. Similarly, in a study by Nelson and colleagues (2001), adults with Down syndrome who showed abnormal physical findings on MRI scans and neurological exams showed a significant ($p = 0.0095$) loss in receptive vocabulary over the span of one year.

In adolescence and adulthood, the acquisition and development of expressive language abilities remain a challenge for people with Down syndrome (Martin et al., 2009). Compared

to typical populations of similar mental age, individuals with Down syndrome demonstrate deficits in expressive syntax and morphology (Finestack et al., 2013). For example, a study by Connors et al. (2018) found no significant group improvements in expressive grammar of 42 adolescents with Down syndrome aged 10 to 21 across a two-year longitudinal study. This contrasts with the study by Chapman et al. (2002) where a group of people with Down syndrome ($n=31$) aged 5 to 20 years, improved significantly over 6 years regardless of starting age. Differences in study findings may be as result of the outcome measures used. Specifically, Connors et al. (2018) used a formal narrative sampling technique to elicit grammar samples, whereas Chapman et al. (2002) used a combination of conversational and narrative samples. The Mean Length of Utterances (MLUs) of adolescents with Down syndrome have also been shown to be lower than that for non-verbal-age matched controls with ID of other aetiologies (Laws, 2004). Similarly, Chapman and colleagues (1998) found that children and adolescents with Down syndrome (ages 5-20 years), produced fewer total, and a smaller number of different words during connected speech (conversation and narration) than non-verbal mental age-matched typically developing peers. When matched for non-verbal mental age, a study by Laws and Bishop (2003) showed that the participants with Down syndrome illustrated higher expressive vocabulary than the language disordered group. This suggests that in relation to expressive language, vocabulary was a relative strength for people with Down syndrome in this study. However, this was likely influenced by the participants having a higher chronological age. Expressive vocabulary is in most cases still at a disproportionate level to receptive vocabulary for adolescents and adults (Chapman, 2006; Grieco et al., 2015; Kristensen et al., 2022)

Language is highly relevant in the context of this study. Reading comprehension appears to be impacted by lower levels of linguistic abilities in those with Down syndrome, such as expressive and receptive syntax, vocabulary and narrative comprehension, knowledge

of story grammar, and sentence comprehension (Roch & Levorato, 2009). For example, lower vocabulary levels in people with Down syndrome are linked to poorer reading accuracy skills (see Burgoyne et al., 2012; Hulme et al., 2012). Challenges in these linguistic areas, as well as barriers such as a reduced likelihood to request clarification (Abbeduto et al., 2008), can have negative implications for the development of reading skills. In typical populations, ‘poor reading comprehenders’ exhibit deficits in vocabulary, grammar comprehension and semantic language (Groen et al., 2006). Similarities in the reading ability profiles of children with language disorders and children with Down syndrome have been noted in the literature (Roch et al., 2021). In the same vein, it has been argued that reading may foster language development in children with Down syndrome, as it capitalises on their visual recognition strengths, thus it has been argued that the relationship between language and literacy may be bi-directional (Buckley, 2003; Laws & Gunn, 2002). For example, Laws and Gunn (2002) found that early word reading skills of individuals with Down syndrome significantly correlated with MLU five years later. Hence, the influence of language abilities on reading are important to recognise.

1.1.5 Speech, fluency, and voice

Speech production is another area of communication which is impacted for people with Down syndrome (Abbeduto et al., 2007; Kent et al., 2021). Speech production issues can be influenced by the anatomical and physiological features associated with the syndrome. These features include a smaller oral cavity with average size tongue, a narrow high arched palate and low muscle tone of the tongue and lips (Bunton & Leddy, 2011). This can lead to people with Down syndrome experiencing reduced speed, range of motion and co-ordination of the articulators during speech production. Although issues with speech production are common in the communicative profiles of adults with Down syndrome, adult speech impairments present as heterogenous in nature and range considerably in severity (Kent et al., 2021). All of the speech subsystems inclusive of voice, articulation, phonology, resonance, fluency, prosody and

intelligibility can be impacted (Crisp et al., 2019; Kent et al., 2021). Although speech intelligibility does improve with age (Burgoyne et al., 2021), articulation errors can frequently persist into adulthood (O’Leary et al., 2020) such that the speech profiles of adults with Down syndrome can include imprecise consonants and distorted vowels (Crisp et al., 2019; O’Leary et al., 2020). Speech fluency disorders such as stuttering or cluttering are also common, with prevalence rates higher than in typical populations. While previous studies have reported a range of 15% to 45% (Crisp et al., 2019; Schieve et al., 2009), a more recent systematic review cited the occurrence of stuttering in school aged children and adults with Down syndrome to be approximately 18–25% (see Hokstad & Næss, 2023). However, this review also acknowledged the challenges of recording the true frequency of stuttering in this population; due to co-occurring communication disorders impacting speech samples. So as a result, the differences across the literature may be impacted by these factors. People with Down syndrome also experience difficulties with their voice and rate of speech. Wilson and colleagues (2019) illustrated that in a sample of 50 adolescents with Down syndrome, divided into two groups of high and low intelligibility, both groups presented with a high percentage of utterances (approximately 25%) coded with a ‘Rough’ vocal quality, by the research team. Furthermore, both the high and low intelligibility groups also had significantly low percentages of utterances with appropriate resonance (33.6% and 29.7%, respectively). Speech disorders and delays are also common for both children and adults with Down syndrome (Kent et al., 2021). With respect to phonology, speech development initially follows a phonological pattern similar to that of typical development, but at a later chronological age although, later-developing sounds can be more difficult to acquire (Burgoyne et al., 2021).

Some adults with Down syndrome do have highly intelligible speech and present overall with typical speech attributes (Kent et al., 2021). However, speech intelligibility is not static across the lifespan. As a person with Down syndrome ages, speech can become impaired

by age-related changes in auditory discrimination and less efficient respiratory support; especially in older adults (Grieco et al., 2015). Speech intelligibility in combination with other communication difficulties can also significantly impact the lives of people with Down syndrome, as it can impact friendships and community participation (see Connaghan et al., 2022). With respect to reading, speech development is also relevant. For example, in a study by Burgoyne et al. (2021) the speech sound accuracy of 50 children with Down syndrome (aged 5-10 years) were significantly related to phoneme blending and word reading ability. As a result, speech development can impact the development and progression of reading in people with Down syndrome.

1.1.6 Hearing and Vision

Conductive hearing loss (when sounds are unable to pass from the outer-ear to the inner-ear, often because of a blockage), sensorineural hearing loss (inner-ear damage) or a mix of both, can be found in nearly two-thirds of children with Down syndrome. This can have negative ramifications for communication development (Abbeduto et al., 2007; Martin et al., 2009). Chronic otitis media, which is an inflammatory disease of the middle ear, persists as children with Down syndrome age, with many requiring grommets until middle childhood (Manickam et al., 2016). Children with Down syndrome usually have their hearing levels monitored very closely due to their increased likelihood of experiencing hearing impairment. However, due to reduced services for adults with Down syndrome, hearing check-ups can become less frequent and hearing impairments can be missed (Meuwese-Jongejeugd et al., 2006). Issues with impairments of the auditory system are not limited to childhood and infections within the auditory system persist and can often worsen over the course of adulthood. In a Dutch study of 307 adults with Down syndrome, the most notable causes of hearing impairment for people with Down syndrome were ear infections (36%) and presbycusis (age-related hearing loss) (37%) (van Schrojenstein Lantman-de Valk et al., 1994). In a study of

hearing function in 72 adults with Down syndrome, Picciotti et al. (2017) found that hearing loss was present in 42.86% of the sample in the 20-29 age group, and this increased to 90.91% in the 50-59 age group. Hearing loss can bring many challenges to communication, learning, employment, and socialisation (Graydon et al., 2019). As highlighted in a US study by Porter et al. (2022) hearing loss can negatively impact a person with Down syndrome socially, academically, and interpersonally. However, the relationship between hearing loss and reading ability for people with Down syndrome in adulthood is not clear, as no available literature has investigated it. In the typical population Parault and Williams (2010) compared the reading abilities and habits of 24 deaf or hard of hearing adults to those of 30 hearing participants. Lower reading skills were reported in the deaf or hard of hearing group. Similar trends may exist for people with Down syndrome, depending on the significance of hearing impairment.

People with Down syndrome are better at processing and remembering visual rather than oral information, which is relevant for reading comprehension (Roch & Jarrold, 2008). However, this can be impacted upon by vision deficits which are commonly experienced by people with Down syndrome (Krinsky-McHale et al., 2014). As they can present with optical, oculomotor and neural issues, this can impact spatial and temporal vision. This impacts the ability to recognise spatial forms, patterns, and colours. Reduced spatial vision can impact the ability to read signs, use a smartphone or watch television (Krinsky-McHale et al., 2014). So, as individuals with Down syndrome age and their vision deteriorates, the impact of reduced vision on everyday functioning becomes more prevalent, especially in the context of successful reading. Van Schrojenstein Lantman-de Valk and colleagues (1994) found that between the ages of 50 and 59, visual impairment was present for 46% of the adults with Down syndrome in their study, and by the age of 60 and above, this increased to 85%. They also noted the presence of cataracts to be more common in adults with Down syndrome, when compared to those with ID of other aetiologies (van Schrojenstein Lantman-de Valk et al., 1994). However,

in a more recent American study of 12,381 users of adult intellectual disability services, inclusive of 1,199 people with Down syndrome, no overall difference was found in the proportion of visually impaired people with Down syndrome relative to those with ID from other aetiologies (Stancliffe et al., 2012). Overall, the prevalence of both vision and hearing impairments increases in adults with Down syndrome as they age (Stancliffe et al., 2012), although the level of impairment varies highly between individuals.

1.2 Social, environmental and communication experiences for people with Down syndrome

1.2.1 A history of education for individuals with Down syndrome; Ireland

Given the clear link between education and reading, it is important to give contextual information regarding the education of people with Down syndrome. This is especially relevant in Ireland, as Ireland's government has historically been criticised for a lack of educational inclusion for people with disabilities. This was described by Murphy, Thompson, and colleagues (2023) where the past and present approaches to special educational needs (SEN) in Ireland were investigated, via paper review and stakeholder interviews. The paper revealed present and persistent issues with inclusive education for students with SEN needs. In recent decades, several countries, including Ireland have undergone changes to promote inclusive education for children and young people with Down syndrome (Bills & Mills, 2020; Murphy, Thompson et al., 2023; Travers et al., 2018). Historically, children with disabilities did not attend mainstream school and were placed in segregated settings (Bills & Mills, 2020). Ireland's progression towards inclusive education for those with ID was described by Swan (2000), in three stages 1) the period of neglect and denial; 2) special school implementation; and 3), integration or inclusion. The national education system was established in Ireland in 1831 and during this time, the education of children with ID was not considered necessary, as their needs were viewed as purely medical. Many of these individuals lived in hospitals,

asylums, or residential homes. In the mid-1800s, some religious-run special schools were established throughout Ireland (Flood, 2013). Between 1910 to the late 1990s, the majority of education in Ireland was carried out by religious orders and no government policy or legislation existed regarding the education of those with ID (Flood, 2013). Segregated schools began to emerge throughout the country during this time, which reflected the ideology that those with ID could not be educated alongside their mainstream peers, and to do so would be detrimental to the education of both the individual with ID and the learning of others (Flood, 2013).

1.2.2 Inclusive education; opinions

Inclusive and equitable education is now recognised as a right for students with intellectual disabilities. In the following sections, the advantages of inclusive education for those with ID and specifically Down syndrome will be presented. Although, it is also important to briefly acknowledge the less positive attitudes which exist surrounding educational options for those with ID, which can naturally impact educational outcomes for people with Down syndrome.

In many countries, inclusion of people with ID in mainstream settings is not considered a priority. For example, Jury and colleagues (2021) investigated the attitudes of the general public towards inclusive education in France and found that participant attitudes were the least positive towards students with an ID in comparison to students with autism; with a sensory disability; with specific learning disabilities; or with a motor disability. The benefits of inclusive education have been advocated for throughout the literature and within Irish legislation (Couzens, et al., 2012; Travers et al., 2018). Nevertheless, critiques of its execution also persist in Ireland (Norwich, 2015). Teacher's willingness and attitudes towards teaching children with Down syndrome can be impacted by the level of support provided within the mainstream school settings (Bills & Bradley, 2020; Bird & Buckley, 1999). Furthermore, studies which have explored teachers' perceptions of inclusive education have shown that

many teachers have negative attitudes to inclusive education and lack confidence in teaching children with ID (Moberg et al., 2020; Song, 2016). This undoubtedly will impact the level of academic support and thus, success achieved by people with Down syndrome, especially in areas such as reading attainment. This as a result, highlights the need for continued and increased support staff in mainstream classes for those with special educational needs (Bills & Bradley, 2020).

1.2.3 Mainstream education for those with Down syndrome: current practices

Although some negative opinions do remain surrounding inclusive education, attitudes and actions for inclusive education have been largely positive. International commitments to inclusive education (UNESCO, 1994), parental advocacy for their children to access mainstream education (Kenny et al., 2005), landmark court cases and societal attitude changes have caused new educational policy formations and legislation which have increased inclusion for those with ID (Education for Persons with Special Educational Needs Act, 2004; Travers et al., 2018). A right to education for every person in Ireland was made law by the Education Act in 1998 (Education Act, 1998). The act emphasised inclusivity and equality of access, including provision for persons with disabilities or other special educational needs and sets out the rights of parents to send their children to a school of their choice. Consequently, people with Down syndrome now have rights to inclusive and equitable, quality education. Educational inclusion is defined as “a transformative process that ensures full participation and access to quality learning opportunities for all children, young people and adults, respecting and valuing diversity, and eliminating all forms of discrimination in and through education” (UNESCO, 2019, p. 1). This definition highlights that those with Down syndrome have the right to attend their local educational setting and should be provided with appropriate support so that they can participate in all aspects of learning (Hargreaves et al., 2021). An Individualised Education Plan (IEP) is one way to aid those with disabilities to access education

in a way that is appropriate and individual to the person (Bills & Bradley, 2020). Teachers have expressed how IEPs have broadened the social opportunities for children with Down syndrome by creating occasions for them to engage with their peers during different play activities, group-projects, and classroom exercises. IEPs are recognised and valued in many countries and are underpinned by law in countries such as the USA, Australia, New Zealand, Canada, and the UK. However, there is no current legal requirement to provide an IEP for children with special educational needs, such as children with Down syndrome, in Ireland (NCSE, 2006).

Nevertheless, such educational policy formations, attitude changes and legislation have led to an increase in children and adolescents with Down syndrome accessing quality and equitable, inclusive education (Cunningham et al., 1998; Flood, 2013). For example, a recent study in the United Kingdom cited that 65% of 530 participants with Down syndrome aged between four and 17, attended mainstream educational settings (Hargreaves et al., 2021). This increase is positive. Attending mainstream education for those with Down syndrome has been cited to lead to better educational and social outcomes (Bills & Mills, 2020; Cunningham et al., 1998; Turner et al., 2008). It is now clear that poor academic gains for individuals with Down syndrome can reflect a lack of opportunity to learn, rather than a lack of capacity for learning, particularly with regard to reading (Bochner et al., 2001). Mainstream environments can provide a richer language environment to develop language and communication skills for children with Down syndrome. So much so, that teenagers with Down syndrome who attended mainstream schools have performed better than their peers who attended special school, on standardised measures of receptive and expressive language, as well as literacy and social competence, despite not showing any obvious differences in abilities before starting school (Buckley et al., 2006). Similar conclusions in relation to reading skills were drawn by Bochner and colleagues (2001). In a review by de Graaf et al. (2012), nine of the 12 studies included which investigated language outcomes found that mainstream school placement gave more

favourable language outcomes, in comparison to special school placement for children with Down syndrome. This point is further supported by a longitudinal, Australian study (Couzens et al., 2012) which investigated the environmental characteristics associated with cognitive development in 89 individuals with Down syndrome. The researchers found that students who received an academic programme in a special school or went to a regular mainstream school, scored an average 2.2 or 5.4 points higher on the vocabulary subtest and an average of 3 or 5.6 points on the comprehension subtest of the Stanford-Binet IV assessment. This was compared against a special school population who received a programme which focused on life skills, rather than academics. However, no data was available in this study as to how schooling impacted the everyday reading habits of this sample. So, how this outcome reflects the everyday functional reading of these individuals, is not overtly clear.

1.2.4 Education in adolescence and adulthood

With respect to adolescence, mainstream schooling for those with Down syndrome has had positive impacts on academic attainment, which also extends beyond the school years (Turner et al., 2008). However, towards the end of primary school, there is a trend for students with Down syndrome to move away from mainstream classes and into special educational settings (Kenny et al., 2005). Hargreaves et al. (2021) reported a stark reduction of only 37% of secondary school students with Down syndrome attending mainstream education, in comparison to 80% of primary school students. Furthermore, the number of educational services available to these students, post-secondary school, is lacking across the world (Bertoli et al., 2011). This is something which was also noted in Ireland. Aston et al. (2021) conducted a study in Ireland which investigated the post-school transition period for students with ID. Many individuals involved in supporting students highlighted the lack of appropriate post-secondary-school programmes designed for people with ID.

Buckley et al. (2006) compared the achievements of 46 teenage students with Down syndrome in different school settings in the United Kingdom, 18 of whom attended mainstream schooling and 28 who attended special schools. Those who attended mainstream educational settings achieved better scores in areas of spoken language, behaviour, social development and academic development. Interestingly, the only measure which showed significantly better outcomes for the teenagers in special education were interpersonal relationships. This was measured using parent questionnaires examining socialisation skills in the Sacks & Buckley Questionnaire (SBQ) and Vineland Adaptive Behaviour Scale (VABS). The older teenagers in the special education group were more likely to have a special friend, boyfriend or girlfriend or belong to a club, than in the mainstream group. Although the number of participants in this study was small and further research is needed, these findings suggest that special education may encourage more mutually reciprocal relationships with peers of similar abilities. Further development of integrated education which fosters increased meaningful, interpersonal relationships for those with Down syndrome is needed; so that they can achieve appropriate academic development whilst also developing close personal friendships. In a British longitudinal study completed by Carr (2008), the everyday lives of 54 people with Down syndrome were followed repeatedly from infancy to 21-years old, and again at 30, 35 and 40-years old. Although 20 were lost at follow-up at the end of the study, only nine went to full time further education at ages 30 and 35 and none attended further education courses or colleges at age 40. However, in typical populations in Ireland, roughly 60% of 25–45 year-olds and 35% of 60-64 year-olds have a third level qualification (Central Statistics Office, 2022). This suggests a history of limited opportunities for lifelong learning for people with Down syndrome (Morgan et al., 2006).

However, within the Irish context, the ethos of organisations such as Down Syndrome Ireland towards education has moved to continuous and lifelong learning for people with Down

syndrome. International guidelines for education for those with Down syndrome also support this (see Faragher et al., 2020). In recent years, there has been a move towards increased opportunities for post-secondary school education for people with ID (Whirely et al., 2020). For example, in the United States, there are approximately 312 college programmes available for people with an ID (Think College, 2022). Students who have completed these programmes have experienced higher rates of integrated employment (Grigal et al., 2019). Similarly in 2022, Down Syndrome Ireland (an organisation which provides support for people with Down syndrome and their families), provided over 25 classes to people with Down syndrome (unpublished data, Down Syndrome Ireland). Thus, although there are some suggestions that there is limited access to lifelong learning for people with Down syndrome, more large-scale, international studies are needed to confirm what opportunities are available for adults with Down syndrome who are interested in pursuing further education. The students' opinions on this process should also be obtained in the research. This is especially the case when considering the options for people with ID to attend mainstream universities or colleges.

1.2.4.1 Inclusive education; Impact on reading There are many positive academic and social benefits associated with mainstream education for those with Down syndrome (Bills & Mills, 2020; Cunningham et al., 1998; Turner et al., 2008), specifically reading (Bochner et al., 2001). As reading is an implicit part of accessing the curriculum in mainstream education, it is not surprising that the number of years spent in mainstream education is a predictor of reading ability in children with Down syndrome (de Graaf et al., 2013). In Italy, special classes were abolished by law in 1977 (de Graaf & de Graaf, 2016). In an Italian study by Bertoli et al. (2011), the reading abilities of adults with Down syndrome were described using a questionnaire filled out by those with Down syndrome and their families. In various age groups under 40, between 34% and 52% families indicated that they could 'read easily' 'and between 6% and 24% could not read at all. However, for those above 40 years of age (who attended

school before 1971), the ability to read with ease, dropped to 11%-29% and the percentages of those who could not read at all were higher at 24%-61%. Authors theorised that the increase in reading abilities were a direct consequence of educational inclusion. However, the effects of ageing may also influence reading outcomes and the subjective nature of the questionnaires used in this study also need to be considered. As discussed above, in Buckley et al. (2006), direct comparisons were made between abilities of teenagers with Down syndrome who were educated in mainstream settings versus special schools. The reading and writing abilities of students attending mainstream education were more than three years ahead of those attending special schools. However, although the groups were compared in relation to academic abilities, these findings did not take into account overall levels of cognitive ability.

In later adolescence and adulthood, continued involvement in some form of education and training in post-school contexts can contribute to and maintain positive literacy skills for people with Down syndrome (Brochner et al., 2001; Moni et al., 2018). Different social environments offered by inclusive schools versus segregated settings can influence an individual's overall literacy development, with those who attend integrated settings achieving more functional reading skills to prepare them for vocational work than those who attend segregated schools (Deagle & Amico, 2016). Increased access to integrated education has undoubtedly impacted the reading levels of those with Down syndrome. To what extent this influences the social and functional reading habits of this population, has yet to be investigated. Given Ireland's stance towards inclusive education and increased commitment towards post-secondary school opportunities for individuals with Down syndrome in more recent times, it may be now hypothesised that those living in Ireland may have increased social and academic reading experiences. However, there is no data which investigates how place of residence influences meaningful reading experiences of individuals with Down syndrome, especially in Ireland.

1.2.5 Transitioning into adulthood

Naturally, stronger reading ability can support decision making and levels of independence. These skills become more relevant as a person transitions into adulthood. However, there is little available research in terms of post-school education outcomes for those with Down syndrome (Channell et al., 2022). The transition from school to adult life is reported as an emotional and challenging time for individuals with Down syndrome (as well as people with ID from other aetiologies) and their families (Dyke et al., 2013). For example, when 12 young adults with Down syndrome (aged 18-29) were interviewed about what they considered to be a 'good life', many expressed that despite the need for parental guidance, they wished for greater autonomy and adult recognition, which led to conflict within their homes (Scott et al., 2014). The American National Down Syndrome Society as quoted in Van Cleve et al. (2006), states that people with Down syndrome should be supported to form a transition plan for this period. This plan can be summarised as one which reflects an understanding of the adolescent's personal strengths and interests, any services they may need, connections with community agencies and organisations, access to programmes which support independence in the workplace, as well as any services that the individual will need to achieve their goals for the future. However, there is little available longitudinal data which examines the impact of these plans in areas of participation and wellbeing (Foley et al., 2012).

Following secondary school and well into adulthood, young people with Down syndrome tend to live with their families and remain dependant on family for support and assistance in everyday life (Chanell et al., 2023; Foley, Girdler et al., 2014; Jobling & Cuskelly, 2002). However, adults with Down syndrome can illustrate strengths in independence skills. This was shown in a study by De Graaf et al. (2019) where the authors examined the functional skills of adults with Down syndrome via survey of both American (n=1955) and Dutch (n=669) parents. In the study, 70% of parents reported that their son or daughter with Down syndrome

independently prepared their meals at least ‘somewhat well’ in young adulthood (21- 30 years of age). Furthermore, 70-80% of the adults could take care of their own grooming and self-hygiene ‘reasonably well’. Like typical populations, some literature suggests that levels of independence can continue to develop across adulthood for people with Down syndrome. Krell and colleagues (2021) found that adults with Down syndrome in their 30s and 40s had attained greater levels of independence than the adolescents in their sample. Levels of independence are undoubtedly supported by reading ability which facilitates decision making, communication and integration into the community. However, there is a significant gap in the literature as to how literacy, or more specifically reading, is used to achieve independence for people with Down syndrome. This is concerning given the clear capacity, motivation and potential to develop greater levels of independence in adulthood for people with Down syndrome (Krell et al., 2021; Scott et al., 2014).

1.2.6 Employment

People with Down syndrome do access employment, albeit with varying levels of support. Employment has been linked to increased social supports, opportunities for decision making, reduced negative behaviours, and independence for people with Down syndrome (Foley, Jacoby et al., 2014). In a paper by Friedman and Rizzolo (2018), of the 1341 people with ID (aetiologies not stated) who took part in the study, those who worked in competitive or supported community employment had approximately twice the likelihood of experiencing friendship than those who did not. These benefits have had positive impacts on family members as well. For example, in a paper by Foley, Girdler et al. (2014), families of young people with Down syndrome attending day recreation programs or sheltered employment reported poorer family quality of life outcomes, compared to those in open employment. Thus, the results of this study suggest that for individuals with Down syndrome, being employed in the mainstream workforce results in more positive outcomes on quality-of-life measures. In Chanell and

colleagues' (2023) paper, the employment experiences of 100 people with Down syndrome were investigated via parent survey. The authors reported that tasks completed by the sample in their various jobs included cleaning, food prep, ushering and greeting (collecting tickets), customer service, clerical tasks, product assembly, and stocking. However, accessing paid, appropriate, and mainstream employment can be difficult for people with Down syndrome. It is also important to acknowledge the limitations of proxy reporting for this population. It would have also been useful to investigate the experience of adults with Down syndrome themselves, with respect to employment.

Integrated community employment among all adults with disabilities in 2013 in the USA was at just 18.6 % (Butterworth et al., 2015). In a sample of 1857 adults with Down syndrome served by state departments in the US, only 16% were in paid community employment (Bush & Tassé, 2017). Low employment for people with ID exists within the Irish context also, as only 17.3% of people with ID were employed in 2016 in Ireland (National Disability Authority, 2019). People with Down syndrome can face many obstacles when trying to access mainstream employment. As they can experience language disorders that are disproportionate to their overall level of cognitive functioning, often people with Down syndrome are underestimated in terms of overall intelligence and capability, which can limit their employment opportunities (Kumin & Scheonbrodt, 2016). For example, some research shows that adults with Down syndrome can develop strong computer skills, yet these skills are rarely capitalized on in office or administrative roles (Lazar et al., 2011). Furthermore, opportunities to work profitable hours can be limited. Young adults with Down syndrome have expressed a desire to work more hours in their jobs or in varying sectors (Scott et al., 2014) but they have limited opportunities to do so (Dyke et al., 2013).

Grantley et al. (2000) explored the challenges of employment for parents and individuals with Down syndrome from a quality-of-life perspective. The authors noted that

adults with Down syndrome were able to articulate their wishes and expectations for future employment, although their aspirations differed from their parents in terms of the reason for employment. The people with Down syndrome in that study were more interested in the type of work they would do; such as their role or specific tasks they would have to carry out. However, their parents were more concerned about their son or daughter and their level of satisfaction or independence in the job. Furthermore, when asked about the type of job they would like to get, the parents nominated traditional jobs considered for people with ID whereas the adults with Down syndrome suggested a wider range of employment options. Although the people with Down syndrome in this study could identify what training they needed for employment, only 28% knew where to access it. This study highlights that people with Down syndrome need to be asked directly about what their employment goals are. Once this happens, appropriate information on training and development courses needs to be provided to them in an accessible way; so that they can make more effective and informed decisions towards employment. This training material may rely on written word and thus, reading skills may be needed.

Reading or literacy skills in typical populations are fundamental to people's employment opportunities (Clark & Formby, 2013). Both men and women with poor literacy skills have a reduced likelihood of accessing full-time employment (Clark & Formby, 2013). Individuals who have taken part in adult literacy programmes have also reported perceived improvements in job performance, job progression and job satisfaction (Meadows & Metcalf, 2008). Although not formally evaluated in this study, it can be assumed that the benefits of increased literacy skills and continued skills training would also translate to better employment outcomes for people with Down syndrome. In fact, Rynders and Horrobin (1996) argued that for students with Down syndrome, reading instruction should extend beyond the adolescent years, to enable students to achieve maximum success in areas of employment, daily living,

and recreation. It is evident that individuals with Down syndrome can express their wishes for employment and post school opportunities (Grantley et al., 2000). Literacy is a key skill for many aspects of employment. Consequently, investigations into how to best support individuals with Down syndrome, from a literacy perspective, to gain employment is important; given that employment has an obvious positive influence on quality-of-life outcomes. To do this, literacy targets need to align with the employment goals of the person with Down syndrome; as this will inform meaningful outcomes. The first step in this process is to establish what the person reads, or would read within their employment setting, and if they are motivated to improve their reading to help them get a job. Nevertheless, no data exists on how reading is completed by adults with Down syndrome in employment settings. Similarly, how reading skills translate to employment opportunities for this population is not well researched.

1.2.7 Middle and older adulthood

Quality of life for people with ID is increasingly being considered within the literature (Coppus, 2013). Both life expectancy and quality of living for this population has increased, especially in relation to people with Down syndrome (Bittles & Glasson, 2004; McCarron et al., 2014). Increased life expectancy has impacted the opportunities available to those with Down syndrome as they progress into middle and older adulthood. Ageing is highly influential on the quality of life of individuals with Down syndrome and their families. Overall, older age for people with Down syndrome presents as challenging. Much of the Down syndrome literature in relation to ageing focuses on the degeneration of skills (Sinai et al., 2016); the impact of accelerated ageing on families (Lemoine & Schneider, 2023); medical health (Bayen et al., 2018); and activity in older age (Agiovlasitis et al., 2020; Fleming et al., 2022). Limited literature focuses on the changes in socialisation, leisure, or community engagement of people with Down syndrome as they age, and even less literature has asked adults with Down

syndrome directly about this period of their lives. An exception to this, is a study by Brown et al. (2010). When asked about their life experiences, accounts from six older adults with Down syndrome in that study described the sense of loss and transitional issues associated with getting older. This is likely linked with the losses in cognitive and adaptive functioning as they age (Coppus, 2013), which creates a need for greater support better met by residential services. In a study by Lemoine and Schneider (2023) the perceptions of siblings of those with Down syndrome and their current and anticipated relationships with their ageing brother or sister were examined. Ninety-two percent expressed generally positive relationships with their sibling with Down syndrome, and most expected to have a very good relationship with them in the future. However, they were anxious about their sibling ageing, becoming less independent and dying, about their parents ageing, and about organising their brother or sister with Down syndrome's future life. This study did not indicate how the person with Down syndrome felt about this.

Towards later adulthood, adults aged 50-59 with Down syndrome experience a greater number of referrals than those without Down syndrome, for evaluations and differential diagnosis relating to psychiatric conditions such as dementia and depression (Patti et al., 2005). Older people with Down syndrome also experience a greater number of life events such as relocating and being subjected to changes in their environment, suffering losses and separations, and undergoing medical changes in comparison to those without Down syndrome (Patti et al., 2005). These events can lead to seclusion and isolation.

Given that getting older results in increasing life changes relating to health, housing and socialisation for people with Down syndrome, reading can have a huge influence on wellbeing. For example, in a study by Ramsten et al. (2023) in Sweden, adults with mild to moderate ID (n=11) in residential care homes reported that they used internet communication technologies to look up (read) recipes and food brands, to make dietary changes and make food for themselves. However, older age does impact reading for adults with Down syndrome. Some

literature exists on the leisure-reading of adults with Down syndrome as they age. For example, Carr (2008) examined a cohort of adults with Down syndrome across the lifespan from infancy to 40-years-old. Their parents were interviewed about topics such as health, independence, occupation, leisure activities and social relationships, at various stages across the individual's life. Reading and/or looking through books during leisure time was done by 88% of the adults at 30 years of age, 82% at 35 and 75% at 40. It is evident that reading habits were negatively influenced by increasing age in this sample. However, future work should investigate whether this continues to decrease past 40 years of age. It would be especially relevant to see if changes in reading habits can predict cognitive changes in older years; given that people with Down syndrome are predisposed to premature aging (Zigman et al., 2013). Furthermore, although people with Down syndrome read for general enjoyment (Frizelle et al., 2023), some literature suggests that reading may also serve as a protective factor against cognitive decline. For example, in an Israeli study by Lifshitz and colleagues (2021), the leisure activities of 80 adults with Down syndrome were compared against intelligence scores. The authors found that stimulating leisure activities such as reading mitigated the negative influences of factors such as increasing chronological age, declining health status and functioning in activities of daily living, on intelligence test scores (Lifshitz et al., 2021). From a more functional perspective, reading abilities can also facilitate the transfer of information for people with Down syndrome during the stressful life changes associated with getting older; especially in terms of choice making, understanding residential home policies and schedules, and consent forms relating to medical procedures. However, data which examines what older individuals with Down syndrome read in these residential settings or indeed in older age is limited.

Chapter Two: Reading and Down syndrome

This study does not directly address reading acquisition in adults with Down syndrome or deliver any reading interventions. This study does however address what individuals with Down syndrome read in every-day contexts. It is evident that people with Down syndrome can and do read (Frizelle et al., 2023; Holyfield et al., 2023; Mihaila et al., 2020; Moni et al., 2018). Firstly however, in order to understand reading experiences, reading development needs to be considered. To understand reading development in adults with Down syndrome, it is relevant to address the theoretical mechanisms involved in initially learning to read for this population. Secondly, this chapter aims to present information regarding the relevant interventions for reading acquisition for adults with Down syndrome, whilst highlighting how none of the literature considers how these interventions (although likely, very impactful) use functional and relevant outcome measures; which reflect gains in everyday reading habits for this population. A focus will be given to detailing the movement within the literature towards a more social-cultural attitude for literacy development for adults with Down syndrome.

2.1 Learning to read; people with Down syndrome

A number of papers have detailed the reading abilities of people with Down syndrome (see Frizelle et al., 2023; Puente et al., 2017; Ratz, 2013; Roch et al., 2021), which overall, appear to be heterogeneous. Factors such as cognitive and language ability (as well as environmental circumstances) all influence outcomes (Boudreau, 2002; Couzens et al., 2012; Kalaycı & Diken, 2022; Næss et al., 2021). Some individuals present as strong readers whereas others may have very limited literacy skills. For example, in one paper by Ratz (2013), teachers reported that out of 49 youths with Down syndrome (> 16), 11.3% of the students did not read at all (as measured by teacher report), 17.2% read at a logographic stage, 42.8% at an alphabetic and 28.8% at an orthographic level. The authors also reported a strong correlation of increased level of ID and lower reading level ($r = -0.434$; $p < 0.01$). However, it is important to note the

limitations of teacher questionnaires. Perhaps the teachers did not consider reading outside of the classroom, or whether the individuals were reading functionally out in their communities. Furthermore, no information was asked directly from the students themselves. Nevertheless, it is evident that a large portion of people with Down syndrome can and do learn to read via the same mechanisms as typical populations, but further research is needed which also considers how they read meaningfully outside of academic settings alone.

2.1.1 Simple View of Reading

There are varying theories and views on the exact mechanisms or stages of learning to read in children, one of which is the Simple View of Reading (Gough & Tunmer, 1986; Hoover & Gough, 1990). This cognitive theory of reading proposes that reading comprehension is a product of two distinct components; word recognition (decoding ability) and language comprehension (Loveall & Connors, 2016; Roch & Levorato, 2009). Decoding describes the ability to translate a word from print to speech using knowledge of sound symbols. Language comprehension is based on one's language skills. At different stages of development, the two components have differing levels of influence. For example, reading comprehension is more influenced by word recognition (decoding ability) in the early stages of reading acquisition. However, in middle childhood, language comprehension is more influential on comprehension success (Roch & Levorato, 2009).

Word recognition or decoding ability is influenced by two main subcomponents: phonological abilities and orthographic knowledge (Loveall & Connors, 2016). In typical populations, skills like phonological awareness (PA) make huge contributions to decoding ability. PA is a verbal language skill and is considered highly influential in reading development in both children and adults (Browder et al., 2009; Kalaycı & Diken, 2022; Tighe & Binder, 2015). It is a skill which nurtures an ability to separate words into their sounds. People who acquire this skill can achieve reading abilities more quickly (Kalaycı & Diken,

2022). PA has been shown to be more influential on reading development than vocabulary, listening comprehension or cognitive level (Boudreau, 2002; Melby-Lervåg et al., 2012; Næss, 2016). Its relationship with reading is also bidirectional; improving as reading improves whilst also being a prerequisite for reading skills (Boudreau, 2002). Orthographic knowledge refers to a person's ability to identify letter positions, combinations and sequences which make a word. Language comprehension is also considered highly impactful to reading comprehension success. This means that how a person understands things like vocabulary, syntax and morphology influences how well they can comprehend information through reading. Expressive language can also influence this too (Hessling & Brimo, 2019). Thus, language knowledge and exposure are highly relevant for the development of reading comprehension.

2.1.2 Simple View of Reading; Down syndrome

2.1.2.1 Word recognition: Across the literature, theories have been developed which suggest that reading comprehension is achieved differently by individuals with Down syndrome than those in typical populations, in terms of word recognition (Fajardo et al., 2014; Loveall & Connors, 2016). The literature suggests that individuals with Down syndrome rely less on the phonological component of word recognition when achieving reading comprehension. This has been shown in studies as individuals with Down syndrome illustrate relative strengths in word recognition (Groen et al., 2006; Martin et al., 2009; Prahll & Schuele, 2022; Rickett, 2011; Roch et al., 2021; Roch & Levorato, 2009), whilst showing weaknesses in non-word reading. Furthermore, children with Down syndrome are stronger with word specific orthographic knowledge than general orthographic knowledge (Loveall & Connors, 2016). This is likely influenced by visual memory strengths (Boudreau, 2002), and phonological weaknesses in the language profiles of those with Down syndrome (Næss, 2016; Robles-Bello et al., 2020).

However, this is not to say that phonological skills have no impact. In a paper by Kalaycı and Diken (2022), the reading skills of 44 Turkish individuals with Down syndrome aged between seven and 30 years of age were examined. When controlling for age, the authors found a strong positive relationship between phonological awareness skills and success on tasks relating to fluent reading and reading comprehension. This suggests that phonological skills do impact reading success in people with Down syndrome. However, authors also cited the need for further investigation into the influence of poor verbal short-term memory and verbal working memory on reading comprehension for this sample. What is suggested however, is that perhaps word recognition skills are less strongly supported by phonological skills in the profiles of those with Down syndrome, than they are in typical populations. Essentially, it is theorised that people with Down syndrome rely more on the visual route during reading, rather than the phonological route (Muscat & Grech, 2023).

2.1.2.2 Language Comprehension: Language comprehension is also impactful on reading comprehension for people with Down syndrome. As both language and reading comprehension involve complex cognitive, linguistic and meta-linguistic skills, reading comprehension can be vulnerable to breakdowns for someone with language comprehension difficulties (Laws et al., 2016; Prahll & Schuele, 2022). For example, language skills have been shown to be more influential than cognition on reading comprehension success in children and adolescents with Down syndrome (Roch et al., 2021). In an American study by Lovell et al. (2023) the reading skills of 21 adolescents and adults with Down syndrome aged 16-36 were assessed. The authors investigated the influence of skills in word recognition, phonological decoding, and language comprehension, to reading comprehension outcomes. Language comprehension emerged as the only significant predictor. Fortunately, language ability continues to develop into early adulthood for people with Down syndrome (Moni et al., 2000;

Roch et al., 2021). This suggests that people with Down syndrome can continue to develop their reading skills well past childhood.

In summary, typically those with Down syndrome can present as ‘good readers’ as they have strong word recognition skills, but in actuality exhibit difficulties in comprehending what they have read due to language processing difficulties (Groen et al., 2006; Roch & Levorato, 2009). Thus, people with Down syndrome can present with an uneven profile in terms of their reading skills; they decode better than they understand. This has implications for real life settings as a person with Down syndrome may appear to have read relevant information for functioning, safety or pleasure, but may not have truly comprehended or processed what they have read (Morgan et al., 2013).

2.1.3 Other influences on reading comprehension

The Simple View of Reading is only one cognitive theory of reading development. It does not consider the impact of social, economic, cultural, or environmental factors on reading development. These aspects are hugely relevant when presenting reading related information on people with Down syndrome. For example, when reading, words need to be recognised and contextual background information then needs to be applied and integrated, inferences are then made, as well as synthesising and generalising the information presented (Kalaycı & Diken, 2022). Naturally, a person’s life experience will influence the ability to infer information or consider background information. If a person has experienced a variety of rich, community literacy experiences, they may have a greater ability to recognise and thus remember words seen in their environment. They then may have a greater ability to apply said contextual information to texts; which can facilitate comprehension. However, inferring information when reading can be an area of weakness for those with ID (Whitbread et al., 2021). In their single case study of a hyperlexic eight-year-old-girl with Down syndrome, Groen et al. (2006) theorised that the reading comprehension skills of their participant were limited to literal

information. Her retention of literal information was age appropriate but her understanding of inferred information explained her lower reading comprehension score. Authors hypothesised that interventions for real-world knowledge to generate inferences may be a useful strategy for this type of comprehension profile. However, unless direct measures are used which investigate the individual community reading experiences for people with Down syndrome, how influential inferential ability is, is not clear.

Environmental factors will further influence developmental reading opportunities for any population, inclusive of those with Down syndrome. When considered from a holistic perspective, reading development can be influenced by a variety of factors such as encouragement and support. The term ‘home learning environment’ describes the opportunities provided by a parent to support their child’s overall academic success (Tolmie & Jo, 2021). It describes the availability of resources that promote learning, a child’s participation in the learning activities, and parental attitudes towards learning. Home learning environments have been proven to be highly influential in typical populations on the development of a child’s literacy skills. Adults with Down syndrome live at home for longer than the general population (Channell et al., 2023; Foley, Girdler et al., 2014; Jobling & Cuskelly, 2002) and therefore, the home learning environment continues to be relevant in adulthood with regard to literacy opportunities for people with Down syndrome. For example, parents who engage in activities themselves tend to promote or encourage similar participation for their children with disabilities (Murphy & Carbone, 2008). If a person is not encouraged to reach their full potential as a reader; views themselves as a poor reader; is not supported to see the value in reading; or is not encouraged to read the texts around them, their opportunities to develop their reading skills can then be decreased.

Naturally, this construct is one that is influenced by socio-economic factors such as parental availability and educational access. As already discussed, school placement type has

an influence on academic attainment for this population. However, so do social advantages such as maternal access to higher education (Couzens et al., 2012; Turner et al., 2008). In all populations, poverty is a major risk factor for poor cognitive outcomes (Couzens et al., 2012). Access to mainstream educational settings can often be influenced by where an individual lives and effective parental advocacy for appropriate school placements. Data from an Australian study indicated that higher maternal education positively influenced school placement decisions (see Couzens et al., 2012). It is important to acknowledge the reach of socio-economic influences which can span far beyond that of the home learning environment. Although, it is not clear how these factors influence the number of every-day reading experiences people with Down syndrome have, as no available literature has investigated it.

To summarise, research has increased regarding the developmental issues concerning language and communication, social, sensory, emotional and motor growth in people with Down syndrome. Limited research however has examined the social-cultural reading habits of this population, especially in terms of meaningful reading such as community reading experiences or personal reading experiences, like reading a favourite novel. This is likely linked to previous underestimations of the reading abilities of people with ID (Boudreau, 2002; Browder et al., 2009; Prahll & Schuele, 2022). It is accepted now that those with Down syndrome can learn to read. This is supported within the literature. For example, in de Graff et al. (2019), the parents of 2,658 people with Down syndrome described how by 31 years of age, 49% were reading ‘reasonably well’, and 46% were writing ‘reasonably well’. However, this process of acquiring reading skills is less automatic than in typical populations, especially in areas of reading comprehension (Boudreau, 2002; Di Blasi et al., 2018; Moni & Jobling, 2001; Nash & Heath, 2011; Prahll & Schuele, 2022; Roch et al., 2021). As a result, adults with Down syndrome may need support to reach their full reading potential. However, with respect to

accessing interventions and progressing in their reading, considerations need to be given to the socio-economic / cultural supports and barriers adults with Down syndrome may encounter.

2.2 Reading interventions for people with Down syndrome

2.2.1 The need for reading intervention for adults with Down syndrome

Increasingly, people with Down syndrome are seeking employment, recreational activities, education and social interactions which are suited to their needs and communication profiles. Seventy-seven percent of countries around the world have now addressed intellectual disability in a specific education policy or programme (Reichow et al., 2019). However, reading difficulty has been reported as the most common secondary condition that causes significant limitations for those with ID (Reichow et al., 2019). It is clear that reading influences everyday functioning for people with Down syndrome. Parents and family members of people with ID are aware of this also, as stated in a study by Wakeman et al. (2021). These factors, along with increased access to education for those with Down syndrome has led to an increased need for effective and meaningful reading interventions for this population. Although, if reading outcome measures which are sensitive to change and personally relevant are not used, how impactful the reading intervention is from a holistic perspective, is not clear. Relevant approaches to reading interventions for adults with Down syndrome will now be presented.

2.2.2 Functional approach

A common approach historically, for teaching reading skills to those with ID (Morgan et al., 2004; Reichow et al., 2019) and more specifically to those with Down syndrome (Groen et al., 2006), is the sight word or whole word approach (Allor et al., 2010; Burgoyne et al., 2012; Burgoyne et al., 2013). This approach is based on learning words which are functional to daily life, for the person with Down syndrome. This approach to reading instruction focuses on memorising and recognising the visual appearance of whole words, without breaking down

the word into its phonemic segments. Sight word approaches can be successful at teaching functional word recognition and building confidence around learning to read (Randel et al., 2015). This approach involves selecting words on the basis of their functional use, such as health information or vocabulary relating to grocery shopping. Printed words are often presented with a visual support to facilitate learning. This approach capitalises on the visual memory strengths and word recognition skills of those with Down syndrome (Goetz et al., 2008). It has previously been exclusively used for those with ID in comparison to phonics-based approaches. This was possibly due to a mis-founded presumption that teaching those with ID how to read through the relationship of phonemes and graphemes would be too cognitively taxing (Randel et al., 2015; Reichow et al., 2019). However, there is now an understanding that the sight word approach can be beneficial in the early stages of learning to read but eventually, a gradual incorporation of phonics-based approaches should be implemented; as a sight word approach gives only a limited understanding of how the writing system represents spoken language (Goetz et al., 2008; Lemons et al., 2017). By not addressing phonological decoding skills, it limits the individual's ability to become an independent reader (Burgoyne et al., 2012; Lemons et al., 2016).

2.2.3 Traditional, phonological approach

In more recent times, the literature has begun to explore a phonics-based approach to learning to read within the ID population (Allor et al., 2010). This approach focuses on creating awareness of the speech sounds that letters and letter combinations represent, in order to move from a printed word to a spoken word (reading). It is used in typical populations, with empirical evidence supporting its use to teach children how to read (Reichow et al., 2019). This approach ensures that the person can independently read words, and not just rely on sight-words. Using this approach is consistent with the literature which suggests that those with ID can learn to read using the same evidence-based strategies used for other readers (Allor et al., 2010;

Browder et al., 2013; Burgoyne et al., 2012; Goetz et al., 2008). Overall, the consensus within the literature is that phonological awareness or phonics-based approaches are suitable approaches to teach children with Down syndrome reading skills (Goetz et al., 2008), with increasingly more studies citing its efficacy (Burgoyne et al., 2013). However, those with ID can experience difficulties with generalising concepts learned in controlled environments, such as school or reading programmes, to outside contexts (Allor et al., 2010; Whitebread et al., 2021). So often, strategies used in educational settings need to be consistently reinforced into other contexts, which can require more time. With respect to students with Down syndrome, allowing this time and process is something that needs to be considered.

As education progresses, literacy goals for people with ID focus more on functional goals such as sight words in activities like grocery shopping. By secondary school, functional activities take priority with little time spent on phonemic instruction for learning how to read (Browder et al., 2009). However, later adolescence or young adulthood has been suggested as the optimal time to focus on this for students with Down syndrome (Browder et al., 2009). In a review by Reichow et al. (2019) which examined beginning reading interventions that target initial acquisition of reading skills for adolescents with ID, authors found integrating phonological awareness and phonics into beginning reading instruction was appropriate for many students with ID. Overall this review cited moderate evidence that phonological approaches towards reading interventions work in outcomes such as word reading, decoding skills, oral reading fluency, and language skills in children and adolescents with ID. Using a phonological decoding approach, gains in single word reading have even been reported for individuals with Down syndrome with extremely limited functional speech. For example in Holyfield et al. (2023), one adult (aged 27), one adolescent (aged 15) and one child (aged 11) with Down syndrome who used Augmented Alternative Communication (AAC) made positive but variable gains in single novel word reading tasks, following intensive reading interventions.

However, neither of these studies addressed whether these newfound gains also reflected gains in community reading experiences or self-perceptions of the participants as readers.

Providing adults with Down syndrome reading instruction which focuses on decoding skills allows them to become more fluent and independent readers, as they aren't solely relying on learnt off sight words for reading. Interventions which also focus on phonics and vocabulary to promote fluency are important because fluency is a bridge that connects decoding to comprehension (Wakeman et al., 2021). Developing said reading skills can bring about better daily functioning for individuals with Down syndrome. Furthermore, becoming an independent reader can ensure that those with ID can progress through years in mainstream school and not be held back by underdeveloped literacy skills (Wakeman et al., 2021).

2.2.4 Meaningful or social-cultural reading approaches

It has been established that young adults with Down syndrome can learn to read but their abilities can vary (Bochner et al., 2001). Thus, approaches to reading for adults with Down syndrome have been developed which focus on increasing reading skills which are also meaningful to the individual and specific to ability, rather than only vocabulary, decoding or word recognition targets. Similar approaches to literacy interventions have also been carried out in typical populations (e.g., Lawrence, 2009). This approach to reading instruction is known as a social-cultural or meaningful approach. It is one that considers both the literacy environment and the social factors of the person's life. People with Down syndrome are reading, speaking, listening to, and viewing text in multiple contexts (e.g., videos, social media, popular culture, as well as functional texts such as safety signs and documents for daily living, education, employment and choice making) (Frizelle et al., 2023). As a result, their reading skills need to enable them to access these texts.

The social-cultural perspective towards literacy instruction is one that takes a holistic approach and draws on a wide range of intervention strategies in literacy-rich environments

(Van Kraayenoord et al., 2001). These literacy-rich environments can be daily functioning tasks such as ordering an item via a menu, reading instructions on a map, or reading a script for a play. Essentially, these are opportunities for reading or literacy development and the goals set are meaningful to the individual person. This approach defines reading and writing as a social practice which develops through meaningful interactions with one's environment (Warschauer, 1997). This mode of delivering literacy intervention is consistent with the ideas of Bochner et al. (2001) who argued that literacy intervention should be considerate of the social aspects of literacy. Interventions such as these encourage shared discussions about texts, brainstorming and scaffolding as well as guiding critical thinking, challenging of perspectives and engaging metacognition (Van Kraayenoord et al., 2001). It acknowledges that a person engages in literacy activities within their communities for meaningful reasons and for genuine outcomes and as a result, produces goals which are relevant to the individual's life (Moni & Jobling, 2001).

In Canada, Deagle and Amico (2016), conducted a literacy intervention which used a social-cultural literacy approach. The intervention was given to six people with developmental disabilities, three of whom had Down syndrome. The group who were aged between 23 and 46 years of age, contained functional readers, fluent readers and non-readers. The authors defined baseline reading ability in the context of familiarity with key print materials. Familiarity with various media in this case was considered analogous to proficiency with their usage. In simple terms, the more familiarity with print-based mediums, the more likely the person was considered a 'fluent reader' at baseline. This baseline information was provided by both the participant and a family member, which adds validity to their baseline measure. This was done to reduce levels of anxiety that can be experienced when doing formal literacy assessments. It also aligns with a more nuanced and meaningful approach to readers with Down syndrome.

The programme itself focused on providing opportunities for participants to read and write for social reasons (Deagle & Amico, 2016). During the first semester, facilitators of the group initially read favourite texts aloud, and encouraged participants to comment. This was done to habituate participants to eventually do this with their own texts. Following this, the participants were invited to present a short informal talk on a topic of interest, which would then be discussed by the group. At the end of this initial period, participants were given writing journals, and instructions as how to write in them in response to texts presented by others. As the weeks moved on, each session encouraged discussions about the community reading experiences group members had had that week, followed by a chance for a group member to present a text they were interested in. Presentations were tailored to the participant's skill level. After said presentations, as the participants gained skills, they were asked to provide written responses in their writing journals. The presenter was then asked to reflect on the process of presenting their favourite text. The second semester then focused more on creative writing. Throughout this programme the participants also received individualised reading instruction. This was tailored to specific issues each person was having with reading, such as reading a certain word or comprehending a certain text.

The journals kept by the participants over the course of the intervention were analysed using content analysis. This along with the participants' own self-assessments of their literacy development gave the emergent themes. Key themes described by the individuals during these discussions and writing sessions were the concept of independence and autonomy over one's own life. The facilitators of this project did report perceived gains in literacy skills, although an objective measure was not used. Similarly, no data was given with respect to increased community reading experiences. However, what is perhaps more relevant is how the participants perceived themselves as readers. Two participants who were described as a non-reader and a functional reader, felt that they learned how to read. Another non-reader expressed

that he learned that ‘reading is good’ and that he could now ask for help with it. Five out of six participants felt that reading and writing on a regular basis helped them be more independent. Although limited by a small sample size, this study illustrated how literacy programmes based on socially oriented tasks can improve the lives of those with Down syndrome (Deagle & Amico, 2016). The results are promising, however, this study did not investigate if this intervention increased the range of items the students read out in their communities. These aspects of reading interventions for adults with Down syndrome can often be overlooked and highlight the need for appropriate outcome measures in the context of social-cultural literacy.

A meaningful approach to literacy instruction was developed recently by Prahll and Gilson (2023) in the United States. They developed an intervention programme in response to a growing concern that students with ID were experiencing difficulties applying their previous reading academic skills to functional reading tasks such as reading emails or text messages. As a result, they created an intervention programme for students with ID who were accessing post-secondary school education. Although the authors labelled their intervention as a ‘functional literacy’ approach, many aspects of the intervention aligned with a meaningful or social-cultural approach. The authors used personally relevant and meaningful literacy goals for their students, considered literacy from a variety of perspectives such as employment or for social and academic reasons, and considered the social validity of the intervention. Instead of focusing on specific outcomes relating to reading comprehension, the team instead focused on the number of comprehension strategies each participant implemented independently. The comprehension strategies included suggestions like repeating out loud, visualisation of the events in a text, or comprehension monitoring. Four participants aged 20 to 23, with functional literacy needs participated in this study. The students had to have at least a 1st grade single word reading level, sustained attention skills and an ability to perform on the dependent variable probe which required an oral think-aloud of the reading strategies. The intervention

focused on functional literacy tasks using the employment, social and academic stimuli. The intervention was completed and then the comprehension strategies were assessed via a probe task at a generalisation and maintenance session. Three participants demonstrated improvements in the percentage of reading comprehension strategies implemented accurately following introduction of the intervention, and all four students maintained some level of skills post-intervention. Furthermore, the study illustrated high social validity as all students gave positive feedback regarding their experience. However, no outcome was used to investigate whether these comprehension strategies impacted or increased the number of things the person read post intervention. This paper does however highlight that meaningful literacy tasks which focus on building independence as a reader can be very valuable to people with ID, especially when goals are personally relevant to the student.

2.2.4.1 LATCH-ON (Literacy and Technology Hands On): LATCH-ON is a literacy instruction programme which also aims to align with the social-cultural model of literacy. It allows people with Down syndrome to avail of literacy instruction after leaving school and throughout adulthood, whilst focusing on relevant and socially meaningful goals. It was developed by Moni et al. (2000) in Queensland Australia. This programme encompasses functional, social and cultural literacy goals led by effective teaching approaches. The focus of this course is on delivering evidence-based literacy interventions which provide adults with Down syndrome an opportunity to develop their literacy skills in their classroom and community. The intervention gives priority to improving literacy-based confidence, independence and enhanced employment skills. This programme is especially relevant for this project given how in 2022, 106 students in 12 different classes accessed the LATCH-ON programme in Ireland (unpublished data, Down Syndrome Ireland). Moni and Jobling (2001) described this model of intervention as a two-year programme which spanned across four modules. The first module was titled ‘exploring my world’. This module focused on teaching

confidence around the member's ability to speak, read and write about familiar topics, build vocabulary around these topics, and introduce the use of technology such as email. In module 2, 'reaching out to the world; popular culture', members were encouraged to use the internet to look beyond their immediate past literacy experiences. Reading and writing in review and report formats were taught at this point. Following this, module 3 'reading the world', focused on developing the student's reading skills in their community. Goals such as how to access helpful information on the internet, reading newspapers, writing about societal and community issues important to them, were targeted at this point. Finally, module 4 'taking on the world' was implemented. This module focused on goals for the future of the students; such as engaging in community texts, accessing community information via technology, interviews and public speaking. When using this programme Moni and Jobling (2001) acknowledged the lack of appropriate outcome measure available to reflect gains in meaningful reading in their earliest cohort of six people with Down syndrome. However, reading ability did increase for the group, by an average mean of over three years. No control or comparison group was used. Accuracy increased by a mean of 14.4 months. Increases in mean gains of 8.8 months in reading comprehension were also noted. Similar findings were also reported for the other cohorts. For example, when examining longitudinal data from these programmes, Moni and colleagues (2018) found that when taking individual participant differences into account, improvements in receptive vocabulary, word reading, and reading comprehension were observed.

Both papers by Moni and Jobling (2001) and Deagle and Amico (2016) highlighted how motivation and a social approach facilitates engagement in reading. For example, texts used in interventions have to be age appropriate, whilst still respecting the abilities of the reader with Down syndrome. This can be difficult given that an adult with Down syndrome's reading interests may not always be accessible in their reading level (Morgan, 2005). Although, to ascertain what these motivating texts are, and what reading outcomes are personally

meaningful to an individual with Down syndrome, researchers need to ask the reader directly. In order to prove meaningful change for the individual, meaningful reading outcome measures, both at baseline and following reading intervention, need to be used. As already stated, the lack of such outcome measures was highlighted by Moni and Jobling (2001) and is evident throughout the presented literature. No study has investigated whether reading interventions reflected an increase in community reading, personal reading, functional reading or changes in reading habits in adults with Down syndrome.

In conclusion, there has been a growing understanding that adult literacy goals should encompass the interests, functioning, social and environmental aspects of the individual, not just what they will need to survive in tasks of everyday living (Deagle & Amico, 2016; Morgan et al., 2006). Individuals with Down syndrome engage with a variety of literacy or reading experiences in their everyday lives that go beyond basic functioning (Morgan et al., 2013). The context specific nature of defining literacy has been highlighted increasingly in recent years (Morgan et al., 2013). Following the creation of an American National Adult Literacy Survey, Kirsch (1993) defined literacy as "using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential" (p. 1). This definition is individually focused, and advocates that each person's community and cultural context is taken into consideration. Unlike many of the traditional definitions of functional literacy (where functioning is only considered from survival perspective), it considers the broad range of skills that adults use to accomplish different literacy tasks they may face in their home, work and community contexts, for meaningful reasons. This should be acknowledged when addressing the reading skills of adults with Down syndrome in research. Acknowledging meaningful reading from a social perspective which considers a multitude of contexts (Morgan et al., 2013) encourages future research to use a social model towards literacy interventions and outcome

measures. This in turn creates a model for literacy goals for those with Down syndrome which are truly functional and consider the individual.

2.2.5 Considerations and barriers to adult reading interventions

Literacy approaches which foster the development of reading skills in adults with Down syndrome have improved. However, there are still areas which need to be further tailored with respect to the controls used in studies, lack of social and environmental considerations and appropriate outcome measures used for adults with Down syndrome. Many studies which investigate reading in adults with Down syndrome compare participants to ability-matched controls in areas of cognition, word reading or language, who are often children. Although research on childhood reading development can inform intervention strategies for adults, children and adults naturally differ in how they experience reading. Differences in reading experiences include degree of exposure to printed words, life experiences, language experience and cognitive functioning (Tighe & Binder, 2015). As a result, adults with low literacy skills can outperform children matched for reading achievement, in word recognition tasks requiring orthographic knowledge (Tighe & Binder, 2015). The argument of how effective these participants are as true controls due to a lack of exposure to literacy materials needs to be recognised in all populations.

Furthermore, in typical populations, there are barriers which impact effective literacy acquisition. These include learning disabilities such as dyslexia, mental health difficulties, or socio-economic factors such as lack of support from educational instructors, and ineffective support at home and within educational settings (Goodacre & Sumner, 2021). Socio-economic factors are given serious consideration in typical populations with respect to literacy acquisition in adulthood. However, a lesser focus has been given to such considerations for adults with Down syndrome. Consequently, an effective reading intervention for adult populations needs to be socially supportive, engaging, flexible, compassionate and consider the life experience

and wishes of its participants (Goodacre & Sumner, 2021). Effective interventions for adults with Down syndrome need to also incorporate these principles. However, no adult reading intervention study has used outcome measures which are sensitive or reflective of gains made in real life reading tasks nor do they consider how their reading gains directly impact quality of life outcomes such as socialisation or employment.

Chapter Three – The need for this study

As has been highlighted in the previous chapter, reading interventions do not always use outcome measures which reflect gains that are personally meaningful or relevant for adults with Down syndrome. Interventions which focus on decoding, word recognition or comprehension have not investigated the direct impact they have on functional or personally meaningful situations for individuals with Down syndrome. This chapter aims to synthesize the literature relating to community, social and personal reading activities experienced by people with Down syndrome every day, and the need for reading skills to maximise participation in both online and real-world contexts. This chapter will also detail how few outcome measures used within the literature reflect community or real-world reading changes by individuals with Down syndrome.

3.1 Inclusion in the modern world; the need for reading skills

As a result of technological advancements in modern society, the dependence on written word and thus, reading skills has increased vastly. Reading culture has changed in that people across the world are spending more free time on social media and using the internet as opposed to reading a book (Dukper et al., 2018). This is largely due to the increased use and dependency on internet-based technologies and communication devices. Computer-based technologies, phone applications and IT skills have been integrated into people's everyday lives. Consequently, reading skills are imperative to navigating everyday situations, as well as functioning online, and in the real world. In typical populations, increased levels of social media and internet usage in adolescents have been reported throughout the literature (Castellacci & Schwabe, 2018). For example, Monacis and colleagues (2017) reported high internet usage in large samples ($n = 712$) of typical young people ($M = 21.63$). In their Croatian study of 132 typical students, between the ages of 13 and 19, Müller (2021) reported that 40 respondents (30.3%) spent up to one hour a day on a computer and 19 respondents (14.4%)

said they spent 4-6 hours a day. Decreased intensity of internet usage is also associated with getting older in typical populations (Castellacci & Schwabe, 2018). It may be hypothesised that these trends towards internet usage and age will be the same for those with Down syndrome. However, there is limited literature investigating how factors such as age influences access to online information and communities, specifically with reference to the Down syndrome population.

Individuals with ID are increasingly using social media and the web (Ramsten et al., 2020; White & Forrester-Jones, 2020). Websites have been designed with people with Down syndrome to facilitate easier web browsing (Alonso-Virgós et al., 2018; Kirijian & Myers, 2007), and staff in adult ID services have reported the benefits of using the internet to facilitate service-users to practice reading comprehension (Löfgren-Mårtenson, 2008). In a US study of 561 children and young people with Down syndrome, Feng et al. (2008) reported that 405 participants had started using computers at age three. In terms of software applications, individuals in the study used educational software, computer games and the web. Email was used, but to a lesser extent. This may have been influenced by the young age of the sample ($M = 11.09$). In a study on the meaningful reading habits of people with Down syndrome, Frizelle and colleagues (2023) reported that in their sample of 33 people with Down syndrome, 29 read text messages, 21 read emails and 28 read the titles of YouTube videos. Similarly, in a Japanese study by Takataya and colleagues (2022) six of the 11 individuals included reported that they spent much of their free time watching television; one reported that they played video games and two reported that they watched YouTube. Other studies have shown that people with Down syndrome play video games, both for enjoyment and educational use, as reported by their parents (Prena & Sherry, 2018). These activities require reading to navigate search bars, TV channels, YouTube video titles and TV menu screens. It is evident that people with Down syndrome are accessing the modern-technological world. However, less literature investigates

the barriers and supportive factors which influence this engagement; such as whether people with Down syndrome use reading skills to access these technologies.

A paper by González-Ferreras et al. (2017) did notice that reduced literacy skills acted as a barrier for people with Down syndrome with respect to using technology. For example, when authors examined the experiences of teenagers with Down syndrome's use of an educational computer game to improve speech intelligibility, users faced difficulties with comprehension of written messages in the interface of the game. The wider literature relating to general ID has reported that there may be a 'technology gap' between typical populations and those with ID (Ramsten et al., 2020). This may be influenced by the challenges that using internet technologies pose, in that reading skills are needed for successful use (Ramsten et al., 2020). Reading skills may facilitate better or easier access to online content, given how much of it relies on the written word. However, with respect to people with Down syndrome, no literature has investigated how reading is completed in order to access online platforms such as social media, web browsing or general internet usage.

In the last two decades, greater attention has been given towards social inclusion and community participation for adults with ID. Social relationships such as friendships have many positive influences on the quality of life of individuals with ID in the areas of emotional well-being and mental health outcomes (Friedman & Rizzolo, 2018). Social media has been posited as a useful tool in developing social relationships (Löfgren-Mårtenson, 2008), and reducing the disparity of accessing information and communication technologies for many people with ID. For example, in a study of social networks and social media usage by teenagers with ID aged 14-16 (n=18), a moderate positive relationship was observed between the percentage of contacts that the person interacted with using social media, and the number of reported friends they had (White & Forrester-Jones, 2020). Further explorations of this in older populations are needed, especially following transitions from secondary school to adulthood, which has been

noted as a time of reduced social contact for those with Down syndrome (Channell et al., 2022). In a systematic review of the social media usage of adults with ID, Caton and Chapman (2016) found that out of 10 papers reviewed, eight described how social media gave individuals with ID opportunities to express social identity and voice opinions. The theme of new friendships and maintaining friendships, and how social media was enjoyable for the individuals were described in six papers. In a Swedish study by Ramsten et al. (2020), the use of internet communication technologies by 11 individuals with ID (mean age 25), were described by their carers. All individuals were living in various residential care homes at the time, and all had access to some form of smart phone and/or computer. The reports from carers found that text messages were an important way people with ID socialised; as it allowed them to communicate with their families. Social media was also used frequently by individuals as a way to maintain existing relationships. Although messaging was described as problematic because of literacy difficulties such as spelling, it did not hinder participation as messages were still understood.

There has been little investigation into whether reading ability poses a barrier to social media usage, resulting in exclusion for the Down syndrome population. However, in a Swedish study (Löfgren-Mårtenson, 2008) which interviewed ten people with mild ID aged 18 to 31, the participants indicated that reduced literacy did not act as a barrier to participation for them. The participants said that the casual nature of many interactions via social media put less pressure on spelling or correct grammar usage; as it was acceptable for individuals to use emojis or abbreviations for words. This suggests that perhaps a lack of advanced literacy and indeed reading skills are not barriers to successful participation in social communities online. On the other hand, the nuanced or double meanings of language use on social media can be challenging for individuals with ID. This was something which was highlighted in a British study by Holmes and O'Loughlin (2014). The authors of this study described three service users with mild ID experience of social media. One individual in this study experienced significant

difficulty understanding the concept of a ‘friend’ on Facebook to mean something different to a friend in everyday life. This exposed the participant to potentially vulnerable situations. To conclude, the literature indicates that people with Down syndrome are using internet and communication technologies for a variety of reasons. Similarly, there is potential for these technologies to have positive quality of life outcomes, with appropriate monitoring and support. However, to what extent reading skills impact this engagement is not well researched. This is likely influenced by the lack of appropriate data on what individuals with Down syndrome read every day, and whether items within social media or new media technologies are part of this profile of reading habits.

3.2 Reading and leisure

People with Down syndrome take part in a variety of leisure activities across areas such as sport, drama, reading, music, gardening, watching TV, shopping and using social media (Channell et al., 2023; Down Syndrome Ireland, 2022; Frizelle et al., 2023). Although there are only two known small studies which investigate the specific, everyday reading of adults with Down syndrome, the literature suggests that reading and literacy activities are part of daily life for both young and older populations (Bochner et al., 2001; Frizelle et al., 2023). Bochner et al. (2001) reported that over half of their 30 participants read books (53%) and magazines (57%) in their free time. In addition, some read menus (40%), recipes (40%), shopping lists (30%) and comics (23%). In a study by Frizelle et al. (2023) 33 adults and young people with Down syndrome were asked what they read in their everyday lives, using a meaningful reading checklist. The participants reported that they read books, picture books, and many reported that they read for enjoyment. In an American study by Mihaila et al. (2020) the leisure time of 44 middle aged adults with Down syndrome was reported on. The authors analysed diaries filled out over a weeklong period by the adults. Authors found that the participants spent time reading, albeit to a lesser extent than partaking in other activities such as computer or iPad

games. Book reading was also a common practice reported within a sample of eight 22-year-olds with Down syndrome in a Norwegian study by Jevne et al. (2022).

Similarly, outside of reading as an activity itself, adults with Down syndrome use reading to pursue many other leisure activities. For example, in a study by Alderson (2001) adults with Down syndrome had roles in plays (which required reading scripts). In other studies such as Ramsten et al. (2023), adults with mild to moderate ID (n=11) in residential care homes made food for themselves and read recipes and food brands to do so. In a study by Muñoz-López et al. (2023), 73 adults with ID completed a variety of leisure activities across physical, social and community domains. For example, the authors reported that participants did things like go to the cinema, cultural exhibitions, theatres, amusement parks or bars. People use levels of reading for these activities. This is further supported by the results of Frizelle and colleague's paper (2023) as adults with Down syndrome reported that they read door signs (n=26), cinema times (n=29) museum information (n=15) which are all items involved in navigating everyday community leisure activities. Thus, there is a clear need to profile what individuals with Down syndrome read, as this can inform appropriate reading goals which facilitate leisure. Similarly, if this profile indicates that people with Down syndrome do not read for leisure or are not reading everyday items such as signs and timetables, finding out what is hard about reading is equally as important as these issues can be then targeted.

3.3 Outcome measures used in the literature

Although the social-cultural model of literacy has been considered from an intervention perspective, there is a significant gap in the literature in terms of outcome measures which would be sensitive to the expected changes these interventions aim to achieve. If adopting a meaningful literacy approach towards intervention, it is not appropriate to use solely formal reading assessments which de-contextualise the reading ability of the individual in terms of what, where and why the person reads. Large examples of increased reading frequency may be

missed by standardised assessments; including an increase in reading for pleasure or increased interest in reading items which relate to everyday activities, such as reading the ingredients in food items. For example, although findings from adult reading interventions such as LATCH-ON indicate that adults with Down syndrome can continue to learn to read into adolescence and adulthood (Moni, et al., 2018), results have been variable and often limited for some students (Holyfield et al., 2023; Moni et al., 2001). This could be because, as Moni et al. (2001) noted, that there is a difficulty in finding appropriate outcome measures which reflect the meaningful gains authors observe for their participants.

Most if not all of reading interventions for people with Down syndrome focus on decoding and/or comprehension (Dessementet et al., 2022; Groen et al., 2006; Randel et al., 2015). No available outcome measure examines specific, itemised, meaningful reading; such as reading in the community or at home. Common assessments used frequently within the literature include the Waddington Diagnostic Reading Test (WDRT) used in Bocher et al. (2001). This assesses recognition of letter sound relationships, sight word knowledge, simple word decoding and semantic and syntactic knowledge. Other assessments used which assess reading comprehension, rate or accuracy, include the Neale Analysis of Reading Ability (NARA) (Neale, 1999), The Word Reading subtest from the British Ability Scales II (Elliot et al., 1996) and the Burt Word Reading Test (Thorpe et al., 1976). While these outcome measures are useful in identifying changes in decoding ability or reading comprehension, they are not sensitive to meaningful changes in terms of everyday functioning. For example, these assessments do not capture increased everyday community reading or increased satisfaction as a reader. Furthermore, in the context of readers with Down syndrome, few outcome measures (aimed to assess at an appropriate reading level), are designed for adults. Assessments designed for children are used to account for lower reading levels of adults with reading difficulties.

However, this can mean that much of the stimulus items used in these assessments use cartoons or child friendly depictions of items associated with children.

Some reading outcome measures have been developed which consider environmental influences on reading comprehension. An example of this is the Test of Everyday Reading Comprehension (McArthur et al., 2013). It aims to assess reading comprehension from a more nuanced perspective. The assessment was designed as a comprehension screener which highlights to parents how their children are actually functioning from an everyday reading perspective. Questions relate to everyday situations, and children are expected to answer questions based on the context-specific texts they have read. This was developed due to the ‘high ecological’ validity functional reading assessments offer. This assessment recognises that everyday reading impacts a person’s ability to function in their society (McArthur et al., 2013). A study by Murphy, Bailey et al. (2023) which used this assessment reported increases in six children (aged 8-12) with Down syndrome’s functional reading comprehension. A clear limitation to this assessment in the context of this current project is that it is designed for children, not adults. Furthermore, although this example is useful in the context of a social-cultural model towards reading outcome measures, this assessment does not investigate how the individual perceives themselves as a reader, nor is it sensitive enough to what adults with Down syndrome are reading in their everyday lives.

None of the presented outcome measures encapsulate the opinions of the reader. Although, some studies are considering this more. In the study by Holyfield et al. (2023) reading instruction which focused on decoding novel single words was given to three people with Down syndrome who used AAC devices. In terms of social validity, participants were asked how they felt towards the intervention, whether they enjoyed it and various other questions relating to their feelings about reading following the intervention. All three participants responded ‘Yes’ to feeling that they had improved their reading; that they were

proud of that improvement; and that they enjoyed spending time on the computer during the intervention. Two of three participants responded, 'Yes' that they had enjoyed sounding out words on the computer, with the third responding 'I don't care'. This is positive considering how confidence and motivation can naturally influence engagement in reading instruction. However, it also highlights the need for a socially orientated outcome measures which ask adults with Down syndrome about their experience of reading.

3.4. The need for participatory research for people with Down syndrome

To achieve meaningful impacts for people with Down syndrome, it is vital to consider their thoughts, opinions and wishes. This is especially the case when conducting research which uses a social-cultural approach to reading. Participatory and inclusive research has been supported by the work of disability rights activists across the world. The slogan 'Nothing About Us Without Us' challenged the traditional model of academic literature which excluded people with disabilities from research (Charlton, 1998). Historically, individuals with ID have been passive subjects of research projects, where the 'expert' is the academic researcher. Gradually this has changed and people with disabilities are now actively participating in research (McDonald et al., 2013). Roll and Koehly (2020) illustrated the importance of considering the viewpoints and opinions of adults with Down syndrome in their study when researching their perceived social networks. The adults (n=27) were asked to describe their social networks, which were compared to proxy reports given by their families. The participants' families had underestimated the number of individuals their son or daughter considered as friends. Furthermore, the participants' families added more paid staff as network members whereas the adults with Down syndrome did not; as they did not perceive their care or support role as important enough, preferring emotional closeness. The authors theorised that had they excluded the people with Down syndrome from the research and just asked their parents, the value of

friendship and closeness for adults with Down syndrome would have been vastly underestimated.

Participatory research is now increasingly recognised and used throughout the literature to highlight the opinions of those who are being studied. Individuals with Down syndrome are now becoming co-authors of academic papers such as the author of Vaccarino et al. (2023), and learning research skills (Morgan et al., 2015; Stevenson, 2014). Although there are many different ways to implement participatory research (Morgan et al., 2015), there are key principles to consider. Principles of partnership, transparency, the promotion of equitable ownership, accessibility and collaboration, and extending the rights and interests of people with intellectual disability are all aspects of this approach (Morgan et al., 2015). For example, Stevenson (2014) described how two people with Down syndrome were supported to be co-researchers in a study about assisting young people with Down syndrome in achieving their life goals and greater social connection. The adults showed clear capability in coding themes within interviews, and both reported positive feedback on their involvement as co-researchers. The author of this study focused on providing clear and transparent details on how and to what level the co-researchers were involved in the study, which aligned with the guidelines to participatory research also stated by Morgan and colleagues (2015). Inclusive research has also cited benefits for both the individual with ID (collaborators) and the academic researcher. Benefits for research collaborators include feelings of empowerment, pride, accomplishment and feeling more in control (Di Lorito et al., 2018), as well as their opinions being heard (Vaccarino et al., 2023). Academic researchers have also reported positive changes in attitudes and expectations of their co-researchers (Di Lorito et al., 2018).

As will be discussed, phase 1 of this research project follows a participatory research design. This design is one that encapsulates an inclusive approach where research is undertaken *with* rather than *on* individuals with Down syndrome (Morgan et al., 2015). The inclusive

research process was described by Johnson and Walmsley (2003) as reflecting research goals which are truly relevant and meaningful to the population; the process must represent the views and experiences of the individuals; and that respect is given to the individuals throughout the process. It emphasises the importance of active participation and the rights of individuals with ID to be involved in research which affects their lives (Davison et al., 2022). With respect to this current study, it means that people with Down syndrome were valued and respected as experts, as they are indeed the experts of their own, everyday lived experience.

3.5 Summary and research aims

It is evident from the presented literature that people with Down syndrome are accessing employment, further education, internet technologies and community socialisation. However, accessing these facets of inclusion and personal development are not always straightforward, or met without challenge for people with Down syndrome. Since the introduction of technology into the modern world, we rely on written word more than ever before. A clear way to help adults with Down syndrome access these parts of modern, daily life is through reading. However, without appropriate literature which details what adults with Down syndrome read in their everyday lives; what they find challenging or positive about reading; or what they want their reading to enable them to do; creating supportive interventions which support these daily pursuits is difficult. Equally, if considerations regarding culture, age and education are not completed, this will also impact outcomes. Therefore, there was a clear need to gather information on meaningful reading for people with Down syndrome. Furthermore, given that this area of research is so broad, it was vital to consult adults with Down syndrome in regard to what research questions should be prioritised. This information can inform future reading interventions which have practical and meaningful outcomes for adults with Down syndrome.

Consequently, this study aimed to

1. Explore the reading habits of adults with Down syndrome, informed by the priorities of adults with Down syndrome themselves.
2. Gather a large, international profile of meaningful reading for young people and adults with Down syndrome using a valid Meaningful Reading Measure (MRM) (Frizelle et al., 2023).
3. Investigate whether age, education and place of residence influence meaningful reading for adults with Down syndrome.

Chapter Four: The current study

This study was carried out in two phases. In phase 1, a participatory research design was used where adults with Down syndrome were collaborators to the research study, not participants. The collaborators involved in this phase aided the research team in prioritising and refining the research questions for Phase 2. Phase 2 uses a more traditional approach where the adults with Down syndrome will be referred to as participants. This phase of the study used a Meaningful Reading Measure (MRM) (Frizelle et al., 2023) to gather an international profile of reading habits of adults with Down syndrome; and investigate the refined research questions. Some general information on the current study will now be presented.

4.1 Easy Read

Easy Read documents were used throughout both phases of this study. Thus, information on Easy Read documents will be presented briefly. Easy Read refers to textual information which is delivered in a way which is accessible and relevant to those with ID. It is not a simple translation of existing documents into easier to understand language but rather, a transformation of long texts to main points, changing font and text sizes, including visuals and considering the medium of delivery of information, such as whether the person needs support to read the document (UK Department of Health, 2010). Information presented to both collaborators and participants was presented in Easy Read format which aligned with guidelines from Nomura et al., (2010) and the UK Department of Health (2010).

4.2 Ethical considerations

This study received ethical approval from the Social Research Ethics Committee of University College Cork (SREC) Log 2022-181A1 (Appendix A). Whilst ethical approval is essential before commencement of any study, the highest ethical standards need to be upheld throughout the research process. Given that the study involved working with people with intellectual disability, procedures were put in place to ensure that the safeguarding of these

individuals was prioritised, and protections were put in place to mitigate any risks (McDonald et al., 2009). When recruiting collaborators and participants, in order to obtain informed consent, all information relating to the study was made available in Easy Read format (Northway et al., 2015). Contact information of the researcher was made available for anyone who had questions about the study before they wanted to take part. Additionally for the online aspects of the study, an instructional video was embedded within the survey platform to give details about the study, before individuals decided to take part (Appendix B). For participants under the age of 18, parental consent needed to be obtained along with assent before participation could commence. Those over 18 were given the opportunity to consent for themselves. Every participant had to give their consent or assent before they could take part. All information sheets and consent forms stated that the individual should only participate if they wished, that there would be no negative ramifications for not participating, and that there was no tangible reward for taking part. The consent forms were created by the student researcher and were modelled on a previous form which was co-designed with the Down Syndrome National Advisory Council (a committee of people with Down syndrome) and facilitators who worked in Down Syndrome Ireland.

Chapter Five: Phase 1 Methodology

Following a detailed review of the literature and extensive discussions with the research team, a range of research aims and areas of interests were developed. At this point, the research team felt that there was a need to establish which of these aims should be prioritised as it may not have been possible to investigate all of them. Consequently, it was decided that the use of a focus group of adults with Down syndrome was the most appropriate way to complete this prioritisation of the research aims. Similarly, if the research aims needed to be further refined or if new research aims needed to be added, this was best informed by the opinions expressed by the people with Down syndrome in the focus group. Phase 1 of this study describes the refinement and prioritisation of the project's research aims. The following sections will detail the recruitment of the focus group as well as the materials and procedure used. Specifically, the group's role was to prioritise research aims for the study, offer feedback on proposed aims and rank various research questions.

The design of Phase 1 aims to align with the participatory research methods described by Ramcharan et al. (2005) in that the methodology must show that the:

Research interest has been guided by people with intellectual disabilities and their allies, show how and why the research will challenge oppression; explain how the research funding will affect their work; make clear the nature of the research relationships and the division of labour involved explain the mechanisms that have been involved in making the participation of people with intellectual disability meaningful; state clearly the values underpinning their research; and, most importantly...publishing their work in ways that are meaningful and useful to not only academics, but also the people with intellectual disabilities and their allies. (p. 105)

5.1 Recruitment

A convenience sample of members of a LATCH-ON adult literacy programme for people with Down syndrome were invited to take part in the focus group as research collaborators. This course was run by Down Syndrome Ireland (DSI), an organisation which provides support for people with Down syndrome and their families. These collaborators had previously been involved in research with the MRM (Frizelle et al., 2023). This meant that the group had an already established rapport with the student researcher and had some understanding of the research project. Before commencement of the focus group, the student researcher contacted the DSI adult education liaison officers and teachers of the adult literacy programme. She explained the purpose of the focus group to the teachers via email and phone call, as well as providing an Easy Read information sheet to be given to the collaborators (Appendix C). This sheet explained the purpose of the focus group, and what would happen during the session. The teacher then sent information about the focus group to the collaborator's families via a newsletter. This allowed the group to discuss the research project with their families before they decided to take part. Following this, time was allocated to the collaborators, in the class setting, to further discuss whether they wanted to participate as a group, with their teachers. Once the group had decided that they did want to take part in the focus group, the teacher of the programme contacted the student researcher via email. The focus group went ahead, and the student researcher then obtained written and verbal consent from the collaborators on the day of the focus group session (Appendix D). At the time of the focus group nine collaborators (5 female, 4 male) (age 22-38) were available and consented to take part in the study (see Table1).

Table 1:
Focus group demographic information

	Average			
	Mean	SD	Median	Range
Age	24.78	5.45	22	22-38

Note: SD = Standard Deviation

5.2 Materials

5.2.1 Broad research questions

Following an extensive review of the literature and discussions with the research team who had extensive experience of working with people with Down syndrome the following proposed, broad research questions were developed (see Table 2).

Table 2:
Broad, proposed research aims

Broad research aims developed by the research team
How will the MRM scores of participants differ across countries?
What do people with Down syndrome find easy about reading?
Does a mainstream or special school education impact the MRM scores of people with Down syndrome?
What would people with Down syndrome like to do with their reading? (Get a job, read more, go to college?)
How does the level of post-secondary school education impact everyday reading for adults with Down syndrome?
Does age impact the number of everyday reading items people with Down syndrome read with respect to new media, community reading or personal reading?
What makes reading easier for people with Down Syndrome?
What is a general profile of everyday reading habits for adults with Down Syndrome?

What are the difficulties associated with reading for people with Down syndrome?

What do people with Down syndrome feel is the best thing about reading?

Do people with Down Syndrome like reading?

Do people with Down syndrome who do courses with Down Syndrome Ireland read more every day reading items? (Than people who haven't done these courses)

What 'every day' reading item do people with Down syndrome read the most?

5.2.2 Focus group presentation

The focus group sought to prioritise and refine the above broad research questions. The student researcher transferred the proposed research questions into Easy Read format in a PowerPoint presentation. She then consulted the research team and made any edits. The final PowerPoint Presentation was then used in the focus group session (Appendix E), a list of these questions is also available in Appendix F. This presentation gave some information on the study, explained what a research question was and finally, showed two to three research questions presented on a slide for the collaborators to vote on. Questions were grouped strategically so that each question represented a different topic and that no three questions perceived as 'most interesting' by the research team were grouped together (see Figure 1). All discussions were audio recorded and then transcribed by the researcher. Once transcription was completed, audio was destroyed. No identifying information was transcribed. Anonymised transcriptions were stored on a password encrypted drive.

Figure 1
Example of a presentation slide

	1. What would people like to do with their reading? (Get a job, read more, go to college?)
	2. Do people with Down Syndrome who have finished more school or college, read more?
	3. What is hard about reading?

5.3 Procedure

In total, the focus group lasted one hour and took place in the classroom of an adult education centre which was familiar to the collaborators. The session was moderated by the teaching staff of the literacy programme and the student researcher. The session was divided into two parts; an introduction to the project and the voting activity. For the introduction, the student researcher gave a PowerPoint presentation which included an online version of the MRM and played the introduction video (for future use to participants), to the collaborators. This video explained the study, how future participants may fill it out and detailed some questions that may be asked in the survey. This refamiliarised the collaborators with the research and gave a brief outline as to what questions would be asked in the MRM for future participants. The concept of researching and a research question were also explained. Following this, the collaborators were invited to ask any question they had about the project. The student researcher explained that adults with Down syndrome have the most expert opinion on the lived experiences of people with Down syndrome and as a result, explained that she wanted their opinion on how to prioritise and edit the research questions. During the

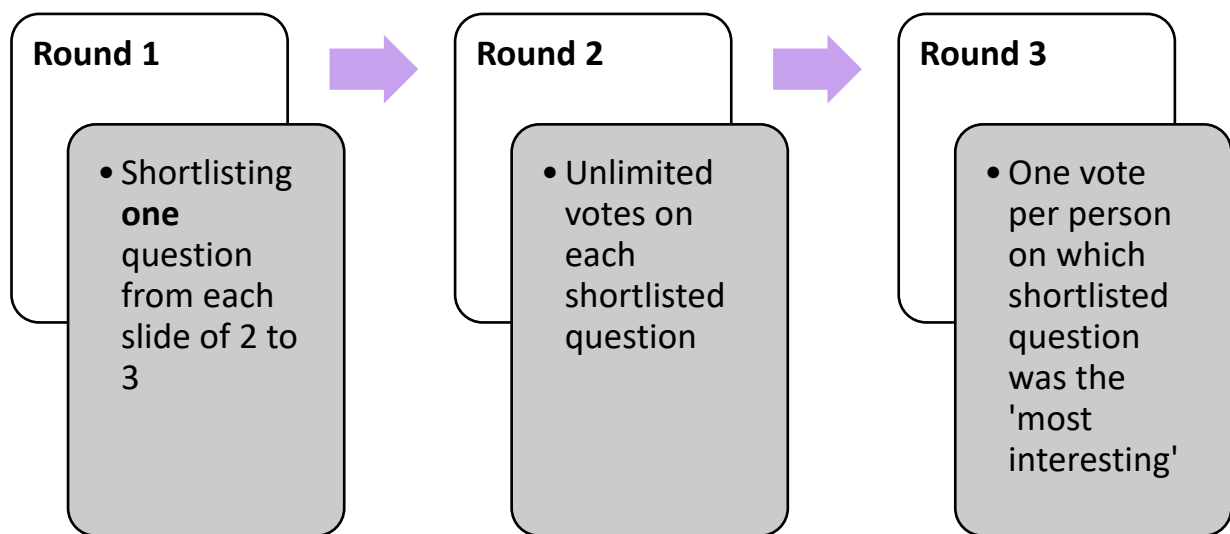
session, collaborators were encouraged to engage in conversations and discussions to establish rapport and a degree of comfort with the researcher.

In the second part of the session, an Easy Read presentation on the possible research questions was given. During previous discussions with the teaching staff of the programme, it was established that members of this group used group voting to decide on the topics covered and trips undertaken over the academic year. For example, whichever decision that received the most votes within the group was chosen. As a result, this established a precedent for this voting style within the group dynamic. The student researcher asked the teachers and collaborators how they felt about using this style again in the focus group, and they all agreed to proceed with this method. The collaborators had to vote on each slide as to which research question of the group, they felt was most important. The student researcher read out each question and pointed to the Easy Read visual each time. She explained the question by giving examples and elaborating when needed. Voting was completed by hand raising. Hand voting was practiced with the student researcher during a practice round before the actual voting commenced. Voting commenced by the researcher asking, *“Who thinks this question is interesting?”*. Collaborators who raised their hands at each question were noted on an extra slide on the student researcher’s laptop.

This voting activity can be sectioned into three parts (see Figure 2). In the first activity, each question was shown in groups of two or three. The collaborators had to rank which question they felt was most important or interesting, within this group. In part two these questions were then shortlisted to a new slide. Given the small size of the group, to ensure that the collaborators weren’t limited to one question of interest, initially the collaborators were given unlimited votes to indicate whether they found the shortlisted question interesting. In part three, the researcher then asked the collaborators to use one vote only to indicate if they found the question interesting. If a collaborator voted more than once

for a given question, the concept of one vote per-person was explained again, a brief break was given, and the round was re-started. Employing both unlimited and singular voting was used as the sample was small. By this method, the participants could express their interests in a variety of shortlisted questions whilst also highlighting which question was of most importance to them.

Figure 2
Voting Procedure



Chapter Six: Phase 1 Results

6.1 Prioritisation of the research questions

As has been detailed in the methodology, collaborators were asked to prioritise potential research questions in groups of two or three, and asked to vote on which questions were most interesting to them; with limited and unlimited votes. The following results account for 1) which research questions were shortlisted by the collaborators 2) how the questions were ranked when the collaborators were given unlimited results and 3) how the collaborators ranked the questions when they had only one vote. No other research questions or areas of interest were noted by the group.

Table 3:
Round 1 shortlisted questions and grouping

Possible research questions for the project	Question voted ‘most interesting’ with unlimited votes by the collaborators (per slide).
- What would people like to do with their reading? (Get a job, read more, go to college?)	What would people like to do with their reading? (Get a job, read more, go to college?) n = 7
- Do people with Down Syndrome who have finished more school or college, read more?	
- What is hard about reading?	
- Do older people with Down syndrome do different reading than younger people with Down syndrome?	Do older people with Down syndrome do different reading than younger people with Down syndrome? n = 5

- What makes reading easier for people with Down Syndrome?
- What do people with Down Syndrome read every day?

- | | |
|--|--|
| - What makes reading harder for people with Down syndrome? * | What makes reading harder for people with Down syndrome? n = 3 |
| - What's the best thing about reading for people with Down Syndrome?* | What's the best thing about reading for people with Down Syndrome? n = 3 |
| - Do many people with Down Syndrome like reading? * | Do many people with Down Syndrome like reading? n = 3 |
| - Do people with Down syndrome who do courses with Down Syndrome Ireland read more? (Than people who haven't done courses) | Do people with Down syndrome who do courses with Down Syndrome Ireland read more? (Than people who haven't done courses) n = 6 |
| - What thing do people with Down syndrome read the most? | |

- | | |
|---|--|
| - Do Irish people with Down syndrome read more or less than other people with Down syndrome? | Do Irish people with Down syndrome read more or less than other people with Down syndrome? n = 4 |
| - What is easy about reading? | |
| - Who reads more? People with Down syndrome who went to a special needs school or people who went to a mainstream school? | |

Note: * = voted equally important by collaborators. n= number of votes received within each group of questions. Each row shows the grouping of the questions per slide.

Table 4:*Round 2 number of votes received when given unlimited votes*

Short listed questions	Number of votes received (unlimited votes)
What would people like to do with their reading? (Get a job, read more, go to college?)	n = 6
Do older people with Down syndrome do different reading than younger people with Down syndrome?	n = 5
What makes reading harder for people with Down syndrome?	n = 4
What's the best thing about reading for people with Down Syndrome?	n = 4
Do many people with Down Syndrome like reading?	n = 6
Do people with Down syndrome who do courses with Down Syndrome Ireland read more? (than people who haven't done courses)	n = 4
Do Irish people with Down syndrome read more or less than other people with Down syndrome?	n = 3

*Note: n= number of people who voted***Table 5:***Round 3 questions of highest priority for the collaborators, when given one vote only.*

Short listed questions	Number of votes received (1 vote per-person)
Do many people with Down Syndrome like reading?	n = 6

Do Irish people with Down syndrome read more or less than other people with Down syndrome? n = 2

What would people like to do with their reading? (Get a job, read more, go to college?) n = 1

Note: n = number of people who voted

6.2 Refining the research questions

The focus group aimed to ascertain whether the overall research aims of this project reflected the interests and priorities of adults with Down syndrome. To ensure transparency in participatory research (Ramcharan et al., 2005), it is important to recognise how the final research questions were chosen. It was not feasible to investigate all the identified ‘interesting’ research questions chosen by the group. The final research questions were finalised by the research team, based on the criteria outlined below.

Following discussions with the research team, given the nature of the sample, it would be likely that only individuals who participated in reading activities, were interested in reading or could read, would fill out the MRM. The sample would, as a result, be biased to reflect only those individuals with these skills or interests. As a result, ‘*Do adults with Down syndrome like reading?*’ was excluded as a possible research question, as following reflection, it was not possible to investigate without substantial bias. Upon consideration of the implications of long-term memory issues for people with Down syndrome and following the collection of some initial responses, the question ‘*Do people with Down syndrome who do courses with Down Syndrome in Ireland read more? (than people who haven’t done courses)*’, was also excluded. Initial responses reflected the long-term memory difficulties evident in many adults with Down syndrome (Godfrey & Lee, 2018) in that 1), older participants who filled out the MRM may

have completed many programmes throughout the years and couldn't remember them all and 2), some previous participants who filled out the MRM with the research team reported that they couldn't remember previous educational history. This made some responses given about previous education unreliable, as individuals may not have remembered how long they had spent accessing education or what education they had completed. All other questions prioritised by the collaborators were deemed feasible to investigate by the research team.

6.3 The final research questions

Consequently, the following research questions were developed for phase 2:

- 1) What is a profile of meaningful reading habits of young people and adults with Down syndrome, over the age of 16, including:
what, why, when, and where they read,
and their preferred medium of reading.
- 2) What do people with Down syndrome perceive as hard about reading?
- 3) What do people with Down syndrome consider to be the best thing about reading?
- 4) What would people with Down syndrome like to be able to do with their reading?
- 5) Is there a relationship between the number of MRM items read and 1) age or 2) country of residence?
- 6) Is there a relationship between age and 1) preferred reading medium or 2) reading habits of people with Down syndrome with respect to reading new media, community reading or personal reading items?

Chapter Seven: Phase 1 Discussion

7.1 Interpretation

This phase of the study allowed the collaborators to express which research questions they felt were important for the study. This process indicated that there were a variety of questions the collaborators were interested in. These were questions such as what their peers wanted to do with their reading skills (like being able go to college or get a job), and the influence of age on the reading of people with Down syndrome. They were also interested in whether doing DSI courses had any impact on the everyday reading of people with Down syndrome. This was perhaps influenced by the fact that the collaborators themselves were completing a literacy course run by Down Syndrome Ireland and wanted to investigate the evidence base behind it. The group was also interested in what other people with Down syndrome found hard about reading. Again, perhaps as the group were targeting their own literacy skills in this course, they may have been more interested in the challenges reported by others, as it was something they were facing themselves. This would align with the comprehension difficulties associated with reading for people with Down syndrome (Groen et al., 2006; Roch & Levorato, 2009) and the self-reported difficulties with understanding words and the length of time it takes to complete reading described by the participants in Frizelle et al. (2023).

Following the shortlisting of the questions, collaborators were asked to rank the questions in order of most interest or importance to them. Notably, the most important question to them differed according to whether they had only one or unlimited votes. For the unlimited voting, the shortlisted question *'What would people like to do with their reading? (Get a job, read more, go to college?)'* received the most votes (n=6). For the limited voting round, *'Do many people with Down Syndrome like reading?'* (n=6) received the most votes. Only one person voted for the same question when they received in both rounds. It is not clear why there

was a difference in the answers of collaborators between the two rounds. Perhaps further / additional reflection time facilitated the alternative responses. It may also be hypothesised that because ‘*Do many people with Down Syndrome like reading?*’ was the last question read out during the shortlisted answer, collaborators who had not decided yet, went with the last option. Nevertheless, this was still voted a popular question during round 1 (n=7), meaning it was a popular choice across two rounds, which does add validity to the results.

7.2 Strengths and Limitations of this Phase

It could be argued that the collaborators in this phase of the study were not reflective of the general population of adults with Down syndrome, as this cohort are in further education and have some functional reading skills. However, they are reflective of readers with Down syndrome and people who have experienced a social-cultural approach to reading intervention. The collaborators involved in this phase of the study were “experts by experience”, a key requirement of having an advisory role to participatory research (Bigby et al., 2013, p. 5). This gave them a unique and valuable perspective on the research project. In their participatory action research study with 16 people with ID, Watchman and colleagues (2021) also agreed that collaborators to research should reflect the needs of the target group. The collaborators in the present group did exactly that, which adds validity to the findings.

Group voting was used in the procedure of the focus group whereby collaborators raised their hands in a group to indicate their preference for a question. The student researcher then counted the number of hands raised. This further aligns the methodology of Phase 1 with inclusive practices in research. As described by Davidson and colleagues (2022), often when using participatory research, verbal communication may not be the preferred mode of communication for adolescents with ID, so methods need to enable the collaborators to express their opinions and perceptions in alternative ways. This may also be the case for adults with Down syndrome, as expressive language can be an area of difficulty for them (Abbeduto et al.,

2007; Martin et al., 2009; Roberts et al., 2007). However, it is also important to acknowledge that voting as a group for decision making may influence the individual votes of collaborators. For example, theorists have investigated the negative impacts of group thinking on decision making (eg. Jones & Roelofsma, 2000); where social biases can impact group-decision making. However, given the already established relationship the collaborators had with each other and the student researcher, their consent to carry out group voting and their already established use of group voting, this was decided with the group as the most appropriate way to carry out Phase 1. Davidson et al. (2022) also used similar collaborative practice with their collaborators when deciding on the voting method to be carried out with collaborators.

One issue noted following the results of this phase was that within each grouping, the question which received the most votes was always the first question read out, apart from one time. This could have been because of what is known as the primacy effect (Waugh & Norman, 1965). This is a short-term memory theory where it is thought that information presented first, is remembered more than information presented later. Although the results could as a result, appear biased, the researcher read voting instructions multiple times and, in some cases, if there was uncertainty surrounding the answers, the process was repeated. This allowed the collaborators to give consistency to their responses and it also aided their understanding. Perhaps in future, each voting activity could be completed twice, and questions presented in different orders; by which all answers could be cross checked to ensure consistency. It is also important to note that often the differences between answers contained only one vote, so although some of the answers may have been the first one presented, the margins were so small that the validity of the methodology still stands.

Finally, an argument which could be made is that the use of a small group has individual biases which impact the results of this phase. However, this is the nature of using focus groups; their role being to give their opinion. This project decided to embrace these biases and the

individual opinions of the collaborators. This ensures that the voices of the collaborators were heard and respected, and that the research team did not assume to have a more correct opinion or speak for the collaborators. The research team's role was to ascertain how feasible it would be to investigate the chosen research questions, with the resources and time available to them. Being transparent about the role of collaborator and 'academic researcher' is a core value of participatory research. This approach to participatory research is one that was taken by Stevenson (2014) where the role of each person involved in the research was clearly outlined.

7.3 Future directions

In future, for this type of research, collaborators should be involved with the formation of the research questions before prioritisation occurs. Although the aims were established by a research team who worked extensively with people with ID, and this study was co-supervised by a member of Down Syndrome Ireland (a group who advocate for the needs of people with Down syndrome and their families), consulting people with Down syndrome in the initial process/steps of the research as well as what parts they wanted to be involved in, would have been beneficial. This would mean that the 'academic researcher' didn't get to solely decide at what points in the research study the collaborator would be involved in. Furthermore, although no other research aims were generated by the collaborators, perhaps this was due to group fatigue. Future work should consider completing a structured brainstorming session concerning the interests of people with Down syndrome first, followed by a separate prioritisation session.

Chapter Eight: Phase 2 Methodology

Phase 2 of this study used a Meaningful Reading Measure (MRM) (Frizelle et al., 2023) to gather an international profile of meaningful reading habits of adults with Down syndrome. Following this, the refined research questions were investigated. This phase involved recruiting participants, making minor adjustments to the MRM so that it was suitable for the online survey platform, distribution of the survey to an international audience, and analysing the gained data.

8.1 Materials

8.1.1 *Meaningful Reading Measure*

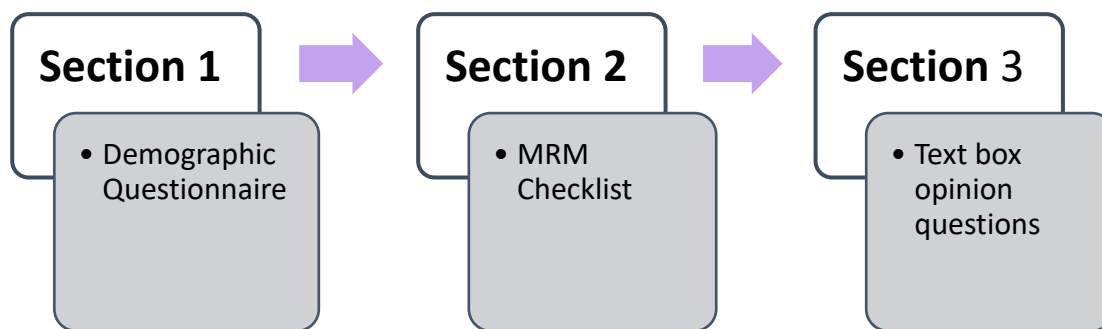
Phase 2 of this study used a Meaningful Reading Measure (MRM) as the tool to profile the reading habits of adults with Down syndrome. This tool was one which was co-constructed by adults with Down syndrome (Frizelle et al., 2023).

Frizelle and colleagues (2023) and a group of adults with Down syndrome (n=46) created this tool in response to the lack of appropriate outcome measures in the literature which considered every day or meaningful reading gains for adults with Down syndrome. The research team took an inclusive participatory research approach to the study, where researching was completed *with* adults with Down syndrome, not on them (Ramcharan et al., 2005). The objective of creating this measure was that it could be used alongside other assessments as a pre- and post-intervention outcome measure for reading programmes. It could also be used to guide the content of reading courses or modules for this population to ensure that targets were reflective of everyday social practices of adults with Down syndrome. Ecological, face and content validity of the tool were established. This was done as the collaborators validated a portion of the images used and generated the meaningful reading items included. The research team also responded to feedback on the ease of completion and the layout / overall appearance of the tool from the collaborators. Concurrent validity was investigated by comparing the MRM against other reading measures. This confirmed that other standardised measures of reading did

not capture reading from a social-cultural or meaningful perspective. Internal and external reliability were established with groups of adults with Down syndrome. The researchers (Frizelle et al., 2023) and collaborators generated the final version of the MRM. This contained Section 1) some demographic questions, Section 2) a reading item checklist where the number of items ticked generated a MRM score, and an open text box for any other reading items not mentioned in the list, Section 3) open ended and closed questions about how the participant felt about reading. These questions asked about when, where and why they read, their preferred medium, what is hard about reading, the best thing about reading, and what they would like to be able to do with their reading.

Figure 3:

Structure of the Meaningful Reading Measure



8.1.2 Minor adjustments for the current study

In this current study, the MRM was going to be presented on an online survey platform. As a result, minor adjustments and updating to the measure were required. This began with ensuring that all written text was in Easy Read format. This was completed following initial inspection of the original MRM. Visual support for all of the demographic information questions was not included for some options in the original version. As a result, this was added by the student researcher. Further changes and additions were completed to account for the international participants who would be filling out the survey. For participants who clicked ‘yes’ to the question “Have you done courses after school in Ireland?” a drop-down menu of

popular courses for adults with Down syndrome in Ireland was available to fill out. These included various Down Syndrome Ireland courses as well general college or personal development courses. For those outside of Ireland, a simple *yes* or *no* answer question was shown in response to the question, '*have you done courses after school?*'. This question did not ask specifically what courses were completed as it was not possible to account for every post-school education option offered internationally.

As the student researcher was part of the research team involved in the validation process of the MRM, she was exposed to feedback and suggestions from participants and teachers involved in the reliability testing phase in Frizelle et al. (2023). Consequently, the student researcher made some further minor adjustments to the tool in response to this feedback. Two further items which had been mistakenly omitted during the reliability stage such as '*social media*' and '*web browsing*' were added at this point. In response to feedback from a participant and a teacher, a third item, '*food items*' was also added to the checklist. When moving the survey online, two previously validated images were changed by the student researcher, these were not validated by the collaborators. One of these was '*recipes*' and was changed due to formatting issues. Although the image for '*subtitles*' was validated by the collaborators, participants expressed some confusion with the image and its corresponding text, for example mistaking '*subtitles*' as meaning the weather or news due to its image reflecting a subtitled scene from a news programme. The student researcher replaced it with an image which highlighted subtitles as a more focal point of the picture (see Figure 4). The final version used in this study contained Section 1) the updated demographic questionnaire tailored to Irish and international participants, Section 2) the final item checklist containing 46 unique items

where each item counted as 1 and yielded the MRM score, and Section 3) the open and closed ended questions about the participants opinions on reading. This final version was then reviewed by the supervisors of the study and the student researcher.

Figure 4:
Updated image for 'Subtitles'



8.2 Recruitment

This project was co-supervised by a staff member who was the national research and support specialist of Down Syndrome Ireland (DSI), an organisation in Ireland who advocates and provides support for individuals with Down syndrome and their families. Participants for phase two were recruited through the help of DSI gatekeepers, social media campaigns and snowball sampling. DSI acted as gatekeepers to reach out to their members who may have been interested in filling out the survey. DSI staff members and one of the supervisors for this study also reached out to various English-speaking Down syndrome support organisations across the world. Organisations, academic researchers, and intellectual disability services were also contacted by the researcher via email and social media. A promotional video was made with a DSI staff member with Down syndrome to increase the awareness of the study (Appendix G). This video detailed why participants should fill out the survey and what it entailed. The researcher also informed social media platforms who advocated for those with Down Syndrome and prominent social media influencers with Down syndrome about the survey.

The student researcher visited various further education programmes for adults with Down syndrome, where the DSI gatekeepers advised that members wanted to take part. DSI gatekeepers also brought paper copies of the survey to the various DSI adult education courses during routine visits also. For these groups, the DSI gatekeeper contacted the teacher of the course and informed them about the study. Following this, either the student researcher or the DSI staff member contacted interested teachers and emailed them an information sheet. If the teachers and group-members were happy to take part in the study, the researcher or DSI gatekeeper visited the class.

8.3 Procedure

The survey was available to fill out over the course of 14 weeks. Initially, it was planned that the survey be available solely online as it was thought to be too difficult to post out a hard

copy to each participant internationally. However, in keeping with the opinions of the collaborators from Frizelle et al. (2023), collaborators preferred to fill out the MRM via pen and paper and as part of a class exercise. Consequently, the survey was also made available to participants as a pdf download. Thus, the participants had the option to fill out the survey online or via paper version.

For the online version, the platform Qualtrics was used (see Appendix H). Qualtrics is an online survey platform. The programme allows text size changes, changing of fonts and incorporation of visuals. This allowed the online MRM to be presented in Easy Read format. Initially participants were supposed to revisit the survey on different occasions and fill it out gradually over the course of a week. The only way to do this on Qualtrics was through an individualised email link (answers were still anonymised). However, uptake of the survey was very low, possibly due to a lack of access to personal email addresses. As a result, the survey was adapted, and the participants were given an option of an anonymous link, where the survey could be filled out in one sitting. This meant that the participants had the option to fill out the survey via email link, anonymous link or via a downloadable paper version. This was to give participants the best chance to complete the survey in a way that suited them. In regard to obtaining consent, the survey only progressed if participants indicated that they were over 16 and had Down syndrome. The information sheet (Appendix I) and video were shown before obtaining consent (Appendix J). For participants who indicated that they were under 18, parental consent was needed (Appendix K). Assent was also needed. The survey automatically finished if both of these were not given. If the participant indicated that they were over 18, only consent was needed.

For the paper version, a downloadable pdf version of the survey was embedded in Qualtrics. This followed the presentation of the information sheet. Participants were able print the pdf and scan and email or post it back (Appendix L). The address of the DSI office and

contact details of the student researcher was given for this. For those who filled out the paper version of the survey, only surveys where consent was obtained were included.

Recruitment using online platforms was very challenging and uptake was very low after three months of active recruiting. As a result, the student researcher also visited various further education and social groups for adults with Down syndrome run by DSI. For these sessions where the MRM was filled out as part of a class exercise, the option was offered to fill out the MRM online or on paper. Adults who wanted to take part were supported to fill out the survey by staff members who were familiar with them, or the student researcher. All participants spoke English, used either oral language, a combination of oral language and key-word-signing or written language to answer the MRM questions. If participants didn't have an answer to a question, it was left blank. This was to ensure that participant answers were not influenced heavily by the support person. As these classes only served adults, parental consent was not needed. Nevertheless, the researcher ensured that all participants were over 18. As with the recruitment method in phase 1, the information sheet was available to read again before commencement of the study and consent had to be given before the participant could complete the MRM. The student verbally went through the information sheet and ensured that each participant had a copy of it. Following this, both verbal and written consent was obtained using the consent form. Once the data collection window closed, the student researcher inputted all paper version copies into Qualtrics to collate all the responses. No personal information or emails were saved.

8.4 Data analysis

This phase of the study involved both quantitative and qualitative analysis. Responses were included once all answers for the 46-item checklist in Section 2 were given. This was done to ensure accurate reflections of MRM scores. Moreover, as it was the participant's own

choice to give their opinions in Section 3; they may not have had a specific opinion on the question asked.

8.4.1 Quantitative Analysis

Quantitative data analysis was completed using the software Statistical Package for Social Sciences SPSS version 28.0.0 (IBM Corporation, 2021). Quantitative data on demographics, and meaningful reading profiles were analysed descriptively. In order to investigate the total items read by the participants linked with factors such as age and place of residence, two methods were used. In order to determine if age and score were related, first the distribution of the data had to be assessed. To identify whether the data was evenly or unevenly distributed, the Shapiro-Wilk Test of Normality was completed where $p \leq .05$ indicates uneven distribution. This identified that a portion of the data was significantly deviated from normal distribution ($p = 0.01$), and as a result, non-parametric analysis was used. Spearman correlation was completed to investigate the associations between the MRM checklist score and age. To compare the scores of participants across countries, a Mann Whitney- U Test was carried out to determine if participants *outside* of Ireland achieved significantly different MRM scores, to those from Ireland.

A Fisher's exact test was completed to address the relationship between age and preferred reading medium. This was done as the chi-square test of independence indicated that (66.7%) of the cells had an expected value of less than 5 (McHugh, 2013). This violated the assumption of the chi-square test. Age was converted from a continuous variable to a categorical variable. These categories aimed to approximately reflect the available literature surrounding the language and cognitive profiles of individuals with Down syndrome. Age categories were 16-25, 26-37, and 38-46 years. This aimed to loosely reflect what is known in the literature about language development continuing into early adulthood, stabilising off in middle adulthood and then the onset of cognitive decline into later adulthood for people with

Down syndrome (Chapman & Hesketh, 2001; Connors et al., 2018; Nelson et al., 2001; Witecy & Penke, 2017).

To investigate the relationship between age and specific reading habits, MRM items were categorised into New Media, Personal Reading or Reading in the community/Out and about. The list of included items is available in Table 6. As the data was unevenly distributed, a Kruskal–Wallis test was used. A post-hoc Dunn test was used to address significance between New Media and the age variable. A Bonferroni adjustment was applied to control for Type-1 errors ($p = 0.05/3=0.0167$).

Table 6:
Items grouped according to reading item type

Personal Reading	New Media	Community Reading
Books	Web Browsing or Searching	Menus
Books that have a lot of pictures	Social Media	Road Signs
E-books	Text Messages	Signs on Doors
Poems	Emails	Travel timetables
Newspapers	Video game and DVD boxes	Cinema times
Magazines	Video game menus	Shop names
Catalogues	YouTube videos	Clothes brands
Ad Leaflets		Food brands
Crosswords or Word Searches		Health information (such as a covid sign)
Board Games		Information about displays in a museum

Cooking Instructions or

Maps

Recipes

Food Items

Homework or Assignments

Lists

Post

Calendars

Invitations, checking the

time and appointment

reminders

Cards

Work Rosters

A contract that you need to

sign

Movie and TV show names

on the TV menu

Headlines on the news

Subtitles

Song titles (for example on

Spotify or Apple Music)

Song lyrics

Sport Fixtures

Sports Results

Lottery Numbers

8.4.2 Qualitative analysis

Section three of the MRM contained open-ended questions for the participants to fill out. These responses were all collated and imported into the software NVivo release 1.7.1 (Lumivero, 2022). These questions provided qualitative data relating to when, where and why people with Down syndrome read; their preferred medium; what is hard about reading; the best thing about reading; and what they would like to be able to do with their reading. As this data was from specific questions, directive qualitative analysis was used to analyse the text box responses. (Hsieh & Shannon, 2005). Content analysis is the use of systematic coding and categorising of large amounts of text, to determine patterns and trends in the words used, their frequency and relationship (Vaismoradi et al., 2013). Directive content analysis involves starting with a general existing category or theory and utilising the data to either support or build upon that category. This approach also allows the frequency of categories to be quantified. As the responses were from specific questions, general themes had already been established. For example, the theme of positives or negatives of reading, locations for reading and motivations for reading. As a result, the established overarching categories were set by the questions asked. However, categorisation of answers within each question response were derived with no preconceived theme and researchers aimed to stay objective to the category generation (Bengtsson, 2016). Categories were formed based on the words said, not a general relationship or meaning behind the text (Graneheim, & Lundman, 2004). Responses given for each category were then quantified.

When considering the truth worthiness of content analysis, there needs to be an acknowledgment from researchers that there is always some degree of difference between individuals when interpreting text. Text can involve multiple meanings, acknowledging this is essential whilst discussing the findings of qualitative content analysis (Graneheim, & Lundman, 2004). As many of the people who filled out the survey had literacy difficulties,

there was a need to deduce meaning from responses that was not always immediately clear. In order to mitigate any risk of bias from using a singular viewpoint when deriving codes, the student researcher originally read through the texts, formulated and abstracted codes as they presented themselves and then read over the data again. Codes were then reviewed by the research team. To minimise bias, double coding was completed. A second researcher coded 20% of the data independently of the primary researcher. Inter-coder agreement was 85%. Any disagreement relating to the codes were discussed and resolved. Responses where it was clear that the participant had mis-understood the question, or the researchers could not interpret the response were labelled as un-codable. This accounted for 3.35% of the data.

Chapter Nine: Phase 2 Results and Discussion

This chapter reports and discusses the results of Phase 2 together. These are the results of the prioritised research questions which were gathered using data generated from the MRM. Results for Phase 2 were analysed using both descriptive and inferential statistics, as well as directive qualitative content analysis. For clarity, coded categories are referred to in quotation marks, direct quotations are depicted in italics and double quotation marks. Free text responses from participants have been quoted verbatim to ensure transparency. Edits have been made to some spelling and grammatical errors only when absolutely necessary, and the meaning of the response was overtly clear to the research team. This was to ensure that the researchers did not alter the intended meaning or infer something that wasn't intended within the text. These edits have been noted in brackets.

9.1 Demographic Information

The survey was opened by 223 people, 104 of which did not answer any of the demographic questions. Seventeen people filled out some demographic questions but none of Section 2 of the MRM checklist. Four people answered some of the checklist items but didn't finish this section. These responses were excluded as only participants who finished the Section 2 of the MRM checklist were included. This resulted in 98 people with Down syndrome being included in the study. The majority of participants completed online surveys with only, 14 completing the paper version. Demographic information for the 98 included participants is available in Table 7. Most participants who completed the survey lived in Ireland (67.35%), with the United Kingdom (17.35%) and the United States of America (8.16%), having the second and third most frequent numbers of responders. A small percentage of individuals were from Canada, New Zealand, Australia, and India (See Table 7). Some participants did not list their country. The age range of participants spanned 30 years, with the youngest person who completed the MRM aged 16 years, and the oldest aged 46 ($M = 24.6$, $SD = 6.8$). Most

participants who filled out the survey had completed some form of post second level education course (n = 72, 73.47%). The majority also filled out the survey with some help (n = 82, 83.67%).

Table 7:
Participant demographics

Complete Responses (n=98)								
Age	Mean	SD	Median			Range		
	24.34	6.66	23			16 - 46		
Place of Residence	IRE	UK	USA	NS	CAN	AUS	Not listed	India
% of Responses	67.35	17.35	8.16	3.06	1.02	1.02	1.02	1.02
Other demographic information given	Post-second level courses completed			Completed survey <i>with</i> help				
%Yes	73.47			83.67				
% No	26.53			16.33				
Method of Completion	Paper			Online				
Number of participants	14			84				

Note: IRE = Ireland, UK = United Kingdom, USA= United States of America, CAN= Canada, NS = New Zealand, AUS= Australia, %= percent of responses per group, SD= Standard Deviation

9.2 What is a profile of meaningful reading habits of young people and adults with Down syndrome, over the age of 16, including: what, why, when, and where they read, and their preferred medium of reading.

9.2.1 What do people with Down syndrome read?

To remind the reader, the MRM has a total of 46 items, each accounting for a score of 1 and yielding a total possible score of 46. Participant scores were highly varied ranging from 0 to 46. Descriptive statistics were used to calculate the mean number of items ticked, which

indicated that participants read an average of 34 meaningful reading items in their everyday lives ($M = 33.55$, $SD 7.9$) (see Table 8). This score reflected 72.93% of the total number of items listed in the MRM. These scores are slightly higher than those reported in Frizelle et al. (2023) in which the average number was 31 items ($M = 31.06$, $SD 9.49$) from a sample of 31 participants. Notably, the range of MRM scores of the Frizelle sample was narrower (12-44) with a minimum number of 12 items read by all participants. In the current study there were two individuals who identified themselves as non-readers and eight who reported that they did not like to read, whereas others expressed their love for reading. There were no non-readers in the study by Frizelle et al. (2023). Perhaps the greater variability in scores of the current sample (0-46) is unsurprising given that it was a larger sample and contained international participants, in comparison those who took part in Frizelle and colleagues' study of 33 people in Ireland. In addition to this, the variability in scores is in keeping with the profiles of people with Down syndrome who can differ hugely in areas of cognition and language ability (Karmiloff-Smith et al., 2016), both of which are drivers for reading (Boudreau, 2002; Lovell et al., 2023).

The fact that most of the sample read a significant proportion of MRM items is not surprising, given the similar findings of Frizelle et al. (2023). It highlights that adults with Down syndrome are reading many different items in their daily lives, and this can be shown when the outcome measure used is not measuring the difficulty of reading. This is due to the functional and meaningful nature of the items included in the checklist. The MRM revealed the reading-related strengths many of the participants had, something which is often not captured by formal, existing reading assessments used in the literature. These scores are also not surprising given the increase in community and educational opportunities available to people with Down syndrome (Moni et al., 2018). Additionally, Bochner and colleagues (2001) reported that the 30 adults with Down syndrome (aged 18 to 36) in their study read a variety of meaningful reading items such as books, magazines, letters, stories, plays and in one case,

the bible. In their study however, these items were generated by the research team and markedly less comprehensive than the number of items included in the MRM.

Table 8:
MRM average scores

	Average				
	Mean	SD	Median		Range
MRM Score	33.55	7.97	34		0 - 46
	MRM Score Range				
	0-10	11-20	21-30	31-40	41-46
Number of participants	2	3	36	48	19

Note: MRM= Meaningful Reading Measure Score, total items ticked. SD = Standard Deviation.

In addition to items listed in the MRM, participants were also asked if there was anything else that they read. Participants listed a total of 106 items. The high volume of items here is due to the specificity of responses e.g., particular / distinct websites, topics, books, or magazines that the participants read. Many of the items listed were in fact included in the MRM or could be conflated into items already listed e.g., one person added “*WhatsApp messages*” as a potential new item, but the MRM already included social media and text messages. Following filtration of all the responses, there were 20 new items listed that could *not* be conflated into items already listed in the MRM. These were drama scripts and speeches for public speaking (n=5); prayers and bibles (n=4); medications or prescriptions (n=3); personal or food diaries (n=2); orders in work (n=2); clothes tags / sizes (n=2); bank statements (n=2); exercise routines (n=2); rules/instructions (n=2) and Easy Read /PECs symbols (n=2). Jokes, Microsoft Word and PowerPoint, prices of items in shops, sheet music, food scanners in shops, horoscopes, Fitbit, and gravestones were all listed once.

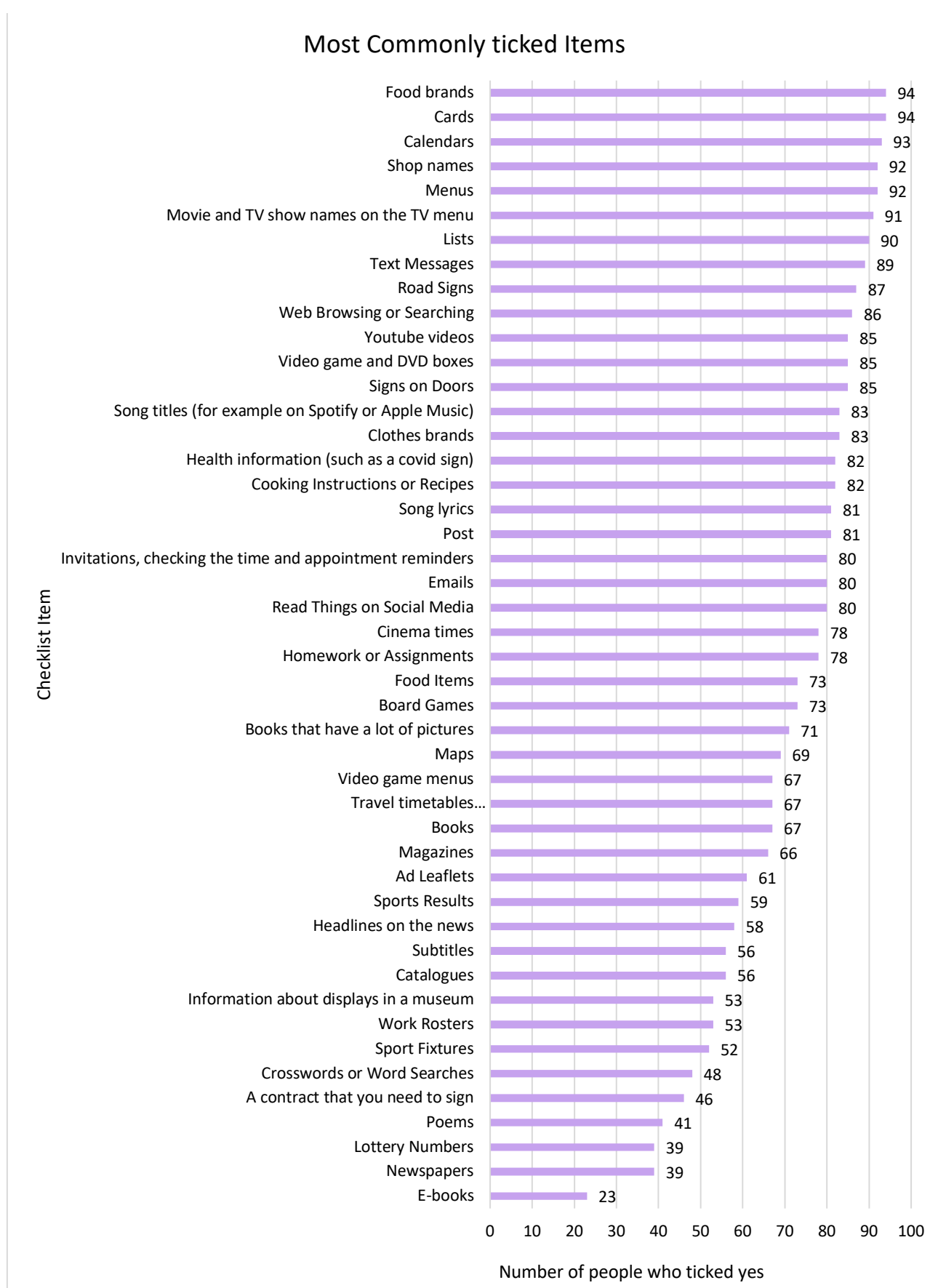
Although these additional items were not generated during the formation of the MRM, their relevance in the context of meaningful reading should not be ignored. One of the aims of

the MRM is to quantify most meaningful reading items read by people with Down syndrome. However, it is impossible to account for every personally meaningful reading item for each person, as this will differ across cultures and lifestyles. Thus, it is important to ask about items that may be missing, as the original collaborators who worked on the development of the MRM were a smaller sample ($n = 46$) and based in Ireland. As a result, the generation of items included in the MRM may be limited to a singular culture, education level or lifestyle. While it is not appropriate to include every new item added into future versions of the MRM, a strength of the tool is that it includes a space which asks about these items. This allows the MRM to be more individualised and culturally sensitive. When taking a social-cultural approach to literacy, one needs to consider the social and cultural environment of the person (Van Kraayenoord et al., 2001). Acknowledging these items supports the attitudes of a social-cultural approach to reading; if the tool used did not ask what else participants read, these valuable answers which were very personal to the participants would have been missed.

The items most read were ‘food brands’ (95.6%), and ‘cards’ (95.6%), and the least popular item ticked was ‘e-books’ (23.5%). For a detailed description of item frequency, see Figure 5. Overall, these findings are consistent with the previous findings of Frizelle et al. (2023) where ‘post’ was the most ticked item and ‘food brands’ was the second. ‘E-books’ was the least common item in their study also. This replication of results adds validity to the findings of the present study and the validity of the MRM. There is an obvious link between ‘post’ and ‘cards’, as many people receive greeting cards via post or mail. However, it is surprising that this was one of the most popular items read by the participants. Receiving post or mail has significantly diminished since the increase in online banking, email replacing letters and an increase in the number of companies using soft rather than hard copy materials. It could be hypothesised that reading cards accounts for most of the post received by people with Down syndrome. Sending greeting cards continues to be a very popular activity. In 2017, the UK

public spent 1.7 billion pounds on greeting cards (Greeting Card Association, 2018). It would be interesting to rank order the most common items read by typical populations as a comparison, however we are not aware of data reporting on this. ‘Food brands’ was the other most popular item read and is likely a reflection of the fact that people eat every day and read food brands as part of this. This is especially relevant given that adults with Down syndrome are being encouraged to make more independent dietary choices and are receiving education on healthy living (Caton et al., 2012; Mohammedi & Augusto, 2021). Courses such as these also are run by Down Syndrome Ireland (Down Syndrome Ireland, 2022). Ramsten et al. (2023) completed a study on the technology usage of adults with mild to moderate ID (n=11) in residential care homes. The authors found that the group used internet communication technologies to look up recipes and food brands, to make dietary changes and make food for themselves. Considerations and training regarding food preparation is also a part of independent living for people with Down syndrome (Jevne et al., 2022). Making choices regarding daily dietary preferences is becoming commonplace for adults with Down syndrome, as outlined in many residential service policies for people with ID (see Brothers of Charity, 2017). The likelihood of reading ‘food brands’ was also supported in the results of a study by de Graaf and colleagues (2019) in which American (n = 1955) and Dutch (n = 669) parents reported on the functional skills of their son or daughter with Down syndrome. In the study, 70% of parents reported that their son or daughter with Down syndrome independently prepared their meals at least ‘somewhat well’ in young adulthood (21-30 years of age). Furthermore, Krell and colleagues (2022) found that the life skills of greatest importance to adolescents and adults with Down syndrome were learning about healthy foods (35%) and preparing meals (34%) among others. Reading food brands is naturally part of this process.

Figure 5:
Frequency table of items ticked



Similar to the findings of Frizelle et al. (2023), there were a high number of individuals in the current study who reported that they read calendars $n = 94$ (95.92%), web browsing or searching $n = 86$ (87.76%), emails $n = 80$ (81.63%) and homework or assignments $n = 78$ (79.59%). This is possibly a reflection of the fact that adults with Down syndrome are partaking in further educational courses which involve reading emails and homework assignments (Prahl & Gilson, 2023), and are likely using tools such as calendars to attend and organise their classes. Many of the participants who filled out the MRM also indicated that they read signs on doors (86.73%, $n = 85$), road signs (88.78%, $n = 87$), shop names (93.88%, $n = 92$), lists (91.83%, $n = 90$) and travel timetables (68.37%, $n = 67$). This is likely linked to items which may be read in the workplace, the community as well as public transport. These items were also commonly read by participants in the study by Frizelle et al. (2023). As discussed previously, young people and adults with Down syndrome are increasingly accessing employment opportunities. For example, Channell and colleagues (2023) investigated the employment experiences of 100 people with Down syndrome via parent survey and reported that tasks completed by the sample in their various jobs included cleaning; food prep; ushering and greeting (collecting tickets); customer service; clerical tasks; stocking; product assembly; film and media work; outreach work; and one person volunteered with young children. The reading items discussed above are also consistent with experiences gained from employment tasks or general community engagement and are likely reflective of the daily, meaningful activities that adults with Down syndrome are doing.

With respect to general meaningful activities for enjoyment, socialisation and relaxation, a high number of participants ticked 'yes' to various items which fell under these categories. Reading a 'movie or TV programme title' was ticked by 91 people (92.86%), 'web browsing or searching' was ticked 86 times (87.76%), reading aspects of 'YouTube videos' was ticked 85 times (86.73%), 'cinema times' was ticked 78 times (79.59%) and 'board games'

was ticked 73 times (74.49%). Again, the high number of responses to these meaningful reading items is not surprising. These responses are similar to the leisure time practices reported by 11 individuals with Down syndrome (aged 20-38) in the Japanese study by Takataya and colleagues (2022). Six of the individuals reported that they spent much of their free time watching television, one reported that they played video games and two reported that they watched YouTube. Although perhaps there is minimal reading involved in these activities, reading is required to navigate channels, television menus, and remote-control buttons. Furthermore, authors reported how their participants saved their wages from various jobs to buy CDs or magazines. This is reflected in this present sample where a significant portion of participants indicated that they read ‘magazines’ (67.34 %, n = 66) and ‘song titles’ (84.7%, n = 83). People with Down syndrome in the present study also indicated that they rarely read ‘e-books’ (23.47%, n = 23). This is in line with results of Frizelle et. al. (2023) who also reported this as the least commonly ticked item. To avoid repetition, this will be examined further in section 9.2.5. where the preferences for reading mediums are discussed.

Reading a book was a common response for participants, with 67 people (68.36%) reporting that they read ‘books’. As stated, the landscape in terms of reading for those with Down syndrome has changed significantly in the last 20 years. Reading culture has changed in that now younger individuals in typical populations are spending more free time on social media and using the internet as opposed to reading a book (Dukper et al., 2018). This is also the case in this sample of people with Down syndrome. While 67 of the participants reported that they read ‘books’, more participants (n = 80) indicated that they read things related to ‘social media’ (n = 80) or ‘web browsing or searching’ (n = 86). This is in keeping with the results of the study by Mihaila et al. (2020) in which the leisure time of 44 middle aged adults with Down syndrome was reported on. The authors analysed diaries filled out over a weeklong period by the adults with Down syndrome. They found that the participants spent less time

reading in comparison to other activities such as computer or iPad games. A preference for activities on a PC or mobile phone in comparison to reading was also highlighted in a Norwegian study of adults with Down syndrome (see Dolva et al., 2014). Therefore, the reading habits reported here align with existing literature regarding leisure time for people with ID. Adults with Down syndrome are showing a preference for the use of internet-based technologies, over books. Similar reading patterns have been reported within typical populations (Huang et al., 2014). There is a clear implication here for future reading interventions. This study along with the discussed literature has shown that internet-based activities are completed frequently by people with Down syndrome; and they may pose as a motivating goal in terms of framing literacy targets.

9.2.2 When do individuals with Down syndrome read?

In response to the question ‘When do you read?’, the free text answers were coded into 11 categories. In order of the most to least popular times, these were ‘afternoon or evenings’, ‘all the time’, ‘weekends’, ‘only when necessary’, ‘free time or when time allows’, ‘during the educational or workday’, ‘mornings’, ‘daytime’ ‘at home’, ‘when information is needed’ and finally, ‘most of the time’. Illustrative quotes and number of references for each category for this question are available in Table 9.

Table 9:
Qualitative content analysis of responses to “When do you read?”

Category/Code	Number of references	Illustrative Quotes
Afternoon or evenings	38	<i>“I like to read before I go to sleep”</i> <i>“after dinner at night”</i>
All the time	26	<i>“any time day and night”</i> <i>“all the time”</i>
Weekends	14	<i>“during the day at weekends”</i>

		<i>“at the weekend”</i>
Only when necessary	7	<i>“only when I have to”</i> <i>“only when I have too (that includes the books my mother makes me read so i do not lose my skills)”</i>
Free time or when time allows	6	<i>“if I am not busy”</i> <i>“when I’m free”</i>
During the educational / workday	5	<i>“at school with my teacher”</i> <i>“in college”</i>
Mornings	5	<i>“also in the morning”</i> <i>“before school”</i>
Daytime	4	<i>“as much as I can during the day”</i> <i>“day time”</i>
At home	3	<i>“when I am at home in my room”</i> <i>“mostly at home”</i>
When information is needed	3	<i>“I like looking up months and dates”</i> <i>“want information”.</i>
Most of the time	1	<i>“most days”.</i>

Firstly, it is evident from the responses that participants interpreted this question in different ways. Rather than naming specific time points during the day, some participants described how they read ‘at home’ *“mostly at home”* or others said during their ‘educational / workday’ *“at school with my teacher”*. As can be seen from these answers, the when and

where of the occurrence of reading can become conflated at times. Despite this interpretation, most participants did describe specific time points. In the paper by Frizelle and colleagues (2023) self-reported data from a cohort of people with Down syndrome (n=33) indicated that they read during the mornings, afternoons, evenings, and weekends. However, apart from that study, there is a lack of data documenting the times of the day when individuals with Down syndrome read, and therefore there are few studies with which comparisons can be made. Although, more attention has been given towards the daily lives / leisure activities of people with Down syndrome (Carr et al., 2008; Mihaila et al., 2020; Takataya et al., 2022), so associations can only be made against these activities and how this may correspond to reading at specific times in the day.

The dominant category within the responses was that the participants read during the ‘afternoons or evenings’. This was referenced 38 times. This is interesting as in their study of 216 adult students with ID, Jenaro and colleagues (2018) described how 45.8% of their sample reported that they used internet technologies most often in the evening. The authors of this study also reported that this contrasted with their typical population comparison group, who used internet technologies more at night, rather than the evenings. The authors did not give information as to how evening or night time were defined. Findings from the Jenero et al. (2018) study along with those from the current study suggest that the evening is a common time for reading activities or using reading skills in populations with ID. Participants described how reading was part of a daily ritual or relaxation time before bed or following meals “*I like to read before I go to sleep*”. This illustrates that for the individuals in this study, reading was not something that was solely confined to an educational setting or practice. On the contrary, reading appears to be an elective practice used as a leisure activity that is, something to do to unwind and relax. For example, one participant described how reading was something they did after coming home from educational settings “*After I get home from my day programme*”. This

is consistent with previous literature in which adults with Down syndrome described reading as a form of leisure (Frizelle et al., 2023; Jevne et al., 2022).

There was considerable variation in the times when people with Down syndrome read. For example, there were six references to reading ‘during free time or when time allows’ “*Whenever i have time*” and there were 14 references to reading during the ‘weekend’ “*Mostly at the weekends, if its not school work*”. In the same vein, there were seven references to reading ‘only when necessary’ “*only when i have too (that includes the books my mother makes me read so i do not lose my skills)*”. Perhaps this highlights that for some people with Down syndrome, the purpose of reading is purely functional, and that furthering functional reading skills and social engagement would be a meaningful goal for these individuals. This type of approach to reading development for adults with Down syndrome was highlighted in Prah and Gilson’s paper (2023). Based on participants’ academic schedule, the authors identified reading goals which were functional and relevant to their everyday lives. In this instance, the use of a tool such as the MRM, to act as a concrete guide to goal setting for literacy interventions and to reflect functional and meaningful intervention outcomes, would have been beneficial.

Many participants described how reading was not limited to a specific time point as they read ‘all the time’, this was referenced 26 times. This was likely influenced by the method used in this study, as once the participants had gone through the checklist in Section 2 of the MRM, it may have been highlighted to them (via the items they ticked such as signposts, books, or menus) that reading is embedded in their everyday functioning. When considering a social-cultural approach to literacy, the scope of what underpins reading is broadened (Warschauer, 1997). Naturally, following completion of the MRM, participants’ definition of reading may have expanded to include more functional activities. Based on the findings of Frizelle et al. (2023) where 46 collaborators with Down syndrome generated the items included in the MRM, people with Down syndrome view reading as an activity completed throughout their day.

Similar to typical populations, many of the participants in this study are reading consistently throughout their day, for a range of reasons. An increasing number of people with Down syndrome are gaining employment (Grantley et al., 2003; Tomaszewski et al., 2008); obtaining independence (Ijezie et al., 2023); participating in social groups (McCarron et al., 2017) and engaging with their various communities (McCarron et al., 2017). Given the need for reading skills to facilitate participation and inclusion in society, it is unsurprising that reading ‘all the time’, was a common response. It reflects how reading is integral to the daily lives of many people with Down syndrome.

9.2.3 Where do people with Down syndrome read?

Following analysis of the free text answers to this question, responses were organised into eight categories. These categories, in order of the most to least frequent were ‘home’, ‘educational settings’, ‘public spaces’, ‘online settings’, ‘in employment or work’, ‘when on transport’, ‘everywhere’ and ‘community or social events’. See Table 10 for the complete list of the categories and some illustrative quotes from participants.

Table 10:
Qualitative content analysis of responses to “Where do you read?”

Category/Code	Number of references	Illustrative Quotes
Home	85	“at home in my room” “I mostly read at home”.
Educational settings	32	“at school” “at college”
Public spaces	26	“Sometimes when I go out I read” “shopping, doctors in my community, swimming”
Online settings	17	“online” “online-anywhere”.
In employment or work	10	“at work” “at..my job

When on transport	8	<i>“in the car going places”</i> <i>“on the bus”</i>
Everywhere	5	<i>“is an everyday thing for me”</i> <i>“everywhere”.</i>
Community or social events	4	<i>“At a youth club”</i> <i>“when I go out with friends”</i>

The most common response given to this question was that reading was carried out at ‘home’. It was referenced 85 times by the participants. This is in keeping with the results of Frizelle et al. (2023) who also found that reading was mostly completed at home. Reading was also reported to be done in a variety of other settings, both for necessity and for meaningful reasons such as relaxation. For example, reading was reported by eight people in the study as something which was done whilst travelling or on ‘transport’ *“in the car going places”* ... *“I read in the car”*. One could hypothesise that reading serves a form of relaxation when on transport. It also aligns with literature which states that reading is a form of leisure for people with Down syndrome (albeit reduced compared to the use of internet technologies). For instance, Mihaila et al. (2020) reported on a cohort of 44 adults with Down syndrome who read for leisure for a minimum of 13 minutes a day.

It was evident that within the current study, many of the participants were accessing further education. There were 32 references to education such as reading *“at college”* and *“at school”*. This is reflected in the reading habits of typical students (Owusu-Acheaw & Larson, 2014). As has been presented in previous chapters, there have been improved commitments and attitudinal changes across the world which have altered the views on education for both children and adults with Down syndrome (The Education Act, 1998; Travers et al., 2018). There also has been increased attention given to the development of post-secondary school education programmes for adults with ID. Whirley and colleagues (2020) investigated the availability of postsecondary-education-programs for people with ID in the USA. They found

that within the literature, there has been a steady increase in the number of papers which provided post-secondary-school education for those with ID. Of the 68 studies included in the review, 5% were published between 2008 and 2009, 47% were published between 2017 and 2018, and just under one third were published in 2018. There is less data on how this translates to opportunities for education in Ireland. However, a recent paper which investigated the post-school outcomes for those with ID (see Aston et al., 2021) suggested that there is a lack of post-school courses available for this population. Nevertheless, perhaps the fact that many of the participants reported that they read at school or at college, reflects that there is a growing appreciation of quality and equitable education for people with Down syndrome (Bills & Mills, 2020; Flood, 2013).

Several people referred to reading within ‘public spaces’, ‘employment’ and at ‘community or social events’. Participants acknowledged how they read in a variety of public places and that it was a consistent activity they completed throughout the day. One person said *“a restaurant and to do my drama and sports things right. I read lots of different times every day”* and another stated *“shopping, doctors in my community, swimming”*. These responses highlight how meaningful reading positively contributed to the community experiences of the participants. Belonging and community engagement has been highlighted as an area of importance for adults with ID. This was highlighted by Renwick and colleagues (2019) exploration of independence and community engagement of 24 people with ID (six of whom had Down syndrome). The authors found that settings such as libraries, shops, social groups and clubs were all cited as places where the adults with ID felt that they were socially included and experienced a sense of belonging. This current sample has given direct examples of reading in places such as these, and how reading facilitates many different forms of functioning in community settings. These responses further highlight how reading is important, relevant, and has clear potential to support inclusion in the lives of people with Down syndrome.

9.2.4 Why do people with Down syndrome read?

When asked why they read, participants in the current study cited examples such as ‘personal learning’, ‘enjoyment’, ‘independence’, ‘education’, ‘necessity’, ‘to make informed decisions’ and for ‘socialisation’ among others. (Table 11). Much like the general population, those with Down syndrome read for a number of reasons including for leisure (Jevne et al., 2022) and for functional reasons (Mohammedi & Augusto, 2021). For example, in Jevne et al. (2022) researchers found that reading was a leisure activity of young people with Down syndrome. Similar reading habits for middle aged people with Down syndrome were reported by Mihaila et al. (2020) and Bochner et al. (2001). In addition to this, papers have shown that reading is used for daily functioning for people with Down syndrome. Mohammedi and Augusto (2021) gathered positive feedback from trialling an Easy Read app with three people with Down syndrome to access and read recipes, learning materials and instructions about food.

Table 11:
Qualitative content analysis of responses to “Why do you read?”

Category/Code	Number of references	Illustrative Quotes
Personal learning and interests	49	<i>“To learn new things For information about football”</i> <i>“I love looking up things about my dog on the internet”.</i>
Enjoyment or passing the time	30	<i>“I enjoy reading mainly because of the fun of it”</i> <i>“it’s nice and relaxing”.</i>
Independence or accessibility	21	<i>“know things for myself”</i> <i>“Lets me do things I like. For example cooking”.</i>
To socialise	8	<i>“To connect with friends”</i> <i>“read out loud to friends that cannot read”.</i>
For education	4	<i>“to do class work”</i> <i>“because some of it helps me for school</i>

Necessity	3	<i>“I have to read “ “to learn to read</i>
Inclusion	2	<i>“It means I am doing the same thing as my sister” “to stalk my friends on Facebook and my brother on Instagram”.</i>
To make informed decisions	2	<i>“make my own choices” “I like to make decisions and choices”</i>
To keep safe	1	<i>“to keep safe”</i>

Reading for ‘personal learning and interests’ and ‘enjoyment or passing the time’ were two of the most coded responses from the participants. This is in keeping with responses from 22 autistic adults in a study by Chapple et al. (2021) who reported their rationale for reading was for learning, pleasure, to increase social understanding and for escapism. Although this current study was concerned with why people with Down syndrome read, this question also gave a large insight into the interests of adults with Down syndrome. The participants described that their various interests and hobbies could be accessed through reading *“I am a spurs fan and get alerts from Spurs Web App telling me all the club news. I play FIFA23 on PS5 - I like to be able to read all the team names and players”*. It is not surprising that this was such a common response given how in the present day, accessible information and learning is more readily available to people with Down syndrome than perhaps in previous years (Chinn, 2019; Whirley et al., 2020). Similarly, now more than ever people with Down syndrome are being encouraged to engage in lifelong learning (Moni et al., 2018; Whirley et al., 2020) and reading appears to enable this. Participants were interested in reading lyrics to sing, as illustrated in the quote, *“[...] I love singing and I look up the lyrics”*. Another participant was interested in famous people; reading allowed them to access information about these people *“I like my pop stars”*. As stated, ‘enjoyment or passing the time’ was also associated with reading. Perhaps

like many other typical populations, people with Down syndrome simply enjoy reading “*I enjoy reading mainly because of the fun of it*”.

The enjoyment of reading was also expressed by participants in the social-cultural reading study by Deagle and Amico (2016). They noted that reading was ‘good’. Similarly, a participant with ID in Prahl and Gilson (2023) described how they enjoyed the reading intervention they received as it helped them to read about things they were interested in. Furthermore, the opinions of 33 adults with Down syndrome in Frizelle et al. (2023) also indicated that enjoyment was one of the main reasons for reading. Other responses to this question detailed how reading facilitated independence; socialisation; inclusion; and making informed decisions. It is necessary to highlight the importance of these categories as they pertain to safeguarding and quality of life for people with Down syndrome. In de Graff et al. (2019), the parents of 2,658 people with Down syndrome described how by 31 years of age approximately 30% of their sons / daughters could travel independently, and 34% were living independently. As has been discussed in Chapter 1 and well documented within the literature, adults with Down syndrome want more independence (and skills which facilitate independence), autonomy and recognition as adults (Deagle & Amico, 2016; Krell et al., 2021; Scott et al., 2014). Furthermore when 408 parents in the US were asked about future goals for their son / daughter with Down syndrome, living independently was highlighted in their responses (Santoro et al., 2022). There were 21 references to ‘independence or accessibility’ and two specific references to ‘informed decision making’ by the participants in this current study. To achieve independence, the ability to make informed decisions is important. However, achieving independence and skills which facilitate this has been reported to be challenging for people with Down syndrome (Khan et al., 2021). For example, in a paper by Scott and colleagues (2014) 12 adults with Down syndrome practiced life skills with their families to prepare them for independent living. However, they also experienced difficulties living at

home; as they weren't always respected as adults. This study provides key information on how reading facilitates levels of independence for people with Down syndrome and the participants were able to recognise this. For example, participants explained that they read for very practical reasons, *"look at my diary and see what is planned for the day or week"*, *"I search online to see if certain foods have gluten in them or not because I am coeliac"* and to know *"what's going on around me"*. This information is invaluable as it can direct the content of literacy programmes for adults with Down syndrome, informed by people with Down syndrome themselves. The participants described the practical ways they seek independence and achieve life goals by in many cases, reading *"I like to know what my day will be"*. The current study adds to the literature as it captures the way independence is achieved through reading from people with Down syndrome, directly.

Similarly, the participants made eight references to reading for social reasons. These examples are in line with studies which have highlighted the importance of communication, socialisation, and friends to people with Down syndrome (Ijezie et al., 2023; Jevne et al., 2022). Participants described how they read because it allowed them to engage with family *"With Mum & Dad it's nice to do"*. It also facilitated the use of social media as well, with one person saying, *"social media and messaging with my family and friends"*. Given that social media usage is becoming more prevalent in the lives of adults with Down syndrome (Ramsten et al., 2020; White & Forrester-Jones, 2020), reading for this reason is not surprising. It is evident that people with Down syndrome read for leisure and for a variety of other reasons. This study highlighted how interventions which foster reading outcomes in these areas, such as leisure reading for personal interests, socialisation, and independence, would be meaningful to people with Down syndrome. The MRM has also shown an ability to profile what adults with Down syndrome read as well as why, when, and where, which can inform future reading interventions and help to meet said outcomes, interests and wishes more readily.

9.2.5 What is the preferred reading medium for adults and young people with Down syndrome?

This was a closed question, and 95 participants chose to answer it. Relevant data for this question is presented in Table 12. Six options were available to select, these were ‘a paper book’, ‘an e-book like a Kindle’, ‘I don’t like to read’, ‘I cannot read’, ‘listening to audiobooks’ and ‘on a tablet or computer’, with a follow up question asking participants the reasoning behind their response. The most common reading medium preference was ‘reading on a tablet or computer’ (45.3%), followed by reading ‘a paper book’ (28.4%). Two individuals reported that they could not read, and eight reported that they did not like to read (see Figure 6 for preference frequencies). Data from the follow up question was analysed using qualitative content analysis under the heading of each choice. Six participants chose to not give a reason why they responded the way they did.

Figure 6:
Preferred reading medium

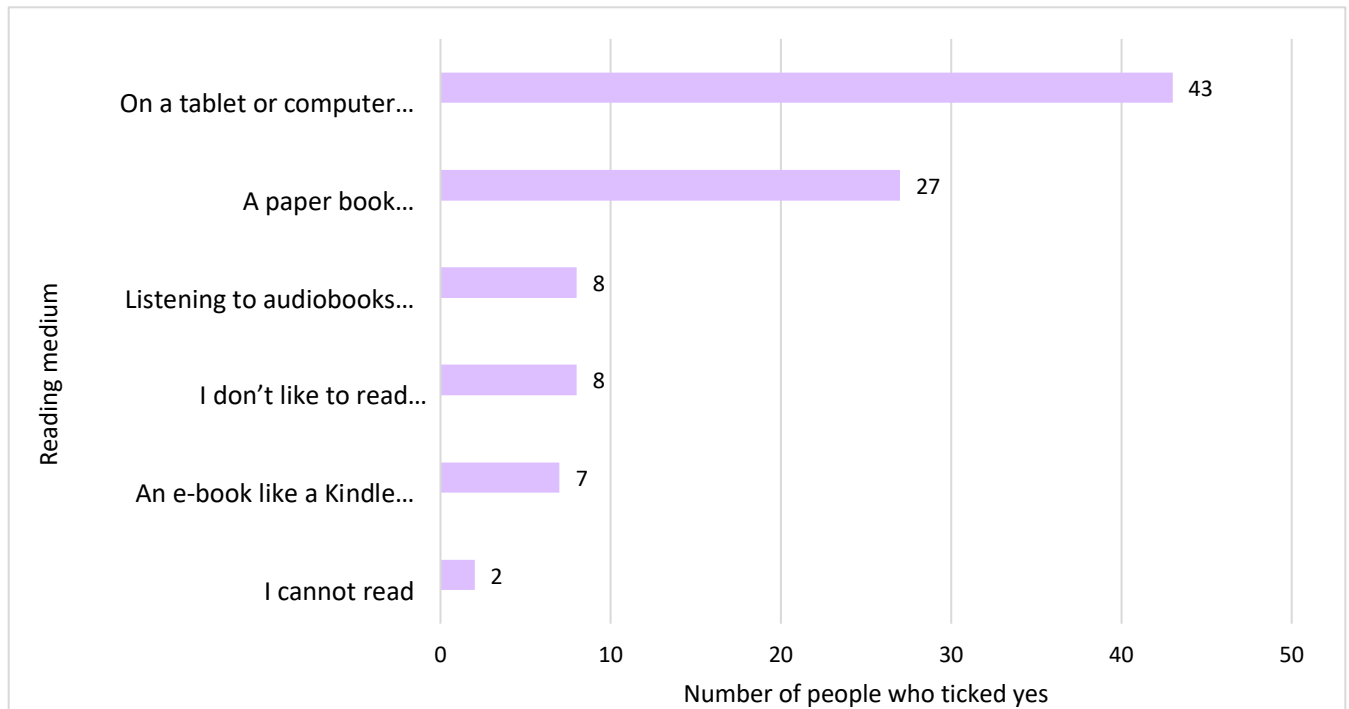


Table 12:
Qualitative content analysis of choice questions.

Medium of choice	Categories	Illustrative Quotes
Computer or Tablet	General preference for technology (13)	<i>"Because I read more online than anything else"</i> <i>"I love my iPad"</i>
	Easier to read or use (11)	<i>"It can be easier to use"</i> <i>"I find it the easiest"</i>
	Access information (10)	<i>"I look up information on my tablet"</i> <i>"Because it has up to date information"</i>
	Features available via technology (8)	<i>"I can save information with screenshots"</i> <i>"Because I can read on the screen and music in background".</i>
	The ability to change text sizes (3)	<i>"I can adjust the size of the text"</i> <i>"Then I can change the size if I need to"</i>
	Social media access (2)	<i>"I like social media, TikTok, snapchat, Instagram, Facebook"</i>

	As it is in line with future career goals (1)	<i>"I want to be a youtuber"</i>
Paper Book	Books are easier to read (8)	<i>"Because it is easy for me to read"</i> <i>"I like to read in a book so I can follow along easier".</i>
	Sensory aspects of a book (8)	<i>"I like the feeling of a book. I love paper books because they have a great smell"</i> <i>"I like to feel the paper and turn the pages"</i>
	Independence and familiarity with books established (7)	<i>"I read books all the time, like reading stuff day and night"</i> <i>"I can choose any of my books and read them without help".</i>
	Learning (3)	<i>"it good to test your brain"</i> <i>"why to learn"</i>
	Visual support (3)	<i>"I like books with pictures which a paper book has - it is visual"</i> <i>"bookmark front cover gives me clues to the story"</i>
	Break from screens (2)	<i>"So that I do not get bad eyesight looking at a screen And I can follow the words in a book"</i> <i>"To take breaks from phone/ computers".</i>
	No preference	<i>"I like both books and my laptop"</i>
Listening to audiobooks	Expression of enjoyment (6)	<i>"because I love to listening and read new things"</i> <i>"I like listening to books and music".</i>
	Easier to understand (2)	<i>"easier and clearer"</i> <i>"I find it easier to understand when I listen to audiobooks"</i>
	Can access on a mobile phone (1)	<i>"I can listen on my phone".</i>
E-Book or Kindle	Easier to read (3)	<i>"easier to see"</i> <i>"these are much easier to read".</i>
	Easier to carry (2)	<i>"I always have it with me at home and in car trips"</i> <i>"It's small and easy to carry around with me".</i>

I don't like to read	Reading is not enjoyable (2)	<i>"I don't like it"</i> <i>"just don't like to"</i>
	Reading is boring (1)	<i>"It's boring"</i>
	Reading is too difficult (1)	<i>"Others [options] too hard for me",</i>
	Only reads when necessary (1)	<i>"sometimes I have to".</i>
I cannot read	n = 2	

Note. () = Number of times code was referenced. n = number of people who chose this option.

The most popular choice was reading on a 'tablet or computer' with just under half of the participants (45.3%) choosing this option. The participants from Frizelle et al. (2023) also indicated this as their top preference. Participants in this current study cited a variety of reasons for this choice and the most common response was that reading on a tablet or computer was just their general preference *"Because I like my laptop and phone and they are nice"*, *"Because I read more online than anything else"*. The second most common category explained how the participants felt a tablet or computer was 'easier to use', *"I find it easy to read"* *"The laptop is quicker for me"*. The third most referenced category for this choice indicated that people with Down syndrome were able to 'access information' and reading material for themselves *"I can look things up using computer or phone"*, *"I do not read books or stories but I do read Wikipedia, maps, weather and news on my phone or iPad"*. Eight people within the sample also indicated that they liked using a computer or tablet as the 'features of technology' aided them when they were reading *"Because I can read on the screen and music in background"*.

Papers by both Giulia-Cataldo and Oakhill (2000), and Mangen and colleagues (2013) proposed that those who have comprehension difficulties may find reading on a computer screen difficult, as the visual support of localising a word onto a specific part of a page has

been shown to aid comprehension; a feature which is eliminated by the scroll bar of a computer or tablet. Given that people with Down syndrome have been described as ‘poor comprehenders’ with respect to their reading (Groen et al., 2006; Loveall & Barton-Hulsey, 2021), it is interesting that there were so many references indicating that reading a tablet or computer was easier (11 references) or that participants just had a general preference for technology (13 references). Comprehension difficulties explicitly related to using a tablet or computer were not substantiated by the responses in this study.

The MRM results indicate a clear preference for internet technologies in the sample. This aligns with recent literature which suggests that people with ID are using internet technologies (Jevne et al., 2022; Ramsten et al., 2020; White & Forrester-Jones, 2020). In a paper by Fritz (2017) 107 caregivers from nine countries reported that individuals with Down syndrome aged 10 to 25 years frequently used tablets (88%), mobile phones (88%), and computers (75%). Gomez et al. (2017) and Jevne et al. (2022) both noted that people with Down syndrome are frequently using smart phones and computers. However, as has been discussed in Chapter 3, the literature has shown that there may be a technology usage gap between individuals with ID and typical populations (Hoppestad 2013; Ramsten et al., 2020). For example, the study by Alfredsson et al. (2020) indicated that adolescents with ID (13-20 years) had significantly lower access to internet technologies and the internet than their typical peers. Similarly, Jenaro et al. (2018) found that a sample of 216 adult students with ID, had lower access to internet technology tools in learning contexts compared to typical students in universities. It is evident from this study that people with Down syndrome have shown a clear preference for reading on tablets or computers and are indeed using these technologies for personal learning. This has clear implications for reading interventions such as ensuring access to appropriate internet resources within academic settings. It could be assumed that given that reading on a tablet or computer is a popular choice; perhaps future reading interventions should

consider delivering materials via internet technologies. This is something that is already being explored in speech interventions for people with Down syndrome (González-Ferreras et al., 2017); to practice reading comprehension (Löfgren-Mårtenson, 2008); and to develop work skills (Gomez et al., 2017). Future reading interventions for people with Down syndrome should consider what is the best medium to deliver interventions, as this may facilitate better engagement with intervention tasks. A tool such as the MRM could be used to ascertain the person's preference.

Reading on a paper book was the second most common choice (28.4%). Given the emerging literature which suggests that people with Down syndrome now prefer internet technologies over books (Mihalia et al., 2020; Dolva et al., 2014), this result is unsurprising. It also mirrors research in the general populations which suggested that book reading is still a common practice for young people (e.g., Loh & Sun, 2019). Although, reading via tablet or computer was the more common choice in this study, book reading was still favoured in comparison to e-books or audiobooks. This is also the case in typical populations, as shown in a US based, telephone interview survey completed by Faverio and Perrin (2022) where 1,502 typical adults preferred reading a book over e-books or audiobooks. Reading a book was the second-most common choice for participants with Down syndrome in Frizelle et al. (2023). However apart from that study, no other data exists on reading medium preferences for ID populations.

For the participants who indicated that they preferred reading paper books, many reasons were given. The most frequent responses for this choice were that book reading was 'easier' and that the participants enjoyed the 'sensory aspects of a book'. *"I can put the book in my bag"* and *"I like the feeling of a book. I love paper books because they have a great smell"*. There are clear similarities in the reports of the participants in this study and those from a study carried out in Singapore completed in 2019 (Loh & Sun, 2019). Many participants in

that study preferred paper books and responses resembled the comments in this current study *“I prefer using printed books, because I like the feel of turning pages, holding a book”* p. 667.

Preferences for reading a book in adulthood may also be influenced by the previous attitudes of parents towards shared book reading, which established the habit of reading a book in childhood. There have been investigations into shared book reading activities between parents and children with Down syndrome. Results from these studies suggest that most parents engage their child with Down syndrome in shared book reading on a regular basis (Ricci & Osipova, 2012). For example, in a study by van Bysterveldt and colleagues (2010) of the home literacy environments of families of a child with Down syndrome, 72% of parents of 9-14 year-old-children had home reading practice weekly, and 31.5% did so daily. Thus, the impact of previous home literacy environments on book reading for people with Down syndrome may be relevant in the context of this study; as people with Down syndrome live at home for longer (Foley, Girdler et al., 2014; Jobling & Cuskelly, 2002). If shared book reading is still practiced into early adolescence for the families in the van Bysterveldt et al. (2010) study, it is not surprising that reading books was such a common preference in this current sample. However, further investigations into the home literacy environments of adults with Down syndrome in the context of preference for reading paper books is needed to confirm this influence.

Additionally, the participants acknowledged the ‘visual support’ paper books offered. Three people in the sample stated how pictures within books offered them clues to the story or how a physical bookmark was useful to them when reading *“I like books with pictures which a paper book has - it is visual”*, *“I like pictures”* and *“bookmark front cover gives me clues to the story”*. The visual support offered by paper books is something that may be relevant in terms of future supports for book reading for people with Down syndrome. Although this was reported by only three of the participants, it does align with the supports used in Easy Read documents as well as the behavioural phenotype of people with Down syndrome, as they

illustrate strengths in visual memory (Godfrey & Lee, 2018). One of the core aspects of Easy Read documents is the visual support provided with each piece of information (Nomura et al., 2010). Three people in the sample acknowledged the contribution of visuals to their reading success. If these supports are deemed useful by the reader, particular attention should be given to incorporating visuals into written materials for reading interventions for people with Down syndrome. Similarly, a preference for visual information may also explain the low preference for audiobooks in the sample.

Finally, when asked which reading medium they preferred, eight people reported that they didn't like to read, and two reported that they could not read. This accounts for 10.2% of the sample. This is similar to the 11.3% of over 16-year-olds who did not or could not read in the paper by Ratz (2013) which reported on the reading skills of children and young adults with Down syndrome. However, this statistic was obtained via teacher report, so results need to be interpreted with a degree of caution as they only observed the students in one setting. This is lower than the roughly 21% of the sample in Frizelle et al., (2023) who indicated that they didn't like reading. Participants in the present study who responded this way described how reading was boring or that they only read when totally necessary *"just don't like too"*, *"i sometimes have too"*. As expected, no reasons were given for the two people who said they could not read. Only a small number of people responded this way, but it would be interesting to see how this would correlate to a larger and more culturally diverse sample. It could also be deduced that participants were referring to reading as part of a leisure activity rather than meaningful reading, as the participants may have interpreted this question as reading mediums used for leisure reading, not every day functional reading.

9.3 What do people with Down syndrome find hard about reading?

When asked what participants felt was difficult about reading, thirteen categories were derived from the data. Some of the most popular categories were 'words that are too complex

or unknown'; 'accessibility of text size, font, or visuals'; 'too many words' and 'understanding and remembering information' (See Table 13).

Table 13:

Qualitative content analysis of responses to "What do you find hard about reading?"

Category/Code	Number of references	Illustrative Quotes
Words that are too complex or unknown	36	<i>"Sometimes the words are hard and I don't know them"</i> <i>"Sometimes I cannot read a word and don't understand it".</i>
Accessibility of text size, font, or visuals	30	<i>"Sometimes it is hard to read because my eyes may get tired. When books have pictures it is like having a brea[k] for your eyes"</i> <i>"Words are too small".</i>
Too many words	16	<i>"too much words"</i> <i>"If there are too many words in the same place".</i>
Understanding and remembering information	15	<i>"find it hard to describe what the book is about when people ask..."</i> <i>"probably to remember the whole sentence when I read".</i>
General negative feelings	5	<i>"I don't like it"</i> <i>"It is too much for me to read and you can't stop"</i>
Happy with current reading ability	4	<i>"nothing"</i> <i>"reading for me is easy"</i>
Didn't know	3	<i>"don't know"</i>
Uninteresting content	3	<i>"If it's boring"</i> <i>"things that are not interesting"</i>
Appropriateness of books	2	<i>"books with short sentences can be for kids not adults"</i> <i>"Some books are challenging to read"</i>

Developed strategies	2	<i>“If there were words I don’t know I’d look it up on Google. If it’s too small print I could take a photo and make it bigger on my iPad.”</i>
Assessments	1	<i>“I find exams hard”</i>
Outside distractions	1	<i>“Outside distractions!! Phone I pad”</i>
Preference for original texts’	1	<i>“I don’t really like Easy Read documents because I prefer to read the original version”</i>

The most common responses from participants fell under the category of *‘reading words that were too complex or unknown’*. This was referenced 36 times. Frequently, participants described how they found words they didn’t understand or know challenging *“I don’t always understand the words. They are difficult words” ... “lots of words that I don’t know”*. It has been theorised that difficulty with language knowledge relates to reading comprehension difficulties in readers with Down syndrome, as discussed in previous chapters (Laws et al., 2016; Nash & Heath, 2011; Snowling et al., 2008). The difficulty with new words or language knowledge reported in the sample aligns with the results of Loveall and colleagues’ (2023) paper where they found that language comprehension was the only unique, significant explanation of variance in the reading comprehension abilities of adolescents and adults (n=21, aged 16-36) with Down syndrome; meaning that those with better language comprehension had better reading comprehension scores.

Participants described issues with reading words which may require the use of more phonological awareness skills e.g., *“Pronunciation of words I’ve never heard of”* or reading *“long words”*. People with Down syndrome have been shown to experience difficulties with phonological awareness skills although have been shown to respond well to intervention (Næss, 2016). Readers with Down syndrome appear to rely on phonological awareness skills to a lesser degree than typically developing children, especially in word-recognition tasks. However, when irregular or new words which can’t be automatically decoded present themselves,

existing phonological knowledge is considered to have a stronger effect on reading (Mengoni, et al., 2014). This means that because people with Down syndrome use phonological awareness skills less than typical populations, this can impact them negatively when reading novel words. Participants illustrated a level of insight into how this difficulty manifests in real world scenarios, in that they frequently experience words they cannot read, and that this is difficult *“I find it hard to break down difficult word names”*. This is reflective of the reading difficulties adults with Down syndrome had in the study by Morgan et al. (2013). The adults in that study demonstrated difficulties in blending and decoding words in community literacy settings. However, further research is needed which investigates the relationship between specific reading tasks and participants’ own perceptions of these tasks. This may reflect how specific difficulties impact functioning for people with Down syndrome.

Another common category was that reading materials were not accessible enough to the participants. There were 30 references to the fact that the participants often found texts too small or that certain fonts were difficult to read *“Sometimes it is hard to read because my eyes may get tired. When books have pictures it is like having a brea[k] for your eye” ... “too many pages, too many chapters, writing is too small, sentences are too long, difficult words. School textbooks were difficult to read”*. The frequent references to words within texts being too small may be explained by visual impairments experienced by people with Down syndrome (Krinsky-McHale et al., 2014). Issues with vision were also alluded to in three participants’ responses as to why they liked computers and tablets, as they could adjust the text size to make it bigger. Text size alone did not account for all the difficulties associated with the accessibility of texts. The lack of visuals, long and complex sentences, and long chapters were also recognised as difficult by the participants e.g., *“I don't like too many words without pictures to read...[.]”*.

Attention has been given to the formation of Easy Read documents in the context of healthcare, legislation, and public communication (Chinn, 2019). However, when forming Easy Read documents for individualised use, the making of the document needs to be in collaboration with the person with ID. This was highlighted by Chinn and Homeyard (2017), who when investigating the use of Easy Read documents across 42 papers concluded that accessible texts need to be individually tailored to meet the personalised needs of people with ID. There is also a lack of literature which shows how accessible texts such as Easy Read are used in everyday contexts (Chinn & Homeyard, 2017), especially in areas of meaningful literacy. One person in the current study actually expressed their dislike for Easy Read documents *“I don’t really like EasyRead documents because I prefer to read the original version”*. Data from this study suggests that people with Down syndrome are reading mainstream texts which are challenging to them. It may not always be possible to access Easy Read documents, and not every person with Down syndrome prefers Easy Read. Therefore, future interventions are needed to provide teaching and adaptive strategies for people with Down syndrome to become independent readers. Interventions such as these should support meaningful reading pursuits (whether they be academic or personal), so that people with Down syndrome may be fully included into society in ways which are important to them.

‘Understanding and remembering the information read’ was another noted area of difficulty for the participants. It was referenced 15 times. Participants implied that it was less about understanding specific words and rather about processing or comprehending the general point being made in the text. Participants’ responses included *“I find it difficult to read and understand”*, *“probably to remember the whole sentence when I read”*. These reports align with the available literature indicating that people with Down syndrome have a specific difficulty with reading comprehension (Nash and Heath, 2011). Similarly, people with Down syndrome can experience difficulties with expressive language (Finestack et al., 2013; Martin

et al., 2009). One of the participants explicitly referred to this issue in the context of reading *“find it hard to describe what the book is about when people ask”*. Thus, the reports from many participants experiencing difficulties with reading, understanding, and describing the information they read does align with the available literature.

Other participants expressed how they didn’t find anything difficult about reading and that they were ‘happy with [their] current reading ability’, *“reading for me is easy”*. Some felt that they ‘didn’t know’ or expressed a ‘general negative feeling’ about reading *“Hard to read”*. Additional issues that people raised were how ‘uninteresting content’ was challenging *“things that are not interesting”* or finding books with ‘appropriate reading levels’ was hard *“books with short sentences can be for kids not adults”*. All these categories emphasise how when setting reading goals for adults with Down syndrome, their individual interests, motivations, skill sets and wishes need to be respected. For example, two participants expressed how they had already developed strategies to facilitate reading comprehension, *“If there were words I don’t know I’d look it up on Google. If it’s too small print I could take a photo and make it bigger on my iPad”* and *“If I don’t know what the word says I ask someone”*. So, providing individualised reading support which builds on their already established strategies, would be more appropriate for those two participants.

As has been outlined in previous chapters, people with Down syndrome can experience unique difficulties in comparison to other populations with intellectual disability (Fernández-Alcaraz & Carvajal, 2020). Specific issues in general expressive language, overall syntax, verbal short-term memory, and phonological awareness skills have been noted (Abbeduto et al., 2007; Laws, 2004; Laws & Bishop, 2003; Martin et al., 2009; Muscat & Grech, 2023). This profile is theorised to manifest in readers with Down syndrome as a specific deficit in reading comprehension (Nash & Heath, 2011; Roch et al., 2021) and relative strengths in (established) word recognition (Martin et al., 2009; Pahl & Schuele, 2022; Rickett, 2011). Consequently, it

was hypothesised that participants would highlight issues such as understanding the language of more difficult texts, complex or novel words, understanding grammar, or remembering and processing what they had read. It was also hypothesized that they would recognise the benefit of visual support, given their relatively stronger visual processing skills (Godfrey & Lee, 2018; Laws, 2004). The answers from the participants broadly aligned with these hypotheses and described these reading difficulties from a practical and real-life perspective.

9.4 What do people with Down syndrome consider to be the best thing about reading?

Participants expressed many positive things associated with reading; these were organised into ten categories (see Table 14). The most common category, with 52 references was ‘knowledge and personal learning’. The second most common response which was referenced 46 times, fell under the category ‘entertainment’. Other categories mentioned to a lesser extent were ‘education’, ‘health and safety’, ‘hearing augmentation’ and ‘informed decision making’.

Table 14:

Qualitative content analysis of responses to “What is the best thing about reading”?

Category/Code	Number of references	Illustrative Quotes
Knowledge and personal learning	52	<i>“Knowing about what I am doing and what my friends and family are doing”</i> <i>“learning new things”.</i>
Entertainment	46	<i>“It is fun”</i> <i>“I love stories. And get lost when reading”</i>
Socialisation	13	<i>“I can talk to my friends about things i read”</i> <i>“I love to read to my sister”</i>
Relaxation	8	<i>“when i am reading i relax”</i> <i>“I can get away from everything”.</i>
Independence reading gives	6	<i>“make me independent”</i> <i>“book tickets, taxis etc”</i>

Negative feelings towards reading	4	<i>"I don't really like it, except for music and menus"</i> <i>"i don't like to read but i do like the stories".</i>
Education	3	<i>"It is my homework"</i> <i>"I read to help me spell words properly".</i>
Health and safety	2	<i>"keep me safe"</i> <i>"doctors blood test"</i>
Hearing augmentation	1	<i>"I sometimes can't hear to I like subtitles on tv"</i>
Informed decision making	1	<i>"to make choices and decisions"</i>

Reading was commonly described by the participants as a way to pursue 'personal interests and learning'. There were 52 references to this category. One person said *"I like maps and to work out where we are going and what things might be there to visit if we go on holiday. I have hundreds of books about birds animals, wildlife and photography"*, another said *"read all the gossip on reality shows"*. Over the last 20 years greater attention has been given to the personal wishes, interests, hobbies, and views of people with Down syndrome (e.g., Alderson, 2001; Dolva et al., 2014; Vaccarino et al., 2023). As a result, more appropriate insight into their interests and everyday experiences have been gained. For example, literature exists which has identified that adults with Down syndrome take part in plays and dramas (Alderson, 2001; Bochner et al., 2001); horticulture (Down Syndrome Ireland, 2022); sports (Bertoli et al., 2011) and contribute to research (Vaccarino et al., 2023). The responses to this question support this, for example *"I can find out what I need to know and am interested in"*. Young people with Down syndrome participate in a variety of cultural, physical, hobby/recreation and computer/media forms of leisure (Dolva et al., 2014). Thus, it is evident that the participants perceive reading as useful to pursue these activities and personal interests, in their leisure time. It is also evident that people with Down syndrome engage with a variety of texts for the same reasons typical populations do. When

it comes to meaningful reading, this study's findings highlight how reading goals need to be individualised to the interests of the person with Down syndrome. These interests should act as a blueprint for goal setting and reading development; as reading is being used by the sample to facilitate personal learning and interests already.

The best things about reading according to the participants were for reasons such as 'relaxation', 'socialisation', 'entertainment' 'education' and 'safety'. They shared their unique insight into what reading added to their lives. Reading was entertaining to many of the participants. Reading for entertainment was referenced 46 times and was simply fun; a hobby to be enjoyed "*It's fun*", "*Reading makes me feel happy, excited*". It also served as a relaxing pastime "*I associate it with relaxing*". However, it also served as a highly functional aspect of everyday life in areas of socialisation and participation. For example, there were 13 references to how the best thing about reading was that it allowed the participants to engage with others and socialise "*Talking to my friends and family about things I read*". Reading provided participants with topics to discuss with friends as well as being a medium of which socialisation relied on "*to contact friends (text or whatsapp)*". This data provides valuable insight into the practical, real-life implications for teaching reading skills to people with Down syndrome. Attention has been given in recent years to developing safe, meaningful, social inclusion for people with ID. In a paper by Vacarion et al. (2023), the negative implications of reduced social interactions and autonomy over interactions for this population following the COVID-19 pandemic were highlighted by a group of self-advocates with Down syndrome. Similarly, family members of those with ID reported the same negative experiences during this time in Ireland (Casey et al., 2023). Jobling and colleagues (2000) gave a course on understanding friendships, socialisation and safety with friends to seven people with Down syndrome (aged 18-21). Interestingly, much of the course material relied on some form of written text. However, the course's literacy

requirements restricted some of the member's participation. It is evident from both an intervention and outcome perspective that reading and literacy skills have a role in enabling social inclusion and participation for people with Down syndrome. The MRM provided a means for the participants to explain and identify how reading skills served them socially. Thus, future goals for reading interventions may be to target reading skills from a social-inclusion perspective.

Other things noted as the best thing about reading by some of the participants was how it enabled independence (referenced six times), health and safety (referenced twice), and informed decision making (referenced once). Reading allowed participants to achieve convenient everyday tasks such as booking taxis, reading restaurant menus, reading signs, have time on their own, and make choices and decisions for themselves *"I can have time on my own to read"*. As has been stressed in previous sections and chapters, independence and supported decision making is imperative in the lives of many people with Down syndrome (Ijezie et al., 2023). There is clear value in exploring literacy opportunities and goals for people with Down syndrome which focus on achieving decision making and independence. Devi and colleagues (2020) drew attention to this in their use of Easy Read documents to allow more independent decision making for people with moderate ID in residential settings. The results of this present study show that reading in the context of the above categories is perceived as valuable to people with Down syndrome. In their systematic review of everyday decision-making in the lives of adults with ID, Casey, Traynor et al. (2023) identified that people with ID regard being involved in decision making as important whilst also viewing support to make decisions as useful. This is especially relevant as in Ireland, the Assisted Decision Making Act 2015 came into effect in April 2023. This act outlines that people in Ireland are presumed to always have capacity to make a decision unless it is proven otherwise, by way of a capacity assessment. Furthermore, this act outlines that if the person

is able to understand a decision “given to him or her in a way that is appropriate to his or her circumstances (whether using clear language, visual aids or any other means)” (such as Easy Read) it should not be presumed that they do not have capacity to make the decision (Assisted Decision Making Act, 2015, p. 15). The present study draws attention to the fact that adults with Down syndrome are reading to help them to make decisions and achieve independence in their daily life. Given that they now are supported to do so in Irish legislation, reading skills will continue to become more relevant in the lives of people with Down syndrome. Thus, they should be supported to develop said skills in ways which are personally meaningful to them.

9.5 What would people with Down syndrome like to do with their reading?

There were nine categories established from the responses to this question. There were a variety of things the participants wanted to do with their reading. The motivations included ‘increasing [their] reading skills’, ‘employment’, ‘personal learning and passions’, to ‘read more independently’, and to ‘increase [their] understanding’. In contrast to this, some of the participants stated that they were ‘happy with [their] reading ability’. See Table 15 for a complete description of the categories and some illustrative quotes.

Table 15:

Qualitative content analysis of responses to “What would you like to be able to do with your reading?”

Category/Code	Number of references	Illustrative Quotes
To further improve reading skills	28	<i>“To read faster and to read more complicated things sometimes”</i> <i>“Read more words or read faster”</i>
To gain employment	25	<i>“progress to find work”</i> <i>“to get a good job”</i>
To continue to pursue personal	18	<i>“write a book about my life”</i> and <i>“I would like to read new things”</i>

learning and passions		
Happy with reading ability	11	<i>"I would like to read the long words but it doesn't matter much to me I just make up a word or skip it. I'm still happy"</i> <i>"Carry on just reading everything like I can already do"</i>
To read more independently	10	<i>"I would like to read without any help but sometimes I need help"</i> <i>"To read without help".</i>
To read more using internet technologies	9	<i>"to use the computer"</i> <i>"read on my phone, read on my computer".</i>
To increase reading understanding or comprehension	9	<i>"To read more words and understand them"</i> <i>"can read words but don't always know what they mean".</i>
Achieve further education	5	<i>"go to college"</i> <i>"go to [X] college".</i>
Use reading for socialisation	4	<i>"join a book club"</i> <i>"read to friends that cannot read"</i>

The most common response to this question was that participants wanted to further 'improve [their] reading skills'. With respect to this, participants wanted to develop their vocabulary *"To expand my vocabulary and knowledge"*, improve their reading speed and to read more words. Other responses instead reported that they wanted to read different things *"To read faster and to read more complicated things sometimes"*, *"I want to read stories"*. Similarly, nine people acknowledged their difficulty with reading comprehension, expressing their desire *"To have better understanding of some of the words"*. Like the previous question, the MRM allowed participants to highlight the invaluable insight they had into their own literacy difficulties. It also draws attention to the understanding people with Down syndrome

have of how improving their reading skills would result in them finding reading easier and having more success with reading tasks, *“To find it easier to read long paragraphs”*. Reading has been shown to be linked to stronger language and learning skills (Næss et al., 2021) and it is evident that the participants in this study could recognise this benefit of reading for their own learning.

The second most coded category was ‘employment’ (referenced 25 times). Participants wanted reading to facilitate them to access work. In Ireland, there is a 17.3% employment rate for people with ID (National Disability Authority, 2019). In the UK, the number of people in paid employment with ID is estimated to be as low as 5.1% (NHS Digital, 2020). In the US, integrated community employment among all adults with disabilities during 2013 was at 18.6 %. As has been presented previously, there are currently limited opportunities for people with Down syndrome to achieve their desired employment goals, such as full-time employment (Dyke et al., 2013; Scott et al., 2014). Reading and general literacy skills are fundamental for many job opportunities, and those with reduced literacy skills are less likely to access full time employment (Clark & Formby, 2013). It is evident that a substantial portion of the participants felt that reading goals which foster future employment opportunities was important to them. They wanted their reading skills to help them *“To get a good job”* or to *“Progress to find work”*. One person said, *“I want to be an author”* and another said, *“be able to read to get a job”*. The benefits of employment for both typical populations and those with Down syndrome have already been detailed in previous chapters. However, the responses from the participants add to the existing literature which supports the idea that employment is something people with Down syndrome are motivated by (Dyke et al., 2013; Scott et al., 2014). These responses also emphasize how people with Down syndrome may expect their reading skills to help them find employment, and that literacy goals which focus on employment may be motivating for them. This idea is not a new one. For example, in 1996, Rynders and Horrobin highlighted the value

of literacy goals which foster future employment for individuals with ID. However, the work reported on here aims to highlight that these reading goals should be meaningful, made in collaboration with the prospective jobseeker, and be relevant to the job the person would like to get.

The MRM allows for profiling of how people with Down syndrome feel about reading; inclusive of their goals for reading and what they find difficult. There were 18 references to ‘personal learning and passions’ within the responses to this question. Participants described how they wanted their reading to aid them to write a book about their life “*Write a book about my life*” or to read about personal interests “*Just enjoy learning about wild animals*”. These are key examples of personally relevant and motivating literacy goals for the participants and highlight how the MRM may be used to measure reading gains that relate to functional activities following intervention. Similarly, ten participants described how they wanted to be ‘more independent’ readers and nine expressed a wish to ‘read using more internet technologies’. Four reported how they wanted to use their reading to ‘increase socialisation’ opportunities “*read with mammy*”, “*read to friends that cannot read*”. Interventions which explore how this can be achieved for these participants are desirable and could start with practicing vocabulary that is frequent in their daily life, reading aloud or practicing using their preferred reading materials. In contrast to this, 11 people felt they were happy with their current reading ability “*like how I currently read. I am applying to go to college*”, “*Carry on just reading everything like I can already do*” and “*I do what I want to*”. These perspectives need to be valued and respected also. Perhaps other, more functional and motivational goals would be more appropriate for these participants. Meaningful reading is only meaningful, if the goals are made in a collaborative practice with the person themselves. This study has shown how adults with Down syndrome are very capable with respect to what they want from their literacy and these requests need to be respected also. Perhaps other, more functional, and motivational

goals would be more appropriate for these participants. Tokenism choice making or trivialisation of the actual wishes of people with Down syndrome will serve as a barrier to motivation in terms of literacy achievement. These realities and challenges of person-centred service delivery have been highlighted within the Irish context of ID services. In a paper by Jackman Galvin and Partridge (2022), staff who worked in residential homes with people with ID often felt confused about delivering person-centred care. Furthermore, they were aware of the injustice that the residents had very little choice over their own lives. Responses from the sample reported on here, emphasise the importance of using a tool such as the MRM to ensure adults with Down syndrome have authority over their own reading goals.

9.6 When considering total items read by individuals with Down syndrome, are scores impacted by 1) age and 2) place of residence?

9.6.1 Age:

To determine if there was a relationship between age and MRM score, a non-parametric Spearman correlation test was completed as the data was not normally distributed. No significant correlation was shown between age and MRM score ($r = 0.11$, $p = 0.275$), indicating that age did not seem to influence the MRM score of the participants in this study. However, it is important to acknowledge that the age range of the participants was 16-46 with a mean age of 24.34. As a result, there may not have been enough variation within this range to reflect significant age-related changes in reading for older people with Down syndrome. As explored in the opening chapters, there are many influences on reading development. Investigating the impact of age on the MRM scores of the participants was prioritised as an area of interest by the focus group in Phase 1. It was hypothesised that younger age may have been positively correlated with MRM score as 1) younger individuals are more likely to have been educated in mainstream school, and thus present with increased reading skills, 2) younger individuals are less likely to experience cognitive decline and 3) there has been greater attention and

expectations for individuals with IDs in recent years in terms of community engagement. In contrast to this, it was argued that there would be a positive correlation, as the life experience of older adults gives them greater exposure to the meaningful reading items displayed in the MRM. As stated, the results of the present study do not suggest an influence of age on the number of daily items read by people with Down syndrome. The results echo those presented in Frizelle et al. (2023) which also did not find a relationship between age and MRM score. As suggested by Frizelle and colleagues (2023), it is possible that the potential negative and positive factors indicating that one age group would out-perform the other, cancelled each other out. This could be because increased exposure to meaningful reading items negated the influence of reduced language skills or reduced reading interventions received, of the older population. Similarly, the increased educational standards experienced by younger people with Down syndrome may have cancelled out the influence of reduced life experience in terms of MRM items. As the concept of meaningful reading items is a relatively new one, it is difficult to compare the results of this study to available literature. These comparisons are also not entirely appropriate as reading proficiency level do not correspond to meaningful reading within assessments as shown by Frizelle et al. (2023). Although it is important to not conflate the number of items read with reading ‘well’ this result is interesting as it contrasts some literature on general reading proficiency which did suggest an influence of age. For example in Bertoli et al. (2011), in a sample of various groups of people with Down syndrome, for those above 40, only 11-29% could ‘read easily’ according to their families. Whereas for those below 40, between 34% and 52% could ‘read easily’. Perhaps the number of items read in everyday contexts is not as significantly impacted by age as reading proficiency is.

9.6.2 Place of residence:

In terms of place of residence, it was initially planned that multi-factor analysis would be used to investigate the influence of country of residence for participants from each

individual country. However, given the low number of international participants ($n = 32$), it was not possible to group by country. Consequently, the group was divided into those residing in and outside of Ireland, and a Mann Whitney- U test was used to determine if there were any significant differences between the two groups. Results indicated that there were no differences between those residing in and outside of Ireland ($p = .09$).

Attitudes towards people with Down syndrome can differ across cultures and countries. For example, inclusive education has been practiced in countries such as Italy since the 1970s. Whereas, Ireland has faced criticism for its delay in implementing appropriate inclusive education for students with disabilities (see Murphy, Thompson et al., 2023). However, state bodies now in Ireland are actively involved with organisations such as DSI in promoting ongoing engagement in education for adults with Down syndrome; as well as increasing the number and range of post-secondary school courses available for people with Down syndrome. Attitudes and expectations towards those with disabilities undoubtedly affects quality of life (Hästbacka et al., 2016) as well as educational outcomes (McKinlay et al., 2022). Ireland has one of the highest rates of people with Down syndrome in Europe (Lagan et al., 2021). As a result, attitudes and expectations towards people with Down syndrome may be more positive, and this may impact quality of life outcomes for people with Down syndrome. As a result, it was important to investigate whether place of residence influenced the meaningful reading experiences of adults with Down syndrome. However, in many ways the lack of difference between those who live in Ireland and those who did not, was not surprising. Perhaps the significant development and appreciation for education for those with Down syndrome has resulted in similar experiences of meaningful reading across the world. It is also noteworthy that the mean age of the sample was 24.34 years of age ($SD = 6.66$). There were similar mean ages across each country. For example, those from the United Kingdom had a mean age of 23.36 ($SD = 6.4$) and those from the United States of America had a mean age of 24.75

(SD=10.05). It could be argued that the lack of difference between scores is indicative of the increased educational opportunities for younger people with Down syndrome across the world. It is also likely that the reduced sample size of the international participants significantly limited the likelihood of exploring any true differences between Irish populations and other countries.

9.7 Is there a relationship between age and 1) preferred reading medium or 2) reading habits of people with Down syndrome with respect to reading new media, community reading or personal reading items?

9.7.1 Preferred reading medium

A Fisher exact test was completed to investigate whether there was a relationship between age and a certain reading medium preference. Ages were grouped into three categories (16-25, 26- 37, 38- 46). Ninety-five people chose to answer this question. There were 65 participants in the 16-25 age group, 23 in the 26-37 group and seven in the 38-46 group. Percentages of reading habits grouped by age-group is available in Table 16. A Fisher's exact test did not indicate that any age group was significantly more likely to choose a certain preference, ($p = 0.141$) (See Table 16).

Table 16:
Grouping according to age and preference

Age	Choice							Total
		A paper book	An e- book like a Kindle	I cannot read	I don't like to read	Listening to audio books	On a tablet or computer	
16-25	Count	19	5	0	4	7	30	65
	%	29.2%	7.7%	0.0%	6.2%	10.8%	46.2%	100%
26-37	Count	6	1	1	2	1	12	23
	%	26.2%	4.3%	4.3%	8.7%	4.3%	52.2%	100%
38-46	Count	2	1	1	2	0	1	7
	%	28.6%	14.3%	14.3%	28.6%	0.0%	14.3%	100%
Total	Count	27	7	2	8	8	43	95
	%	28.4%	7.4%	2.1%	8.4%	8.4%	45.3%	100%

Note: % is within each age category

The results indicated that reading using a tablet or a computer was the most common choice across all age groups. It was anticipated that younger individuals would exhibit a preference for a tablet or computer due to the trends within typical populations for younger individuals to exhibit increased internet-technology usage than older populations (Castellacci & Schwabe, 2018). For example, high levels of computer and technology usage were reported in 132 young typical students (aged 13-19) by Müller (2021). The author reported that 40 respondents (30.3%) spent up to one hour a day on a computer and 19 respondents (14.4%) said they spent 4-6 hours a day. No comparisons against older groups were reported. Although, the results of this present study show that the use of internet technologies was the preferred medium for reading for adults with Down syndrome, regardless of age. However, these findings may be biased as the mean age of the sample was relatively young ($M = 24.34$, $SD = 6.66$, Range = 16 - 46). An increase in the number of older participants may have revealed an effect of age with respect to preferred reading medium.

There were also no significant differences according to age group with regard to reading a paper book. This maps onto trends for book reading in typical populations also. For example, Faverio and Perrin (2022) did not report any major differences in the book reading habits of 1502 typical adults as 68% of the 18-29 group read books and 67% of the 30-29 group also did so too. As is the case for many of the results of this study, it appears that the reading habits and preferences of adults with Down syndrome resemble those of typical populations. With respect to preferences for reading a book, results again may have been different if older participants had taken part in the survey. Similarly, no one age group showed more of a preference for e-books. In the Croatian study by Müller (2021), e-books were not a popular choice. E-books are a relatively new concept and require a level of technological literacy, but their use was not significantly linked with age in the current sample. Results from this study show that across all age groups e-books were not a popular choice; with only 5 people in the 16-25 group reading using an e-book, one in the 26-37 group and one in the 38- 46 group. Across all groups, audiobooks were also not popular.

9.7.2 Reading habits with respect to reading new media, community reading or personal reading items.

Ages were grouped into the same three age groups variables as above. Of the 98 people with Down syndrome who filled out the MRM, there were 66 in the 16-25 age group, 24 in the 26-37 group, and eight in the 38-46 group. A Kruskal-Wallis test revealed a statistically significant difference between the number of grouped New Media items read, and age, $\chi^2 (2, n = 98) = 7.25, p = 0.03$. The same test revealed no statistically significant difference between age and the number of items read grouped under Personal reading ($\chi^2 (2, n = 98) = 2.352, p = .309$) or Community/Reading when out and about ($\chi^2 (2, n = 98) = .305, p = .859$). A post-hoc Dunn test revealed that there was a statistically significant difference between the number of New Media items read in the 16-25 age group (Md =6) and the 26-37 group (Md =4.5) ($p =$

.007). There were no significant differences between any of the other groups (26-37 and 38-46 group, $p = .27$), (16-25 group and 38-46 group, $p = .603$). Bonferroni adjustment was applied for the post hoc test for all p values ($0.05/3 = 0.017$).

The youngest group of adults with Down syndrome aged 16-26 were significantly more likely to read more New Media items, than those in the 26-37 group. However, they were not more likely to do so than the older 38-46 group. This is likely linked to the low number of participants in the 38-46 group which reduced the significance of the results ($n=8$). So, although the medium of reading did not differ according to age, the types of items read did. These items were social media, web browsing or searching, text messages, emails, video game and DVD boxes, video game menus and YouTube videos. As has already been highlighted at various points throughout this study, younger people are engaging with internet communication devices and digital media more than ever before (Dukper et al., 2018) and this is also the case for people with Down syndrome (Ramsten et al., 2020; White & Forrester-Jones, 2020). In terms of reading new media, it can be argued that the habits of young adults with Down syndrome are no different from typical people. For example, Fritz (2017) via parental report concluded that 107 children and adults with Down syndrome between 10-25 years of age, used technology devices for a broad range of reasons 99 (93%) reported their children used technology for leisure/entertainment; 83 participants (78%) reported their children used it for education; 55 participants (52%) reported they used it for satisfying curiosity; 21 participants (20%) reported their children use it for communication; and 5 participants (5%) reported they use it for employment. It is evident that younger people with Down syndrome are being exposed to technology at young ages, and that this is likely influencing them to read more New Media items in young adulthood. So much so, that there is a significant difference in reading these items in comparison to the 26-37 age group in the current sample.

Chapter Ten: General Discussion

This study sought to gather a large, international sample of reading habits of adults and young people with Down syndrome, which was informed by the population themselves. The findings give invaluable and foundational information, both qualitatively and quantitatively, regarding meaningful reading for people with Down syndrome, from an international perspective. This data was gathered using a valid measure, the Meaningful Reading Measure, which was co-constructed by adolescents and adults with Down syndrome (Frizelle et al., 2023). This study also sought to investigate the perspectives that people with Down syndrome had on reading. This can inform future reading interventions and direct specific outcomes, such as what people with Down syndrome hope to achieve with their reading, identify difficulties they are having with their reading, and establish what they are already using reading for. Furthermore, the data collected allowed investigations to be completed into the influence that age and country of residence had on the reading habits of this population. The research questions prioritised for this project were informed by the interests of adults with Down syndrome. These facets of the project aligned it with participatory research guidelines; as the data which was gathered and what was done with it was informed by the people who the research was about.

10.1 Strengths and limitations

This current study is an important exploration of the ability of the MRM to profile an international sample of the reading habits of people with Down syndrome, from the perspective of meaningful reading. Findings, however, must be considered in the context of the methodological strengths and limitations of the study design. The use of a participatory research approach is a key strength of this study design. It ensured that the research questions of the project were interesting to the community it aimed to serve (Johnson & Walmsley, 2003). This approach along with the profiling instrument, the MRM, which was co-constructed with

young people and adults with Down syndrome, adds validity to the research findings. As the measure used in this study was one which was co-constructed by adults with Down syndrome, it reduces the risk that the questions asked in the measure were not accessible or relevant to people with Down syndrome (Davison et al., 2022). Underpinning the participatory research method is the need to understand how people with Down syndrome experience the world; through ensuring that they are at the centre of the data collection (Davison et al., 2022). This study explored the direct perceptions and views of the adults with Down syndrome. Adults with ID have already shown that they have a unique perspective into their daily life and well-being (Ikeda et al., 2016). Thus, the results of this study highlight the credible motivations for why adults with Down syndrome read, what they feel are the challenges of reading, and their reading goals for the future. Indeed, this study highlights potential, meaningful literacy goals to adults with Down syndrome, which can scaffold future intervention targets. However, in terms of participatory research, there are some limitations to the study. Although adults with Down syndrome were involved in the formation of the MRM and the development of the research aims of the study, they were not involved in data analysis, nor did they contribute to the conclusions or interpretation of the data within the write-up of this work. This does limit the credibility of the conclusions of the data, as the student researcher did not consult adults with Down syndrome in the interpretation of the qualitative research. Involving adults with Down syndrome in these phases of the research process is something which has been carried out and reported on within the literature (e.g., Vaccarino et al., 2023). It has also been highlighted as an important part of the participatory research process (Davidson et al., 2022). Financial and time constraints meant that it was not possible to facilitate this process at the time, however, this is something that should be implemented in future research. The reduced diversity of the sample with respect to the number of international participants is another limitation to the data. However, those who did respond provided detailed replies on this under-

researched topic. This project was designed to capture the experiences and perceptions of adults with Down syndrome. This was achieved and is a strength of the study design. Although, we acknowledge potential limitations in statistical generalisability of the data in relation to the influence of age, as the oldest participant was only 46. Furthermore, it is also acknowledged that the sample is likely biased to reflect a particular group of people with Down syndrome. Although this sample did contain two non-readers and eight who did not like to read, it is possible that the sample was skewed towards people with Down syndrome who had an interest in reading or had established reading skills, as they would be more likely to take part. The basis of the study was to profile the reading habits of adults with Down syndrome, so naturally this data aims to reflect those who do read. It does not assume to account for the habits of all adults with Down syndrome or suggest that all individuals with Down syndrome feel the same way about reading. Irrespective of this however, the results of this study have shown how these readers use this proficiency, meaningfully, which is beyond valuable to future reading related research.

The MRM scores were similar from both the current study and Frizelle et al. (2023) which further validates the items included in the MRM and strengthens the results of the current study. However, the MRM was originally co-constructed by a group of adults with Down syndrome who attended a post-second level literacy course in Ireland. As a result, the generation of the items included in the MRM may be limited to a singular culture and environment. As has been already stated, there were some responses which could not be conflated into other items already included in the MRM. For example, medications, drama scripts and speeches or religious texts. This prompts the question as to whether further minor adjustments need to be made to the MRM so that items are more generic. For example, some responses said that they read clothes tags. The MRM covered clothes brands. Perhaps this item should be changed to clothing items such as tags, brands, and labels.

Two images were changed by the student researcher from the original validated images chosen by the co-constructors of the MRM. As already stated, this was done for practical reasons associated with moving the MRM online and reducing confusion expressed by some participants. However, upon reflection, to ensure validity and appropriate participatory research practices, these images should not have been changed. Although it is not felt that this changed the results of the study, it is important to acknowledge this as a limitation. Also, one item ‘receipts’ which had been included in the original MRM was mistakenly left out by the student researcher in this current study.

Finally, there were a number of supportive prompts embedded into the open-ended questions in the MRM. It could be argued that the phrasing of the question may have influenced the answers received. For example, for the question “*What would you like to be able to do with your reading?*”, embedded prompts to support the person with Down syndrome were given e.g. “*For example...To read without help, to read more words, read faster, read new things, read on my phone, read on my computer, get a job, go to college*”. The supportive prompts embedded in the question aimed to support the participants. This is not viewed as a limitation to the data, but rather a support to scaffold and remind participants of some general difficulties associated with reading. The participants were free to write whichever answer they wished. However, in terms of transparency it is important to acknowledge that some of the examples given in the question could be interpreted as leading questions and could influence answers. Nevertheless, although some answers resembled the prompts, as can be seen from the variety and diversity of the answers given, participants gave their own ideas and supported them with examples. Thus, the supportive prompts are not likely to have significantly impacted the results.

10.2 Future steps and new directions

Following the responses obtained through the MRM, it is evident that future edits and adjustments may need to be made. For example, changes to phrasing of some of the questions may need to be completed. Some of the participants interpreted the “Where do you read?” question as “When” and vice versa. In some senses, as the approach taken in this project was meaningful reading, underpinning this method is that a person would read throughout the day, whenever is needed. Whereas some participants interpreted this to mean when do they read for pleasure. So perhaps this question needs to be adjusted to say, “What days or times of the week do you read?” to achieve a consistent and timeline of specific points during the day when reading is completed. Similarly, maybe the ‘where’ question should say “What locations do you read in?”.

Regarding future steps and directions for this research, while this work has achieved a profile representative of a variety of different people with Down syndrome across different ages and countries, further samples are needed. This is especially relevant for older people with Down syndrome who are not represented in the sample, given that the oldest person who partook in this study was 46 years of age. As has been suggested by Frizelle et al. (2023) the MRM may serve as an appropriate measure to profile and monitor the reading habits of adults with Down syndrome as they age, given their predisposition to premature ageing and cognitive decline (McCarron et al., 2017). Using the MRM to complement cognitive assessments may be useful to monitor meaningful reading activities, as declines in such activities could be indicative of developing cognitive impairments. Secondly, expanding this research to further countries is also needed. Although this sample achieved a broad understanding of reading from participants across various countries, within each country-group, the numbers were low. Further research should target people with Down syndrome in these countries as well as non-

English speaking countries. This will ensure that the implications for reading interventions will be more culturally sensitive.

Although educational history was gathered from the participants within the demographic section, many of the participants were unable to answer questions relating to previous educational history. If using the MRM clinically, perhaps it should be filled out by the individual with Down syndrome with the help of a trusted support person. This person may remember or have access to information pertaining to previous educational history. This would allow future investigations into the influence of mainstream school versus special school education on MRM score, as well as the level of post-second-level education on MRM score. Study designs which would facilitate these research aims should be investigated in the future.

There is a key use of the MRM within reading interventions as it captures both the functional and leisure reading of young people and adults with Down syndrome. Future research may benefit from using the MRM to supervise progress alongside other standardised reading assessments. It is evident from the findings of this research that young people with Down syndrome are reading using internet communication devices and reading various new media. It has been established that people with Down syndrome are using social media and participating in various social networks (Ramsten et al., 2020; White & Forrester-Jones, 2020). Future research should investigate the influence of meaningful and functioning reading on the successful use of internet-technologies and new media, and how this influences quality of life outcomes in areas of socialisation and inclusion. This profile of meaningful reading for individuals with Down syndrome is valuable, as the data on which it is based comes directly from the opinions of people with Down syndrome. As a result, a clear use of this profile may be to guide and support future reading interventions, so that their content may be more functional to the students they serve.

10.3 Conclusion

This study contributes to the growing literature regarding a social-cultural approach to reading for adults with Down syndrome. This was the first study of its kind to profile the meaningful reading habits of adults with Down syndrome internationally, inclusive of their opinions about reading. As discussed above, this study has generated clear implications for future reading interventions for this population as well as for future research. These being that reading goals should be decided on with the individual, and that outcomes should be measured in a way that is appropriate. In particular, this study illustrated that the meaningful reading habits of adults with Down syndrome are not dis-similar to typical populations; that adults with Down syndrome hold a unique perspective into their own strengths and challenges with meaningful reading; that younger individuals are reading more new media items than older individuals; and that reading skills are being used for independence, employment, leisure and personal learning. It is also evident that reading is a way to access the modern, technological world for adults with Down syndrome.

On a more personal note, I want to acknowledge how much I appreciate the level of insight and honesty the individuals who partook in this study gave. As this study is based on the opinions of people with Down Syndrome directly, this research could not have happened without them nor would the implications for future reading interventions be so pertinent and meaningful. I have learned so much from the people with Down syndrome in this study, I hope that it highlights how other people can learn from them too.



Chapter 11: Easy Read Version

Introduction



Research is about learning new things.

Research is **thinking of important** questions and trying to find the answers.



We can answer research questions by **looking up information and doing projects.**



This **research project was finding out what** adults and young people with Down syndrome **read every day.**

This research was also about how adults with Down syndrome **feel about reading.**



The **research team** was

- A student researcher in **University College Cork**
- Two senior researchers in **University College Cork**
- A researcher from **Down Syndrome Ireland**.
- **Adults with Down syndrome** were included in the **research team**.

The research is **split up** into **2** phases. **Phase 1** and **Phase 2**.

Phase 1:

In Phase 1 adults with Down syndrome **voted** on research questions which were **important to them**.

These questions were then **sorted** by the student researcher.



What do you read? Click **yes** if you do read the item shown. Or **no** if you don't read the item shown.

	 Yes	 No
 Books	☐	☐
 Books that have a lot of pictures	☐	☐

Phase 2:

The **student researcher** investigated these **research questions**.

The student researcher used an **online survey** and **paper survey** to ask adults and young people with Down syndrome **what they read in everyday life**.

This survey had been **designed with adults** with Down syndrome before.

Q23



What would you like to be able to do with your reading?

For example...

To read without help, to read more words, read faster, read new things, read on my phone, read on my computer, get a job, go to college, other

You can **type** your answers in the box.

12:29

Q23



What would you like to be able to do with your reading?

For example...

To read without help, to read more words, read faster, read new things, read on my phone, read on my computer, get a job, go to college, other

You can **type** your answers in the box.

The survey also asked:

- **About the best thing** about reading.
- **What was hard** about reading.
- **What people would like to do with their reading.**

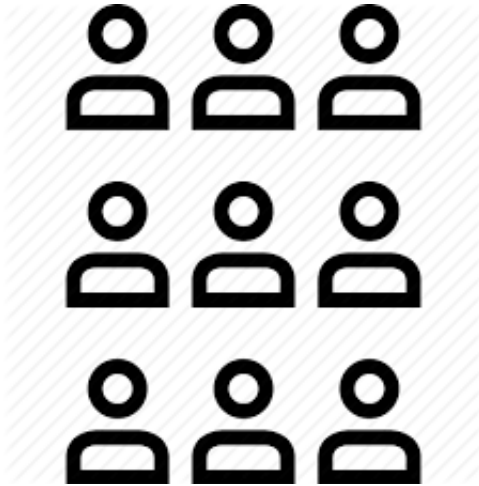


The number of items each person ticked gave them a **Meaningful Reading Score**.



This **score** said how many items the person read in their **everyday life**.

Phase 1 Method



9 adults with Down syndrome **helped** with the research questions.



They chose which **research questions** were most important to them.



They **voted** by putting their **hands** up



The student researcher **wrote** down the results.

Phase 1 Results



The group **chose** “Do people with Down syndrome like to read?” as the **most** interesting question.



They also **ranked** these questions as **important**:



What would people like to **do** with **their reading**? (Get a job, read more, go to college?)



Do **older** people with Down syndrome do **different** reading than **younger** people with Down syndrome?



What makes reading **harder** for people with Down syndrome?



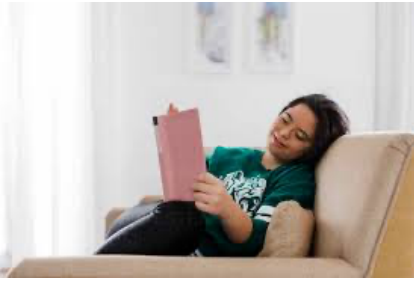
Do **many people** with Down Syndrome like reading?



Do people with Down syndrome **who do courses** with **Down Syndrome Ireland** **read more**? Than people who haven't done courses.



Do **Irish people** with Down syndrome read more or less than other people with Down syndrome?



What's the **best thing** about reading for people with Down Syndrome?



The team was **not** able to research:



Do people with Down syndrome like reading?

Because some people who cannot read may not be able to take part in the survey.



It was also **not possible to** research:

Do people with Down syndrome who do courses with Down Syndrome Ireland read more? (Than people who haven't done courses)



As many people **could not remember** the courses or schooling, they had done! This is because people **do** so **many things** in their lives, it's hard to **remember** them all.



The **final research** questions were fixed thanks to the **opinions** of people with Down syndrome.

These were:



- **What** do adults and young people with Down syndrome all over the world read?



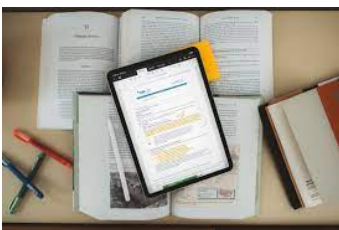
- **Why** do adults and young people with Down syndrome all over the world read?



- **When** do adults and young people with Down syndrome all over the world read?



- **Where** do adults and young people with Down syndrome all over the world read?



And **what do they prefer to read on?**



What do people with Down syndrome find **hard** about reading?



What do people with Down syndrome think the **best thing** about reading is?



What would people with Down syndrome **like to be able to do with their reading**?



Does **age** change the number of things people with Down syndrome read?



Does where **someone live** change the **number of things** people with Down syndrome read?



Does **age** change what you **prefer to read on**?



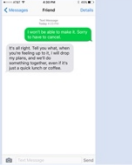
Does **age** change the **types** of things you read?

Phase 2 Method

This is a list of some of the things people read		Tick all the things that you read	
		YES	NO
	Books that have a lot of pictures		
	Poems		
	Newspapers		

20

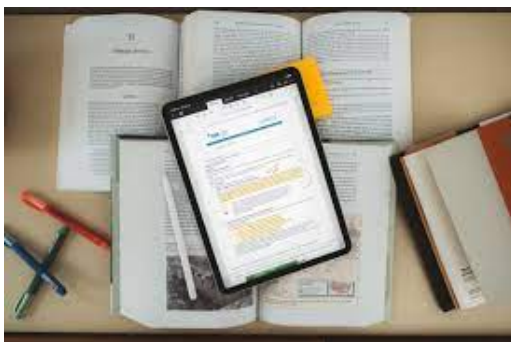
The **Meaningful Reading Measure** is a reading checklist designed with adults with Down syndrome.

This is a list of some of the things people read		Tick all the things that you read	
Q11 Personal Reading		YES	NO
	Read things on Social Media		
	Text Messages		
	Emails		

23

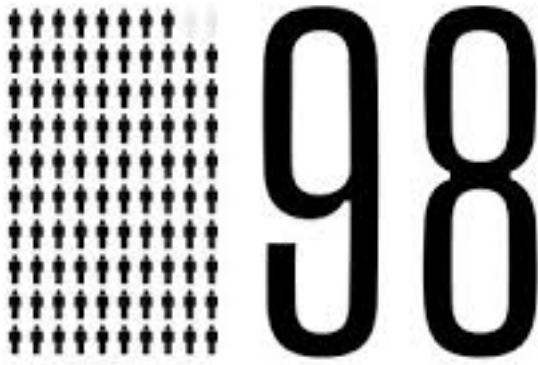
This **checklist** was used as a **survey** to find out about the reading of adults with Down syndrome.

The **list** had things like reading social media, food labels or books in it.

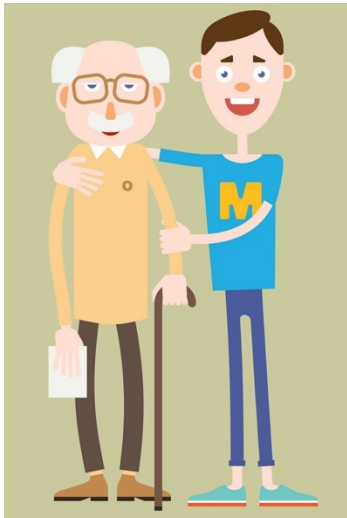


The **survey** was available **online** and on **paper**.

Down Syndrome Ireland helped **ask** people if they wanted to **take part**.



98 people filled out this **survey**.



They were aged between **16 and 46**.



They were from different countries.
These countries were **Ireland, United Kingdom, United States, New Zealand, India, Canada, and Australia**.



What do people with Down syndrome read?



People with Down syndrome read **many** things **every day**.

These items were things like calendars, text messages, social media and street signs.



Most people read at least **33 different things**.

Some people read **no** items at all.

Some people read **every** item on the list.

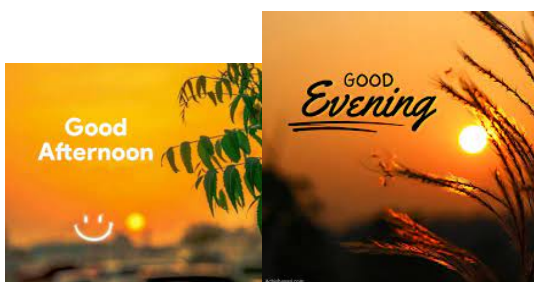
The **most popular** items were **cards** and **food brands**.



The **least** common thing was **e-books**.



When do people with Down syndrome read?



The **most common time** to read was in the **afternoon or evening**.

A lot of people also said that they **read all of the time!**



A **small** amount of people read **only** when they had to.



Where do people with Down syndrome read?



Most people read at **home**



A lot of people read in **public places like shops.**



A lot of people also read in **school or college.**



Some people read in their **job**.



Why do people with Down syndrome read?

This study found that people with Down syndrome read:

- So, they can **learn** about stuff they are **interested in**.
- For **enjoyment**.
- For **independence**.





What do people with Down syndrome prefer to read on?



A lot of people said (45%) a **tablet or computer**.

This was the most **common choice**.



Paper book was the second most common choice.



A few people said that they **did not like** reading or **could not read**.



What was hard about reading?

The people in this study said that they found reading words **they didn't know** difficult.

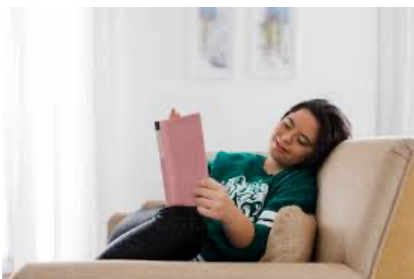
They also said that **reading complicated** words was hard.



Some people said that they found it hard to **understand or remember** things that they had read.



Other people said that they **didn't find** reading hard at all.



What was the best thing about reading?



The **best thing** about reading for the people in this study was **reading about things** they were **interested** in and learning.



Lots of people in the study said that reading was **fun** and that that's why they liked it.



Many people also liked reading as they could **talk to their friends**, and it was a **hobby** for them.



What do people with Down syndrome want to do with their reading?



People in this study wanted to **improve** their reading skills.
They wanted to read **faster and easier**.



Many people in this study said that they wanted their reading to **help them get a job.**



Other people said that they wanted their reading to **help them with their interests.**

For example, to help them to write a book.



Does age change the number of things people with Down syndrome read?



No.

Being younger or older **did not** make a difference to how many things the people in this **study read every day.**



Does where someone lives change the number of things people with Down syndrome read?

No.

Irish people read the **same** amount of everyday reading items as people from **other countries**.

But we need more people from different countries to investigate this more



Does age change what you prefer to read with?



All of the groups of young and old people **all preferred** reading on a tablet or computer.

The **second most common** choice was reading using a **book** for all age groups.



Does age change the types of things you read?



Younger people were **more likely** to read things on the

- Internet
- social media
- text messages
- emails
- video games and DVD boxes
- video game menus
- YouTube videos.

Conclusion



This survey gave **really important** information about what people with Down syndrome read every day



People with Down syndrome **helped with this research.**



This research can **help** people with Down syndrome with their **reading.**

It can let organisations **know how to best help** people with Down syndrome with their reading.

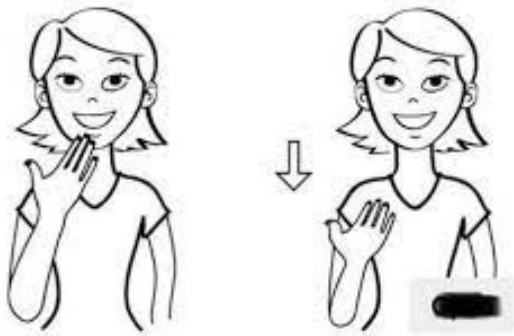


The **next steps** are

- to see what **older people** with Down syndrome read



- to see **how education changes reading**



Thank You

Thank you to the research team of adults with Down syndrome in **Phase 1** who helped make this study possible.

It could not have been done without their **expert opinion**.



Thank you to every person who filled out the survey.

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Appendix A. Ethical Approval Letter



Ms Mary Jolley
Department of Speech and Hearing Sciences,
School of Clinical Therapies,
College of Medicine and Health,
University College Cork

30th March 2023

**Oifig an Leas - Uachtaráin Taighde
agus Nuálaíochta**
Office of the Vice President
for Research and Innovation

4th Floor, Block E,
Food Science Building,
University College Cork,
College Road,
Cork, Ireland.

+353 (0)21 4903500
vpresearch@ucc.ie
www.ucc.ie

Dear Mary

Thank you for submitting your research project, Log 2022-181 (entitled "Profiling functional reading in adults and young people over the age of 16 with Down Syndrome"), to SREC for ethical perusal. I am pleased to say that we see no ethical impediment to your research as proposed and we are happy to grant approval. Approval date was 21st October 2022. An amendment request for this application (Log 2022-181A1) was approved on 9th January 2023.

We wish you every success in your research.

Yours sincerely,

Dr Claire O'Neill,
Chair of Social Research Ethics Committee

Professor John F. Cryan Ph.D. MRIA
Vice President for Research and Innovation

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

Appendix B. Informational Video



Appendix C. Focus group information sheet

Information Sheet about Focus Group:



Hello, my name is Mary, and I am doing a project about adults with **Down Syndrome**. I am a **student** in University College Cork.

We are doing a project with Down Syndrome Ireland to **find out more** about what people with Down Syndrome **read**.



I am doing a project about what **adults with Down Syndrome** across the world **read**.

I want to know what you think are **important questions** to ask in my project.



I want to have a **chat** about my project with **you**.
We will **talk about reading**.

We will also think of some **questions you may have about reading** have when you have **Down Syndrome**.



You know **best** what it is **like to read** when you have **Down Syndrome**.



That's why I want to talk to **you** about what are important things I should investigate in my project!



If you take part in this project the answers you give **are private. Nobody will know your name.**



Only take part in this project **if you want to.**



No one will be **upset** if you do **not want** to answer questions about **your reading.**



If you **do** want to take part we will ask you to sign a **consent form**.

Appendix D. Focus group consent form

Consent to take part in Focus Group



I have read the **information sheet** and know what the study is about



I have had a chance to **ask questions** about the study



I understand how to **ask a question or complain**



I know it is **my choice** to answer the questions and that I can decide **not to take part** in this study.



I understand that **my answers will be shared** with researchers in **University College Cork**.



I understand that there will be **no reward** for this study



I understand that my **details** will be kept **private during the study** and in **any report** about the study.



I understand that information I **give may** be used in other studies in the future,

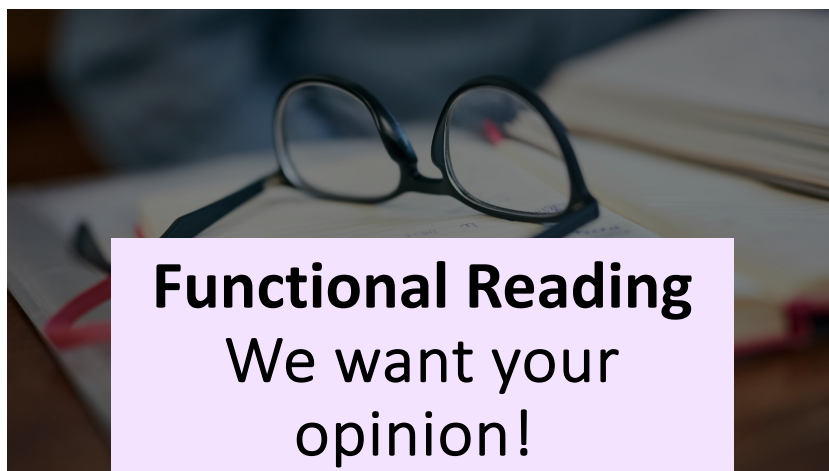
without my name and details.

and will be stored openly for other researchers to look at (Open Science platform).

By **ticking this box**,
I agree to **take part** in this research study:

☐

Appendix E. Focus group presentation



This project...



This **project** is being done by **University College Cork** and **Down Syndrome Ireland**.

We want your opinion about reading!

https://ucc.qualtrics.com/jfe/preview/previewid/Occfea2a-5aa2-414f-88a1-827eab2e3a77/SV_ekxkt76qk33WOP47Q_CHL=preview&Q_SurveyVersionID=current

(Play video too!)

The Reading Survey



First.. We want to say **thank you!**



Your **information helped** us make this **survey!**

Research Questions



A **research question** is an important question that we want **answered**.

We try to get it **answered** from our **work and studies**.



We can **answer research questions** by looking up information and completing projects.



This is **researching**!

Your opinion...



So, you saw our **survey**.. And you **helped** us design it!



We now want **your opinion** on what **our research questions** should be!

What are **important** questions for our project about reading, in **your opinion**?

What should our research Qs be?



We want **your opinion** on what our **research questions** should be!



We want to know what **you think is important** and what is **not important**!



We will show **you questions**.

We then want you to **vote** on the **most important question**! This is **your opinion**.

You can put up your hand to **vote**!

Before we Start...

Does anyone have any **questions**?

Is everyone okay to **keep going**?



The Research Questions.....



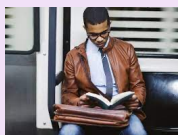
1. Do **Irish** people with Down syndrome read **more or less** than other people with Down syndrome?



2. What is **easy** about reading?



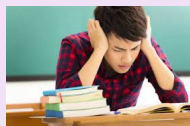
3. **Who** reads more? People with Down syndrome who went to a **special needs school** or people who went to a **mainstream school**?



1. What would people like to do with **their reading**? (Get a job, read more, go to college?)



2. Do people with Down Syndrome who have **finished more school or college**, read more?



3. What is **hard** about reading?



1. Do **older** people with Down syndrome do different reading than **younger people** with Down syndrome?



2. What makes reading **easier** for people with Down Syndrome?



3. What do people with Down Syndrome read **every day**?



1. What makes reading **harder** for people with Down syndrome?



2. What's the **best thing** about reading for people with Down Syndrome?



3. Do **many people** with Down Syndrome like reading ?

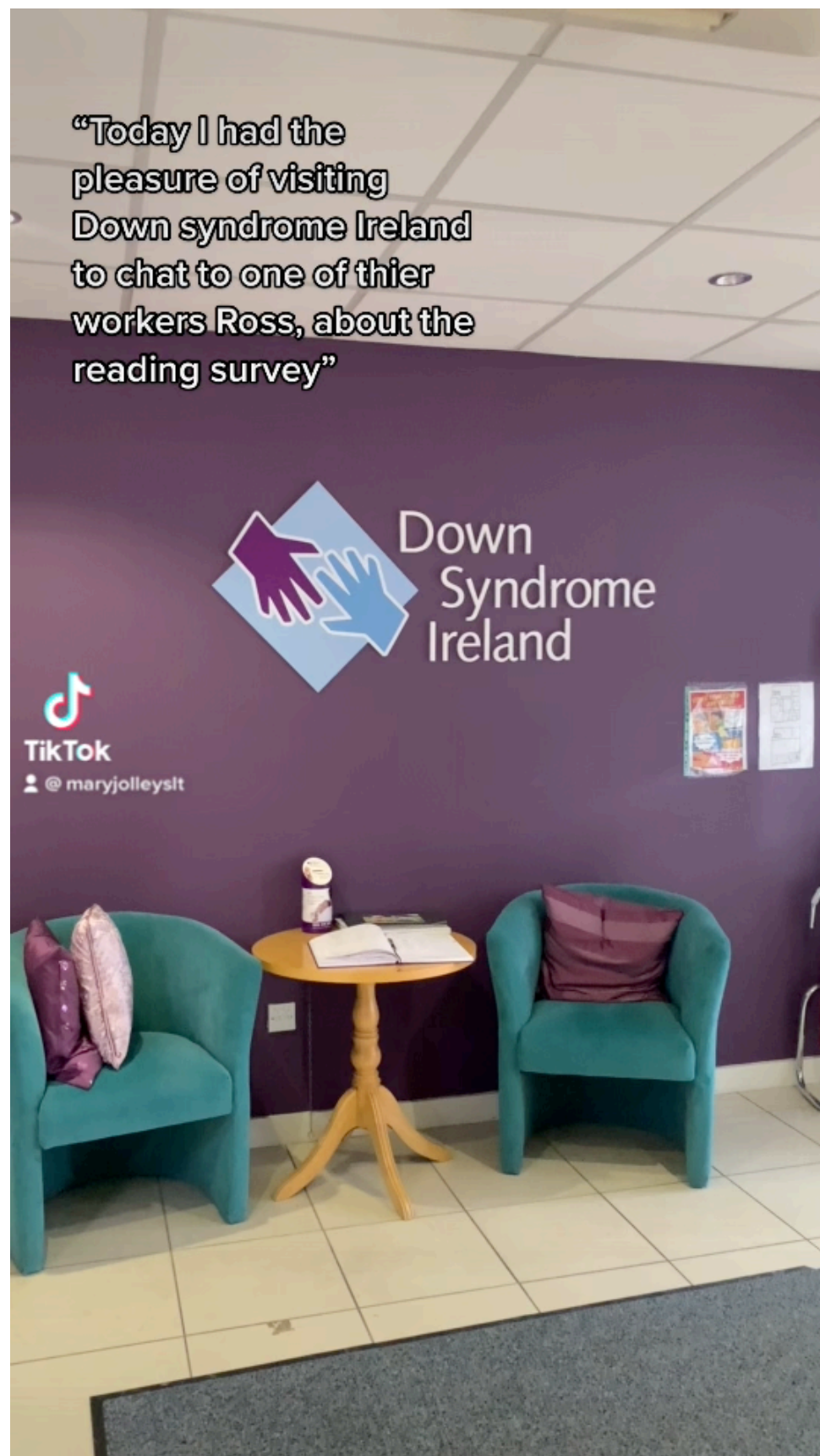


1. Do people with Down syndrome who do **courses** with Down Syndrome Ireland **read more**? (Than people who haven't done courses)
2. What thing do people with Down syndrome read **the most**?

Appendix F. List of presentation research questions

-
- What would people like to do with their reading? (Get a job, read more, go to college?)
 - Do people with Down Syndrome who have finished more school or college, read more?
 - What is hard about reading?
 - Do older people with Down syndrome do different reading than younger people with Down syndrome?
 - What makes reading easier for people with Down Syndrome?
 - What do people with Down Syndrome read every day?
 - What makes reading harder for people with Down syndrome?
 - What's the best thing about reading for people with Down Syndrome?
 - Do many people with Down Syndrome like reading?
 - Do people with Down syndrome who do courses with Down Syndrome Ireland read more? (Than people who haven't done courses)
 - What thing do people with Down syndrome read the most?
 - Do Irish people with Down syndrome read more or less than other people with Down syndrome?
 - What is easy about reading?
 - Who reads more? People with Down syndrome who went to a special needs school or people who went to a mainstream school?
-

Appendix G. Promotional video



Appendix H. Online version of the MRM Survey

Qualtrics Survey Software

27/09/2023, 15:21

If you have any questions about the project, you can ask your parent or teacher or carer for help.

It can be helpful to fill out this survey with help of someone.

If you have any other questions you can email

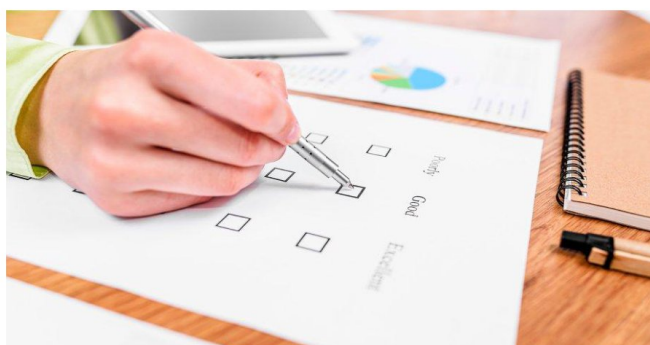
Nicola

Nicola@downsyndrome.ie

or

Mary

maryjolley@umail.ucc.ie



You can do the survey 3 different ways

1.

Online with your email address, so you can come back and change your answers.

Click the [next](#) button to put in your email address - if you want to do the survey that way.

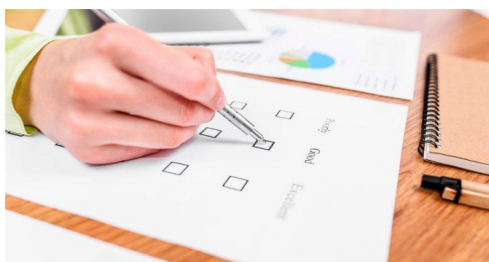
2.



Online by clicking [this link](#) to go to the survey without your email.

https://ucc.qualtrics.com/jfe/form/SV_ekxkt76qk33WOP4

We recommend you fill out the survey **all at once** if you do it this way.



But if you prefer to fill out the **survey** on **paper**.

You will need to **print it** and **write** your answers.

You can **download a pdf** version by clicking [HERE!!](#)

Please then **scan** it and email it back to me.

My email is maryjolley@uemail.ucc.ie

You can ask someone you trust to help you.

You can also **post it**.

The address is:

Mary Jolley and Nicola Hart

Western Parkway Business Park,
Down Syndrome Ireland,
Unit 3, Park Way House,
12 Ballymount Dr, Dublin,
Ireland
D12 HP70



If you want to **take part** in the survey **using your email** - Please **type** your **email address** here.

We will send you a **link** to the survey to your email address!

Please check your email!

Powered by Qualtrics



Default Question Block



Hello, my name is **Mary**, and I am doing a **project** about **reading**. I am a student in **University College Cork**.

We are helping **Down Syndrome Ireland** to find out more about what people with Down syndrome **read**.

This survey has been made with adults and young people with Down syndrome.

These adults have helped create the survey and the research questions for the project.

You can contact me if you have **questions!**

My email is maryjolley@uamail.ucc.ie



There are some questions in this survey that will ask you about your **past education!**

We **recommend** filling out this survey with some **help from someone!**

This can help you **remember** some things you might forget!

Functional Reading Survey Information Video



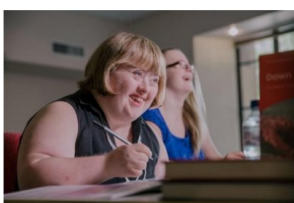
Do you have **Down syndrome** OR are you **helping** someone **with Down syndrome** to fill this out?

- ☐ Yes
- ☐ No

Functional Reading Survey Information Sheet



We want to know **more** about what adults with Down syndrome **read**.



We are asking lots of people **with Down syndrome** if they would like to answer our **questions**.



We may ask you questions about: How **well** you read?

What **things you read**?

Where adults with Down syndrome read?

Why do you read?



You will be shown **pictures** of some things people **read**.

You will be asked to **answer** some questions about reading.



You can **read** the survey **first** and have a think about reading.

Then you can **fill it out**.

You can go **back** and **change your answers**!

You may remember **new** information.



You can **type** out your answers.

You can also **click yes or no**.



You can fill out the survey on your **computer or phone**.



Only **answer** the **questions** if **you want to**.

Only **take part** in this project if **you** want to.



No one will be upset if you **do not want** to answer questions about your

reading.



If you **do** want to **take part** in this project, we will **ask you** to click **yes** to a **consent form**.

A consent form tells us **you understand** what we are asking you to do in this project.



If you **start** answering questions and **change your mind**, you can stop.
Don't submit your response.



If you are doing this survey through **your email**, we will email you a survey link and 1 reminder.

Your email address **will not be used for any other reason**.

Your email address will not be **stored after the survey has finished**.



Your **details** will be kept **private** during the study and in any report of the study.



No one will know **which answers** are yours.



At the **end** of the project we will **write** about it in the Down Syndrome Ireland e-letter.

You can **read** about it there when it is **finished**.

The **information** we get from the study may also be used to **teach people about** what adults with Down syndrome read.

We may also **publish it in a journal**.



If you have any questions about the project, you can ask your parent or teacher or carer for help.

It can be helpful to fill out this survey with help of someone.

If you have any other questions you can email

Nicola

Nicola@downsyndrome.ie

or

Mary

maryjolley@umail.ucc.ie



Are you of **18 years** of age or **older**?

☐ **Yes**

☐ **No**



Are you **16 years of age or older?**

- ☐ No
- ☐ Yes



As you are **under** the age of 18, we need to **ask** your guardian or parent if it is **okay** that you **take part in this project!**

Please show this page to your guardian.



Functional Reading in Adults with Down syndrome Research Study

What is the purpose of this study? This study aims to establish what adults with Down syndrome read in a functional way. There is very little information about what adults with Down syndrome read in their everyday lives and this is why we are carrying out this research. We have created a Functional Reading Tool from previous research with adults with Down syndrome, who helped us create the tool. This Functional Reading Tool contains various questions about what people with Down syndrome read on a daily basis such as "do you read magazines?". Your son or daughter can click yes/no boxes in response to these questions. Your son/daughter will also have a chance to type out their opinions in relation to some text box questions. We then want to use the tool to describe what functional reading means for adults with Down syndrome. Your son or daughter may need help/support to complete the survey.

What does the study involve? This study involves participants filling out Functional Reading Tool via online survey. This survey involves clicking boxes in response to certain questions about reading. There will also be some comment boxes to fill out which will ask some subjective questions about reading. These answers are to be filled out by your son/daughter with your support, when needed. All responses are anonymous. As your son/daughter is under the age of 18, we ask that you sign the consent form to let us know that you are happy for your son/daughter to fill out the survey and be a part of our research. They will also be asked to give their assent.

Why has my son/daughter been asked to take part? Your son/daughter has been asked to take part as they are over the age of 16 and have Down syndrome. Their participation in this study is voluntary, there will be no negative consequences if they decline to participate. If you or your son/ daughter changes your mind and don't wish to submit your responses, you can stop completing the survey at any time and **do not submit your responses**.

How will my son/ daughter consent? Your son/ daughter will be given an easy read version of this information sheet and consent form. It will be made clear that they do not have to take part in this study if they do not want to. They will also be given a point of contact if they have any queries relating to the project.

I accessed this survey through an email link, what will the email address be used for? The email address will be used to send your son/daughter a specific link to the survey. This makes sure that your son/daughter can do the survey at different time points and that your answers won't be deleted between breaks. It also means that if your son/daughter forgets to finish the survey, they will receive one automated reminder to complete it. All their answers will still be anonymous. Their email address will be deleted after the survey is completed. The email

address will be used for no other reason. If you accessed this survey through social media or a direct link, this information does not pertain to you. No email address has been collected from you.

What information will be collected? Information collected will include questionnaire responses regarding what your son/daughter typically reads during the day. All of this information will be anonymous.

Will my son's/daughter's participation in the study be kept confidential? All participant information and their responses will be anonymous. Email addresses will be used for the sole purpose of sending the survey link and will be deleted immediately after.

How will my information be kept? All anonymous information will be stored securely on UCC's Microsoft Sharepoint for the duration of the project.

What about the results? If the results of this study are published in a peer reviewed journal, details of this publication will be forwarded to the Down Syndrome Ireland website. The anonymous results will be made available on an Open science repository for scientific transparency and potential future analysis.

Are there any disadvantages to taking part? We do not foresee any disadvantages to taking part in this study. We have designed the checklist so that it is easy to complete, and completion online means that your son/daughter can do this at a time that is convenient to them.

Has this study been reviewed for ethical implications? Yes, this study has been approved by the Social Research Ethics Committee, UCC.

I have further queries, who can I ask? If you have any further questions, issues or complaints about this study, then you can contact Down Syndrome Ireland Member Support Team Leader Nicola Hart, student researcher Mary Jolley or the research supervisor Dr Pauline Frizelle. They will be very happy to answer any questions you may have.

Mary Jolley: 118439296@umail.ucc.ie

Nicola Hart: Nicola@downsyndrome.ie

Dr Pauline Frizelle: p.frizelle@ucc.ie



Consent Form for Parent

I have read the information sheet above and understand the details of the study.

I understand that the project has received ethical clearance through the University College Cork Clinical Therapies Social Research Committee, and understand who will have access to my data and how it will be stored and what will happen at the end of the study.

I understand how to raise a concern or ask a question and have had opportunity to do so.

I understand that my son/daughter will not benefit directly from participating in this study and that their participation is voluntary.

I understand that my son/daughter can withdraw from the study with no negative consequences at any time **prior** to submission of their answers in the survey.

I understand that the information my son/daughter provides for the purpose of this study will be treated with confidentiality.

I understand that any data extracted from my son/daughter's responses can be quoted in publications, conferences and/or lectures and that their anonymity will be upheld should this occur.

- ☐ Yes I consent to my son/daughter participating in this study.
- ☐ No I do not consent to my son/daughter participating in this study.

This page is for the participants!

**Reading Survey
Consent/Assent Form**



I have read the **information sheet** and know what the **study is about**.



I have had a chance to **ask questions** about the study.



I understand **how** to ask a question or complain.



I know it is **my** choice to **answer** the questions.

I **do not** have to take part in this study and can **stop if I change** my mind.



I **understand** that my answers will be **shared** with researchers in University College Cork.



I **understand** that there will be **no reward** for this study.



I **understand** that my details will be kept **private** during the study and in any report about the study.



I understand that information I give may be used in **other studies in the future, without** my name and details and will be stored openly for **other researchers** to look at (Open Science platform).



Yes I consent



No I do **not** consent



Hello, my name is **Mary**, and I am doing a **project** about **adults with Down syndrome**. I am a student in **University College Cork**.

We are helping **Down Syndrome Ireland** to find out more about what people with Down syndrome **read**.

You can contact me if you have **questions**!

My email is maryjolley@umail.ucc.ie



There are some questions in this survey that will ask you about your **past education**!

We **recommend** filling out this survey with some **help from someone**!

This can help you **remember** some things you might forget!

Q1: First, tell us **who** is filling in this form by **clicking one** of the boxes below:



I am a person with Down syndrome doing this **with some help**.



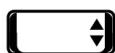
I am a person with Down syndrome doing **this on my own**.

Q2



How **old** are you?

(You can use the drop down menu to **click** your age)



Q3



Where do you **live** ?

- ☐ Ireland
- ☐ United Kingdom
- ☐ Antigua and Barbuda
- ☐ Australia
- ☐ The Bahamas
- ☐ Barbados
- ☐ Belize
- ☐ Canada
- ☐ Dominica
- ☐ Grenada
- ☐ Guyana
- ☐ Jamaica
- ☐ Malta
- ☐ New Zealand
- ☐ St Kitts and Nevis
- ☐ St Lucia
- ☐ St Vincent and the Grenadines
- ☐ Trinidad and Tobago
- ☐ New Zealand
- ☐ United States of America
- ☐ If your country is **not on this list** you can **type** it here !



For these next questions it will help to **know** what these words **mean**:

- **Special School:** This is a school **only** for people with **extra needs**.
For Example, people who have **Down Syndrome, Autism** or another **learning disability**.
- **Mainstream school:** This is a school for **all children**. People who **live near you** and **people with extra needs** going to school **together**.

Q4



How **many years** did you spend in a **special school**?

(ask your family if you are not sure)

Type how many **years** in the box! (If you don't know type "don't know")

Q5



How **many years** did you spend in a **mainstream school**?

(ask your family if you are not sure)

Type how many **years** in the **box**! (If you don't know type "don't know")

Q6



Have you done courses in Ireland **after school**?

- ☐ Yes
- ☐ No

Q6 (a)

Have you done any of these courses **after** leaving school?

(Click yes or no)





A university
course

☐☐

Yes



No



An **Education
and Training
Board (ETB)**
course

☐☐

Yes



No



Down
Syndrome
Ireland **Ability
Online** course
like...

☐☐

*DSI "Music",
"Movies" or
"Fun, Food and
Fitness"*





Down
Syndrome
Ireland **Latch
On** course

Yes

No



Yes



No



course

Down
Syndrome
Ireland **MOTE**



Yes



No



Down
Syndrome
Ireland **Work
Skills** course



Yes



No



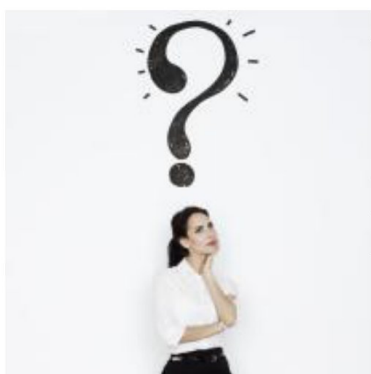
Personal Development course

☐
☐


Yes



No



Another course not on this list

(You can type your answer into the box if you want!)

☐
☐

Q7 Please let us know if you have or have **not done **any other** courses **after** school.**

☐


No courses after school!



Yes I did **do** courses after school

Q8



How many **years** have you spent doing courses after school?

Type how many **years** in the **box**. If it is **zero** - **type 0!**

Q9



How many **months** have you spent doing courses **after** school?

Type how many **months** in the box. If it is **zero** - type **0**!

Q10



Is there **anything else** you would like to tell us about **school** or about **reading**?

Please **type** your answers in the box!

So here are the questions! Take your time.

You can come take breaks and change your answers if you want!



Here are some **questions** about what you read.

We will **ask** you:

- About **yourself**
- About the **things** you read
- About **why** you read



Take as **much time** as you need to **answer** the questions. Ask for **help** if you need it!

You can ask your **parent / teacher / carer or friend!**

General Reading

Q11

This is a list of some of the things people **read**. Tick **YES/NO** to all the things that **you read**.

What do **you read**? Click **yes if you do read the item shown**. Or **no if you don't read the item shown**.



Books



Yes



No



Yes



No



Books that have a lot of pictures



Yes



No



E-books



Yes



No



Poems





Yes



No



Newspapers



Yes



No



Magazines



Yes



No



Catalogues



Yes



No



Ad Leaflets



Yes



No





Crosswords or Word Searches



Yes



No



Board Games

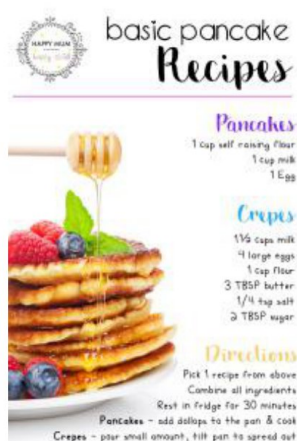


Yes



No





Cooking Instructions or Recipes



Yes



No



Food Items



Personal Reading

Q12 These questions are about your **personal reading**. Click **yes** or **no** if you read these:



Read Things on **Social Media**



Yes



No



Yes



No



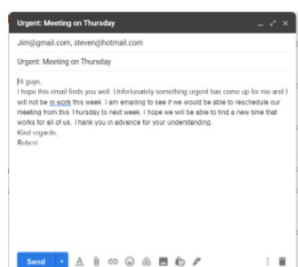
Text Messages



Yes



No



Emails



Yes



No



Homework or Assignments



Yes



No



Lists



Yes



No



Post



Yes



No



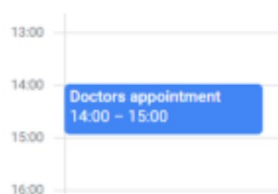
Calendars



Yes



No



Invitations, checking the time and appointment reminders



Yes



No





Cards



Yes



No

Bookstore Weekly Schedule

Week of: May 1-7

	Mon 5/1	Tue 5/2	Wed 5/3	Thu 5/4	Fri 5/5	Sat 5/6	Sun 5/7
Monahan, M.	Open/Sign	Open/Sign	Open/Sign				
Monahan, M.	Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.		Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.			Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.		Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.			Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.		Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.			Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.		Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.			Open/Sign	Open/Sign	Open/Sign	Open/Sign	
Monahan, M.		Open/Sign	Open/Sign	Open/Sign	Open/Sign	Open/Sign	

Work Rosters



Yes



No



A contract that you need to sign



Reading when out and about

Q13 These are things people can read when they are out and about. Click yes or no for things you read.



Menus

 Yes  No

☐ ☐

 Yes  No



Road Signs



Yes



No



Signs on Doors

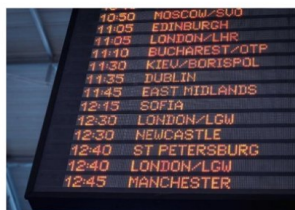


Yes



No





Travel timetables
(like timetables at the **Train Station**,
Bus stop, **LUAS** or **Airport**)



Yes



No



Cinema times



Yes



No



Shop names





Clothes brands



Yes



No



Food brands



Yes



No



Yes



No



Health information (such as a covid sign)



Yes



No



Information about displays in a museum



Yes



No



Maps

☐☐

Q14 These are things people may read on a **screen** and read for **fun**. Click **yes** or **no** for things you read.



Video game and DVD boxes

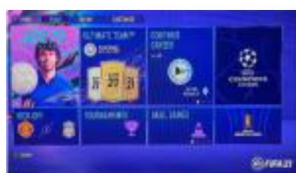
☐☐



Yes



No

☐☐

Video game menus



Yes



No

☐☐**Movie and TV show** names on the **TV menu**

Yes



No



Headlines on the news

☐☐

Yes



No



Subtitles

☐☐

Yes



No

☐☐



Youtube videos



Song titles (for example on Spotify or Apple Music)

☐
☐


You are the **dancing queen**
Young and sweet
Only seventeen
Dancing queen
Feel the beat from the tambourine

☐
☐

Song lyrics



Yes



No

SELECT COMPETITION OR DATE BELOW THEN OPTIONALLY FILTER BY TEAM

Barclays Premier League 16-08-2014 31-08-2014 All Filter

August 16 5:30pm BT SPORTS	Arsenal V Crystal Palace More details	August 16 8:00pm BT SPORTS	Burnley V Chelsea More details
August 16 3:00pm BT SPORTS	Leicester City V Everton More details	August 17 1:30pm BT SPORTS	Liverpool V Southampton More details
August 18 12:45pm BT Sport	Man United V Swansea City More details	August 17 4:00pm BT SPORTS	Newcastle V Man City More details

Sport Fixtures

☐☐

Yes



No

Premier League · Sun, 24 Oct Full-time

	0 - 5	
Man United		Liverpool

N. Keita 5'
D. Jota 13'
M. Salah 38', 45+5', 50'

P. Pogba 60'

Sports Results

☐☐

Yes



No



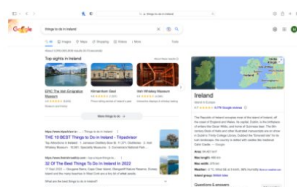
Lottery Numbers

☐
☐


Yes



No



Web Browsing or Searching

☐
☐

Qualitative Qs



Here are some questions where we ask what ***you*** think! You can **type** out **your answers** in the **boxes**!

Q15



What else do you read?

Put anything you read that was not on the list above here:

Q16



What is the **best thing** about reading?

For example...

It is **fun?**, it **helps** to pass time, I can talk to **my friends about things I read**

Q17



What is **hard** about reading?

For example...

the words are **too small**, there are words **I don't understand**, words are hard to **remember**, **too many** words,

Q18



Why do you read?

For example...

To learn **new things**, because I **enjoy** it, to **find out information**

Q19



Do you most like to **read?** (pick 1!)



A paper book



An e-book like a Kindle



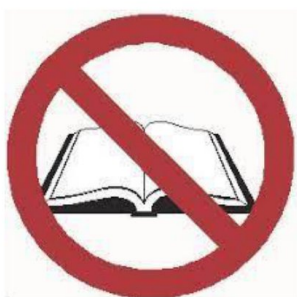
On a tablet or computer



Listening to audiobooks



I **don't** like to read



I cannot read

Q20



Tell us **why** you chose this choice:

Q21

**Where do you read?**

For example: At **home**, at my **day service**, at **school**, the **library**, at **college**, or **online**

You can **type** your answers in the box.

Q22

**When** do you read?

For example....

All the time, only when I **have** to, In the **morning**, in the **afternoon**, in the **evening**, at the **weekend**, after **work**,..

You can type your answers in the box.

Q23



What would you like to be **able to do** with **your reading**?

For example...

To read **without help**, to read **more** words, read **faster**, read new things,
read on my **phone**, read on my **computer**, get a **job**, go to **college**, other

*You can **type** your answers in the box.*



Do not submit your answers until you are **sure you are finished!**

Once you submit your **answers** you will **not** be able to go back and **change** them!



You're **finished**? Great!

Thank you for doing our survey, you can now click **next** and finish!

Remember!!! After this question you can **not** go back and **change** your

answers!

Block 6

Powered by Qualtrics

Appendix I. MRM survey information sheet

Functional Reading Survey Information Sheet



We want to know **more** about what adults with Down syndrome **read**.



We are asking lots of people **with Down syndrome** if they would like to answer the **questions**.



We may ask you questions about:
How **well** you read?
What **things you read**?
Where adults with Down syndrome read?
Why do you read?



You will be shown **pictures** of some things people **read**.

You will be asked to **answer** some questions about reading.



You can **read** the survey **first** and have a think about reading.

Then you can come **back** and **fill it out**.

You can go **back** and **change your answers**!

You may remember **new** information.



You can **type** out your answers.

You can also **click yes or no**.



You can fill out the survey on your **computer or phone or write your answers.**



Only **answer** the **questions** if you **want to.**

Only **take part** in this project if **you** want to.



No one will be upset if you **do not want** to answer questions about your reading.



If you **do** want to **take part** in this project, we will **ask you** to click **yes** to a **consent form**.

A consent form tells us **you understand** what we are asking you to do in this project.



If you **start** answering questions and **change your mind**, you can stop.

Don't submit your response.



If you are doing this survey through **your email**, we will email you a survey **link** and **1 reminder**.

Your email address **will not be used** for **any other reason**.

Your email address will not be **stored** after the survey has finished.



Your **details** will be kept **private** during the study and in any report of the study.



No one will know **which answers** are yours.



At the **end** of the project we will **write** about it in the Down Syndrome Ireland e-letter. You can **read** about it there when it is **finished**.

The **information** we get from the study may also be used to **teach people about** what adults with Down syndrome read.

We may also **publish it in a journal**.



If you have **any questions** about the project, you can **ask your parent or teacher or carer for help.**

It can be helpful to fill out this survey with **help of someone.**

If you have any other **questions** you can email

Nicola

Nicola@downsyndrome.ie

or

Mary

maryjolley@umail.ucc.ie

Appendix J. Consent/Assent form for the MRM survey

This page is for the participants!

Reading Survey Consent/Assent Form



I have read the **information sheet** and know what the **study is about**.



I have had a chance to **ask questions** about the study.



I understand **how to ask a question or complain.**



I know it is **my** choice to **answer** the questions.

I **do not** have to take part in this study and can **stop if I change** my mind.



I **understand** that my answers will be **shared** with researchers in University College Cork.



I **understand** that there will be **no reward** for this study.



I **understand** that my details will be kept **private** during the study and in any report about the study.



I understand that information I give may be used in **other studies in the future, without** my name and details and will be stored openly for **other researchers** to look at (Open Science platform).

Tick the box to let us know if you **want to take part!**



Yes I consent

☐

No I do not consent

☐

Appendix K. Parental Consent Form



Functional Reading in Adults with Down syndrome Research Study

What is the purpose of this study? This study aims to establish what adults with Down syndrome read in a functional way. There is very little information about what adults with Down syndrome read in their everyday lives and this is why we are carrying out this research. We have created a Functional Reading Tool from previous research with adults with Down syndrome, who helped us create the tool. This Functional Reading Tool contains various questions about what people with Down syndrome read on a daily basis such as "do you read magazines?". Your son or daughter can click yes/no boxes in response to these questions. Your son/daughter will also have a chance to type out their opinions in relation to some text box questions. We then want to use the tool to describe what functional reading means for adults with Down syndrome. Your son or daughter may need help/support to complete the survey.

What does the study involve? This study involves participants filling out Functional Reading Tool via online survey. This survey involves clicking boxes in response to certain questions about reading. There will also be some comment boxes to fill out which will ask some subjective questions about reading. These answers are to be filled out by your son/daughter with your support, when needed. All responses are anonymous. As your son/daughter is under the age of 18, we ask that you sign the consent form to let us know that you are happy for your son/daughter to fill out the survey and be a part of the research. They will also be asked to give their assent.

Why has my son/daughter been asked to take part? Your son/daughter has been asked to take part as they are over the age of 16 and have Down syndrome. Their participation in this study is voluntary, there will be no negative consequences if they decline to participate. If you or your son/ daughter changes your mind and don't wish to submit your responses, you can stop completing the survey at any time and **do not submit your responses**.

How will my son/ daughter consent? Your son/ daughter will be given an easy read version of this information sheet and consent form. It will be made clear that they do not have to take part in this study if they do not want to. They will also be given a point of contact if they have any queries relating to the project.

I accessed this survey through an email link, what will the email address be used for? The email address will be used to send your son/daughter a specific link to the survey. This makes sure that your son/daughter can do the survey at different time points and that your answers won't be deleted between breaks. It also means that if your son/daughter forgets to finish the survey, they will receive one automated reminder to complete it. All their answers will still be anonymous. Their email address will be deleted after the survey is completed. The email address will be used for no other reason. If you accessed this survey through social media or a direct link, this information does not pertain to you. No email address has been collected from you.

What information will be collected? Information collected will include questionnaire responses regarding what your son/daughter typically reads during the day. All of this

information will be anonymous.

Will my son's/daughter's participation in the study be kept confidential? All participant information and their responses will be anonymous. Email addresses will be used for the sole purpose of sending the survey link and will be deleted immediately after.

How will my information be kept? All anonymous information will be stored securely on UCC's Microsoft Sharepoint for the duration of the project.

What about the results? If the results of this study are published in a peer reviewed journal, details of this publication will be forwarded to the Down Syndrome Ireland website. The anonymous results will be made available on an Open science repository for scientific transparency and potential future analysis.

Are there any disadvantages to taking part? We do not foresee any disadvantages to taking part in this study. We have designed the checklist so that it is easy to complete, and completion online means that your son/ daughter can do this at a time that is convenient to them.

Has this study been reviewed for ethical implications? Yes, this study has been approved by the Social Research Ethics Committee, UCC.

I have further queries, who can I ask? If you have any further questions, issues or complaints about this study, then you can contact Down Syndrome Ireland Member Support Team Leader Nicola Hart, student researcher Mary Jolley or the research supervisor Dr Pauline Frizelle. They will be very happy to answer any questions you may have.

Mary Jolley: 118439296@uemail.ucc.ie

Nicola Hart: Nicola@downsyndrome.ie

Dr Pauline Frizelle: p.frizelle@ucc.ie

Appendix L. Paper version of the MRM survey.

Easy read checklist for adults with Down Syndrome

● WEEKLY PLANNER ●						
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
						

You can fill out this survey **over a week!** Take breaks!

You should fill out the questions on **different days.**

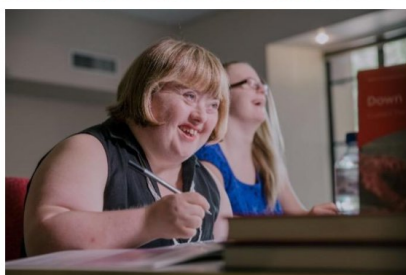
You can also **change** your answers this way!

You might **remember** different answers.. so go back and **change** them if you want!

Functional Reading Survey Information Sheet



We want to know **more** about what adults with Down syndrome **read**.



We are asking lots of people **with Down syndrome** if they would like to answer our **questions**.



We may ask you questions about:
How **well** you read?
What **things you read**?
Where adults with Down syndrome read?
Why do you read?



You will be shown **pictures** of some things people **read**.
You will be asked to **answer** some questions about reading.



You can **read** the survey **first** and have a think about reading.
Then you can come **back** and **fill it out**.
You can go **back** and **change your answers**!
You may remember **new** information.



You can **type** out your answers.
You can also **click yes or no**.



You can fill out the survey on your **computer or phone or write your answers**.



Only **answer** the **questions** if **you want to**.

Only **take part** in this project if **you** want to.



No one will be upset if you **do not want** to answer questions about your reading.



If you **do** want to **take part** in this project, we will **ask you** to click **yes** to a **consent form**.

A consent form tells us **you understand** what we are asking you to do in this project.



If you **start** answering questions and **change your mind**, you can stop.

Don't submit your response.



If you are doing this survey through **your email**, we will email you a survey **link and 1 reminder**.

Your email address **will not be used for any other reason**.

Your email address will not be **stored after the survey has finished**.



Your **details** will be kept **private** during the study and in any report of the study.



No one will know **which answers** are yours.



At the **end** of the project we will **write** about it in the Down Syndrome Ireland e-letter. You can **read** about it there when it is **finished**.

The **information** we get from the study may also be used to **teach people about** what adults with Down syndrome read.

We may also **publish it in a journal**.



If you have **any questions** about the project, you can **ask your parent or teacher or carer for help**.

It can be helpful to fill out this survey with **help of someone**.

If you have any other **questions** you can email

Nicola

Nicola@downsyndrome.ie

or

Mary

maryjolley@umail.ucc.ie

This page is for the participants!

Reading Survey
Consent/Assent Form



I have read the **information sheet** and know what the **study is about**.



I have had a chance to **ask questions** about the study.



I understand **how to ask a question or complain.**



I know it is **my** choice to **answer** the questions. I **do not** have to take part in this study and can **stop if I change** my mind.



I **understand** that my answers will be **shared** with researchers in University College Cork.



I **understand** that there will be **no reward** for this study.



I **understand** that my details will be kept **private** during the study and in any report about the study.



I understand that information I give may be used in **other studies in the future, without** my name and details and will be stored openly for **other researchers** to look at (Open Science platform).

Tick the box to let us know if you **want to take part!**



Yes I consent

☐

No I do not consent

☐

Easy read checklist for adults with Down Syndrome

● WEEKLY PLANNER ●						
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
						

You can fill out this survey **over a week!** Take breaks!

You should fill out the questions on **different days.**

You can also **change** your answers this way!

You might **remember** different answers.. so go back and **change** them if you want!



Q1 Hello, my name is **Mary**, and I am doing a **project** about **reading**. I am a student in **University College Cork**.

We are helping **Down Syndrome Ireland** to find out more about what people with Down syndrome **read everyday**.

You can contact me if you have **questions!**

My email is maryjolley@umail.ucc.ie



There are some questions in this survey that will ask you about your **past education!**

We **recommend** filling out this survey with some **help from someone!**

This can help you **remember** some things you might forget!

We will ask you:

1. About **yourself**
2. About the **things you read**
3. About **why** you **read**

Take as much **time** as you need to answer the questions.

If you would like **help** when answering these questions you can **ask your teacher**

First, tell us **who is filling in this** form by **tick**ing one of the boxes below:

Q2

	Who is answering these Questions?	Please tick a box
	I am a person with Down Syndrome doing this on my own	☐
	I am a person with Down syndrome doing this with some help.	☐

Q3 Next, we will ask you some **questions** about **yourself**:



How **old** are you?

Write **your age** here:

Q4



Where do you **live** (what country)?

Write your **answer** here:



For these next questions it will help to **know** what these words **mean**:

- **Special School:** This is a school **only** for people with **extra needs**.
For Example, people who have **Down Syndrome**, **Autism** or another **learning disability**.
- **Mainstream school:** This is a school for **all children**. People who **live near you** and **people with extra needs** going to school **together**.

Q5

How **many years** did you spend in a **special school**?

(Ask your family if you are not sure)

Write how many years here: _____

Q6

How many years did you spend in a **mainstream school**?

(ask your family if you are not sure)

Write how many years here: _____

If you are NOT from Ireland, please fill out this page.

Q7

Please **let us know** if you have or have **not** done **any other** courses **after** school.

Please **tick** which one you did.



No courses after school



Yes I did **do** courses after school.

Please **write** what course you have **done**.

EVERYONE can fill out from here.



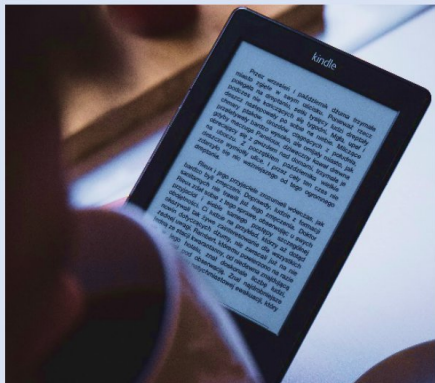
Q8 How **many months or years** have you spent **doing courses after school?**
(if you didn't do any you can write 0!)

Write the **amount of time** here:



Q9 Is there **anything else** you would like to tell us about **school** or about **reading?**

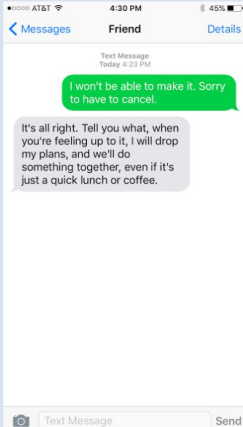
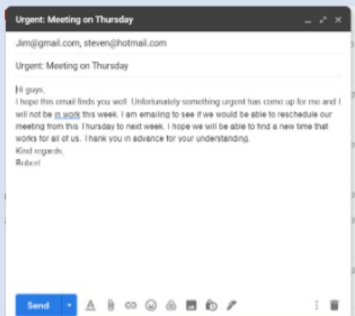
Write any **extra information** here:

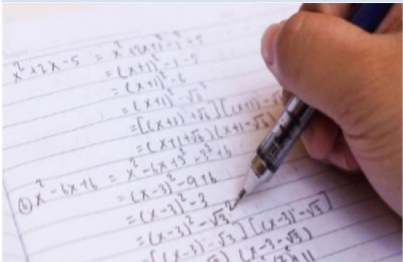
This is a list of some of the things people read		Tick all the things that you read	
Q10 General Reading			
		 YES	 NO
	Books		
	E-books		

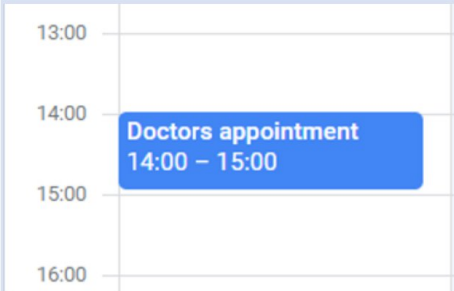
This is a list of some of the things people read	Tick all the things that you read	
	 YES	 NO
	Books that have a lot of pictures	
	Poems	
	Newspapers	

This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Magazines		
	Catalogues		
	Ad Leaflets		

This is a list of some of the things people read	Tick all the things that you read	
	 YES	 NO
	Crosswords or Word Searches	
	Board Games	
	Cooking Instructions or recipes	
	Food Items	

This is a list of some of the things people read		Tick all the things that you read	
Q11 Personal Reading		 YES	 NO
	Read things on Social Media		
	Text Messages		
	Emails		

This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Homework or Assignments		
	Lists		
	Post		

This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Calendars		
	Invitations and appointment reminders		
	Cards		

This is a list of some of the things people read		Tick all the things that you read																																																																																																	
																																																																																																			
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Bookstore Weekly Schedule Week of: May 1-7 <table border="1"> <thead> <tr> <th></th> <th>Sun 5/1</th> <th>Mon 5/2</th> <th>Tue 5/3</th> <th>Wed 5/4</th> <th>Thu 5/5</th> <th>Fri 5/6</th> <th>Sat 5/7</th> </tr> </thead> <tbody> <tr> <td>Bourne, M.</td> <td>9am-6pm</td> <td>9am-6pm</td> <td>9am-1pm</td> <td></td> <td>9am-6pm</td> <td>9am-6pm</td> <td></td> </tr> <tr> <td>Brown, M.</td> <td>11am-8pm</td> <td>11am-8pm</td> <td>7am-11am</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Gatsby, A.</td> <td></td> <td>11am-8pm</td> <td>11am-8pm</td> <td>7am-11am</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Gordon, A.</td> <td></td> <td></td> <td></td> <td>11am-8pm</td> <td>11am-8pm</td> <td>7am-11am</td> <td></td> </tr> <tr> <td>Hender, V.</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>Lawson, N.</td> <td></td> <td>11am-8pm</td> <td>11am-8pm</td> <td>7am-11am</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Shim, I.</td> <td></td> <td></td> <td></td> <td></td> <td>9am-6pm</td> <td>9am-6pm</td> <td>9am-1pm</td> </tr> <tr> <td>Smith, T.</td> <td>9am-6pm</td> <td>9am-6pm</td> <td></td> <td></td> <td></td> <td>9am-6pm</td> <td>9am-6pm</td> </tr> <tr> <td>Talbot, P.</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td>9am-6pm</td> <td>9am-6pm</td> </tr> <tr> <td>Tate, L.</td> <td></td> <td></td> <td></td> <td>9am-6pm</td> <td>9am-6pm</td> <td></td> <td></td> </tr> <tr> <td>Vinquez, A.</td> <td>11am-8pm</td> <td>11am-8pm</td> <td>7am-11am</td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		Sun 5/1	Mon 5/2	Tue 5/3	Wed 5/4	Thu 5/5	Fri 5/6	Sat 5/7	Bourne, M.	9am-6pm	9am-6pm	9am-1pm		9am-6pm	9am-6pm		Brown, M.	11am-8pm	11am-8pm	7am-11am					Gatsby, A.		11am-8pm	11am-8pm	7am-11am				Gordon, A.				11am-8pm	11am-8pm	7am-11am		Hender, V.								Lawson, N.		11am-8pm	11am-8pm	7am-11am				Shim, I.					9am-6pm	9am-6pm	9am-1pm	Smith, T.	9am-6pm	9am-6pm				9am-6pm	9am-6pm	Talbot, P.						9am-6pm	9am-6pm	Tate, L.				9am-6pm	9am-6pm			Vinquez, A.	11am-8pm	11am-8pm	7am-11am					Work Rosters		
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	A contract that you need to sign																																																																																																		
Q12 Reading when out and about																																																																																																			
	Restaurant menus																																																																																																		

This is a list of some of the things people read	Tick all the things that you read	
	 YES	 NO
	Road Signs	
	Signs on doors	
	Travel timetables (like at the train station or airport)	

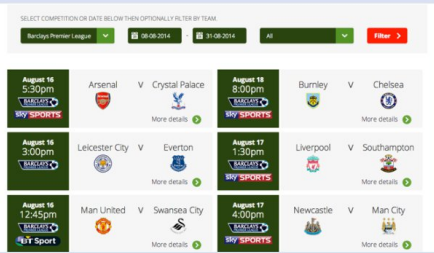
This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Cinema times		
	Shop names		
	Clothes brands		

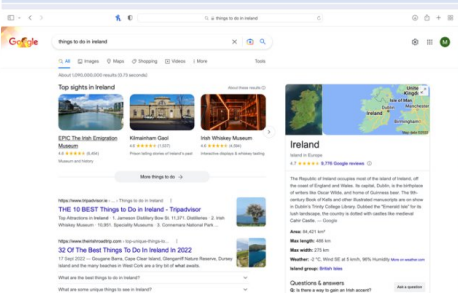
This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Food brands		
	Health information (Such as a covid sign)		
	Information about displays in a museum		

This is a list of some of the things people read	Tick all the things that you read	
	 YES	 NO
	Maps	

This is a list of some of the things people read	Tick all the things that you read
	  YES NO
	Video game and DVD boxes
	Video game menus
	Movie and TV show names on the TV menu

This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Headlines on the news		
	Subtitles		
	YouTube Videos		

This is a list of some of the things people read		Tick all the things that you read	
		 YES	 NO
	Song titles (for example on Spotify or Apple Music)		
You are the dancing queen Young and sweet Only seventeen Dancing queen Feel the beat from the tambourine	Song Lyrics		
	Sports Fixtures		

This is a list of some of the things people read	Tick all the things that you read	
	  YES NO	
Premier League · Sun, 24 Oct Full-time  0 - 5  Man United Liverpool N. Keita 5' D. Jota 13' M. Salah 38', 45+5', 50' P. Pogba 60'	Sports Results	
	Lottery Numbers	
	Web browsing or searching	

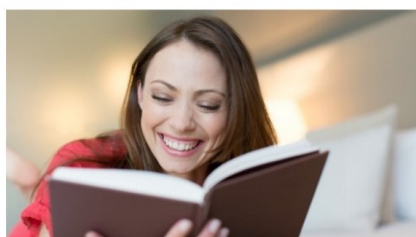


Q14

What **else** do you **read**?

Put anything you read that was not on the list above here:

1. _____
2. _____
3. _____
4. _____
5. _____



Q15 What is the **best** thing about **reading**?

For example: It is **fun**, it helps to **pass time**, I can **talk** to my **friends** about **things I read**

Write your answer in the space here:



Q16 What is **hard** about reading?

For example: the words are **too small**, there are words **I don't understand**, words are **hard to remember**, **too many** words,

Write your answer in the space here:

**Q17 Why do you read?**

For example: To **learn** new things, because I **enjoy** it, to find out **information**

Write your answer in the space here:

Tick which
one!

Q18 Which do you most like to read?



A paper book



An e-book
like a kindle



On a tablet or
computer



Listening to
audio books



I don't like to
read



I cannot read

Tell us **why** you chose this choice:



Q19

Where do you read?

For example: At **home**, at my **day service**, at **school**, the **library**, at **college**, or **online**

Q20



When do you read?

For example....

All the time, only when I **have** to, In the **morning**,
in the **afternoon**, in the **evening**, at the **weekend**,
after **work**,...

Q21



What would you like
to be **able to**
do with **your**
reading?

For example...

To read **without help**, to read **more** words,
read **faster**, read new things, read on
my **phone**, read on my **computer**, get a **job**, go
to **college**, other...



ONLY fill out the next pages if you live or have lived
In **IRELAND**.



Have you done any courses **after leaving school?**

Tick any of the courses you did:

		YES	NO
	1. A university course		
	2. An Education and Training Board (ETB) course		
	3. Down Syndrome Ireland Ability Online course like... <i>DSI "Music", "Movies"</i> <i>or "Fun, Food and Fitness"</i>		

		YES	NO
	6. Down Syndrome Ireland Latch On course		
	7. Down Syndrome Ireland MOTE course		
	8. Down Syndrome Ireland Work Skills course		
	9. Personal Development Course		

		YES	NO
	10. Another course not on this list		
	No other courses after school!		

If you ticked **yes** to **option**

1 write the **university**

course you studied here:

If you ticked **yes** to **option**

9 write the **name of the**

course you studied here:



You're **finished**? Great!

Thank you for doing our survey.
You can change your answers before sending them!

This is the **end** of our questions