

Dyslexia – The Hidden Disability in the Workplace

Thesis submitted by

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Statement of authorship

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Shae Wissell

Date: 20 June 2023

All research procedures reported in the thesis were approved by the La Trobe University Human Ethics Committee.

In loving memory and honour

of my mum Victoria Wissell; an educator, leader, grandmother, wife, sister and dear friend to many. My beautiful mum, there are no words, but I know you are always by my side. I'm finally here ma, I made it.

I promised you I would!

Acknowledgement

She silently stepped out of the race she never wanted to be in, found her own lane and proceeded to win.

- *Unknown*

It's hard to acknowledge everyone who has supported me through this crazy journey, from family to friends to complete strangers. It is the gift of time that people have offered so generously even though they have busy lives, competing priorities and families of their own. These people have offered guidance, support, and mentorship. I set out on this journey to prove something to myself; that I was smart and intelligent. There was something inside of me determined to complete a doctorate. I discovered on this journey how determined, persistent and resilient I really am, all very strong dyslexic traits. There have been some significantly difficult personal times, when I thought I would not get to the end of this chapter of my life that I have so carefully and passionately carved. It is that passion that has kept me going, the ongoing injustice I see so many people with dyslexia face daily. That injustice and an insatiable drive for social equity and justice have pushed me through the dark times of self-doubt, questioning and personal struggles of having dyslexia. This has been one of the hardest journeys of self-discovery I have been on. But the sum of what I hope to achieve is greater than me, and I hope this thesis gives a voice to those who participated in this research. I hope that with these voices and the voices of so many others we can start to create systemic changes for young people and adults with dyslexia in Australia. For far too long we have been silenced, we have not had a voice, we have been spoken for and about but until now we

have not been at the table, we have not been part of the conversation. I hope this thesis will start to give a voice to the silenced, the unseen, the ignored, the ill-treated, the 1 in 10 Australians who, like me, have dyslexia.

It has been an honour and privilege to bring these stories to life through this research and for the first time in Australia have research that starts to paint a picture of what life is truly like for those with dyslexia. It's a hard story to share; there have been many tears in hearing and representing these through our research. Through the sharing of these stories of people with dyslexia in Australia and the ongoing support of my family, friends, supervisors and the dyslexic community, I have reached the end of this destination.

To my family, my biggest supporters – full of neurodiversity. They have run the hard race, stood by my side, edited my work, never once questioned my hopes and dreams, and said “go for it”. My Auntie Leanne Di Stefano who has supported my doctoral journey, editing and reviewing my work and spending countless hours going through my thoughts and ideas with me.

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To the participants, thank you for sharing your experiences and thoughts so candidly. At times I wept in silence, recalling your trauma and shared in your hopes for a better world. I hope I have made you proud of being part of this first of its kind Australian research. I am proud of the work we have achieved, and this work is for you – the greater sum of me.

Last, but not least, I would like to acknowledge the dyslexic community and all those who have struggled to reach their dreams and to see their full potential. This research, all the blood, sweat, and tears are for you. I hope you can see that you can dream, and those dreams can come true. It's not easy, I won't lie, and sometimes our dreams are adjusted, but we can all reach our full potential, whatever that means to you.

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Shae Wissell, June 2023

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I declare that this thesis is my own work and has not been submitted in any form for another degree or diploma at any university or other institution of tertiary education.

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Thesis abstract

The adult population with dyslexia represents a considerable portion of the neurodivergent community and ten percent of the general populace. Nonetheless, there has been a paucity of research conducted in Australia that examines the experiences of living with this learning disability from the perspective of adults. Research efforts in Australia have primarily been focused on children and adolescents, covering topics such as early intervention, educational support, mental health, and wellbeing. However, as individuals transition into adulthood, a notable gap in research has emerged. Given that dyslexia is a recognised disability under Australian laws and regulations, it is imperative that research is conducted in Australia to better understand how adults with dyslexia navigate their day-to-day lives, particularly in relation to their workplace experiences (where adults spend a significant amount of time) and the support they require in the workplace. Such research would provide valuable insights into this population and enable the provision of more effective support measures.

The objective of this doctoral research was to examine the subjective experiences of adults with dyslexia, with a specific emphasis on their employment status and social and emotional wellbeing. To achieve this objective, three distinct studies were undertaken. The first study was dedicated to the examination of the social and emotional wellbeing of adults with dyslexia. The second study was devoted to exploring the workplace experiences of this population. The third and final study sought to investigate the perceptions and experiences of employers and managers working with employees who have dyslexia.

The results of the three aforementioned studies shed light on a broad spectrum of challenges encountered by Australian adults with dyslexia. These challenges, often originating in childhood, persist into adulthood for many individuals, with diagnosis often not occurring until later in life. Despite this research identifying high levels of education and

employment across diverse industries, individuals with dyslexia often face several challenges and disadvantages throughout their employment trajectory, dictating the need for individual coping mechanisms to navigate workplaces and daily activities. Because of pervasive barriers, several participants in these studies experienced lower levels of mental health and wellbeing compared to the general population.

The combined findings of these three studies highlight the difficulties in obtaining a dyslexia diagnosis, the potential for negative educational experiences during childhood leading to lasting traumatic effects, the identification of personal strengths and resources, the role of family support, and the influence of other interpersonal relationships on those who live with dyslexia. These findings have been brought together to present a collection of empirically informed propositions and recommendations for policymakers, government agencies, and company executives, managers, or leaders within organisations, including consideration of further research and implementation of support strategies within their respective institutions and workplaces.

Chapter 1

Thesis overview

*If you work on something a little bit every day, you end up with something that
is massive.*

– Kenneth Goldsmith

1.1 Context for this project

Dyslexia became a passion of mine at the age of 37. Ten years earlier, at 27, I was diagnosed with dyslexia and dysgraphia; two labels I did not understand even though I had trained as a speech pathologist. What became evident as I learnt to live with and understand these labels was that there was limited formal support for someone like me, with this diagnosis. After my diagnosis, I suffered a complete mental breakdown. There was no professional or other person to talk to, and no one I knew at the time had dyslexia. I felt “dumb” and ashamed, and I felt that my identity had been stripped from me. After some years of being unwell, and with the support of my family, I recovered and started to wonder what happened to all the people like me who didn’t recover, who did not find hope in the darkness, and who didn’t have the amazing ongoing love and support I had.

Over the years, as I moved from one job to the next, a black cloud of shame followed me; the shame of not being able to read and write like others. As I progressed in my career, I struggled more and more, unable to meet deadlines, complete tasks on time, write emails and lengthy reports or organise my thoughts and ideas on paper. I was performance managed, refused the advertised pay offered and even terminated from a role because of my dyslexic difficulties. My dyslexia made me feel that I did not have the literacy skills of reading and writing that I needed, not if I was to eventually achieve career progression into senior executive roles. Most of my employers appeared to lack the understanding and empathy to help me, and I was frustrated and angry at the systems around me. I felt that three levels of education (primary, secondary and tertiary) had failed me, workplaces were failing me, shaming me, embarrassing me, and questioning my integrity and capacity. There were many nights I cried, feeling lost, unsure of what to do with my life. This uncertainty though was to eventually lead me to find clarity in terms

of my future. I was determined to help other people, so they did not feel the isolation, frustration and hurt that I had felt throughout my education and eventual employment.

This was to eventually lead me onto my doctorate journey. I wanted to make a contribution towards the growing body of information around dyslexia in adulthood, and particularly, to look for the evidence that identifies the desperate need for change for the adults with dyslexia in Australia. I wanted to give a voice to the voiceless and to translate this research into practice. Also, I was hoping to enable Australian society, especially Australian workplaces, to truly see the value of difference, and to be inclusive of all. I hope this research educates and informs, but most of all, I hope it contributes to the start of systemic change across access to the working environment, so that those with dyslexia can contribute to society in meaningful ways, and can, as a result, lead healthier, happier and more connected lives.

1.2 Organisation of the thesis

This chapter provides an overview of the structure and organisation of studies undertaken in this research. The PhD research employed a mixed methods approach comprising two main studies: 1) a quantitative study involving an online cross-sectional survey and 2) a qualitative study utilising in-depth interviews. From these two studies, three journal articles were published. A visual guide to the positioning of these studies within this research is provided in Figure 1.

Study A employed a quantitative method of enquiry, and involved an online, anonymous survey of 65 Australian adults with dyslexia (Chapter Four). Study B was qualitative in nature and involved interviews with two participant groups: B.1 comprised in-depth interviews with 14 Australian adults with dyslexia (Chapter Five) and B.2 consisted of in-depth interviews with four Australian managers and employers without dyslexia (Chapter

6). Study B resulted in two published journal articles reporting on the perspectives and experiences of each of the two participant groups. An associated chapter making recommendations based on the two studies on how to improve outcomes for adults living with dyslexia follows the analyses (Chapters 7 & 8).

Figure 1. Thesis visual guide

DYSLEXIA IN AUSTRALIA: AN ACCOUNT OF LIVED EXPERIENCES IN ADULTHOOD

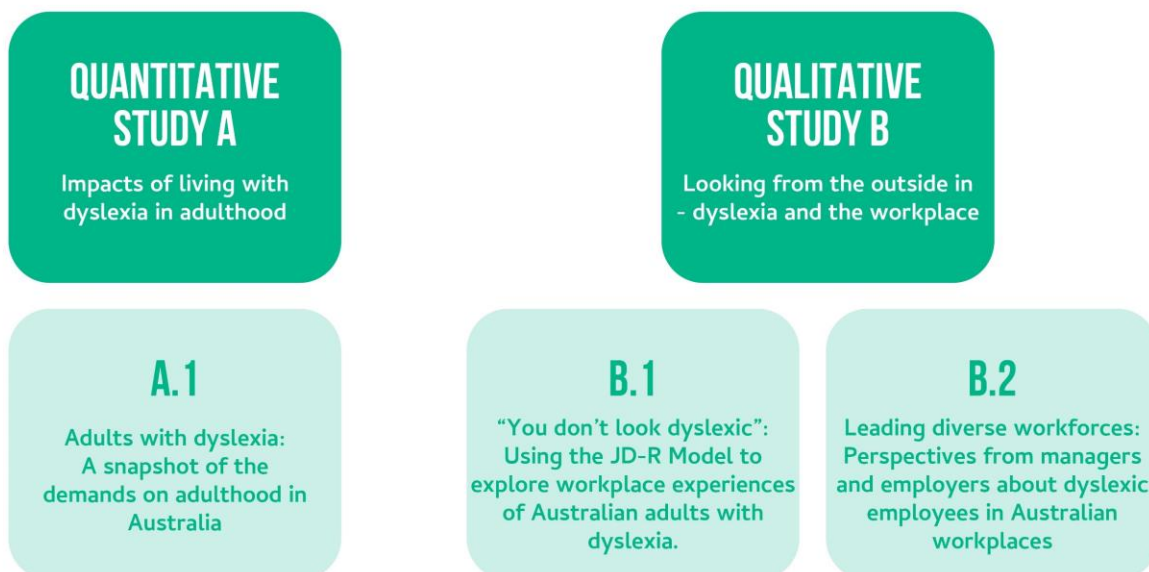


Figure 2 provides a visual overview of the chapters in this thesis.

Figure 2. Thesis overview

CHAPTER 2	Rationale for the study
CHAPTER 3	Literature review
CHAPTER 4	Study A: Journal Article 1. Adults with dyslexia: A snapshot of the demands on adulthood in Australia
CHAPTER 5	Study B 1: Journal Article 2. “You don’t look dyslexic”: Using the Job Demands - Resource model to explore workplace experiences of Australian adults with dyslexia
CHAPTER 6	Study B 2: Journal Article 3. Leading diverse workforces: Perspectives from managers and employers about dyslexic employees in Australian workplaces
CHAPTER 7	Discussion
CHAPTER 8	Serendipitous findings, limitations, recommendations and conclusion

Chapter Two provides a synopsis of the thesis. It outlines the rationale for this research and concludes with a statement of the aims and the research questions that have been addressed.

Chapter Three reviews the literature on dyslexia and explores what is known about the impact this has on individuals with this lifelong condition. Factors such as prevalence, models of causation, common co-morbidities/co-occurring conditions and the medical and social models of disability are described. Chapter Three also introduces the ecological systems model as an alternative to the medical and social models in understanding the complex impacts of dyslexia (Bronfenbrenner, 1974, 1977; Bronfenbrenner & Evans, 2000). The ecological model takes account of the effects of multiple levels of influence upon the individual's surrounding environment and settings. These influences occur through family and through cultural values, laws and customs throughout their lifespan, and here, offer a means of contextualising dyslexia within the broader social and cultural context.

Chapter Four presents the first study conducted within this doctoral research and draws on quantitative data from Study A .1 (Journal Article 1). The study was published in 2021 in the *Australian Journal of Learning Difficulties* and is entitled: “*Adults with dyslexia: A snapshot of the demands on adulthood in Australia*”. The main objective of this chapter is to examine the demands confronted by adults diagnosed with dyslexia residing in Australia. This investigation is centred on an evaluation of the social and emotional wellbeing of the 65 participants, as determined by the standardised Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Taggart et al., 2016; Tennant et al., 2007). This chapter also presents an analysis of the educational and employment outcomes of the study's population and examines the disclosure rates of individuals diagnosed with dyslexia. Additionally, it delves into a discussion of the implications of the WEMWBS findings.

Chapter Five presents the second study conducted within this doctoral research and draws on qualitative data from Study B.1 (Journal Article 1). This article was published in 2022 in the *International Journal of Environmental Research and Public Health: Special Edition on Dyslexia* and is entitled: “*You don’t look dyslexic*”: *Using the JD-R Model to explore workplace experiences of Australian adults with dyslexia.*” The study sought to explore the lived experiences of 14 working Australian adults who are dyslexic. The instrument employed as a guiding framework for this study was the *Jobs Demands-Resources Model of Burn Out (JD-R Model)* (Bakker & Demerouti, 2007; Demerouti et al., 2001). The findings from this instrument are also discussed in this chapter.

Chapter Six continues to focus on the second study of the PhD research, presenting findings from Study B.2 (interviews with Australian managers and employers). The resulting journal article was published in 2022 in the *International Journal of Environmental Research and Public Health: Special Edition on Dyslexia* and is entitled “*Leading diverse workforces: Perspectives from managers and employers about dyslexic employees in Australian workplaces.*” This analysis delves into the views and experiences of four non-dyslexic employers and managers who work with dyslexic employees. Very little has been published on this topic and to our knowledge this type of research has not been previously conducted in Australia.

Chapter Seven offers a comprehensive discussion and interpretation of the findings from all three studies through the lens of the ecological framework. Points raised in the three journal publications are presented, including (for participants with dyslexia) factors relating to diagnosis of dyslexia, educational attainment, employment pathways, disclosure of dyslexia within the workplace setting and workplace wellbeing, and (for participants without dyslexia) the experience of managing dyslexic employees in the workplace.

Chapter Eight provides a summary of the thesis, additional ‘serendipitous’ findings, and outlines some of the limitations of the research. The final and critical section of this chapter is the presentation of a set of recommendations stemming from the research findings that aim to address challenges associated with dyslexia with regard to systems factors outlined within the ecological model and the social determinants of health. Finally, a discussion of future research directions to build on the findings is provided.

This thesis is an original contribution and Australian-first research developed with oversight from my supervisors:

- Dr Leila Karimi, A/Professor of Organisational Psychology; Accredited Statistician, Assistant Associate Dean –Applied Health, STEM College, School of STEM/Health Biomedical Sciences, RMIT
- Dr Tanya Serry, Associate Professor of Literacy, School of Education, La Trobe University
- Dr Lisa Furlong, Adjunct Research Fellow Education School Operations, La Trobe University and Senior Lecturer, Flinders University
- Dr Judith Hudson, Adjunct Associate-Honorary, College of Arts, Law and Education (CALE), School of Education, University of Tasmania.

Leila Karimi and Tanya Serry are co-authors of Study A.1, B.1 and B.2. Lisa Furlong and Judith Hudson are co-authors of Studies B.1 and B.2.

To the best of my knowledge, this thesis brings new learnings about the lived experiences of Australians with dyslexia in adulthood. This research sought to better understand the experience of dyslexia by way of its impact on key social determinants of health: education, employment, social and emotional wellbeing. The research introduces the ecological model to explore the impact of dyslexia more holistically, to show the way in

which societal systems can influence the experience of dyslexia and to explain how those systems could be adjusted to provide better support. This research is in response to the need to raise and develop a deeper understanding of this invisible disability and to shine a light on the general lack of awareness of dyslexia that appears to exist within Australia.

Chapter 2

Research overview and key research questions

Doing nothing encourages the status quo. We must make a conscious decision to reject the status quo to improve the quality-of-life outcomes for those with dyslexia, their families and the broader community.

- Shae Wissell

2.1 Rationale for this study

Despite significant research efforts into dyslexia in Australia, the demands experienced by adults with dyslexia have received limited exploration to date. The existing literature has mainly concentrated on early intervention and support, teacher education standards, risk factors associated with compromised mental health and wellbeing among dyslexic children and assessment processes (Boyes et al., 2016; Firth et al., 2013; Maxwell, 2019; Serry & Oberklaid, 2015; Yang et al., 2022). Initial inquiries into the impact of dyslexia have also been carried out in the Technical and Further Education (TAFE) and Higher Education sectors in Australia (Caskey et al., 2018; Maccullagh, 2014; Tanner, 2009).

Comprehending the intricacies of dyslexia and its impact is crucial, given it is a lifelong disability with implications for navigating employment, financial independence, and social and emotional wellbeing. Nevertheless, there is a paucity of research in Australia that examines the long-term ramifications of dyslexia and how individuals with this disability can be effectively supported to achieve meaningful societal participation and improved quality of life.

The purpose of this research was to take a deeper dive into the impact of dyslexia on adults in Australia; to move beyond the ‘simplistic’ framing of dyslexia being a condition that primarily affects reading and writing, towards a more comprehensive understanding of the multi-faceted impact of dyslexia on dyslexic adults’ ability to meet societal expectations. In doing so, this research uses an adapted version of Bronfenbrenner’s ecological systems model (Bronfenbrenner, 1974, 1977, 2009) to explore the way adults with dyslexia may be shaped and influenced by their environments and particularly how that plays out in the workplace environment. The ecological model is explored further in Chapter 3.6.

Gerber et al. (1992) and Spekman, Goldberg, and Herman (1993) have stressed the importance of understanding the interconnectedness of individuals, families, social networks, and communities for individuals with dyslexia. They emphasise that the development of individuals is closely intertwined with a complex context. Hence the Bronfenbrenner model is a useful tool in highlighting the importance of considering these interconnecting different levels of influence that impact an individual's development, including the individual themselves, their immediate environment (such as family, peers, and work), and broader societal and cultural factors faced by those with dyslexia (Bronfenbrenner, 1977; Bronfenbrenner & Evans, 2000). The aim is to utilise the framework and a perspective to facilitate a more nuanced comprehension of the findings presented in this thesis.

2.2 Scope and aims

The overarching aim of this thesis was to examine the real-life experiences of Australian adults with dyslexia with particular focus on the domains of education, employment, and social and emotional wellbeing, and to explore the experiences of Australian employers and managers overseeing dyslexic employees. A primary objective was to establish a series of recommendations that could be translated into evidence-based practices and practical resources for individuals working with, and supporting, adults with dyslexia, particularly within professional environments.

2.3 Key research questions

Outlined below are the three key research questions that shaped this study. The questions were concerned with exploring the lived experiences of adults with dyslexia, with a

primary focus on the demands placed on them, their workplace experiences, and how experiences can shape and inform our sense of self.

- Question 1: How are Australian adults living with dyslexia faring compared to their non-dyslexic counterparts?
 - (a) What are their highest educational attainments?
 - (b) What are their rates of employment and what sectors do they work in?
 - (c) What is the likelihood of self-disclosure of their dyslexia diagnosis to family members, friends and work colleagues?
 - (d) How do participants score on the standardised Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS)?
- Question 2: How do Australian adults living with dyslexia perceive and experience the workplace?
- Question 3: What are the experiences and perceptions of individuals responsible for supporting and managing employees with dyslexia in the workplace?

2.4 Significance of this research

Dyslexia is a public health issue and there is a significant body of international research that has explored the impact of dyslexia across the social determinants of health, including educational attainment, employment opportunities, access to health care services and experiences, and social-emotional wellbeing. This robust body of research underscores the importance of addressing social determinants in efforts to promote health equity and wellbeing among individuals and communities (Alexander-Passe, 2012; Bartlett et al., 2010; Bell, 2009; Brunswick, 2012; Burden, 2005; Burnett, 2019; Burns & Bell, 2010; Cotton, 2009; David, 2020; Gerber & Price, 2003; Kulkarni, 2021; Livingston et al., 2018; Moody, 2009; Moojen et al., 2020).

However, the current state of research in Australia regarding the experiences of adults with dyslexia is deficient. Compared to other developed countries, Australia lags behind in comprehending the requirements of this population (Alexander-Passe, 2015b; Alexander-Passe, 2012; N. Alexander-Passe, 2015b; Beetham & Okhai, 2017; Gerber et al., 2012; Nalavany & Carawan, 2012; Nalavany et al., 2018; Olympia, 2006; Strawn, 2008). Additionally, no previous studies have investigated the lived experiences of Australian adults with dyslexia across multiple social determinants of health, such as healthcare accessibility, educational achievements, employment status, and social and emotional wellbeing. Moreover, to the best of our knowledge, no Australian studies have focused on employers' and managers' experiences with dyslexic employees. Therefore, this research aims to illuminate the realities of Australian adults with dyslexia and offer suggestions on enhancing their quality-of-life outcomes.

To strengthen the methodology of this research, an adaptation of Bronfenbrenner's Ecological Systems Model underpins enquiry. This model has been used in investigations of other public health issues, as it enables a holistic analysis of the various elements and influences from social and environmental contexts that impact people.

Two standardised tools were also adopted for this research: 1) the Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS) (Taggart et al., 2015; Taggart et al., 2016) and; 2) the Job Demands-Resource Model of Burn Out (JD-R Model) (Bakker et al., 2005; Benson, 2019). Globally, the WEMWBS and the JD-R Model have not been used on a sub population like dyslexia and this brings a new, exciting, and innovative element to the way we can understand the lived experiences of Australia dyslexics.

Chapter 3

Literature review

dyslexia. noun. dys·lex·ia dis- 'lek-sē-ə

a variable often familial learning disability that involves difficulties in acquiring and processing language and that is typically manifested by a lack of proficiency in reading, spelling, and writing.

- Merriam-Webster Dictionary (Merriam-Webster Dictionary, 2023)

Dyslexia (dɪsˈlɛksɪə) NOUN

A developmental disorder which can cause learning difficulty in one or more of the areas of reading, writing, and numeracy.

- British English (Collins Dictionary, 2023)

Dyslexia, (dis 'leksɪə) NOUN

Pathology: any of various reading disorders associated with impairment of the ability to interpret spatial relationships or to integrate auditory and visual information.

- American English (Collins Dictionary, 2023)

3 Introduction

3.1 Origins of dyslexia

Originally known as ‘word blindness,’ dyslexia first came to the attention of the medical fraternity more than 100 years ago when German ophthalmologist, Rudolf Berlin observed patients having difficulties reading printed words (Hudson, 2014; Kirby, 2020). The difficulty was initially attributed to problems with vision (hence, word blindness), but it was quickly recognised that peripheral visual mechanisms were not the cause, and attention moved to the functions of the brain.

Reading and writing are cultural inventions (Eden et al., 2015). They are not innate skills as is oral language that has been around for hundreds, if not thousands of years (Eden et al., 2015). Reading and writing have only been around for around 4000 - 6000 years (Dehaene & Dehaene-Lambertz, 2016; Eden et al., 2015). Rather than being born literate, we must learn to read through instruction, deploying parts of our brain that are not naturally suited for that purpose (Dehaene, 2021; Eden et al., 2015). Today, it is understood that dyslexia is a neurobiological disorder that affects 1 in 10 people in the population (Lyon et al., 2003; Yang et al., 2022).

3.2 Causation

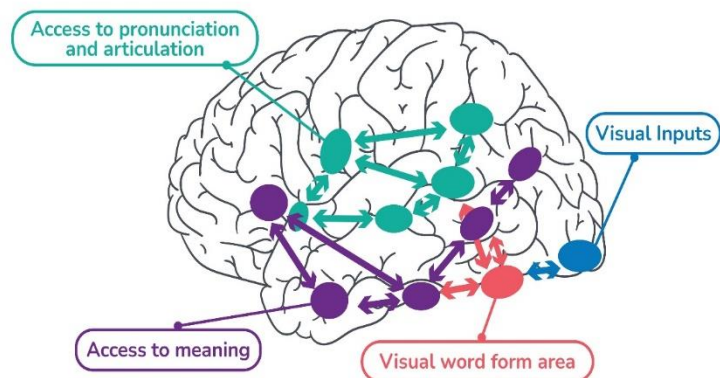
3.2.1 Brain architecture, neurobiological basis of dyslexia

Rather than being born literate, we must learn to read and write through instruction, deploying parts of our brain that are not naturally suited for that purpose (Dehaene, 2021; Eden et al., 2015). Specifically, the ability to read requires several distinct parts of the left hemisphere of the brain to be active (see Figure 7) (Dehaene, 2021; Hudson et al., 2007). Evidence indicates that dyslexia is neurologically based in origin and is caused by under-

activity of the left hemisphere's language network, including the occipito-temporal and parieto-temporal areas (Berlinger et al., 2008; Eden et al., 2015; Maisog et al., 2008; Peterson & Pennington, 2012). There are signs of abnormal grey matter and white matter development in the brains of those diagnosed with dyslexia (Dehaene, 2021; Hudson et al., 2007). Magnetic Resonance Imaging (MRI) scans have shown that those with dyslexia have less grey matter in the left parieto-temporal area compared to those who do not have dyslexia. A reduction in grey matter and white matter in this area has been associated with difficulties with phonological awareness and a decrease in reading skills (Hudson et al., 2007). MRI scans have also indicated that individuals with dyslexia tend to have symmetrical brain structures compared to the general asymmetrical brains of non-dyslexics (Hudson et al., 2007). In simple terms, those with dyslexia appear to be born with a different brain structure and composition compared to the general population.

Figure 3. Adapted from Dehaene, S (2019) *Reading in the Brain: The New Science of How We Read*

The brain architecture for reading



In recent years, research has established that dyslexia is not caused by poverty, developmental delay, speech, hearing or visual impairments, or learning a second language (Hudson et al., 2007). Dyslexia is also unrelated to intellectual functioning, with dyslexia occurring across the intellectual quotient (IQ) range of intelligence (Aaron et al., 1999; Siegel, 1989).

3.2.2. The influence of genetics

There is now considerable evidence that there is a genetic influence involved with dyslexia, and it is often found in more than one member of a family (Berninger et al., 2008; Eden et al., 2015; Fisher & DeFries, 2002; Goldstein, 2011; Hudson et al., 2007; Snowling et al., 2003; van Bergen et al., 2012). It has also been found that children who have at least one parent with dyslexia have a 33% to 66% chance of having dyslexia themselves (van Bergen et al., 2012). Other estimates of familial inheritance range from 50-60% (Brimo et al., 2021; Grigorenko et al., 2003; Pennington & Smith, 1983; Snowling et al., 2003).

3.3 Prevalence

Estimates of the prevalence of dyslexia vary depending on the metrics used for diagnosis. It has been estimated that 7-10% of the global population and some 2.5 million Australians are dyslexic (Ashraf & Najam, 2020; Kita et al., 2020; Wagner et al., 2020; Yang et al., 2022). However, as the Australian Bureau of Statistics does not collect data on the number of children and adults diagnosed with dyslexia, estimates of prevalence are difficult to confirm. This may change with the advent of the National Consistent Collection of Data (NCCD) introduced and mandated for all schools Australia-wide in 2015, to collect information on students with disabilities, including a learning difficulty such as dyslexia. Teachers are required to record the number of students within their classroom that have a disability and what classroom accommodations have been implemented. These recordings are then linked to funding support (Australia, 2022). Over time these data may provide more accurate information regarding the prevalence of dyslexia in Australia.

3.4 Diagnosing dyslexia

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), a clinical evaluation is necessary to diagnose specific learning disorders like dyslexia. This assessment involves reviewing the person's developmental, medical, educational, and family history (American Psychiatric Association, 2013; Lockwood, 2015). In addition, test scores, teacher observations, and responses to academic interventions are taken into account (American Psychiatric Association, 2013; Lockwood, 2015). To be diagnosed with a specific learning disorder, an individual must consistently struggle with reading, writing, arithmetic, or mathematical reasoning during their school years (American Psychiatric Association, 2013; Lockwood, 2015). Their current academic skills should be significantly below the average range of culturally and linguistically appropriate tests in these areas. Before a diagnosis can be made, the person must have received six months of evidence-based, high-quality instruction or intervention. Moreover, the individual's difficulties must not be better explained by developmental, neurological, sensory (vision or hearing), or motor disorders (American Psychiatric Association, 2013). These difficulties must also have a significant impact on academic achievement, work performance, or daily activities (American Psychiatric Association, 2013; Lockwood, 2015).

The DSM-5 considers reading underachievement in relation to instructional opportunities, specifically through the response-to-intervention criterion. For individuals aged 17 and above, a history of documented learning difficulties can replace standardised assessment (American Psychiatric Association, 2013, p. 67). On the other hand, the International Classification of Disease (ICD-11) does not provide adult-specific criteria and determines underachievement based on cognitive ability (World Health Organization, 2020). Due to these differences, there are various ways of diagnosing dyslexia in adults. However, the DSM-5's response-to-intervention criterion may hinder diagnosis for individuals who

have not had these opportunities, such as adults who are assessed later in life. As a result, concerns have arisen in the literature regarding the accuracy and consistency of dyslexia diagnoses in adults (Sadusky, Reupert, et al., 2021).

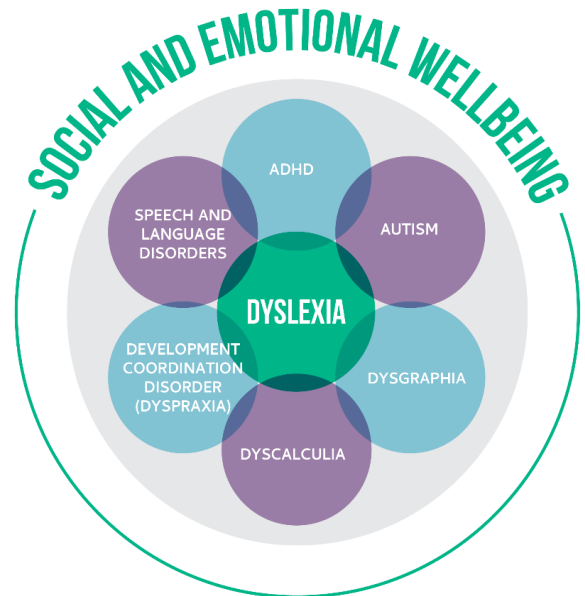
In countries like the UK, there are nationally recognised guidelines for identifying dyslexia in adulthood within higher education environments (Sadusky, Reupert, et al., 2021). These guidelines include a list of standardised assessments for cognitive achievement (such as the Wechsler Adult Intelligence Scale (Wechsler, 2008) to ascertain discrepancies between high cognitive abilities and low literacy abilities (assessed by instruments such as the Woodcock Reading Mastery Tests (Proger, 1975) (Sadusky, Reupert, et al., 2021). The literature states that a major component of meeting the criteria for dyslexia is to score 1.5 standard deviations or more below the mean on measures of reading and IQ/achievement tests in conjunction with the DSM-5 diagnostic criterion (Fletcher et al., 2019; Peterson & Pennington, 2012; Sadusky, Reupert, et al., 2021; Wagner et al., 2020).

However, in Australia there are no such guidelines to support clinicians in assessing children, adolescents or adults (Sadusky, Freeman, et al., 2021; Sadusky, Reupert, et al., 2021). The DMS-5 diagnostic criteria are predominantly used to assess dyslexia along with standardised assessments such as the Wechsler Adult Intelligence Scale and the Woodcock Reading Mastery Tests (Sadusky, Freeman, et al., 2021). The lack of consistency and access to diagnosis, especially as an adult, can impede one's ability to access support and services within the workplace and beyond.

3.5 Dyslexia and co-occurring difficulties

Figure 4. Dyslexia and co-occurring difficulties

As a neurodevelopmental disorder, dyslexia may often co-exist alongside other developmental disorders such as speech sound disorders, language disorders, autism spectrum disorder (ASD), dyspraxia/developmental coordination disorder (DCD), dyscalculia, dysgraphia, attention deficit hyperactivity disorder (ADHD), and



other related conditions encompassed by social and emotional wellbeing as illustrated in Figure 7 (Brimo et al., 2021; Goldstein, 2011; Hendrickx, 2010; Pham & Riviere, 2015; Russell, 2013; Yeo, 2003). Comorbidity between developmental disorders in childhood appears to be the norm rather than the exception (Bradshaw et al., 2021).

3.5.1 Dyslexia and dyscalculia

Approximately 3–7% of the general population have dyscalculia (Butterworth, 2019; Haberstroh & Schulte-Korne, 2019; Kucian & Aster, 2015; Wilson et al., 2015). An individual with dyscalculia can have severe difficulties performing arithmetic calculations that will persist into adulthood, even in the absence of intellectual disability (Butterworth, 2019; Wilson et al., 2015). Dyscalculia leads to marked impairment in academia, work, and everyday life and is linked to co-morbid mental disorders (Haberstroh & Schulte-Korne, 2019; Wilson et al., 2015). Between 30-70% of individuals have co-occurring dyslexia and

dyscalculia (Willcutt et al., 2013; Wilson et al., 2015). Although dyslexia and dyscalculia are distinct disorders, working memory weakness, processing speed impairment, and verbal comprehension difficulties are common to both (Willcutt et al., 2013).

3.5.2 *Dyslexia and dysgraphia*

Approximately 3-15% of the general population have dysgraphia, a specific learning disorder affecting the written expression of symbols and words (Döhla & Heim, 2015; McBride, 2019; McCloskey & Rapp, 2017). Dysgraphia causes motor control difficulties affecting the motor planning or production processes required for handwriting, visual-spatial difficulties or impairments in acquisition of writing (spelling, handwriting, or both). Dysgraphia can persist despite adequate opportunities to learn, and in the absence of obvious neuropathology or gross sensory–motor dysfunction (Drotár & Dobeš, 2020; McBride, 2019; McCloskey & Rapp, 2017).

People with dysgraphia can have illegible handwriting, difficulty spacing things out on paper or working within margins (poor spatial planning), exhibit frequent erasing and present with inconsistencies in letter and word spacing. They also tend to have poor spelling, including leaving words unfinished or missing words or letters (Berninger & Amtmann, 2003; Berninger et al., 2008; McBride, 2019; McCloskey & Rapp, 2017). Although dyslexia and dysgraphia are separate disorders, up to 30% of those with dyslexia will also have dysgraphia (McBride, 2019).

3.5.3 *Dyslexia and dyspraxia*

Dyspraxia, also known as developmental coordination disorder (DCD), yields difficulties in gross and fine motor co-ordination and perceptual and spatial-perceptual weaknesses (Yeo, 2003). DCD affects around 5% of the general population and frequently

overlaps with other developmental disorders including ADHD, ASD and dyslexia (Kirby et al., 2014). Individuals with DCD commonly have difficulties in several areas including left-right confusion, tactile perceptual skills, hand-eye co-ordination, working memory, visual memory, sequencing skills, short-term visual or auditory memory, verbal memory and/or memory for verbal instructions (Yeo, 2003, p. 12). DCD overlaps with dyslexia and ADHD in 35-50% of cases (Kirby et al., 2008). While DCD is not commonly associated with difficulty learning to read, it is often associated with significant spelling difficulties (Yeo, 2003).

3.5.4 Dyslexia and ASD

ASD, which can affect the domains of social interaction and communication, is estimated to impact about 1% of the general population. Individuals with ASD may also exhibit repetitive behaviours (Hofvander et al., 2009; Russell, 2013; Valkanova et al., 2013). Children and adults with ASD are at a higher risk of having co-occurring difficulties such as dyslexia, with the frequency of ASD and dyslexia at 14% (Hofvander et al., 2009).

3.5.5 Dyslexia and ADHD/ADD

According to the DSM-5, there are three subtypes of ADD/ADHD, also known as ‘hyperkinetic disorder’ (Russell, 2013). The first subtype – ADD – is characterised by difficulties with attention (including being easily distracted), an inability to focus for any extended period of time, and difficulties responding to instructions (Russell, 2013). Wiggling, squirming, being unable to sit still, interrupting, and difficulty with waiting in turn-taking activities are characteristics associated with the second sub-type – ADHD – which demonstrates hyperactivity and impulsivity (Russell, 2013). The third subtype is a mesh of both attention problems and hyperactivity (Russell, 2013). Approximately 25-40% of

people with ADHD also suffer from dyslexia (Peterson & Pennington, 2012; Willcutt et al., 2007).

3.5.6 Dyslexia and Developmental Language Disorder

Developmental Language disorder (DLD), previously known as a specific language impairment (SLI), can co-occur with dyslexia. A multinational and multidisciplinary Delphi consensus study by Bishop and colleagues (2017) established consensus on the preferred terminology for conceptualising language difficulties. Consensus was reached for the use of ‘developmental language disorder’ (DLD) to describe language difficulties that emerge in the course of development and are not associated with a known biomedical aetiology and ‘language disorder,’ used to describe language difficulties that will likely persist beyond childhood and are often associated with known biomedical conditions (e.g., sensorineural hearing loss, Down Syndrome, ASD) (Bishop, 2015; Newbury et al., 2005). Bishop et al. (2017) noted that dyslexia can co-occur with DLD but that the causal relation is unclear. Therefore, for the purpose of this thesis, DLD will be used. An individual with a DLD has trouble developing structural language, which includes syntax (grammar) and semantics (extracting meaning from words, a phrase or text). DLD and dyslexia are separate neurodevelopmental disorders and the causal relationship is unclear (Oliveira et al., 2021). Individuals with dyslexia and co-occurring DLD have difficulties with oral language, and impairments in reading, difficulties with phonological awareness and, generally, they present with more severe difficulties compared to those who only have dyslexia or DLD (Snowling et al., 2019). The prevalence rates for dyslexia and DLD vary considerably due to age of diagnosis and the criteria used to diagnose these disorders, however rates appear to be between 14-63% (Catts et al., 2005; McArthur et al., 2000; Price et al., 2022).

3.5.7 *Dyslexia and social and emotional wellbeing*

“If we continue to see dyslexia as being merely a reading and writing problem, we will continue to deprive these people of any real understanding or support in terms of the extent and depth of their difficulties.”

- Laughton King, Author and Educational Child and Family Psychologist

More than half a million Australian children experience significant mental health difficulties each year, and 8.2% of children (4-11 years old) and 20% of adults have been diagnosed with a mental health disorder (Lawrence et al., 2015; Tully et al., 2019). Half of all mental health disorders emerge before the age of 14 years, and poor mental health in childhood and adolescence is a predictor of poor mental health in adulthood (Nishida et al., 2016).

A growing body of international and national research has highlighted the link between dyslexia and mental health and wellbeing (Alexander-Passe, 2018a; Boyes et al., 2016; Carawan et al., 2016; Firth et al., 2013; Leitao et al., 2017; Morgan et al., 2012; Nalavany et al., 2011; Stampoltzis & Polychronopoulou, 2009). Children and adolescents with dyslexia face substantial psychosocial and emotional challenges throughout their schooling years, including feelings of stigma, discrimination, alienation and isolation, and the requirement to have to hide their authentic self or create a second persona (Alexander-Passe, 2015a; Alexander-Passe, 2018a; Riddick, 2000; Shaw et al., 2017).

After accounting for other disorders such as ADHD, dyslexia has been found to have a distinct association with reduced levels of wellbeing and increased occurrences of anxiety, depression, and thoughts of suicide (Alexander-Passe, 2012; N. Alexander-Passe, 2015a; Daniel et al., 2006; Willcutt et al., 2013; Wilson et al., 2009). It has also been associated with

a higher risk of self-harm (N. Alexander-Passe, 2015a), and strong feelings of shame (Bohdanowicz, 2015).

An Australian study by Boyes et al. (2015) suggested that “reading difficulties are a risk factor for the development of later mental health problems” (p. 264). It is proposed that early experiences of struggle and continued failure in the foundational academic areas of reading and writing may produce damaging lifelong effects (McNulty, 2003).

3.6 The impact of dyslexia according to different models of health

3.6.1 Medical model

Dyslexia and its co-occurring difficulties are traditionally derived from the medical model of health; a model that has dominated how society conceptualises health and wellbeing since the 18th century (Huda, 2019). The medical model views health as an attribute measured by whether disease is present or not; that is, the absence of disease equals good health.

Under the medical model, dyslexia is classified as a specific reading disability, specific reading disorder, specific learning impairment, learning disability or specific learning disorder/difficulty (American Psychiatric Association, 2013; Beetham & Okhai, 2017; Bond, 2021; Glazzard & Dale, 2013; Luria et al., 2014; Lyon et al., 2003; Mody & Silliman, 2008; Peterson & Pennington, 2012; Serry & Hammond, 2015; Snowling et al., 2020). The Diagnostic and Statistical Manual (Fifth Edition) – the reference handbook for mental disorders – provides the following distinction:

“Specific learning disorder, often referred to as ‘learning disorder’ is a medical term used for diagnosis. ‘Learning disability’ is a term used by both the educational and legal systems. Though learning disability is not exactly synonymous with specific learning

disorder, someone with a diagnosis of specific learning disorder can expect to meet criteria for a learning disability and have the legal status of a federally recognized disability to qualify for accommodations and services in school” (Frolov & Schaepper, 2013).

In Australia, ‘learning difficulties’ and ‘learning disabilities’ are the accepted – if inconsistent – terms used to describe dyslexia across the education and higher education sectors, and amongst health professionals including general practitioners, educational, clinical psychologists and speech pathologists.

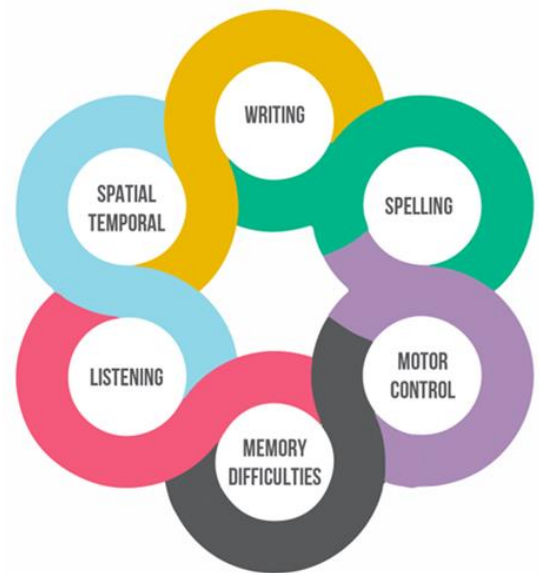
Specific reading disability, also known as specific reading disorder, is the predominant form of learning disability, comprising approximately 80% of all cases (Yang et al., 2022). These terms are often used interchangeably to describe this reading deficit, however, they have caused confusion within the medical and education professionals and the wider public. Under the Discrimination Act, the term 'specific learning disability' is the umbrella term used to describe dyslexia, dyscalculia and dysgraphia (Bond, 2021; Commonwealth of Australia, 1992). However, terms used are different between states and territories in Australia. For example, in New South Wales, the term learning difficulty is legislated under the Educational Support for Children with Significant Learning Difficulties Bill 2008 (Bond, 2021) while in Victoria, the State Government uses the term specific learning difficulties to encompass dyslexia, dysgraphia, dyscalculia, developmental coordination disorder and ADHD (Education, 2022).

The DSM-5 outlines three types of learning disorders: deficits in reading, deficits in writing and deficits in mathematics (Moll et al., 2014). While the DSM-5 attempted to streamline terminology and diagnosis, the definitions still leave themselves open to ambiguity. The International Classification of Diseases provides similar criteria for

diagnosing dyslexia but also includes underdeveloped reading comprehension skills (World Health Organization, 2020).

Given that dyslexia is classified as a “disability”, individuals with this diagnosis are protected under Australian disability-related legislation, including the Disability Discrimination Act 1992, Fair Work Act 2010 and the Equal Opportunity Act 2010 (Commonwealth of Australia, 1992, 2009, 2010). While this protection brings with it many benefits, the labelling of dyslexia as a disability is not universally accepted (Al-Yagon et al., 2013; Macdonald, 2010), and brings with it other considerations (see 3.6.1.1 *Labels and their impact*). Under the medical model paradigm, the focus of dyslexia’s impact is on the physiological. This includes issues with reading and writing, verbal comprehension, perceptual organisation, working memory, processing speed, motor control, and concentration (Hudson, 2014; Leveroy, 2013; Waterfield, 2002) (See Figure 5).

Figure 5. Dyslexia and its impacts – the medical model. Adapted from work by Dr Judith Hudson



However, it is important to acknowledge that people with dyslexia are not all the same, and variation can occur across the spectrum (i.e., people may experience mild to severe difficulties that cause varying degrees of functional impact) (Waterfield, 2002).

3.6.2 *Social model*

The social model of disability was developed in opposition to the medical model's conceptualisation of disability being a health condition that requires medical attention, that people with disabilities are 'abnormal', and that disability is an individual's problem (Hyde, 2001; Owens, 2015; Shakespeare & Watson, 2010). Instead, the social model argues that “people with impairments are disabled/excluded by a society that is not organised in ways that take account of their needs” (Tregaskis, 2002, p. 458). That is, disabilities result from physical and social barriers in society that limit or take away opportunities for people to participate on an equal basis with others (Glazzard & Dale, 2015).

Over the last thirty years the social model has been successful in political activism, but it has not been free of criticism (Owens, 2015; Shakespeare & Watson, 2010), some of which has come from within the disability community. It has been argued that the model has focuses too much on physical impairment and excludes those with learning difficulties or other adjustment disorders that may appear as ‘invisible’ disability (Chappell et al., 2001; Owens, 2015).

In more recent years, as the association between dyslexia and mental health and wellbeing has become more apparent, there has been growing recognition that the impact of dyslexia is far broader and more complex than the original focus on learning deficits. This understanding of dyslexia’s impact on mental health has coincided with a greater understanding of how people’s sociological context (the social, cultural and political environments in which people live) affect how they live. For people with dyslexia, ‘societal barriers’ such as prejudice, stigma, a lack of awareness or understanding, and social exclusion can all affect how dyslexia will impact a person throughout their life (Anastasiou & Kauffman, 2013; Denhart, 2008; Hughes, 2010; Macdonald, 2009; Riddick, 2000). This

multi-dimensional nature of the impact of dyslexia is now being explored in disability theory and in various models of disability (Leveroy, 2013; Macdonald, 2009).

A modest yet noteworthy body of research has focused on contextualising dyslexia within a sociological framework (Alexander-Passe, 2018b; Chappell et al., 2001; Elftorp & Hearne, 2020; Goodley, 2001; Macdonald, 2009; Riddick, 2001). The purpose of positioning dyslexia within this framework is to acknowledge the importance of combating discrimination and marginalisation against individuals with this disability, by breaking down barriers and transforming societal attitudes. (Alexander-Passe, 2015a; Owens, 2015).

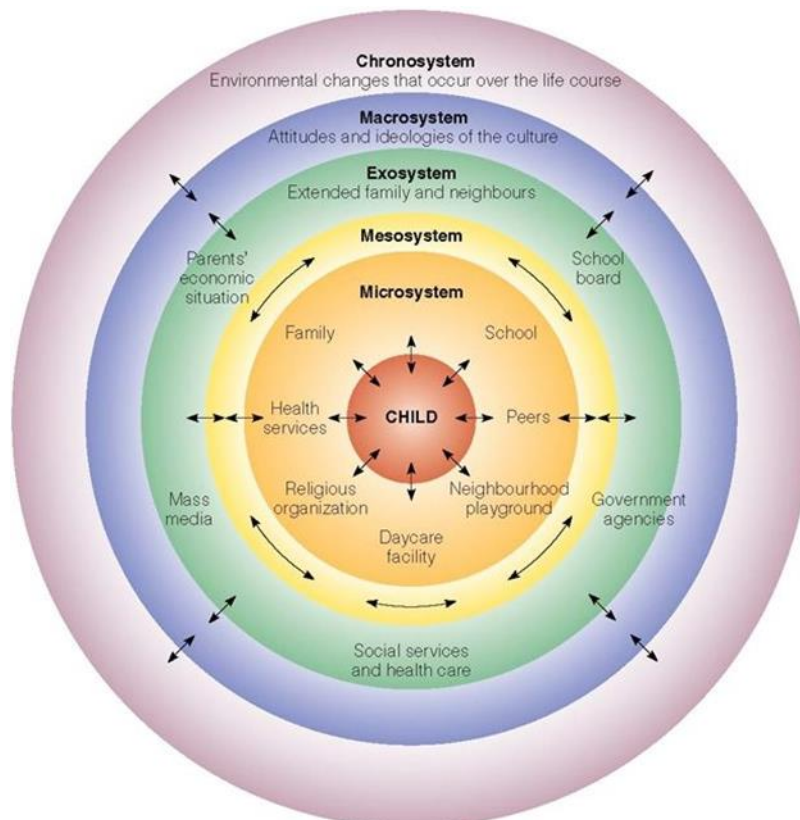
3.6.3 The ecological model

A model that has garnered a considerable following and has been widely adopted and adapted for use in the design and implementation of reform across various sectors, including public health and education, is the ecological model (Hudson, 2014). In 1979, American psychologist Urie Bronfenbrenner developed an ‘ecological systems’ theory of child development (Bronfenbrenner, 1974, 1977, 2009) in response to what he considered to be inadequacies in other theories of child development. The purpose of the theory was to show how children are shaped and influenced by factors that are not static, but rather, ever evolving. This includes their immediate environments (family, school, healthcare, etc.), interactions within and between their immediate environments, and the broader societal, cultural, and political factors that assert influence over these immediate environments (Bronfenbrenner, 2009; Leitao et al., 2017). Over time, Bronfenbrenner adapted his model to encompass biopsychosocial functioning to include experiences of adults and how as human beings, we are shaped and influenced by environments throughout the lifespan (Greenfield, 2012; Hoare, 2009). The model is now widely used to consider issues associated with

populations including young adults, adults, older adults and within vulnerable populations such as LGBTQI, religious groups and at-risk youth (Backonja et al., 2014; Bankier-Karp, 2022; Greenfield, 2012; Hamwey et al., 2019; Lim et al., 2019; Lintott et al., 2022; Thomas, 2023). However, prior to this study, it does not appear to have been adapted and used in relation to a dyslexic adult population.

The ecological model is defined by five concentric circles or systems: the *microsystem*; *mesosystem*; *exosystem*, *macrosystem* and *chronosystem* (Bronfenbrenner, 1974). The original model depicts how each system either influences, or is influenced by, the next (and sometimes both) (see Figure 3).

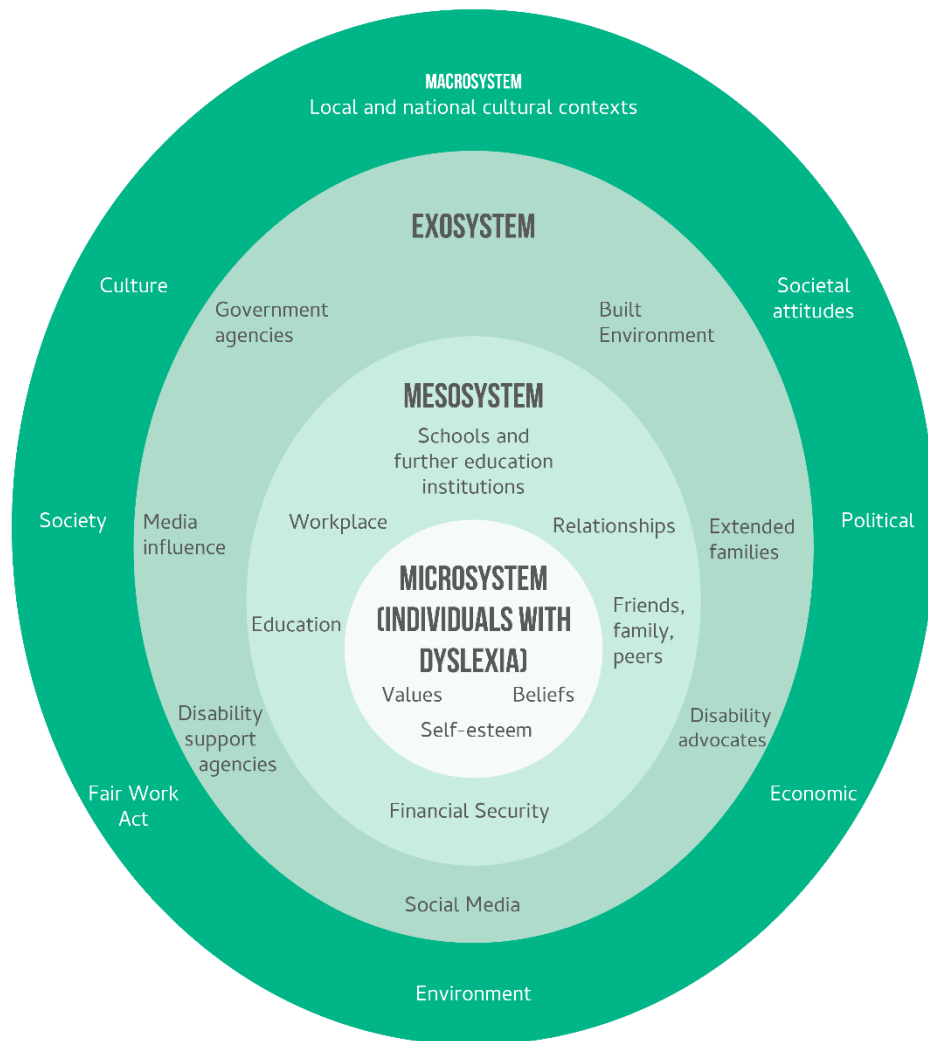
Figure 6. Bronfenbrenner Ecological Model, 1974



Ecological systems theory and the ecological model address some of the key failings of the medical and social models, through their depiction of the complexities of human life within an ever-evolving social, cultural and political environment. This has implications for numerous groups within society, including people with dyslexia (Bronfenbrenner, 1974, 1977).

The present research encompasses both qualitative and quantitative approaches and incorporates an adapted ecological model (Figure 7), that was developed for this study, and which comprises four systems: the *microsystem*, *mesosystem*, *exosystem*, and *macrosystem*. This adapted model places the individuals with dyslexia at the core of concentric layers of influence, which represent the numerous factors that can impact the life of an adult with dyslexia. Bronfenbrenner's ecological model is a useful framework for this research as it provides a comprehensive and multi-dimensional approach to understanding the various factors that can contribute to the lived experiences of dyslexia. Gerber et al. (1992) and Spekman, Goldberg, and Herman (1993) have stressed the importance of understanding the interconnectedness of individuals, families, social networks, and communities for individuals with dyslexia. They emphasise that the development of individuals is closely intertwined with a complex context. Hence, the Bronfenbrenner model highlights the importance of considering these interconnecting different levels of influence that impact an individual's development, including the individual themselves, their immediate environment (such as family, peers, and work), and broader societal and cultural factors (Bronfenbrenner, 1977; Bronfenbrenner & Evans, 2000). Each of these systems will be explored separately in more detail.

Figure 7. Adaptation of the Bronfenbrenner Ecological Systems Model, for use with dyslexic adult populations (2023)



3.7 Dyslexia across the ecological model

3.7.1 The Macrosystem

The macrosystem (outermost circle) encompasses the broader societal-level influences on individuals' lives. These include our cultures, societal attitudes and laws, political ideologies, economic factors, technological advancements, and the environment (Bronfenbrenner, 2009). In Bronfenbrenner's model of child development, it is the microsystem (family, school, neighbourhood) that is considered most influential, with the macrosystem influencing the child more indirectly (Bronfenbrenner, 2009). However, in adulthood the macrosystem exerts a more direct influence on an individual. A key example of the influence of the macrosystem is the way society views and treats difference and disability, with society often following its lead from the political ideology of the government of the day, this being a particularly important aspect of the macrosystem.

Government support and legislation

In recent times, the concept of "disability" has expanded to encompass not only visible conditions such as physical limitations but also invisible conditions like ASD, ADHD chronic fatigue and multiple sclerosis (Doyle & McDowell, 2020 ; Sumner & Brown, 2015). This broadening of the term has been accompanied by a cultural shift in global and national policies, emphasizing the importance of increasing community awareness and promoting greater inclusion. Both disability and inclusion are fundamental principles outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), of which Australia is a signatory. Consequently, Australia holds the responsibility to safeguard the human rights and inherent dignity of individuals with disabilities (McCallum, 2020). Australia's commitment to this is confirmed by its being a signatory. Most poignantly, Article 27: "Work and employment" recognises ...

‘the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities ("Convention on the Rights of Persons with Disabilities," 2006).’

In Australia, the establishment of the National Disability Insurance Scheme (NDIS) and the National Disability Strategy 2021–2031 (Commonwealth of Australia, 2021b) progressed a broader national conversation about how we value, care for, and support people with disability. Australian legislation has also helped to drive cultural change, with the introduction of the Fair Work Act (2009), Equal Opportunity Act (2010) and the Disability Discrimination Act (DDA) 1992 (Commonwealth of Australia, 1992, 2009, 2010).

Under the Equal Opportunity Act (2010), disability is one of the nine protected characteristics, and dyslexia is classed as a disability. In particular, the DDA prohibits discrimination against individuals with disabilities in employment, education, and in access to premises, goods, and facilities (Commonwealth of Australia, 2021b). These laws and the work of the government are instrumental in supporting educational institutes and workplaces to consider the support requirements of people with dyslexia. They work to ensure that, where possible, discrimination is prevented, opportunity is equitable (as illustrated by Figure 9), and those with disabilities compete on a level playing field with non-disabled peers (Gerber et al., 2012).

However, there is still progress to be made. For example, under the NDIS, learning disabilities such as dyslexia have not been recognised or included. There is also no collection of data on the number of people diagnosed with dyslexia beyond the age of 16 (up to age 16, data is collected through the National Consistent Collection of Data or NCCD described elsewhere. (See Chapter 3.3 *Prevalence* of this thesis, p.40). Without data, it is difficult to

guide national disability policies and strategies, and while legislation is important, enforcement of legislation and other regulations is equally important if the rights of people with disability are to be upheld, including those with dyslexia. This could also reduce stigmatisation, particularly if awareness about dyslexia is raised in the community. It could also bring Australia more in line with countries such as the UK and US whom Australia is lagging well behind (Alexander-Passe, 2015a; N. Alexander-Passe, 2015b; Gerber et al., 2012; Gerber & Price, 2012; Marshall et al., 2020; Morris & Turnbull, 2007b; Price et al., 2003; Sabat et al., 2014; Sheldon, 2017; von Schrader et al., 2014).

The lack of recognition of dyslexia under Australia's disability insurance scheme and the inconsistent enforcement of disability protections influences societal understanding of dyslexia and its impacts. Improving community attitudes is critical for those with disabilities to feel accepted and valued as members of society (Stampoltzis et al., 2018; Wadlington & Wadlington, 2005). However, despite dyslexia being one of the most prevalent disabilities in Australia, there is a significant lack of awareness and understanding of the condition.

3.7.2 The Exosystem

The exosystem encompasses elements that exert more immediate influences on individuals' lives, but ones that are still generally not within the control of the individual themselves (Bronfenbrenner, 2009; Hudson, 2014). These include traditional and social media, government agencies (for example, the National Disability Insurance Agency), extended family and the communities within which people live. It is often these elements that, either intentionally or inadvertently, create the labels that come to define people within a society, through the development of administrative classification systems.

Labels and their impact

There is ongoing debate about how people with dyslexia recognise themselves and are recognised by others. On one hand, classifying dyslexia as a disability defined by literacy deficits ensures those with dyslexia can access treatments needed to support their disability. This can give access to resources for a child with dyslexia in the school system, but on the other hand, a medicalised definition of dyslexia coming from a deficit perspective fails to acknowledge the strengths of the individual in addition to the challenges (Leveroy, 2013), and ignores the contribution to society by people with dyslexia. Additionally, it can also potentially neglect the psychological and emotional impacts of dyslexia, which are often just as detrimental as any academic challenges, possibly even more so.

In recent times, disability advocates have broadened the discourse around the term ‘disabled’ to include more positive framing, including terms such as ‘able-bodied’ and ‘people with lived experiences’ (Burnett, 2019; Harpur, 2014; Ortiz, 2020). There has also been a recent cultural movement towards the term ‘neurodiversity’.

First coined by Judy Singer in the late 1990s, neurodiversity is a collective label used to depict people who think and learn differently (Burnett, 2019). It encompasses a range of specific learning disabilities and differences including dyslexia, dyspraxia, dyscalculia, ADHD and ASD (Burnett, 2019; Reid, 2016). Neurodiversity is a positive statement of differentiation, which rejects the belief that variations are dysfunctional (Moody, 2009; Reid, 2016). However, Australia has been slow to embrace both the concept of neurodiversity in general, and dyslexia’s inclusion within that concept. This lack of consensus on how to define people with dyslexia, at the level of Bronfenbrenner’s exosystem, can, in turn, influence how organisations, people and communities within the mesosystem, understand and interact with people with dyslexia.

3.7.3 The Mesosystem

The mesosystem encompasses those elements of society that have a more immediate relationship to the individual. For example, a person's family, school, workplace, friends, peers and regular health professionals are all part of the mesosystem (Bronfenbrenner, 2009; Hudson, 2014; Leitao et al., 2017). Organisations and people within the mesosystem are an important source of support (or otherwise) for a person with dyslexia and play a role in influencing critical life outcomes, including an individual's age at diagnosis, experience getting a diagnosis, educational attainment, employment opportunities and experiences in the workplace, and their relationships with friends, family, colleagues and intimate partners.

Diagnosis

Australian and international research has shown great variability in the age of diagnosis for individuals with dyslexia (Barbiero et al., 2019; Bazen et al., 2020; Sadusky, Freeman, et al., 2021; Torppa et al., 2015; Yang et al., 2022). This is at odds with other neurodevelopmental disorders such as ASD and ADHD, both typically identified in childhood, and often by an interdisciplinary team (Bent, 2017; Sullivan et al., 2015). For some, if not most people with dyslexia, this delay in diagnosis may result in the loss of critical early interventions and support, including through the crucial years of schooling.

In comparison to other developed nations, Australia's policies and practices pertaining to the identification of dyslexia and provision of support for dyslexic individuals are comparatively deficient (Bond, 2021; Bond et al., 2010). In the UK, qualified specialist teachers and educational/occupational psychologists can diagnose dyslexia (British Dyslexia Association, 2020). In Australia, educational psychologists and/or neuropsychologists and some speech pathologists are generally professionals that assess for learning disabilities such as dyslexia. Australian research undertaken by Sadusky et al. (2021) found that the way psychologists assess adults for dyslexia was not uniform, with a variety of diagnostic

standards used. This is also generally compounded by a lack of national guidelines for operationally defining and diagnosing dyslexia within the adult population (Sadusky, Freeman, et al., 2021; Sadusky, Reupert, et al., 2021). Access to these professionals can involve lengthy wait times and can also be financially prohibitive. As a result, many dyslexic people go undiagnosed or receive a late diagnosis. If diagnosis is delayed, the challenges that dyslexia creates in the school setting can, and often does, continue into adulthood and the workplace.

Educational attainment

Educational attainment, or the level of education an individual achieves, has been found to be strongly linked to various health outcomes in adulthood. Having a tertiary qualification has been associated with better overall health, increased access to healthcare, lower rates of chronic diseases, and improved mental health (Raghupathi & Raghupathi, 2020). In contrast, lower education attainment has been associated with poorer health outcomes, higher rates of chronic diseases, increased risk of mental health issues, and reduced access to healthcare (Lynch, 2003; Raghupathi & Raghupathi, 2020).

There is a body of international research that looks at the educational experiences and outcomes of dyslexic adults (Brunswick, 2012; Glazzard & Dale, 2015; Jordan et al., 2014; Mortimore & Crozier, 2006; Stampoltzis & Polychronopoulou, 2009). A large longitudinal study in Norway explored the educational trajectories of 530 young adults (including 75 dyslexic students) over a 13-year period. Researchers examined developmental milestones including reading ability and development and educational levels at various points throughout their schooling years. This study revealed that most of the students by the age of 23 years continued to struggle with dyslexia, yet their educational attainment levels were only slightly lower compared to their non-dyslexic peers. However, to date there is only a handful of local research (Caskey et al., 2018; Maccullagh, 2014; Smart et al., 2017; Tanner, 2009) that

examines how dyslexia impacts educational experiences and attainment across vocational training and higher education.

The only known Australian study used data drawn from the Australian Temperament Project, a life-course longitudinal study of psychosocial development (Smart et al., 2017). This study investigated early adulthood education and employment outcomes related to reading difficulties and behavioural problems in childhood, although not specifically or solely relating to people with dyslexia. According to the study, experiencing reading difficulties during childhood can lead to lower educational achievement and occupational outcomes. Additionally, if a child experiences co-occurring difficulties (e.g., ASD, ADHD, dyscalculia) alongside reading problems, the risk of poorer educational outcomes is significantly increased (Smart, 2017).

The remaining local studies (Caskey et al., 2018; Maccullagh, 2014; Tanner, 2009) focused on the experiences of adults with dyslexia within vocational training and higher education settings rather than educational attainment outcomes. Tanner's paper (2008) explored the concept of failure in the context of the perceptions of dyslexic individuals participating in tertiary education. Tanner's work highlights that there were recurring issues relating to ongoing feelings of failure and these feelings had a significant impact on the perceptions and life choices of their participants. The prevalence of this issue in both the literature and reported experiences of the research participants emphasises the necessity for societal, institutional, and attitudinal change (Tanner, 2008).

MacCullagh (2014) conducted a literature review synthesising the experiences of students with dyslexia in the higher education sector. Specifically, this literature review examined how students with dyslexia participate in and experience higher education. It combined Australian and international literature on representation, strengths, challenges, support practices, and potential strategies for promoting equitable access to higher education

for individuals with dyslexia with the aim to provide a foundation for discussion and a call to action for the Australian higher education community.

Lastly, research undertaken by Caskey (2018) investigated the life experiences of adult students with dyslexia attending Technical and Further Education (TAFE) colleges in Australia. The findings suggested that adult students with dyslexia can develop a positive social identity by establishing supportive relationships and interactions within educational institutions, leading to a shift from a negative self-perception to a more positive one.

As the literature demonstrates, local and international postsecondary institutions are witnessing a growing number of adults with dyslexia enrolling in trades and degrees, despite the likelihood of encountering academic difficulties (Caskey et al., 2018; Jordan et al., 2014; Maccullagh, 2014; Schabmann et al., 2020; L. Stack-Cutler et al., 2015; Tanner, 2009). They are not just enrolling in higher numbers, but are also reporting success in their academic and personal endeavours (Mull et al., 2001; H. L. Stack-Cutler et al., 2015). Litner et al. (2005) found that for these students with learning disabilities, academic and personal success was largely influenced by personal traits such as tenacity and determination, as well as their involvement in extracurricular activities that supported the development of a positive identity (Litner et al., 2005).

Nonetheless, the literature also highlights that although these adults are achieving academic success, they continue to face persistent social and emotional wellbeing challenges, undermined by societal constructs concerning dyslexia, insufficient comprehension and awareness regarding how to assist these students, and continuous educational trauma that extends into multiple domains of adulthood (Alexander-Passe, 2018a; Humphrey & Mullins, 2002; Ridsdale, 2004) as described by Alexander-Passe:

“...the sudden exclusion from their peer group; intense anger from a teacher or parent; physical bullying at school; the realisation that something unrecognisable is wrong

(maybe realising that they are not normal or do not learn normally), being called stupid, lazy etc (Alexander-Passe, 2015c, p. 3)."

Employment opportunities

Employment opportunities and experiences play a significant role in shaping the health and wellbeing of adults. Research has shown that employment status, job security, job satisfaction, and income are important social determinants of health (Australian Institute Health and Welfare, 2022). Positive employment opportunities, such as stable employment, fair wages, and job satisfaction, are associated with better overall health, improved mental health, and reduced risk of chronic diseases. Social interaction and economic independence are promoted by gainful employment, allowing individuals to participate meaningfully in society (Lemos et al., 2022). On the other hand, long-term unemployment and underemployment can have adverse effects on mental health and wellbeing, and lead to financial strain, social isolation and can reduce wellbeing (Australian Institute Health and Welfare, 2022; Lemos et al., 2022). While employment difficulties can be caused by many factors, people with disabilities tend to be unemployed more than those without disabilities (Colella & Bruyère, 2011; Lemos et al., 2022). Working-aged people with disabilities, including those with dyslexia, make up 53% of the Australian workforce, compared with 84% of people without disabilities. Depending on the year of publication, the unemployment rate is also higher for those with disability (8.3%) than those without (5.3%) (Australian Institute Health and Welfare, 2022). Over a period of 12 months, people with disabilities (45.2%) report experiencing discrimination and unfair treatment by their employers because of their disability (IncludeAbility, 2023)

Local and international research has found that despite their difficulties, most individuals with dyslexia enter the labour market after completing their education (de Beer et al., 2014; Kirby & Gibbon, 2018; Smart et al., 2017). Research also tells us that those with

dyslexia work across all industries at different levels (Beetham & Okhai, 2017; Fink, 2002) However, there is limited evidence in Australia that examines how educational attainment can affect employment outcomes for individuals with dyslexia.

Studies undertaken by Maughan et al. (Maughan et al., 2009; Maughan et al., 2020) have shown that reading problems can lead to early school departure, resulting in low levels of formal educational qualifications and limited occupational choices. This included one study based in the Isle of Wight in the UK, which found an “understandable reluctance [of people with dyslexia] to consider entering jobs with high literacy demands, and this meant that most went into unskilled or manual occupations as they left school, and many remained in manual roles later in their lives” (Maughan et al., 2020, p. 435).

An article by MacDonald et al. (2019) reported on a quantitative study of 442 adult participants with dyslexia, conducted between 2015 and 2017. The study applies the social model of disability, informed by 23 years of anti-discriminatory social policies, to interpret its findings. The results reveal that socioeconomic status plays a significant role in the diagnosis, educational experiences, and employment outcomes of people with dyslexia. However, they also found that regardless of socio-economic background (working class, middle class or elite), this cohort reported that dyslexia constantly impacted on their lives and expressed concerns about how their disability affected career progression opportunities (Macdonald & Deacon, 2019).

Building on this work by MacDonald and Deacon (2019) was another study that examined the lived experiences of 15 adults with dyslexia. According to the study findings, the participants' encounters with dyslexia were predominantly shaped by an educational system that hindered their progress and a workplace that exhibited discriminatory practices. These experiences resulted in adverse psycho-emotional effects on their self-esteem. As a result, they often internalised their experiences of failure. As a result of internalising these

emotions, many individuals reported a sense of lacking direction and aspirations in their careers. Consequently, this often led to accepting low-paid temporary contracts with limited prospects for advancement (Deacon et al., 2020).

Workplace experiences

Limited research exists in Australia on the effects of dyslexia in the workplace, particularly concerning the impact on work roles, performance, and the views and reactions of colleagues. It is well-established overseas that effective communication through various written mediums is a crucial requirement in many professional settings. However, individuals with dyslexia entering the workforce are often required to navigate a complex environment with multiple demands while receiving insufficient support (de Beer et al., 2014).

Specific problems those with dyslexia may face in the workplace include: overly complex tasks that increase workload stress; reliance on support from colleagues or family members at home; and challenges the physical working environment may present, such as background noise and other distractions (de Beer et al., 2014; Kirby & Gibbon, 2018). This can be further exacerbated by a mismatch between employees' abilities and employers' expectations (Stacey, 1998) leading to a heightened risk of undue stress and anxiety, an employee not meeting work-based performance expectations, limited career prospects and compromised social and emotional wellbeing (de Beer et al., 2014; McLoughlin, 2015; Morris & Turnbull, 2007a, 2007b; Taylor & Walter, 2003).

Additionally, there are attitudinal challenges due to a lack of understanding and awareness among employers and work colleagues as to how the characteristics of dyslexia can affect workplace performance. For those with dyslexia, this can lead to feelings of discrimination and being stigmatised (Morris & Turnbull, 2007a). The cost of excessive work stress, such as feeling overwhelmed and emotionally exhausted, may have significant consequences for individuals and their organisations (Wallace & Lemaire, 2013).

Relationships

Irrespective of a dyslexia diagnosis, adulthood entails a range of fresh encounters and adjustments for everyone. Nevertheless, for numerous adults with dyslexia, having an overlay of a disability along with negative past experiences during childhood and adolescence, may result in extra and ongoing difficulties when managing the demands of adulthood, particularly regarding managing day-to-day activities, employment, parenting and relationships (Alexander-Passe, 2015b; Berresford & Kjersten, 2019; Gerber et al., 1990; Kjersten, 2017; Nelson & Gregg, 2012).

Social connectedness, peer support, strong collegial and positive family relationships have been shown to be protective factors against lower quality of life outcomes (Mousa et al., 2020; Ross A. Thompson, 2014; Weziak-Bialowolska et al., 2020). International studies have demonstrated that when dyslexic children and young adults have strong family supports and social networks they are more likely to have successful academic outcomes, including completing secondary school and transitioning into TAFE and/or tertiary education (Alexander-Passe, 2020; Carawan et al., 2016; Nalavany & Carawan, 2012; H. L. Stack-Cutler et al., 2015; L. Stack-Cutler et al., 2015). Nalavany and Carawan's (2021) study demonstrated that adults with dyslexia who perceived their parents as supportive exhibited higher levels of positive self-esteem compared to those lacking family. Recent research suggests that the presence or absence of family support can serve as a protective factor for self-esteem, assisting adults in managing emotional challenges and mitigating negative experiences related to dyslexia (Carawan et al., 2016; Nalavany & Carawan, 2012).

However, the literature also suggests that individuals with dyslexia may have difficulties relating to peers and forming intimate relationships (Carawan et al., 2016; Moore & Carey, 2005; Nalavany & Carawan, 2012). Research now strongly supports the notion that friendships and positive relationships are protective factors in reducing the risk of poor

mental health and wellbeing for all people. However, several studies have highlighted that those with dyslexia can have difficulties developing friendships and intimate and collegial relationships (Alexander-Passe, 2015a; Moore & Carey, 2005; Stack-Cutler, 2017; Weigel et al., 2006). To date, there have been no studies in Australia that have looked at dyslexia and adult relationships.

3.7.4 The Microsystem

In this version of the ecological model, the microsystem refers to the individual with dyslexia and their values, beliefs, thoughts, feelings, self-worth, capacity for resilience, and internalised thoughts and self-perceptions. As outlined, the macrosystem, exosystem and mesosystem exert a considerable influence on an individual's life outcomes. An individual's own personal resources (e.g., temperament, personality, resilience) also play a role.

Mental health and wellbeing

In addition to educational attainment and employment opportunities, the impact of dyslexia on social and emotional wellbeing has also been studied extensively. International research has shown that individuals that face challenges with educational attainment, employment, and social interactions can face a greater negative impact on their social and emotional wellbeing (Alexander-Passe, 2015a).

As we transition from being a child to an adult, the development of our self-concept evolves. How we see ourselves and the world in which we live is influenced by our childhood experiences and the environment we grow up in (Stenner & William, 1976). For people with dyslexia, the struggle to attain functional literacy skills can lead to the development of low self-esteem and low self-confidence (McNulty, 2003). A study by Palombo (2001) found that people with learning disabilities may develop negative self-narratives (stories one tells

themselves), to make sense of their emotional and personal experiences. Those who feel they are not good enough or that they are a failure may have difficulties accepting their disability and the functional struggles they will have throughout their life (Graham, 1992).

As young people move into the developmental stage of adulthood and begin to interact more directly within the mesosystem, they begin to face a different set of experiences and challenges. Many people with dyslexia find the social adjustments into adulthood difficult as they try to navigate the complex demands of both the work environment and social interactions (Gerber et al., 1990; Nelson et al., 2015). Confronted by these challenges can contribute to heightened psychological distress and can be linked to lower income, lower educational achievement, and un/underemployment (Smart et al., 2017).

There has also been an increase in the number of psychological disorders stemming from the workplace, including depression, post-traumatic stress disorder and anxiety. Psychological disorders may occur due to mental and emotional fatigue, bullying or harassment, and excessive or prolonged work pressures. While there is no research in Australia that addresses the psychological disorders that stem from working adults who have dyslexia, international data suggests that dyslexic employees are susceptible to psychological and personal stress in the workplace (de Beer et al., 2014; Deacon et al., 2020; Livingston et al., 2018; Moody, 2009).

It has also been found that people with dyslexia are over-represented in the criminal justice system (Alexander-Passe, 2006; Carroll & Iles, 2006; Dewalt et al., 2004). Figures cited range from 14%-47% of the general offender population (Ankney, 2019; Samuelsson et al., 2003), while in young offender institutions, dyslexia may be present in as many as 50% of the population (Kirk & Reid, 2001).

In Australia, there is a gap in the literature concerning the link between negative childhood experiences within the education system and their flow-on effects into adulthood.

However, the research is clear that early life experiences can considerably influence people's health and wellbeing, education, employment, interpersonal relationships and community and economic engagement (Campbell et al., 2014, Maggi, 2010). Experiencing stressful events at any stage of life can have significant implications for both psychosocial and physical wellbeing in later years (Katz & Calasanti, 2015). It is therefore probable that the experience of dyslexia, whether diagnosed or not, will have a considerable impact on an individual's sense of self-worth, and on their values and belief systems throughout adulthood.

Disclosure

One of the most significant and personal decisions a person with a disability such as dyslexia must make is whether to disclose their condition, and research tells us this is a difficult decision for many to make (Gignac et al., 2021; Goldberg et al., 2005; McLoughlin, 2015; Morris & Turnbull, 2007a). In the workplace, there appears to be a variety of obstacles that can prohibit someone from sharing a hidden disability such as dyslexia, including perceptions of workplace discrimination and stigmatisation, workplace culture (for example, whether there is likely to be access to reasonable adjustments to work demands following disclosure), workplace relationships (whether supportive or demanding) and perception of the impact of disclosure on career progression (Madaus et al., 2002; McLoughlin, 2015; Newlands et al., 2015).

According to disability researchers, disclosing one's disability in the workplace can have adverse consequences on various aspects of a worker's life, including their physical and mental health, social relationships, and job performance, as well as the organisation they are employed in (Sabat et al., 2014; Santuzzi et al., 2014). Nonetheless, disclosing a disability voluntarily has also been shown to alleviate the stress of concealing an invisible disability (Alexander-Passe, 2015a; Santuzzi et al., 2014). Disclosing one's disability may reduce

feelings of isolation by enabling individuals to establish social connections with supportive individuals and to request workplace accommodations (Santuzzi et al., 2014).

Personal strengths and resources

Although the literature review has focused on the difficulties that those with dyslexia face across the lifespan, a very small body of research is emerging that discusses the specific strengths that those with dyslexia possess. These strengths may develop over time as dyslexics are forced to adjust to the environment around them. Some of the associated strengths of dyslexics include exceptional creativity, complex problem-solving skills, critical thinking and the ability to think outside the box, certain kinds of visual-spatial strengths and an interest in exploring the unknown, which could play an essential role in helping humans to adapt (Earnest and Young, 2019; Eide & Eide, 2011; Geiger et al., 2008; Robert & Gary, 2017; Taylor & Vestergaard, 2022; Von Karolyi, 2001; von Károlyi et al., 2003). People with dyslexia are often highly intuitive, and they may excel in fields such as art, music, and entrepreneurship (Franks & Frederick, 2013; Wiklund et al., 2018; Wolff & Lundberg, 2002). Dyslexia is not a sign of low intelligence or a lack of effort; rather, it is a unique way of processing information that can offer many strengths and advantages in certain contexts. With the right support and accommodations, individuals with dyslexia can thrive academically and in their personal and professional lives.

When we focus on the workplace, personal strengths and resources seem to play a crucial role in work engagement and how dyslexic employees navigate and adapt to the working environment. Researchers examined possible factors that could contribute to the success of people with dyslexia, including self-esteem, perseverance, resilience, initiative, and goal setting (Burns et al., 2013; Leather et al., 2011). People with dyslexia who were able to develop intuitive personal strategies to manage workplace stresses were also more likely to

experience a successful working environment and career (Burns et al., 2013; Price et al., 2003).

Chapter 4

Study A.1

Journal Article 1

Adults with dyslexia: A snapshot of the demands on adulthood in Australia

4.1 Prologue

Approximately 7-10% of people will encounter difficulties learning to read due to having dyslexia (Al-Yagon et al., 2013; Kita et al., 2020; Leitao et al., 2017; Wagner et al., 2020; Yang et al., 2022). Despite the prevalence, there is little known in Australia about how those with dyslexia manage the multiple demands of adulthood such as access to diagnosis, education and employment outcomes and disability disclosure. In addition, the psychosocial and emotional wellbeing of people with dyslexia is poorly documented for those (Boyes et al., 2016) beyond adolescence.

A mounting body of literature emphasises that the challenges encountered by individuals with dyslexia extend beyond mere difficulties with reading and literacy (Alexander-Passe, 2015c; Beetham & Okhai, 2017; Boyes et al., 2016; Leitao et al., 2017). For example, national (Boyes et al., 2016) and international studies (Alexander-Passe, 2020; Alexander-Passe, 2006; Daniel et al., 2006; Fuller-Thomson et al., 2018; Shanahan et al., 2011; Wilson et al., 2009) highlight that those with dyslexia are at elevated risk of experiencing psychosocial and emotional problems during late adolescence and adulthood, with these mental health concerns starting in childhood.

The primary objective of this first study was to investigate the challenges faced by adults with dyslexia, encompassing aspects such as their education, employment, and social and emotional wellbeing. In addition, demographic characteristics such as participants' age at diagnosis and their rates of disclosure were explored. While investigations into some of these factors have been carried out on adult populations elsewhere, no comparable research has been conducted in Australia on adults with dyslexia. The purpose of this analysis was to address gaps in knowledge related to participation in education and the workforce and the social/emotional wellbeing of adults with dyslexia in Australia.

This study was published in the *Australian Journal of Learning Difficulties*. The published manuscript included in this chapter has been reproduced with permission from Taylor and Francis Online.

4.2 Publication

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Adults with dyslexia: A snapshot of the demands on adulthood in Australia

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Adults with dyslexia: A snapshot of the demands on adulthood in Australia

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ABSTRACT

This study explored the educational and employment profiles and the psychosocial wellbeing of 65 Australian adults with dyslexia. Participants were also asked about their age at diagnosis of dyslexia. These domains have been under studied in the Australian adult dyslexic community. Data was collected using an anonymous online two-part survey. Part one was purpose-designed to collect personal and demographic information in line with the study's aims. Part two comprised the standardised Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS). Results revealed that participants' educational attainments and employment profiles closely reflected those of the general Australian community. Age at diagnosis was highly variable ranging from adolescence to over 50. Based on the normative data from the WEMWBS, participants had significantly lower levels of mental wellbeing. Results suggest that despite many participants meeting key external markers of success, many appear to do so under personal and psychological strain.

ARTICLE HISTORY

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Approximately, 1 in 10 people will encounter difficulties learning to read due to having dyslexia (Leitao et al., 2017, p. 24; Snowling & Hayiou-Thomas, 2006; Wagner et al., 2020). Dyslexia is characterised by one or more problems within the word-level reading system, which affects the ability to read words accurately and automatically. Comprehension is often affected because the word-level deficits affect the quality of the 'signal' extracted from the print (Perfetti & Hart, 2002). Even when individuals with dyslexia learn to read accurately, they often remain as slow and dysfluent readers (Cavalli, Duncan, Elbro, El Ahmadi, & Colé, 2017; Fink, 1995) which can affect the amount of reinforcement they receive from the task, and in turn, may discourage future reading. Low reading volume means that readers have less access to and less opportunity to build their vocabulary and general knowledge (Duff, Tomblin, & Catts, 2015); something that arguably has a greater impact than the dyslexia itself.

There is a growing body of research highlighting that the challenges faced by those with dyslexia are far greater than just reading and literacy challenges alone (Alexander-Passe, 2015; Beetham & Okhai, 2017; Boyes, Leitao, Claessen, Badcock, & Nayton, 2016; Leitao et al., 2017; Livingston, Siegel, & Ribary, 2018). A Canadian study reported that young people and adults with dyslexia are more than 'twice as likely to report high levels

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of distress, depression, anxiety disorders, suicidal thoughts and overall poorer mental health compared to the general population' (Wilson, Deri Armstrong, Furrie, & Walcot, 2009). Further, a 2012 National Canadian Community Health Survey ($n = 21,744$) found that individuals with specific learning disorders, such as dyslexia, had '46% higher odds of having ever attempted suicide, even after adjusting for most known risk factors such as childhood adversities, history of mental illness and substance abuse' (Fuller-Thomson, Carroll, & Yang, 2018, p. 287).

A systematic meta-analysis review by Francis, Caruana, Hudson, and McArthur (2019) that evaluates associations between learning disabilities such as poor reading and internalising behaviours in children, adolescents and adults, provides additional weight to the psychosocial and emotional risks faced by people with dyslexia. Their review revealed "statistically significant differences between poor readers and typical readers on general measures of internalising problems ($d = 0.41$), as well as specific measures of anxiety ($d = 0.41$) and depression ($d = 0.23$)" (Francis et al., 2019, p. 46). Kalka and Lockiewicz (2018) further demonstrated this through their research with 152 students, of whom 72 had dyslexia and were enrolled at a university in Poland. Their study reported that those with dyslexia experienced lower levels of positive emotions, low satisfaction and were less happy with their lives compared to their non-dyslexic peers (Kalka & Lockiewicz, 2018).

Australian research has described the mental health and wellbeing of dyslexic children and adolescents (Boyes et al., 2016; Firth, Frydenberg, Steeg, & Bond, 2013; Leitao et al., 2017). Collectively, they have reported that dyslexia is a risk factor for poor mental health and wellbeing in childhood with lasting effects into adolescence. Further, an Australian study by Tanner (2009) investigated the perception of failure, disclosure within an adult learning environment and the lived experiences of adults with dyslexia. Tanner highlighted that a 'conundrum of failure' (Tanner, 2009, p. 786) underpinned the perceptions of her participants, and this was influential in their life decisions.

In summary, the existing evidence suggests that having dyslexia increases the risk of enduring psychosocial and emotional difficulties in late adolescence and adulthood. However, little is known about the mental health, educational attainment, employment rates and the likelihood of disclosure of dyslexia, among Australian adults with dyslexia. Further, the term "dyslexia" is not widely used as an educational and/or clinical term in Australia (Bond et al., 2010) and continues to be poorly understood by educational professionals (Serry & Hammond, 2015; Stark, Snow, Eadie, & Goldfeld, 2016). The current study therefore sought to conduct a preliminary pilot investigation into the wellbeing of adults with dyslexia in Australia.

Aims

The specific questions for the study of Australian adults with dyslexia were:

- (1) What are their highest educational attainments?
- (2) What are their rates of employment and what sectors do they work in?
- (3) What is the likelihood of self-disclosure to family members, friends and work colleagues?
- (4) How do participants score on the standardised Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS)?

Methods

Ethics

Ethical clearance was granted by La Trobe University (HEC18233). The Warwick Medical School (Warwick and Edinburgh Universities) granted permission to the first author to incorporate the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Warwick Medical School, U. o. W, 2015) as part of data collection.

Procedure

Participants

To be eligible for recruitment, participants were required to be at least 18 years of age, living in Australia, and had previously received a formal diagnosis of dyslexia. A total of 65 participants were recruited via social media channels.

Data collection

This study adopted a cross-sectional design using an anonymous online survey (see Appendix 1) hosted on the Qualtrics platform. The survey comprised two parts. Part one was purpose-designed to collect background information about the participants, including their age, gender, educational history and employment status. Questions also elicited information about participants' dyslexia diagnosis and choices about disclosure of their dyslexia. Part two comprised the standardised WEMWBS (Warwick Medical School, U. o. W, 2015). This tool was designed to assess the mental wellbeing of people aged 16 years and over. It was validated on the general adult populations in the UK and is used as both a population health surveillance tool, and with individuals to support intervention. The scales within the WEMWBS divide mental wellbeing into two perspectives: (i) happiness and life satisfaction (the hedonic perspective); and (ii) positive psychological functioning, including, good relationships with others and self-realisation/acceptance (Warwick Medical School, U. o. W, 2015).

The WEMWBS has 14 questions, each worded to address aspects of positive mental health. Each question has five response categories (ranging from "none of the time" to "all of the time"). The responses to each question are summed to obtain a single score. Higher scores are associated with greater levels of positive mental wellbeing. Scores range from a minimum of 14 and a maximum of 70. The WEMWBS has a reported reliability of $\alpha = 0.89$ (Warwick Medical School, U. o. W, 2015). We asked participants to respond to the WEMWBS questions reflecting over the last six months. In the original WEMWBS, participants were asked to rate their mental wellbeing over two weeks. We selected a longer time period, as we were specifically focused on people with dyslexia, which, as a lifelong learning disability, may continuously affect individuals' mental wellbeing.

Data analysis

The data were entered into SPSS software (version 24) for analysis. Descriptive statistics were used to analyse the characteristics of participants as well as their education level, employment status and disclosure rates. The measures of central tendency were used to analyse participants' WEMWBS group data. The data were then compared with the standardised WEMWBS scores. An independent *t*-test was conducted to determine how the sample in the present study compared with the established norms. Due to the relatively small sample size, the bootstrapping procedure of 1000 random generation of the sample was used to assess measures of accuracy (here confidence intervals) for sample estimates.

Results

Participants' characteristics

Table 1 describes the characteristics of the 65 participants, which comprised mostly females (72%). The participants were aged from 18 to 65 but mainly clustered across the ages of 20 to 49. Over half (58%) of the participants reported receiving their diagnosis of dyslexia in adulthood. This included one participant, who was aged 51. The reported diagnosticians were from several disciplines but most were psychologists (educational psychologists 54% and neuropsychologists 6%).

In terms of participants' highest educational attainment, 70% had completed Year 12 (final year of school in Australia) and attained post-school qualifications at various levels (diploma 11%, undergraduate degree 37%, postgraduate degree 21%). Of the remaining 30% of participants, half had completed their final year of school (Year 12) while the remaining half had not (Year 11 or below).

Over three-quarters of our participants were working either full-time or part-time, while 23% were either not working, looking for work or not looking for work at all. Eighty per cent of participants reported the type of work they undertook. Although 58% had an undergraduate or postgraduate qualification, only 38% worked in roles that required a tertiary qualification, including senior management, allied health, information technology, finance, social services and education roles. Nearly one-quarter (23%) worked in jobs that required a diploma (e.g. childcare, disability, and correctional services) or little to no post-secondary training (e.g. house cleaning, retail and administration). Eight per cent of participants were self-employed (e.g. farming, artist, running their own business), 8% were currently in post-secondary education and 3% were primary carers at home. Notably, five participants (8%) were either employed to support and work with students with disabilities, such as dyslexia, or ran their own dyslexia-related business.

Most participants (90%) reported that they were likely to disclose their dyslexia to a family member, while 78% reported that they were likely to disclose their dyslexia to friends. Over half of the participants (57%) said that they were likely to disclose their dyslexia to a work colleague.

Table 1. Participants' Characteristics.

Characteristics	N	%
Gender		
Female	47	72.3
Male	18	27.7
Age		
16–20	2	3.1
20–29	15	23.1
30–39	16	24.6
40–49	17	26.2
50–59	11	16.9
60 +	4	6.2
Education Level		
Year 11 or lower	10	15.4
Completed Year 12	10	15.4
Diploma qualification	7	10.8
Undergraduate degree	24	36.9
Postgraduate degree	13	20.0
PhD	1	1.5
Employment Status		
Working full-time	32	49.2
Working part-time	9	13.8
Self-employed	9	13.8
Not employed	6	9.2
Looking for work	5	7.7
Not looking for work	4	6.2
Diagnosed By		
Educational Psychologist	35	53.8
Neuropsychologist	4	6.2
Speech Pathologist	2	3.1
General Practitioner	2	3.1
Other (please specify)	4	6.4
Can't recall	18	27.7

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

The mean score on the WEMWBS for our participants was 46.8 (SD = 9.49, bootstrapping 95% CI = 44.4–49.0). Conversely, the mean score on the WEMWBS for participants of the Health Survey for England in 2016 was 49.9 (SD = 10.84). The reliability of the WEMWBS was assessed for the current study ($\alpha = 0.93$). Our results were compared against a population-based Health Survey for England conducted in 2016. The mean score of the WEMWBS Health Survey for England was 49.9, with a standard deviation of 10.84 ($n = 6,955$).

Prior to our analysis, we determined that there was a relatively normal distribution of WEMWBS scores for our participants). An independent *t*-test was conducted to compare the mean difference between participants (46.8) and those from the WEMWBS Health Survey for England in 2016 (49.9) with an effect size (Hedges' *g*) of 0.29. This revealed that our participants scored significantly lower than those who participated in the Health Survey for England in 2016 ($t = 2.37, p < 0.01$) on the WEMWBS. The means and standard deviations for the 14 questions are presented in Table 2.

Table 2. Warwick-Edinburgh Mental Wellbeing Scales Scores.

Questions (scored from 1 to 5)	Mean	SD
Happiness and Life Satisfaction		
I've been feeling optimistic about the future	3.46	.812
I've been feeling cheerful	3.37	.741
I've been feeling relaxed	2.85	.939
Positive Psychological Functioning		
I've been feeling interested in other people	3.69	.983
I've had been dealing with problems well	3.35	.759
I've been thinking clearly	3.35	.891
I have the energy to spare	2.71	1.057
I've been feeling close to people	3.14	1.059
I've been feeling confident	3.12	.976
I've been feeling good about myself	3.12	.960
I've been feeling loved	3.66	1.065
I've been able to make up my own mind about things	3.74	.973
I've been feeling useful	3.65	.799
I've been interested in new things	3.58	.998

Subfactors of the WEMWBS

With respect to the *Happiness and Life Satisfaction* component of the WEMWBS, just under half (48%) of our participants felt optimistic about the future, either "often" (39%) or "all the time" (9%). Further, 52% did not feel very optimistic about their future with 11% reporting that they rarely felt optimistic and 41.5% reporting that they sometimes felt optimistic ($M = 3.46$, $SD = 0.812$). Concerning the *Positive Psychological Functioning* component of the WEMWBS, 67% of the participants reported that they did not feel good about themselves. Explicitly, two participants (3%) stated they "never" felt good about themselves, 15% said they "rarely" felt good about themselves and only 26% stated they "sometimes" felt good about themselves ($M = 3.1$, $SD = .96$). In response to the question asking about their confidence, three participants (4%) stated they felt confident "never", 18% "rarely" and 46% "sometimes". Regarding personal relationships, 27% of the participants reported that they did not feel close to people, while only 33% stated they "sometimes" felt close to people. When asked if they felt loved, 3% of the participants responded "never", 12% responded "rarely" and 23% responded "sometimes". Finally, in relation to mental wellbeing, 73% of the participants stated that they felt they only had energy to spare "sometimes" or "never".

Discussion

This pilot study surveyed 65 Australian adults who reported receiving a formal diagnosis of dyslexia about receiving their diagnosis, their educational and employment history, self-disclosure and a measure of their mental wellbeing. More than half (58%) of the participants reported receiving their diagnosis of dyslexia in adulthood. This implies that many may have been under-identified or unidentified and, therefore, inadequately supported during their schooling and, perhaps for some participants, in post-secondary training as well. Given the educational and employment status across our sample, we suggest that these participants had to work extremely hard at school and draw on many personal resources to achieve the outcomes that they did and continue on to enter post-secondary education and/or the mainstream workforce. Late diagnosis has been reported

elsewhere including countries such as Italy where two out of three children between the ages of eight and ten with dyslexia had not been formally diagnosed (Barbiero et al., 2019).

The broad variability of the age when a diagnosis for dyslexia was received by our participants stands at odds with other neurodevelopmental disorders such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) where children are typically identified in early childhood (Bent, 2017; Sullivan et al., 2015), often by interdisciplinary teams. This stark contrast is an important issue that requires urgent attention. A delayed diagnosis inevitably means that intervention, if available at all, is provided later than what is ideal as evidenced by literature (Leij, 2013; Lovett et al., 2017; Reynolds, Wheldall, & Madelaine, 2011). Late intervention has a serious impact on the gap between the dyslexic student and his/her peers. As the dyslexic student waits to receive intervention, other students are moving forward in advancing their reading and literacy skills (Duff et al., 2015; Stanovich, 1986). Accordingly, catching up, if possible at all, will require significantly more time, effort and cost for both the individual and service providers (Spira, Bracken, & Fischel, 2005). There are many possible reasons for late diagnosis of dyslexia, and this was not under investigation in our study. However, one possible contributor may be related to the cost of a diagnostic assessment in Australia, which can be upwards of A\$1500.00 (SPELD Victoria, 2020), and may be prohibitive for many people to access.

Dyslexia as a neurodevelopmental disorder often co-occurs with other neurodevelopmental disorders such as Autism Spectrum Disorder, Developmental Coordination Disorder and ADHD (Brimo et al., 2021; Hendrickx, 2010; Pham & Riviere, 2015; Russell, 2013; Yeo, 2003). Although we did not ask participants if they had any other comorbid diagnoses, it is likely that at least a significant minority are also managing other areas of difficulty; such as poor oral language skills, social communication difficulties, poor fluency with numeracy etc. There is a significant body of literature that discusses how these co-occurring difficulties can be a predictor of clinical-related mental health problems and disorders (Gunnell, Harbord, Singleton, Jenkins, & Lewis, 2009; Koenen et al., 2009; Mathiassen et al., 2012; Linde Melby et al., 2020; L. Melby, Vik, Indredavik, Lohaugen, & Skranes, 2016). Therefore, we cannot state conclusively that dyslexia alone is the primary reason for our participants' emotional and wellbeing challenges. However, our results suggest that having a diagnosis of dyslexia (no matter from what age) seems to be a marker for poorer perceived mental health and/or life satisfaction.

The profile of our sample closely reflected the general Australian population terms of educational attainment and employment status (Australian Bureau of Statistics, 2017, 2020). More than 80% of our participants had attained a post-secondary education and this compares favourably to the national average of 78% of the people completing an education level of Year 12 and above (Australian Institute of Health and Welfare, 2019). Of the participants who had continued to higher education, 58% held an undergraduate degree or above.

The employment profiles of our participants were also favourable compared to national data. Three-quarters of our participants reported being employed across a range of activities. According to ABS data, the national disability average for employment is 53%. However, we are cautious when comparing the two results as the Australian Bureau of Statistics (ABS) data includes people with a diverse range of disabilities.

Nevertheless, high participation in the workforce is an important indicator for life satisfaction and personal well-being (Kun & Gadanez, 2019; Weziak-Bialowolska, Bialowolski, Sacco, VanderWeele, & McNeely, 2020). Our participants' low level of life satisfaction could be related to their workplace experiences. The challenge for those with dyslexia is to be able to meet task demands in the workplace and adapt to advancing technologies, which increasingly rely on literacy (and numeracy) skills (Livingston et al., 2018; Snow, 2020).

The literature highlights the concern that adults with learning disabilities are frequently unemployed or underemployed (Gerber, Price, Mulligan, & Shessel, 2004; Macdonald & Deacon, 2019). Within our cohort, unemployment was 7.7%, which is marginally above the current ABS data for the general population, which sits at 7.1% (Australian Bureau of Statistics, 2018b). However, underemployment was not measured by this survey, and this may give a fuller picture of employment and work satisfaction for those with dyslexia.

With respect to the type of vocations taken up by those with dyslexia, research tends to diverge. According to a systematic review by De Beer, Engels, Heerkens, and van Der Klink (2014), some choose creative or administrative professions, others choose more practically-focussed jobs such as trades. There was no consensus however, on whether people with dyslexia were more likely to be employed in white – or blue-collar jobs. In our sample, participants worked across the spectrum from low-skilled jobs (e.g. house cleaning), creative work (e.g. full time artist) to being self-employed small business operators. From our data, we cannot determine the degree to which vocational choices were influenced by low confidence and self-belief which has previously been documented (Humphrey & Mullins, 2002; Nalavany, Logan, & Carawan, 2018). It is notable however, that although more than half of our participants (58%) had an undergraduate or postgraduate qualification, only 38% worked in roles that required a tertiary qualification. This appears to align with data collected from the WEMWBS where participants expressed a "lack of confidence" or "feeling not good enough". It is also consistent with some studies where participants indicated they were working at a level lower than their education (De Beer et al., 2014).

Our participants scored significantly less well on levels of mental wellbeing, as measured by the WEMWBS, compared to than those in the general population nationally (and internationally). International evidence has demonstrated this phenomenon for some years (Alexander-Passe, 2015; Fuller-Thomson et al., 2018; Kjersten, 2017; Tecosky-Feldman, 2004; Wilson et al., 2009) and our study suggests that the picture may be similar for Australian adults with dyslexia. This was particularly apparent in the finding that two-thirds of our participants did not appear to "feel close to other people", to "feel loved" or "had not been feeling interested in other people". Although our findings are from a brief scale, it seems to resonate with reports such as Kjersten (2017) who interviewed couples in which one partner had dyslexia. The results revealed multiple challenges that can occur in intimate relationships such as communication breakdowns and an ongoing reliance and support required by the non-dyslexic partner to manage day-to-day activities (Kjersten, 2017). Similarly, both Alexander-Passe (2012, 2015) as well as Moore and Carey (2005) have also documented the difficulties that individuals with dyslexia are more prone to having relationship difficulties including relating to peers and forming intimate relationships (Kalka & Lockiewicz, 2018; Moore & Carey, 2005). Given that friendships and positive

relationships are protective factors in mental wellbeing, the potential psychosocial consequences for adults with dyslexia must be recognised (Livingston et al., 2018; Sias & Bartoo, 2007; Wilson, 1984).

Disclosure is a complex and personal decision and for those with dyslexia, their sense of self. It has been reported elsewhere (Alexander-Passe, 2015; Macdonald, 2009; Morris & Turnbull, 2007; von Schrader, Malzer, & Bruyère, 2014; Yeowell, Rooney, & Goodwin, 2018) that those with dyslexia may feel the risk of discrimination and stigmatisation is likely if they disclose their dyslexia. The reported disclosure of dyslexia among our participants seemed quite high but unsurprisingly, participants were more likely to disclose to family and friends, rather than to people at work (90% v. 57%). Although close to three-fifths of our participants reported disclosing to a colleague at work, we do not know if this person was a peer or a line manager. This is worthy of further investigation, particularly in light of findings by Beetham and Okhai (2017) who reported that adults with dyslexia and other specific learning difficulties who did not access workplace support, either through lack of awareness or fear of disclosure, risk poor mental health and wellbeing due to struggling to manage their workload.

Limitations

This pilot study had several limitations that must be acknowledged. The sample size was small and dominated by female participants and, therefore, we cannot be confident that the data are representative of Australian adults with dyslexia. There was a reliance on social media to recruit, which may have limited the number of people who saw the recruitment flyer. There was also no way to verify that those who completed the survey actually had a formal diagnosis of dyslexia. The online survey required a certain level of digital literacy and general literacy skills, which may have excluded those with limited access or capacity to technology and those whose reading difficulties precluded them from participating. In terms of the WEMWBS, our findings assume that the wellbeing of the Australian population is comparable to the UK population. Lastly, the WEMWBS was designed to ask people how they have been feeling over the last two weeks whereas we asked participants how they had been feeling and managing over the last six months.

Future research

While this pilot study was small in scope and limited to one country, a larger sample would be ideal for verifying our findings. Further investigation exploring the lived experiences of adults with dyslexia would allow for more in-depth insights about the way those with dyslexia manage their study and work and what specific aspects are contributing to feeling poorly about themselves. Given the slight gap between educational attainments and employment rates that we found, it would be worth gaining insights from employers on their perspectives and experiences of having employees with dyslexia. In addition, an evaluation of the implications of disclosing dyslexia in the workplace and the link between this and mental health and wellbeing outcomes could provide important insights into policies and practices in the workplace.

Conclusion

Our study sought to explore how Australian adults reportedly diagnosed with dyslexia were making their way through adulthood. We found their age at diagnosis of dyslexia varied markedly. This is likely to have a flow-on effect regarding educational and vocational opportunities; particularly in relation to if and when intervention was received. Participants' educational attainment and employment status were generally close to or on par with the general Australian population. However, according to the WEMWBS, their mental wellbeing was compromised across the domains of happiness, life satisfaction and positive psychological functioning in comparison to adults in the general community. Our study highlights the divide between the fact that participants are likely to present similarly to people in the general population regarding key metrics of education and employment but for many, appear to be doing so at high personal cost.

These results, albeit a snapshot, highlight the current need for improved pathways for assessments in line with other neurodevelopmental disabilities. Further, while their educational rates reflect the general Australian community and employment rates were not far behind, a personal sense of wellbeing cannot be assumed. To optimise the capacity of adults with dyslexia to participate fully in society and derive satisfaction, stakeholders (e.g. practitioners, employers, peers and colleagues) are encouraged to consider and address the potential cost to wellbeing faced by many adults with dyslexia.

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Declarations

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon satisfactory request.

Disclosure statement

No conflict of interest.

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Ethical approval

Ethical clearance was granted by La Trobe University (HEC18233). The Warwick Medical School granted permission to the researchers to incorporate the WEMWBS (Warwick Medical School, U. o. W, 2015) as part of our survey.

Consent to participate

Participants consented to participate in the research.

Consent for publication

Participants consented to this research being published.

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Appendix 1 Survey – Effects of Living with Dyslexia in Adulthood

Part 1. General information about yourself.

Q1 What is your gender?

Female Male Transgender Other Prefer not to say

Q2 What is your age?

16–20 20–29 30–39 40–49 50–59 60 +

Q3 How old were you when you were diagnosed with dyslexia? If you are not sure of your age please put an approximate age or write unsure. _____

Q4 Can you recall which professional diagnosed your dyslexia?

Educational Psychologist Neuropsychologist Speech Pathologist GP Can't recall
Other (please specify) _____

Q5 What is the highest level of education you have completed?

Year 11 or lower Completed Year 12 Diploma qualification
Undergraduate degree Postgraduate degree

(Continued)

Part 1. General information about yourself.

Q1 What is your gender?

Female Male Transgender Other Prefer not to say

Q2 What is your age?

16–20 20–29 30–39 40–49 50–59 60 +

Q3 How old were you when you were diagnosed with dyslexia? If you are not sure of your age please put an approximate age or write unsure. _____

Q4 Can you recall which professional diagnosed your dyslexia?

Educational Psychologist Neuropsychologist Speech Pathologist GP Can't recall
Other (please specify) _____

Q5 What is the highest level of education you have completed?

Year 11 or lower Completed Year 12 Diploma qualification
Undergraduate degree Postgraduate degree

Q6 Which of the following categories best describes your current employment status?

Working part-time Working full-time Self-employed
Not employed Looking for work Not looking for work

Q7 If you are currently employed, can you please state your current role?

Q8 How likely are you to disclose your dyslexia to your family?

Very likely Likely Unlikely Very unlikely Unsure

Q9 How likely are you to disclose your dyslexia to your friends?

Very likely Likely Unlikely Very unlikely Unsure

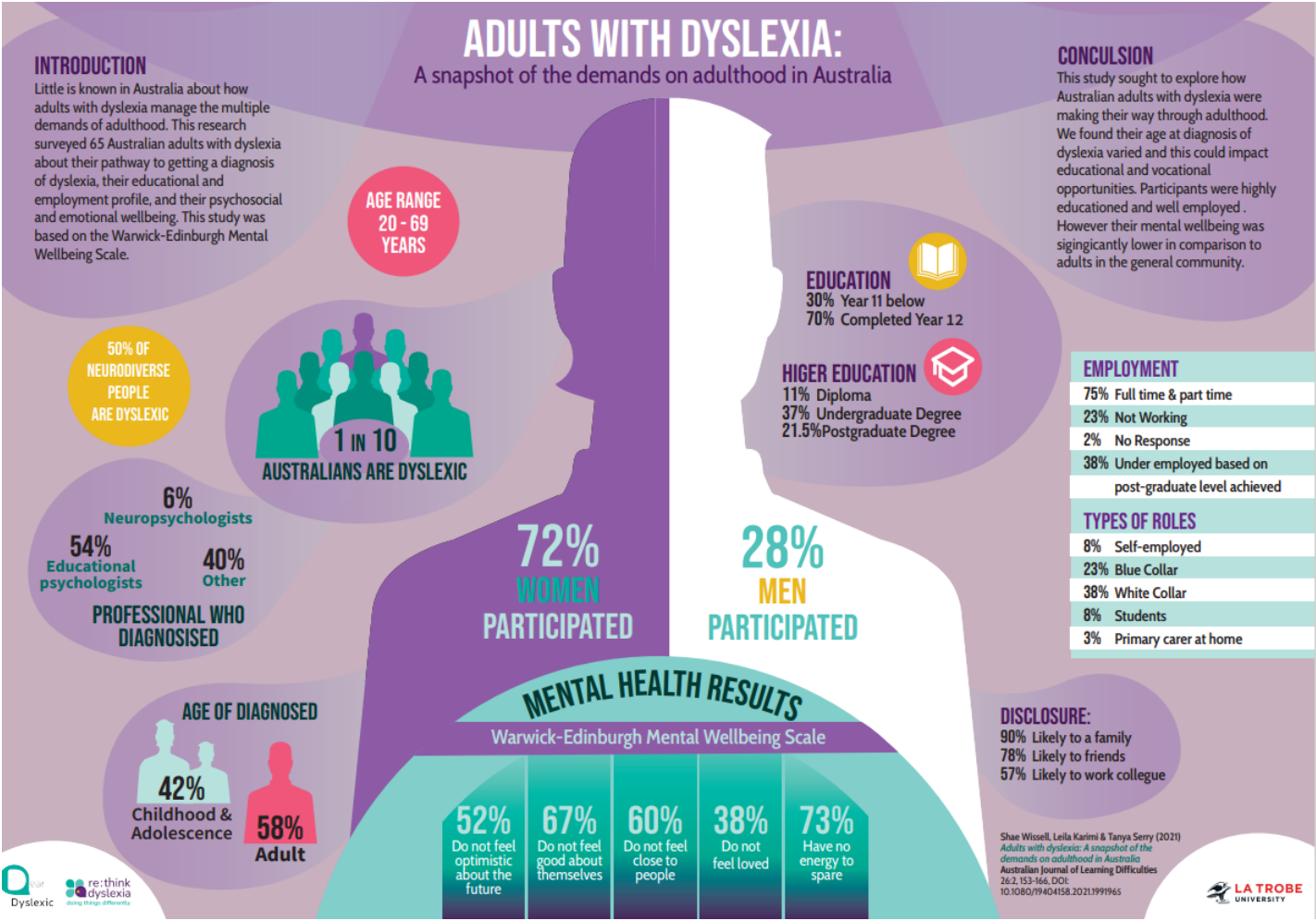
Q10 If you work, how likely are you to disclose your dyslexia to your work colleagues?

Very likely Likely Unlikely Very unlikely Unsure

Part 2: Information on your wellbeing. Please read each statement and decide how often, over the last six months you have felt the following:

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	All of the time (5)
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been feeling interested in other people					
I've had been dealing with problems well					
I've been thinking clearly					
I've had energy to spare					
I've been feeling close to people					
I've been feeling confident					
I've been feeling good about myself					
I've been feeling loved					
I've been able to make up my own mind about things					
I've been feeling cheerful					
I've been interested in new things					

4.3 Infographic 1. Adults with Dyslexia: A snapshot of the demands on adulthood in Australia



Chapter 5

Study B.1

Journal Article 2

“You don’t look dyslexic”: Using the Job Demands - Resources model to explore workplace experiences of Australian adults with dyslexia.

5.1 Prologue

The article presented in Chapter 4 (Study A.1) revealed that, despite comparable rates of employment to the general community, individuals with dyslexia were more likely to exhibit low levels of psychosocial wellbeing. This second research study (Study B.1) aims to extend the findings of Study A.1 by exploring the subjective experiences of adults with dyslexia, with a particular emphasis on their workplace experiences and gain deeper insight into some of the potential underlying factors that could be contributing to these experiences.

Despite the development of legislative policies in Australia and other countries to safeguard individuals with dyslexia against discrimination (Anderson et al., 1995; Bell, 2009; Commonwealth of Australia, 1992, 2010; Price et al., 2003), ensuring compliance with these requirements in workplaces has not been as firmly established (Bell, 2009; Bond, 2021; Bond et al., 2010). As technology and digital communication continue to advance, literacy competence has become increasingly crucial for vocational success, potentially leaving individuals with dyslexia vulnerable in professional settings (Bartlett et al., 2010; Lemos et al., 2022; Livingston et al., 2018; Moody, 2009). A systematic review conducted by De Beer et al. (2014) examining the workplace experiences of individuals with dyslexia suggested that negative experiences could be mitigated by providing employees with dyslexia: (i) greater independence to contrivance their own workplacea daptations and managing strategies, including access to assistive technology, (ii) improved self-awareness of their strengths and challenges, and (iii) increased support from employers and colleagues to disclose their dyslexia and utilize accommodations in the workplace.

Chapter Five presents a journal article (Study B.1) published in the *International Journal of Environmental Research and Public Health*. This study examined the work-related experiences of adults with dyslexia, with a specific focus on organisational policies and practices and effective strategies to facilitate the successful participation of individuals with

dyslexia in the workforce. This study adopted a qualitative research design. In-depth interviews (n=14) were conducted with dyslexic adults either currently, or previously, in the labour market.

In the absence of a dyslexic theory-driven workplace model within Australia, the Job Demands-Resource Model of Burnout (JD-R Model) was adopted to frame and interpret the research findings. The JD-R Model is a validated tool that has been used to evaluate how organisational working conditions can influence employee experiences (Kim & Wang, 2018; Lee, 2019; Van den Broeck et al., 2010). It has broad application for all workplaces and their variable composition of employees. Currently there is only a small body of research using the JD-R Model on populations with disabilities (Efimov et al., 2022; Flores et al., 2021; Lehmann et al., 2021); however, none with a disability population such as dyslexia.

As above, this second study builds on the findings from Study A.1, which found that those with dyslexia had lower levels of mental health and wellbeing across several life satisfaction factors. In Study A.1, it could not be determined why a highly educated group of workforce participants had such low levels of mental health across the life satisfaction scores. There may be a causal link between Study A.1 and Study B.1, which has demonstrated elevated levels of job burnout. Job burnout may be contributing to overall lower levels of mental health and wellbeing and life satisfaction. A key finding from this second study is that employees with dyslexia frequently report a distinct set of barriers that hinder their ability to access the necessary support and accommodations to perform at their optimal level in the workplace. In light of these findings, practical recommendations for employers to establish more inclusive and supportive work environments have been provided.

This chapter presents an article published in the *International Journal of Environmental Research and Public Health*, Dyslexia Special Edition. The published manuscript included in this chapter has been reproduced with permission from the International Journal of Environmental Research and Public Health, Molecular Diversity Preservation International (MDPI).

5.2 Publication

Wissell, S., Karimi, L. & Serry, T. Furlong, L. & Hudson, H. (2022) “You don’t look dyslexic”: Using the Job Demands - Resource model to explore workplace experiences of Australian adults with dyslexia. *International Journal of Environmental Research and Public Health*. *S Ed.* doi.org/10.3390/ijerph191710719



Article

“You Don’t Look Dyslexic”: Using the Job Demands—Resource Model of Burnout to Explore Employment Experiences of Australian Adults with Dyslexia

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Abstract: Background: Employment and job security are key influences on health and wellbeing. In Australia, little is known about the employment lifecycle of adults with dyslexia. Materials and Methods: Using a qualitative research design, this study sought to explore the experiences faced by adults with dyslexia seeking and retaining employment. In-depth interviews were conducted with a cohort either currently or previously in the labour market. We used the Job Demands Resource Model of Burnout (JD-R Model) to explore links between workplace characteristics and employee wellbeing. Deductive content analysis attained condensed and broad descriptions of participants’ workplace experiences. Results: Dyslexic adults (n = 14) participated; majority employed part/full-time and experienced challenges throughout their employment; exhaustion and burnout at work were reported, also fear and indecision about disclosure of dyslexia. A minority reported receiving positive, useful support from team members following disclosure. Conclusion: The JD-R Model provided a guiding framework. We found participants experienced a myriad of challenges that included risk of mental exhaustion, discrimination, limited access to support and fatigue, leaving them vulnerable to job burn-out. Dyslexia does not have to be a major barrier to success in any occupation. Yet, when in supportive, informed workplace environments, employees with dyslexia thrive.

Keywords: JD-R Model; dyslexia; workplace; burnout; disability; employment



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1. Background

Gainful employment is a crucial social determinant of health, allowing for individuals to participate meaningfully in society and providing a scaffold for social interaction and economic independence [1]. Extended periods of time in unemployment or underemployment are associated with financial strain, social isolation, and poor mental health and well-being [1,2]. Although there are many factors that contribute to employment difficulties, people with various types of disability are more likely to be unemployed compared to people without disability [1,3]. In Australia, 53 per cent of working-age people with disability were in the labour market compared to 84 per cent of people without disability [4,5]. Australian research by Wissell et al., (2021) identified that working Australian adults with dyslexia had an unemployment rate of 7.7% which is slightly above the current ABS data for the overall population, sitting at 7.1% [6,7].

Dyslexia is a specific type of learning disability associated with poor reading and spelling skills, thought to be underpinned by an underlying phonological processing deficit [8–10]. Dyslexia is a lifelong condition [11–13] and affects individuals across the IQ range [11]. Evidence suggests that dyslexia occurs in up to one in ten people [11,14–16].

Over the last decade, there has been an increased focus on the psychological risks and educational needs of dyslexic individuals who are still at school or in post-secondary education [17–20]. However, less attention has been focused on the process of dyslexic adults entering the workforce [21]. Additionally, while legislative policies in Australia and overseas have been developed to protect people with dyslexia from discrimination [22–26], a commitment to those with dyslexia in workplaces has not been as well established [24,27].

With advances in technology and digital communication, vocational success increasingly relies on competency in literacy, which can leave those with dyslexia vulnerable in the workplace [1,28,29]. A systematic review by De Beer et al., (2014) examining the workplace experiences of people with dyslexia [30], suggested that adverse experiences could be minimised if employees with dyslexia had: (i) greater autonomy to implement their own workplace adaptations and coping strategies to manage their work, including access to assistive technology, (ii) enhanced self-awareness of their own strengths and difficulties, and (iii) more support from employers and colleagues to disclose their dyslexia and use adaptations at work.

Various authors [1,24,31,32] reinforce the importance of training to be offered to employers and their leadership teams to improve their knowledge of dyslexia. It appears from the research that without a coordinated effort from employers, managers, workplace leaders and human resources staff to provide accommodations and adjustments, employees with dyslexia are likely to struggle to complete designated work tasks [24,30,32]. However, when employers and workplace leaders have insufficient knowledge about dyslexia, employees with dyslexia are more reluctant to disclose their condition, fearful that exposure may result in stigma and discrimination [21,33–36]. This is unfortunate, given the evidence demonstrating that disclosure can have positive effects on a worker's health, social relationships, self-identity and job performance, as well as the organisation in which the worker is employed [37,38].

There is scarce theory-driven research and a significant need in Australia to increase understanding regarding aspects in the work environment that enrich or hamper occupational health and satisfaction, from the standpoint of employees with dyslexia. Therefore, in this study, we wished to explore and better understand the working environment for people with dyslexia. To do this we have adopted the Job Demands–Resources Model of Burnout (JD-R Model), proposed by Demerouti et al. [39] as a theory-driven framework.

The Job Demands–Resource Model of Burnout (JD-R Model) (Appendix A) is a validated tool that has been used to evaluate organisational outcomes across several workplace settings [39–42] and has generic application for all workplaces and their varying composition of employees. Currently, there is only a small body of research using the JD-R Model on populations with disabilities [43–45], however not on a disability population such as dyslexia. For those with dyslexia it is not clear if, how and why workplace job resources and job demands can be connected to work-related outcomes (such as job burnout).

The aim of this research was to investigate the work experiences of adults with dyslexia by exploring organisational practices and derive suitable recommendations to support their participation in the workforce. This paper forms part of a larger project investigating the lived experiences and the social and emotional wellbeing of adults with dyslexia in Australia across the domains of education and employment.

2. Methods

2.1. Design

Methodological Framework

As there is little research exploring the associations between workplace demands and employee wellbeing for people with dyslexia, we adopted a qualitative design utilising in-depth interviews to gather substantive responses from participants. We chose semi-structured interviews, utilising an interview guide with a set of pre-determined questions. Further follow-up and clarifying questions emerged during interviews with participants. Qualitative research does not specify a fixed amount of data to be collected but continues

until saturation is reached and the available data tell a rich, complex and in-depth story about the phenomenon of interest. Compared to quantitative research, sample sizes for qualitative research are typically much smaller [46,47]. Saturation of data occurs when no new insights can be gained; this is commonly achieved with minimum sample sizes of 12 for qualitative studies [46–49]. As a result, 14 participants were considered adequate for this qualitative analysis and the scope of this research.

We have not used the JD-R Model to compare whether our population are facing different challenges to the general population. Instead, the aim was to support the development of our categorisation framework and to utilise a theoretical framework to better understand and study the association between job demands and employee wellbeing and motivation, and to explore how job demands may be mitigated by job or personal resources (occupational support/adjustments or personal characteristics/strategies).

2.2. Participants

Purposive sampling is generally used for qualitative research as recruitment is based on the shared experience of participants that is of relevance to the research question [46]. Purposive sampling was used to enroll participants who met the subsequent criteria: (1) living in Australia; (2) at least 18 years of age; (3) have received a formal diagnosis of dyslexia and (4) have participated in the workforce for a minimum of three years. Notification of the study was sent via electronic mail to all members of the Dear Dyslexic Foundation (DDF) database and the Equal Employment Opportunity Network Victoria database (a forum dedicated to educating decision makers on creating more diverse, inclusive and equitable workplaces). In addition, various open and closed social media platforms, including LinkedIn, Twitter and Facebook, were used for study recruitment. Fourteen participants were recruited: eight females and six males.

2.3. Data Collection

The first author, who is also dyslexic, conducted one semi-structured in-depth interview with each of the 14 participants via Zoom. The 42 interview questions (Appendix B) were generated by the authors, based on previous literature about the profile of adults with dyslexia, e.g., [28,30,50–52] and in line with the study's purpose. Of the 42 questions, 15 questions asked about participants' dyslexia history and education, but the remaining 27 questions focused on their workplace experiences and their perceived psychological wellbeing in relation to working. Interviews ranged from 24 min to 72 min (mean = 47 min) and were audio-recorded for later transcription and analysis. At the beginning of each interview, the lead investigator disclosed her own dyslexia to participants. This was intentional since disclosure can enhance a researcher's vulnerability [53], and enable authenticity and transparency to be established early on, and provide greater context for participants of the research [53–55]. The interviewer kept field notes and conducted reflective audio recordings following each interview to assist in building a rich understanding of participants' experiences in the context of the phenomena under review [56,57].

Prior to data analysis, each participant received their verbatim transcript and was invited to review and request changes to any part of the contents within two weeks of receipt. Minor amendments were requested by two of the 14 participants to remove identifiable data. At this point, transcripts were uploaded to NVIVO software (version 12), participants were assigned a number code, and their transcripts were de-identified. Ethics approval was granted from La Trobe University to conduct this study.

2.4. Analysis

Deductive content analysis [58] was used to prepare, organise and analyse the interview data. The preparation phase involved familiarisation with the interview data through multiple active readings of the transcripts and listening to audio files.

To organise the data, a categorisation framework was developed based on the six main areas of the interview questions; (1) diagnosis; (2) dyslexia across the life span; (3) dyslexia

and support networks; (4) mental health; (5) workplace experiences and (6) workplace improvements). Categories of data across the interview transcripts were identified such as, the major category of *Workplace Experiences*, with the subcategory *Reasonable Adjustments-including text to speech software, editing support and mobile phones*. The *workplace experiences* and *workplace improvements* categories were interrogated further by searching for frequently recurring words (e.g., *anger, frustration*), and coding ideas reflected in utterances (e.g., *no one could make me feel as bad as when I was six years old; I have a team that supports me with day-to-day activities*). This open coding process led to the clusters of content that fell under *workplace experiences* and *workplace improvements* categories. To demonstrate, under *workplace experiences*, the subcluster of content about job demands emerged and included sub-categories such as *not being able to meet the expectations of 'normal' people, fractures to 'on-the-job' working relationships* and *systemic organisational barriers* were created [58].

Finally, all transcripts were re-read for reflection and to ensure that interpretation of participants' data was captured authentically by the categorisation matrix. Direct quotations from participants were cross-checked against the categories to ensure the categories were reflective of the participants' narrative [59,60]. While the researchers had predetermined topics for discussion within the interviews, the generic and sub-categories themselves were generated from the interview data using the process described.

2.5. Ensuring Rigour

Several steps were implemented to ensure rigour in our data collection and deductive content analysis. Data collection methods were co-constructed by the entire research team to ensure that the interviewer's personal experience of dyslexia did not introduce potential bias in the interview questions. A second member of the team verified the fidelity of the structured interviews by listening to 10% of the recordings. Three weekly research meetings were held to reflect on the findings, coding processes and analysis to ensure that the interpretation of data was not overlaid with the interviewer's lived experiences. These meetings were recorded, and an audit trail was kept of all research actions undertaken from the start of the research project through to the reporting of findings, including the steps taken to ensure verification and dependability of findings [61]. The researchers also ensured the transferability of the project by providing detailed characteristics of the participants [61].

3. Results

3.1. Participant Characteristics

Results are represented in three sections: participant characteristics, workplace experiences as reflected by participants, and their suggested ideas for workplace improvements. Fourteen participants were recruited: six male and eight female. They ranged in age from 20 to 69 but clustered within the ages of 30 to 49 (See Table 1). To protect their privacy, participants will be referred to as 'they'. Eight participants reported receiving their diagnosis of dyslexia in childhood or adolescence, while the remainder received their diagnosis as an adult, with one participant reportedly being diagnosed in their early fifties. Four participants reported additional co-morbid diagnoses such as auditory processing disorder, dysgraphia, or dyscalculia.

Diagnoses were largely provided by psychologists, although there was some variation. Over half (8 out of 14) of participants reported a past familial history of dyslexia among first- or second-degree relatives and three (21%) also stated that they had children with dyslexia.

In terms of education, all but one participant had completed secondary school in Australia, and all had attained post-school qualifications at various vocational or tertiary levels. More than 93% of participants had completed a post-secondary education, which is notably higher than the national population average of 78% [62].

Table 1. Participant characteristics.

Gender	Age Range	State	Diagnosis Age Range	Professional Who Diagnosed	Education Level	Occupation	Employment Status	Industry
M	50–59	TAS	26–30	Psychologist	Postgraduate	Dean of University	Full time	Higher Education
F	50–59	NSW	5–12	Educational Psychologist	Postgraduate	Paediatric Nurse Manager	Full time	Government
M	30–39	WA	13–19	Educational Psychologist	Diploma	Mechanic	Full time	Mining
F	40–49	NSW	5–12	Psychologist	Diploma	Project Officer	Part time	Education
F	20–29	VIC	20–25	Provisional Psychologist	Diploma	Call Centre Operator	Full time	Call Centre
F	30–39	NSW	13–19	Psychologist	Postgraduate	Allied Health Assistant	Unassigned	Health Care
M	50–59	QLD	20–25	Educational Psychologist	Undergraduate	Project Officer	Full time	State Government
M	30–39	ACT	36–40	Neuropsychologist	Diploma	Tour guide	Casual	Hospitality and Tourism
F	50–59	QLD	46–50	Educational Psychologist	Year 12		Unemployed	Banking
F	40–49	VIC	5–12	Educational Psychologist	Postgraduate	Marketing and Communication Manager	Part time	Marketing
M	30–39	QLD	13–19	Unsure	Postgraduate	Unassigned	Full time	Government
F	30–39	VIC	20–25	Psychologist	Postgraduate	Senior Finance Manager	Full time	Mining
M	60–69	VIC	5–12	Other	Postgraduate	Professor Higher Education	Retired	Education
F	40–49	VIC	5–12	Unknown	Diploma	Disability Support Worker	Full time	Disability

Participants worked across a variety of settings including service industries, education, public service, and commercial enterprises. The majority ($n = 8$) worked in full time roles. One participant, previously employed, was actively seeking work at the time of interview, and one was semi-retired.

3.2. Pre-Employment

Although our aim was to examine workplace practices, many participants also shared their experiences of seeking work. Therefore, we have also explored perceptions with the process of recruitment. Due to the challenging and somewhat traumatic experiences spontaneously expressed by some participants, and given most participants attributed these difficult situations to their dyslexia, we felt it was important to describe their perspectives of the pre-employment process because of its intimate and essential connection to employment.

Participants ($n = 3$) were required to complete tasks such as pre-interview aptitude tests or write a report in the pre-employment process and were not provided with any adjustments (such as additional reading time), even when some tried to advocate for their needs. These participants stated in general they were left with a sense that they were not on an even playing field with other candidates during the interview process. For example, Participant 8 (P8) explained that they were asked to write a report on one of the interview questions using a computer that did not have any assistive technology. P8 stated, “I can’t do this,” and was told “Just try your best”. P9 described being unable to complete an aptitude test and feeling humiliated. They said: “... I failed the government test. After the test, two ladies sat in front of me and said, ‘You don’t look dumb. We’ve never seen anybody fail a test as bad as this.’ And I said ‘Well, I’m dyslexic’ as my eyes dropped ...” Likewise, many participants

felt unable to demonstrate their full capacity and employability to prospective employers and associated this with being unsuccessful in securing certain jobs.

3.3. Employment

3.3.1. Workplace Experiences

Job Demands

Three sub-categories were identified in relation to job demands. These were: (i) *not being able to meet expectations*, (ii) *fractures to 'on-the-job' working relationships*, and (iii) *systemic organisational barriers*. These are discussed below.

- **Not being able to meet expectations**

All participants reported perceiving stigmatising attitudes by managers and colleagues at some point within their careers. Regardless of sector or role, they spoke universally of how they struggled to meet job demands, a struggle they ascribed to having dyslexia. For example, P10 said:

"... [How do I] manage priorities of conflicting pressures and multiple tasks with the burden [of] writing and editing it? How do I get it done in time with [an] influx of work at the same time? The mental load that this has on someone who struggles to organise thoughts, priorities', juggle the plethora of parts ... It's an enormous mental load ..."

This was compounded by participants feeling that there was little understanding from many colleagues about what dyslexia is (and is not), leading to feelings of being 'unheard'.

P13 explained that even after disclosing their dyslexia, *"... the disability was quickly forgotten ..."* and workplace literacy demands such as reading large amounts of text, using correct spelling, and producing reports to a certain standard were still presumed and *"... added to stress levels within the workplace ..."*

Many participants linked their stress to feelings of anger, frustration, anxiety and for some, feelings of depression. For P10, trying to do a good job at work elicited a complex mix of emotional responses, *"... you don't want to be judged on it all the time and yet you can't put in the hours that it takes to make it perfect either, so I just feel so much anxiety. I'm so angry that I have to be so dependent, and I can't do my own job and I have this extra pressure on me ..."*

Finally, some participants also felt their dyslexic struggles had affected their career prospects either within the organisations they worked currently or when seeking new career opportunities. Lack of career progression created frustration for participants who knew they could take on new work given the right support. This was demonstrated by P3 who said, *"... I want to use the big word that's in my head, but I can't because I don't know how to spell it. So, I've got to crank it down to a simpler term. It's probably cost me, promotion wise, a few times ..."*

- **Fractures to 'on-the-job' working relationships**

Collegial relationships can be integral to managing job demands and collegial workplace environments. Many participants felt relationship building was constrained by their shame about having dyslexia and ironically, some felt somewhat fraudulent when they performed well at work. P6 articulated this when recalling a comment by a colleague, *"... Well, if you can achieve that then there's not a problem with you. You don't have a disability ..."* Some participants described being the recipient of seemingly innocent but hurtful and demeaning comments. P3 spoke of feeling humiliated but powerless by so-called jokes and said *"... I felt like walking out of a meeting—one guy said, 'If you're dyslexic this won't make any sense to you', making a joke of it like you're stupid or something. I don't really appreciate that. But then you can't really take it to heart. I mean it's just a simple joke really ..."* P6 was told *"... you don't look like a dyslexic ..."* P13 also described a different experience where their colleagues were well-intentioned and tried to help but were misguided in their efforts. *"One of my colleagues started to speak to me slowly so that I would understand. Another wrote to me in very large font ..."*

Participants repeatedly described that colleagues either assumed that having dyslexia meant they were ‘incompetent’ or ‘lazy’. As P11 described, “... In any form of written communication it’s very hard to proof my work, very hard to see the mistakes I make. Therefore, any mistakes can be contrived to be a factor of laziness or a reflection of not understanding the topic or rushing my work...”

- Systemic organisational barriers

Many participants maintained that at the systemic level, their workplace lacked various inclusive practices that would have assisted them both at the onboarding phase and as employees. As a newly appointed employee, P8, who was required to sign a lengthy contract of employment and given very little time to do so, noted “... [Dyslexics] are just going to sign off on it regardless and so there needs to be an alternate strategy for them to, at least, comprehend what was in it...” P13 spoke of the dilemma of whether to tick the box that indicated they had a medical condition/disability “... I remember the form I had to sign to gain employment, [it] said ‘do you have a medical condition?’. I hesitated—I still remember it, I hesitated, because I wondered whether this would be attributed as a medical condition. I ticked the box that said I didn’t and was gainfully employed for several years...” Participants expressed that these experiences left them feeling disheartened, devalued and at times humiliated, prior to even commencing in the role.

Although participants were provided with standard workplace documents that met statutory requirements (e.g., anti-discrimination policies and, in some organisations, inclusion and diversity policies), many noted an absence of formal processes and procedures to support those with dyslexia. P12 stated that “... although there was an inclusion and diversity committee at work, there’s nothing in place at the moment for people with learning disabilities...” Some felt dyslexia did not attract the same level of awareness and support as other types of diverse needs, such as employees with English as a second language.

Even when individual leaders/managers took the time to understand and provide support to dyslexic employees, a lack of consistent, organisational-wide practices left some participants feeling vulnerable to changes in leadership. P9’s story demonstrates this: “... I told him [my supervisor] that I was dyslexic. He did research on it and then sat down with me and said ‘Okay, well, we’ll work on this together. Feel free to tell me when you’re struggling and things like that.’ Which was really good. But then he left. My next supervisor turned around and said he didn’t care that I was dyslexic. Too bad...”

The lack of system-wide inclusive practices described by participants meant that for many, their workplace culture became one of concealment rather than authentic embracement of and support for diversity. This was exacerbated by the fact that many participants believed their leaders or colleagues had little awareness of dyslexia and its impact. P11 stated: “... Sometimes I just needed to work from home because I needed to concentrate. At the moment when I say that, they would think that I’m being a bit precious. They wouldn’t relate that to dyslexia...”

Employee Wellbeing

- Employee self-awareness

Most participants had constructed much of their identity around their dyslexia. P1 stated, “... I think fundamentally it’s [dyslexia that] made me who I am and I love it and I love the strength that it gives me in other areas...” and P2 said, “... I learnt to be resilient, to be strong in myself, to build confidence...” Participants in leadership positions (n = 5), reported that their seniority afforded them the capacity to take advantage of supports which eased the burden of dyslexia on their work. P12 described: “... My team know I’m [dyslexic] and I need time to read through [documents] before we discuss them. They’ll say, ‘Hang on, why don’t I leave this with you for a little bit and we’ll come back to it.’ They are probably more respectful of how our brains work...” For some, disclosure helped to build autonomy and control in the workplace. As P10 explained: “... I needed my team to know [I’m dyslexic] because that’s where

my weakness is, it's in the execution of things and I needed their support to execute, [so I can] then report up to the CEO ... "

- Resilience

When participants had a sense of autonomy about how they managed their dyslexia in the workplace, it appeared they were more likely to have strong levels of self-efficacy. P2 stated, *"... I've become very strong with strategies and resilience around how to cope and how to achieve—and build on my strengths, and then I've learnt probably over the last 10 years, probably 20 years to get people in to help me ... "*

Conversely, a failure of some organisations to respond to reasonable requests for workplace adjustments was perceived by some participants as a trigger for feelings of mistrust towards the organisation. One participant noted that in their workplace, *"... it took a long time to do anything ... "*, while another commented, *"... They always put on their best face, but when it comes to actioning items, it takes a long time if it is going to happen ... "* Some participants believed that if the change or support requested was going to cost money, management were less likely to follow through.

- Job burnout

Mental fatigue was described frequently as being the result of excessive cognitive demands. For example, P9 said *"... It takes me more of an effort than most people to do things. I would come in early or stay late or skip lunch and things like that. I had to work extra hard ... "* Even when participants took extra time and used various tools to support their writing or spelling, they still did not necessarily feel they met required standards. P3 noted: *"... I use spellcheck ... that's great, and then re-read three, four times, make sure it makes sense. And still you sometimes get an email back and they say, 'I don't really understand what you meant' ... "*

Additionally, some participants felt that the sensory environment at work was not conducive to their work productivity and compounded mental fatigue. P5 said: *"... I realised I was struggling quite a lot. I wasn't able to make my normal KPIs. I realised I was getting sensory overload. [My dyslexia] was making me feel quite unhappy, uneasy, making me fear going to work ... "* Other participants spoke of choosing to wear headphones in the office, locking themselves away in rooms or working from home (pre COVID-19) to enable them to concentrate on completing tasks. The culmination of feelings such as stress and sensory overload that some participants described, as well as the mental energy required to get through the day, meant that mental fatigue was a significant and widespread problem and a source of frustration for many of our participants.

Despite the commitment to their workplaces, many participants described a sense of chronic stress related to their work. Participants regularly reported experiencing ongoing exhaustion, often leading to low levels of professional self-efficacy including feelings of self-doubt and fear about work. These feelings arose because of the perceived challenges they linked to their dyslexia. P12 illustrates *"... I have such mixed feelings about it [my dyslexia] because on some days [...] you see more mistakes from people who don't have disabilities, [so] why do you care? But I think it's kind of self-consciousness that you build up. It [dyslexia] contributes to that sense of being overwhelmed [with] self-doubt ... "*

Participants commented repeatedly about feeling self-conscious about how long it took to complete tasks, which in turn appeared to generate negative feelings such as paranoia, worry and frustration. Some began to question their own capacity. P5 shared that their dyslexia made them feel *"... quite unhappy, uneasy, making me fear going to work and made me question my own career path as well ... "* P11 spoke openly about how her dyslexia mistakes could be *"... contrived to be a factor of laziness, a reflection of not understanding the topic or rushing work. And therefore, I think that does limit my ability to communicate and limits my ability to progress in the work ... "* P3 believed their dyslexia had actively limited their career: *"... I get depressed about it sometimes ... I can easily say it's cost me one promotion ... "*

- Self-disclosure of dyslexia

Self-disclosure was a vexed issue for the participants in this study, with some choosing to disclose and others feeling great reluctance. For those participants that did disclose, some did so during the job interview while others disclosed when they felt the need to justify why there were errors in their work. Two participants explained that they chose to disclose only when they had more freedom in senior roles and felt the need to advocate. P1 stated, “... I felt it almost an obligation to figure out how to make it known, so that I could fight the very prejudice that I’d seen for so long, by normalising it ...”

Experiencing work as a psychologically unsafe environment also posed barriers to disclosure. This reluctance was largely motivated by a fear of being judged as *different* and consequently being stigmatised. Nevertheless, some noted that their disclosure was met with acceptance but often led to a greater sense of vulnerability, pity, not being taken seriously and being perceived as a weakness. This was articulated by P11 who said “... I would avoid that [disclosure] because I don’t feel it would have a beneficial outcome. [I would be] exposing myself as [having a] weakness ...” P14 described feeling humiliated when colleagues would find errors such as leaving out words in emails “... [it was] humorous to them which I really got a bit defensive of and a bit upset about ...”

3.4. Workplace Improvements

All the participants typically described a lack of disability-appropriate job resources (the physical, social, or organisational factors that help an individual achieve their work goals and reduce stress) that they need to work at their full capacity at different points in their careers. For example, as noted earlier, P11 described sensing that working from home from time to time (which they felt enhanced their concentration) was not acceptable.

Provisions in workplace budgets for reasonable adjustments to the working environment and access to training or assistive technologies were also urgently recommended. As P1 illustrated “... I think there’s probably two parts. I think there is a part about helping people see the strengths and what dyslexic people can do and then I think there’s a part about some of those accommodations, like access to proof reading and readily available technological help would be very useful. Making sure those things are just readily available without it being a fuss ...”

Some participants also described what a ‘dyslexic friendly workplace’ could look like. Central to this notion was training for all colleagues, at all levels of the hierarchy, in dyslexia awareness (including disclosure of disability), equal rights, and the use of assistive technology. Learnings would also need to be actively embedded into the workplace.

Several participants believed that the culture of their workplace could be strengthened by simple organisational changes championed by the leadership team in a ‘top-down’ approach. This was highlighted by P13 who said: “... I believe in the tone at the top being important, that the culture of the organisation is accepting of diversity and equal opportunity ...”

Participants displayed an eagerness to succeed at work and believed that the introduction of formal and informal strategies would create a sense of trust and autonomy within teams benefitting both the employer and employees. P1 discussed:

“... I’m very lucky. I have one person who looks after the diary and I have others who makes sure I am where I should be with what I need, we’ve got that organised. There is an overall strategy and structure to how we shape the week’s commitments at work and ongoing tactical conversations to keep the day-to-day bit organised. There really isn’t a bit of my day—in fact, not much of my life—that isn’t planned and organised ahead of time, to keep me where I need to be, doing what I need to be doing ...”

4. Discussion

This study sought to investigate the lived experiences of working Australians who have dyslexia. Based on the JD-R Model, it has been established that high job demands in the absence of job and personal resources can lead to poor mental health and wellbeing [40,41,63–66]. We wanted to investigate the workplace practices described by employees with dyslexia and how job demands, job resources and personal resources might be further impacted by dyslexia, and what the result might be on mental health

and wellbeing. We also wished to explore whether organisations are fostering inclusive practices to support employees with dyslexia or other learning disabilities, and what more they might seek to do.

Our research highlighted challenges for adults with dyslexia in seeking work, starting and retaining employment, retaining employment and progressing a career. Although we did not anticipate exploring job seeking experiences, it became apparent during data collection that many participants experienced what they perceived to be discrimination, unfair judgments, and a lack of access to reasonable adjustments during screening and recruitment processes. This accords with previous international literature suggesting people with dyslexia are hesitant to disclose their disability during the recruitment process due to fear of discrimination [34,67–69], despite legislation which is designed to be protective.

Once employed in a role, people with dyslexia face a myriad of challenges trying to keep up with workplace demands, particularly when their disability was unsupported. Similar to local [70–75] and international research [39–41,63,76] that has used the JD-R Model we also found that when employees are faced with high job demands and low job resources that they can face high levels of job burnout. However, we could not determine whether those with dyslexia faced additional job burnout because of their disability compared to the general population, or differences in job burnout based on specific industries.

Research undertaken by Lehmann (2021) found that an increase in Multiple Sclerosis (MS) work challenges could lead to complications meeting job requirements and could consequently lead to feelings of increased fatigue and burnout, leaving employers vulnerable to employees with MS leaving their jobs. When MS-related work difficulties were integrated within the health-impairing process, it's believed that taxing job attributes enhance apparent MS-related work difficulties [45]. In line with Lehmann's work, we found for our participants that their dyslexia difficulties could lead to burnout and reduction in energy due to the difficulties of meeting work requirements. As dyslexia difficulties are embedded within the health-impairing process, demanding job characteristics are assumed to make dyslexia work more challenging for people. This may indicate that those with disabilities are at greater risk of job burnout and further research is warranted to better understand whether people with dyslexia are experiencing the same workplace difficulties as those within the general population or if their perceived dyslexia difficulties add another layer of complexity leading to exacerbated job burnout.

For those with dyslexia their difficulties were compounded by participants' reluctance to disclose their disability or self-advocate for support for fear of discrimination, stigmatisation and retribution. This lack of perceived safety meant individuals had to apply their own strategies to manage workplace demands, leading to significant feelings of mental exhaustion. This concurs with reports by Nalavany et al. (2011) and McNulty (2003) who also noted substantial fatigue among adults with dyslexia as they managed the demands of work along with other competing life demands. The ripple effect of working longer hours to try to keep up with work demands led to some of our participants experiencing the additional impact of feeling isolated from their peers [77,78].

Inadequate Job Resources

Workplaces are still largely designed to accommodate an abled population [37,79], and the results from our study suggest that adjustments and accommodations for people with dyslexia are not the norm. This echoes the findings of Deacon et al. (2020), who reported that when assistive technologies were not routinely offered, employees had to implement their own work-around strategies or procure their own assistive technologies to complete tasks. This is in the face of government legislation stating that adjustments should be applied to support workers with disabilities [22,25,79–81].

An important issue in the workplace is the ability for one to disclose their disability. Australian research by Wissell et al. (2020) found reasonably high rates of disclosure with 60% among (n = 65) participants were likely to disclose to a colleague at work. Evidence has found that for individuals to disclose, they must feel psychologically safe [68,69,80,81]. We

cannot infer how psychologically safe participants in this study felt from the data collected, but it is notable that many had chosen not to disclose for fear of discrimination and/or shame, or because they felt their internal workplace policies were not adequately sensitive to the unique experiences of employees with dyslexia.

In the right environment, disclosure can be a positive process. It may facilitate a reduction in feelings of isolation, as being 'out' can facilitate social networks with others who can provide support to the employee and the employer [37]. It has also been found that self-disclosure may potentially reduce the stress related to concealing one's identity [37,80,82–84].

Perceived limits to workplace progression were raised by several of our participants and this is unsurprising given their descriptions of burden, overwork, and fear of failure. Our findings align with MacDonald and Deacon (2019) who found that 44.4% of their cohort felt they had missed out on promotion opportunities due to their dyslexia. As positions advance, increased emphasis is often placed on organisational skills and written communication [34]; tasks that can be more difficult for employees with dyslexia. These limitations to career progression opportunities made some of our cohort feel trapped within their current roles or question their chosen career paths.

While many years have passed since the enactment of the Fair Work Act 2009 and the Disability Discrimination Act (DDA) 1992 [22,85], our participants maintained there was a lack of employer knowledge about their legal responsibilities in relation to supporting employees with disability in the workplace. The DDA was designed to prohibit discrimination against individuals with disabilities in employment, education, and in accessing premises, goods, and facilities [86]. However, our findings, along with those from other authors, suggest that there is still much to be done in ensuring that people with dyslexia do not feel stigmatised [33,69,87]. Australia must follow in the footsteps of countries such as the UK and US, where regulations are enforced to ensure people with dyslexia are properly protected under the law. This goes further towards ensuring employees with dyslexia can work to their full potential without fear of stigmatisation and discrimination.

5. Recommendations

5.1. Provide Supportive Job Resources

A review of workplace policies and procedures is needed to ensure (i) that recruitment practices are fair, reasonable and explicit in the type of support available to employees with learning disabilities [88,89]; and (ii) that employees with dyslexia and other learning disabilities clearly understand what supports are available to help them achieve their work goals.

Additionally, organisational training made available, especially for leaders could help develop understanding and awareness of dyslexia and create more inclusive workplace that may benefit dyslexic workers. This could include establishing avenues for peer support, building a psychologically safe environment for disclosure of disability and ongoing inclusion of people with disability, and building an understanding of what reasonable work adjustments are [29,30,88,90–94]. For example, when employers are cognisant that dyslexia can cause an employee to experience fatigue over and above someone without dyslexia, they may feel more equipped to provide appropriate job resources such as flexible working hours, additional breaks, and additional time to complete tasks.

Finally, strong working relationships and positive social interactions with peers, supervisors and managers is pivotal to the success of individuals with dyslexia and their ability to undertake help seeking and self-advocacy behaviours [95]. It is important for organisations to foster and encourage collegial relationships, where employees feel valued and accepted. High quality relationship with colleagues and one's supervisor may alleviate the negative impacts of job demands, reduce the risk of job burnout, and improve workplace engagement [96].

5.2. Build a Culture That Fosters Autonomy

Our research brought to light that a work culture that enables individuals the opportunities to develop self-awareness, utilise their personal resources, and access the job resources they need for their roles fosters career satisfaction and leads to greater role autonomy. Job autonomy and work self-efficacy are vital for the health of employees, as it offers more opportunities to deal with high pressure situations [97], especially for people with dyslexia [13]. We found when participants had job autonomy, they described feeling high levels of self-efficacy, were less likely to feel job stress, workplace stress and job burnout, and were more likely to manage the day-to-day challenges of dyslexia.

It appeared that participants have high levels of self-efficacy and were also more likely to draw on their own personal resources, such as accessing external support or using personal software programs to assist them at work. This helped some to build a small sense of autonomy and control over their work environment even in cases where little or no job resources were provided.

5.3. Moderate Job Demands

Organisations could also focus on identifying job demands that are more likely to overwhelm the employee with dyslexia, leading to potential burnout. In this study, participants presented high levels of work engagement, but also significant levels of job burnout. Burnout can be moderated by various factors including being given greater autonomy at work, having supportive colleagues and managers, organisations taking steps to allow reasonable work adjustments [30], and employer training for more informed leadership teams [1,24].

6. Limitations and Future Directions

This study had several limitations. Our sample size was small, therefore the transferability of the findings in this study would need to be treated with caution. The personal experiences and knowledge of the interviewer, who has dyslexia, may have shaped data collection, although every attempt was made to counteract this through the prices of reflexive thinking and the close collaboration of the research team. There was a dependence on social media to enlist participants, which may have restricted the number of individuals who saw the recruitment flyer. Finally, of note, usually those with dyslexia will only have one assessment to diagnose their disability and then will not need to have any further assessments. However, we did not formally validate if participants had a formal diagnosis of dyslexia.

While our findings suggest an association between dyslexia, job demands, lack of job resources, and poor mental health, our methodology does not enable us to determine the strength of this association or confirm a causal relationship. Future research should consider using the JD-R Model within a quantitative case-control study to compare dyslexic and non-dyslexic employees.

7. Conclusions

This research explored the lived experiences of Australian adults with dyslexia in the employment context. Our work aligns with earlier conclusions in the general working population indicating that a rise in job demands reduces individual's perceptions of their ability to complete work tasks [98–102]. We found that our 14 participants experienced a myriad of challenges across their employment histories. The result from this sample attributed many of these challenges to a lack of, or limited, awareness about dyslexia as a disability among managers, employers, human resource personnel, and colleagues, and being subject to negative perceptions, stereotypes, misunderstandings or discrimination. The JD-R Model proposes that excessive job demands, in the absence of supportive job resources and personal resources leads to poor mental health and wellbeing. Although preliminary, our results seem to suggest that employees with dyslexia face challenges in

the workplace related to their disability including excessive mental exhaustion, and fatigue, leaving them vulnerable to workplace stress and job burnout.

Improving psycho-social workplace environments, increasing job resources, decreasing job demands, and critically influencing work engagement, will reduce job burnout and reduce apparent difficulties for individuals with dyslexia in the workplace.

In conclusion, even though this study was relatively small, it contributes to the expanding body of evidence regarding the challenges dyslexic employees face in Australian workplaces [30,31,34]. Employers play a vital role in mobilising job resources (e.g., social support, policies and procedures and increase self-efficacy) and avoid overwhelming job demands (e.g., work overload, and access to reasonable adjustments), to ensure those with dyslexia stay engaged and mentally healthy at work. Ensuring as well, organisational wide strategies that aim to improve engagement for those with disabilities such as dyslexia, and by developing more inclusive workplace cultures, as per Australian legislative requirements. This will likely result in increased productivity, which will ultimately benefit both employees and employers.

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Appendix A

Table A1. Categories of Job Demands Resource Model of Burnout [39].

Workplace characteristics (job demands, job and personal resources)	
Job demands	Job demands are the “physical, psychological, social, or organisational aspects of the job that require sustained physical and/or psychological effort or skills and are associated with certain physiological and/or psychological costs”.

Table A1. *Cont.*

Job resources	Job resources are the physical, social, or organisational factors that help an individual achieve their work goals and reduce stress. They include autonomy, strong work relationships, opportunities for advancement, coaching and mentoring, and learning and development. Job resources are supposed to act as a positive buffer between an individual and the demands of their role and reduce job burn out.
Personal resources	Personal resources are an individual's "positive self-evaluations that are linked to resiliency and refer to individuals' sense of their ability to control and impact upon their environment successfully". Employee wellbeing (burn out and work engagement)
Job burnout	Job burnout is described as "a chronic state of work-related psychological stress that is characterised by exhaustion (i.e., feeling emotionally drained and used up), mental distancing (i.e., cynicism and lack of enthusiasm), and reduced personal efficacy (i.e., doubting about one's competence and contribution at work)".
Work engagement	Work engagement is defined as "a persistent positive, fulfilling, work-related state of mind that comprises three components: energy or vigour, involvement or dedication, and absorption".

Appendix B

Interview guide: looking from the outside in Dyslexia and the workplace

Group 1—Adults who have a formal diagnosis of dyslexia and are currently employed or have previously been employed

The following interview guide has been developed as part of the Looking from the Outside In—Dyslexia and the Workplace research project. This guide will be used to collect dyslexic participants' views of and experiences with their involvement in the workforce.

Hi XXXXX,

Thank you for meeting with me today and for agreeing to participate in this interview. Do you have any questions before we begin? Do you have any questions about the PICF?

As the recruitment flyer mentioned, this is the first time in Australia that there has been the opportunity for those with dyslexia to discuss what it is like for them in the workplace. I am going to start by asking you some background information and then I will move on to some questions about your current or previous work experiences.

The information you provide today will be recorded and everything you say is confidential. Can I confirm that you are still happy for our interview to be audio-recorded?

Once we are finished, your interview will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information, which means it will be deidentified, so no one will be able to tell who provided which answer. Does that make sense?

Do you have any questions before we start?

OK, let's get started.

Section I: Background questions

1. What is your gender?

- Female
- Male
- Transgender
- Other (54)
- Prefer not to say (55)

2. What is your age?

- 18–20
- 20–29
- 30–39
- 40–49
- 50–59

- 60+
- 3. **What state do you live in?**
- 4. **What is the highest level of education you have completed?**
 - Year 11 or lower (1)
 - Year 12 (2)
 - Diploma qualification (3)
 - Under-graduate degree/Post-graduate degree (4)
 - PHd

General Questions

5. How old were you when you were diagnosed with dyslexia?
6. Do you have any other learning disabilities? What word would you like me to use?
7. Do you remember what type of professional made the diagnosis, if one was made?
8. Do you recall how you came to be assessed?
9. Throughout your education, what type of support, if any, did you receive?
10. Does your family know about your dyslexia?
11. If needed, the following prompts can be used: Educational Psychologist, Neuropsychologist, Speech Pathologist, GP, etc.

Based on the response: Could you tell me more about that?

12. Have you told any friends about having dyslexia?
13. Has your family played a role in your successes?
14. What was school life like for you, higher education, did you get support?
15. Anything else you would like to add about your childhood, before we move into the workplace

Based on the response: Could you tell me more about that?

Section 2: About your work

The next few questions are about work.

16. Are you employed at the moment, what do you work in?
17. If yes: Can you tell me a bit about your work? (Prompts as needed)
18. Is that casual work? Full time? Part-time?
19. How big is the company you work for?
20. If no: Is there a previous job that you could tell me about?
21. Disclosure about having dyslexia.
22. Could you tell me more about that? Depending on response:
23. Thinking about your current or previous work and their HR systems and processes, did they have any policies and procedures to support you with your dyslexia?
24. Did they support people with learning disabilities?
25. Could you access reasonable adjustments?
26. Could you access the Employer Assistance Program?
27. Did your workplace have an inclusion and diversity program?
28. If not, what types of HR systems and processes for those with dyslexia would you have liked to have seen?

Section 3: About Dyslexia at work

Thinking about your workplace (now or previous):

29. Do you think that your dyslexia impacts on your day-to-day work?
30. Could you tell me more about that?

Possible probes:

31. Do you think dyslexia can have positive and negative effects at work?
32. Have you heard of the term neurodiversity?

If no, interviewer to explain that neurodiversity is a term used to look at people with learning disabilities as a difference rather than a disability and a strength.

If yes, what is your perception of the term, do you see your dyslexia as a strength/s?

33. Some people use the term that dyslexia is a superpower, do you think dyslexia is a superpower or a disability? Why/Why not?
34. What would be your top three strengths?
35. Explore responses of colleagues/line managers etc. In your view, what are the attitudes of other staff towards employees who have dyslexia?
36. Is there someone you can go to at work, like mentor/dyslexia supporter?
37. Your experiences of telling colleagues and line managers.
38. Your perception about how much/little line managers knew about dyslexia.
39. Are there any resources or supports you would like to see developed to support assist you in the workplace?
40. Who would be your biggest support networks?
41. Does your dyslexia affect you outside of work, you day to day activities?
42. Does dyslexia ever affect your mental health and wellbeing work or outside of work?

If yes, how do you manage this:

If yes, have you ever sought any help for this, such as a psychologist, counsellor, peer support, family and or friends?

In a perfect world, is there an ideal scenario in the workplace for people with dyslexia?

I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know or that you'd like to add?

I should have all the information I need. Would it be all right to call you if I have any more questions?

As mentioned above, your interview will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript.

After that, I will put your transcript together with everyone else's information, and it will be deidentified, so no one will be able to tell who provided which answer.

Thanks again for your time and for your invaluable feedback for this research project.

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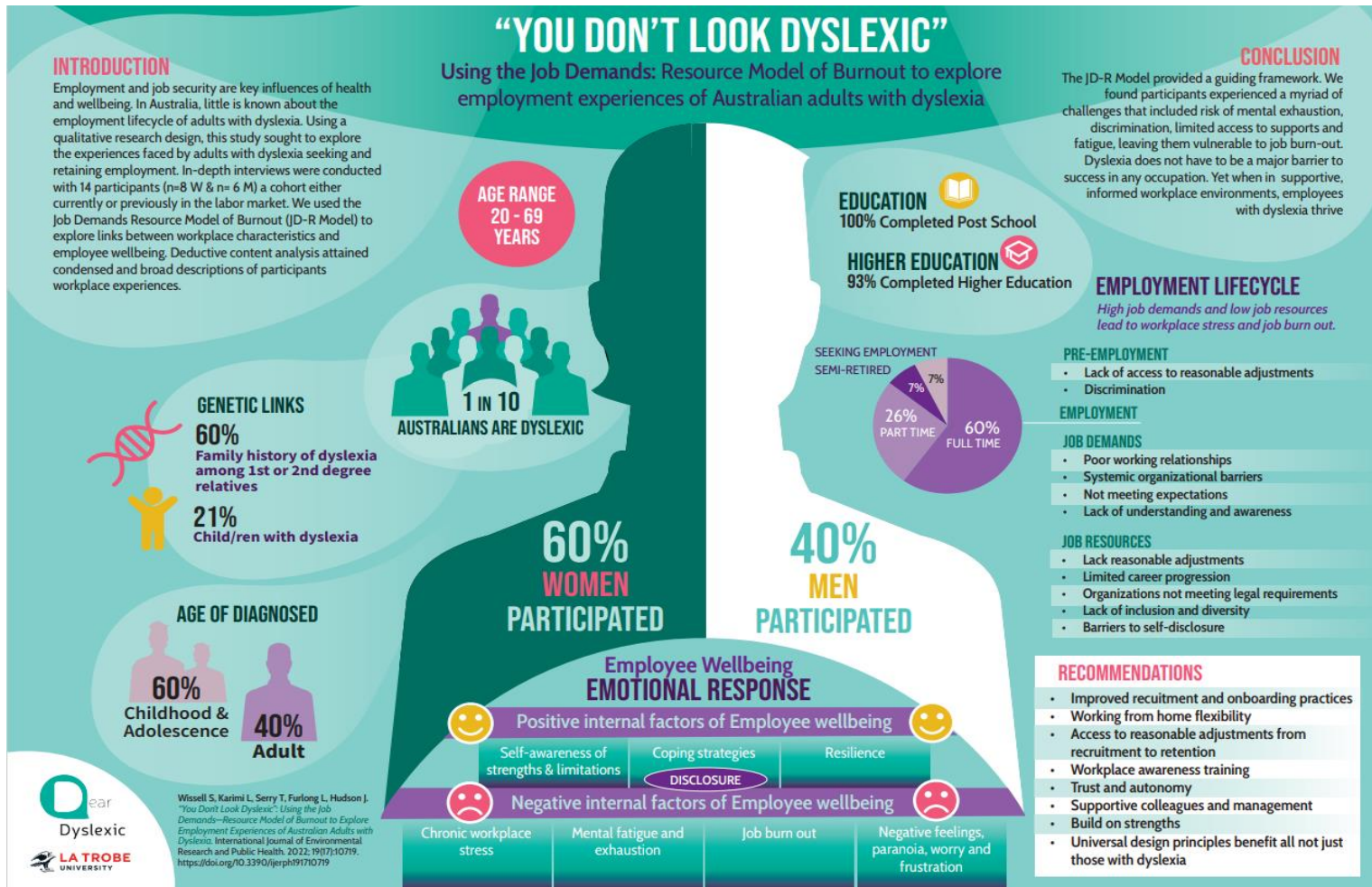
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5.3 Infographic 2. “You don’t look dyslexic”: Using the Job Demands - Resource Model of Burnout to explore employment experiences of Australian adults with dyslexia.



Chapter 6

Study B.2

Journal Article 3

*Leading diverse workforces: Perspectives from managers and employers
about dyslexic employees in Australian workplaces*

6.1 Prologue

The objective of Study B.2 was to expand on the discoveries of Study B.1 by delving into the personal encounters of non-dyslexic employers and managers of dyslexic employees. This investigation is a unique addition to the field since there has been no previous examination of this kind in Australia and scant examinations internationally (O'Dwyer & Thorpe, 2013; Thorpe & Burns, 2016). The study presented here clarifies and highlights potential underlying factors that could be contributing to the obstacles that dyslexic employees face in the workplace, from the perspective of managers and employers.

Although the prevalence rates of dyslexia are high, there remains a limited understanding of the impact of the disability in the broader community (Taylor, 2017), and this is likely to be reflected in Australian workplaces (de Beer et al., 2014; Livingston et al., 2018). International research shows people with dyslexia work across a range of sectors, spanning low-skilled (e.g., disability support workers; tourist guides) to highly skilled (e.g., teachers, nurses, CEOs, deans of universities, professorial roles) (Beetham & Okhai, 2017; Burns & Bell, 2010; de Beer et al., 2014; Macdonald & Deacon, 2019). Consequently, employers often find themselves overseeing employees with dyslexia in their workplace. However, research by Thorpe and Burns (2016) and O'Dwyer and Thorpe (2013) has revealed that employers and managers may lack access to adequate training on effectively working with dyslexic staff. Consequently, dyslexia continues to be an invisible or "hidden" disability within the workforce, placing the burden on dyslexic employees to disclose their condition and advocate for the necessary support.

Australia has experienced a notable change in perspective concerning the importance of raising community awareness about disability and promoting inclusion. This shift has led to the implementation of various initiatives, including Australia's National Disability Strategy, which was introduced in 2010 (Commonwealth of Australia, 2021a) and expanded

in 2021. The National Disability Strategy in Australia delineates the country's aspirations for promoting inclusivity and equality, while also assigning responsibilities to both state governments and the wider community (Commonwealth of Australia, 2021b). Additionally, legislative requirements like the Discrimination, Equality, and Fair Work Acts (Commonwealth of Australia, 1992, 2009, 2010) endorse a shift towards greater inclusivity. These laws make it evident that workplaces should prioritise diversity and inclusion for all individuals, especially those belonging to minority groups and those more susceptible to discrimination based on factors such as sexual orientation, cultural background, age, gender, and disability. (Carter, 2017; Garg & Sangwan, 2021; Grissom, 2018; Kun & Gadancz, 2019).

Despite the implementation of national strategies and legislative changes, there remains a scarcity of research on the specific benefits and challenges associated with managing a diverse workforce within the Australian context, particularly regarding dyslexia. As societal expectations increasingly emphasise inclusivity, including within the workplace, employers, managers, and leaders must contemplate how to effectively integrate dyslexia into their inclusion and diversity frameworks. By doing so, they can create a genuinely safe and inclusive work environment that caters to the needs and abilities of all employees.

This final study of the Professional Doctorate research explored the experiences of employers and managers of dyslexic employees within the Australian workforce. Using a qualitative research design, in-depth interviews were conducted with one employer and four managers of dyslexic employees. According to feedback received from employers and managers, while they possessed some level of awareness regarding the difficulties experienced by employees with dyslexia, they perceived a general lack of awareness and understanding of dyslexia as a disability among their colleagues and within the broader

workplace. This lack of awareness and understanding could create obstacles for individuals with dyslexia in various aspects of their work environment.

Although this sample size is small, this journal adds depth to the findings presented in Study B.1 (Chapter Five) by building further understanding of some of the workplace experiences faced by people with dyslexia and ways to improve organisational practices and inclusion from the perspective of employers and managers.

This chapter presents an article published in the *International Journal of Environmental Research and Public Health*, Dyslexia Special Edition. The published manuscript included in this chapter has been reproduced with permission from the International Journal of Environmental Research and Public Health, Molecular Diversity Preservation International (MDPI).

6.2 Publication

Wissell, S., Karimi, L. & Serry, T. Furlong, L & Hudson, J. (2022). Leading diverse workforces: Perspectives from managers and employers about dyslexic employees in Australian workplaces. *International Journal of Environmental Research and Public Health. S Ed Dyslexia*. doi.org/10.3390/ijerph191911991



Article

Leading Diverse Workforces: Perspectives from Managers and Employers about Dyslexic Employees in Australian Workplaces

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Abstract: Background: Dyslexia is a specific learning disability affecting around 1 in 10 Australian adults. It presents unique challenges for employees in the workforce, yet community and workplace awareness of the challenges of dyslexia is limited. The aim of this preliminary research was to explore the experiences and perspectives of Australian employers and managers responsible for supervising employees with dyslexia in the workplace. Materials and Methods: Using a qualitative research design, we conducted in-depth interviews with four managers who had current or previous experience managing employees with dyslexia. We used a deductive approach to analyse the data and categorise responses to the study questions. Results: Participant responses indicated that there is a lack of awareness and understanding of dyslexia within Australian workplaces. Participants identified challenges facing employees with dyslexia in the workplace including, differing personal levels of confidence and comfort in disclosing disability; the possibility of discrimination, and a lack of inclusive organisational practices and processes. Suggestions for ways to improve workplaces for dyslexic employees included: additional support for leaders and managers to drive inclusive leadership, and additional training for leaders and managers on how to best support employees with dyslexia. Conclusions: While only a small sample size, this study indicates that further research is needed to better understand the working environment of Australian leaders and managers. It appears that leaders and managers need skills and knowledge to better support employees with dyslexia and in doing so create more inclusive workplaces.

Keywords: dyslexia; workplace; employers; managers

1. Background

Dyslexia is the most common type of Specific Learning Disability (SLD) and affects the capacity of individuals to learn, to read and to write [1–3]. These skills are impacted by deficits in phonological and associated orthographic processing skills. Difficulties in decoding individual words has the greatest impact on reading [2,4,5]. Reported estimates of the prevalence of dyslexia varies due to diagnostic criteria but ranges from 5% to 20% [6–10]. Dyslexia occurs across the spectrum of intellectual ability [11–13]. Many individuals with dyslexia do become readers, although the route to achieving this is typically much slower and requires a significant amount of intervention from suitably trained practitioners [2,14]. In addition, because dyslexia is a lifelong condition [2,15], reading (along with spelling and writing) remains somewhat effortful and less automatic for people with dyslexia compared to their non-dyslexic peers [4,16]. Approximately 3–7% of the population have dyscalculia [17–21] have severe difficulties performing arithmetic calculations that persist into adulthood [17–21]. While approximately 3–15% of the population have dysgraphia,

a specific learning disorder affecting the written expression of symbols and words that persist into adulthood [22–24].

Australian and international research has identified that people with dyslexia work across a range of sectors, and skill levels [25–30]. Accordingly, many employers may find themselves in the position of supervising employees with dyslexia in their workplace. Given the expected trajectory of difficulties related to reading, spelling, and writing, individuals with dyslexia are at increased risk of not meeting workplace demands or timeframes, despite having the training and/or qualifications to do so [30]. This is particularly evident if there is limited provision of suitable accommodations in the workplace [31–35].

There also remains a limited understanding of the impact of dyslexia in the broader community [36], and this is likely to be reflected in Australian workplaces [26,37]. For example, various authors, including Thorpe and Burns (2016) [38] and O'Dwyer and Thorpe (2013) [39] have identified that employers and managers may not have access to quality training about working with staff who have dyslexia. As such, dyslexia is still an invisible or 'hidden' disability within the workforce, with dyslexic employees bearing the brunt of the responsibility to disclose their disability and self-advocate for support. Several studies have found limited policies and procedures in place to support managers of teams that include dyslexic staff.

Recently the term 'disability' has also broadened to encompass both visible (e.g., physical limitations) and invisible (e.g., chronic fatigue, attention deficit hyperactivity disorder) conditions [40,41]. Along with the broadening of the term 'disability' there has been a cultural shift in global and national policy regarding the need to increase community awareness of disability and inclusion as seen through the United Nations Convention on the Rights of Persons with Disability in 2006 which Australia is a signatory of, and as such has a responsibility to protect the human rights and inherent dignity of persons with disabilities [42]. More poignantly, Article 27—Work and employment that recognised the "right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities" [43]. At a national level Australians have seen initiative such as the Australia's National Disability Strategy, implemented in 2010 [44] and expanded in 2021 and more recently the National Disability Insurance Scheme, which provides "support to people with intellectual, physical, sensory, cognitive and psychosocial disability" [45]. The initiatives outline Australia's national aspirations to respect inclusivity and equality and outlines state government and 'whole of community' responsibilities [44]. Change towards greater inclusivity is also endorsed in legislative requirements such as the Discrimination, Equality and Fair Work Acts [46–48]. This makes clear that workplaces need to intensify their focus on diversity and inclusion for all people, particularly minority groups and those more likely to experience discrimination relating to sexual orientation, cultural background, age and gender, and disability [49–52].

However, despite the rollout of progressive international and national strategies [44,45] and changes to legislation [47,48] individuals with dyslexia have been left behind in particular within the employment sector as highlighted by research undertaken by Wissell et al. (2022) [30] who found those with dyslexia faced a significant number of barriers to succeeding in the workplace despite these legislations and national strategies. In fact, those with learning disabilities have been excluded from the National Disability Insurance Scheme (NDIS) and the Medicare Benefit Scheme (MBS) an Australia medical healthcare services subsidy scheme [53].

Considering these global, national policies and more inclusive and flexible workplace trends, employers are now expected to hire and support a diverse workforce [54]. However, there is minimal research to date investigating the benefits and challenges of managing a diverse workforce with a focus on dyslexia in the Australian context. As society demands more inclusivity, including from within the workplace, employers, managers and leaders will need to consider how best to incorporate dyslexia into their inclusion and diversity frameworks to provide a truly safe and inclusive workplace for employees of all abilities.

2. Aim

This research aimed to explore the experiences and perspectives of Australian employers and managers responsible for supervising employees with dyslexia in the workplace. This is a preliminary study that forms part of a larger research project that investigated the lived experiences of adults with dyslexia in Australia, focusing on the workplace.

3. Method

A qualitative design was selected for this study to explore individuals' experiences of employing and managing people with dyslexia in Australian workplaces. We adopted a deductive content analysis approach using a set of pre-defined questions conducted through in-depth interviews to collect substantial responses from participants enabling us to draw specific conclusions from the data. Further follow-up and clarifying questions emerged during interviews with participants. Unlike quantitative research, qualitative research gathers data until saturation is reached, and the collected data tell a rich, complex, and in-depth story about the topic under examination. Compared to quantitative research, sample sizes for qualitative research are typically much smaller [55,56]. It has been suggested in a large number of articles, book chapters, and books that anywhere from five to fifty participants is sufficient [56].

3.1. Participants

Purposive sampling was used to recruit four participants. This method was chosen to select participants who could provide a detailed understanding of the experience of managing and working with employees with dyslexia [57]. Inclusion criteria required that participants: (i) worked in Australia within an Australian-owned company to keep the research focus within the Australian context, (ii) held a management position and/or position at a leadership level (iii) had a minimum of 10 employees within their organisation. It would be expected that with over 10 employees one would be dyslexic based on prevalence rates (iv) had worked in that organisation for more than three years and (v) had managed staff that had disclosed they had dyslexia. Ethics approval was received from [redacted University] to conduct this study.

Four eligible participants (three female and one male) agreed to participate. Table 1 displays their characteristics. Two participants were business owners, and two participants held senior leadership positions. The size of each organisation ranged from 13 to more than 1000 employees.

Table 1. Participants' Characteristics.

Participants	Gender	Company Size (Employees)	Industry	Length of Time in Current Role	Occupation	Participant Location (State)	Location of Business
P1	F	95	Hospitality and Tourism	5–10 years	Challenge and Culture Manager within an international chain hotel, oversaw staff across front office, food and beverage, finance, kitchen, and maintenance	New South Wales	Metro
P2	F	100	Non-Government Organisation	3–5 years	Associate Director working in an international not-for-profit organisation with an Australian branch	Victoria	National
P3	M	13	Graphic Design Agency	10+ years	Director and an Account Manager for their own national marketing and communication company, responsible for looking after projects and staff.	Victoria	Metro
P4	F	30,000	Manufacturing	18 months	Business Development Officer, had previously worked as a Human Resources Manager for two national companies in manufacturing.	Victoria	National

Three of the four participants had at least one other family member with dyslexia (a parent and/or a parent and a sibling). The participant with a non-familial dyslexic background had been educated about dyslexia via a formal workplace training and assessment course early in their career.

Data Collection

Author one, held one structured in-depth interview with each participant via online platform communication Zoom®. A purpose-designed set of questions was used to elicit participants' views and experiences of leading or managing work colleagues with dyslexia (Appendix A). Questions were drawn from the literature about disability, in general, and dyslexia, more specifically, in the workplace [52,58,59] and from the lived experiences of the first author who has dyslexia. Interviews ranged in length from 30–107 min (mean = 54 min). Author One positioned herself within the context of this study by disclosing her dyslexia at the beginning of each interview. This was done to acknowledge and establish the authenticity, transparency, and context of the research [60–62].

The interviews were assigned a number code, and transcripts were deidentified by the first author and then sent to an external company to be transcribed verbatim prior to analysis. The interviewer kept field notes and conducted reflective journaling following each interview to assist in building a rich understanding of participants' experiences in the context of the phenomena under review [63,64].

Prior to data analysis, each participant received their transcript and was invited to review and request changes to any part of the transcript within two weeks of receipt. No amendments were requested. Following this, transcripts were uploaded to NVIVO software (version 12).

3.2. Analysis

Deductive content analysis was used to analyse the data [65]. The choice of this analytical approach was based on the nature of the data; that is, data collected via structured interviews.

Over a three-phase process: preparation (phase one), organisation (phase two), and reporting (phase three), the data were sorted into several categories [65]. Phase one initially involved familiarisation with the interview data through multiple active readings of the transcripts and listening to audio files. This resulted in the identification of two main categories: (1) Employees with dyslexia and their workplace challenges and (2) Workplace enablers that support dyslexic employees.

During phase two, text from the interview transcripts were sorted into the two main categories developed in phase one. Following this, further analysis was conducted. Descriptive open coding, involving a search of the data for high-frequency words, phrases, and sentences (e.g., 'very skilled, but she was a little bit slower to understand briefs'), was undertaken to identify critical features and nuances in the data. These open codes and high-frequency words, phrases, and sentences formed sub-categories of data. For example, the sub-category 'Workplace performance' was identified under the main category identified in phase one, 'Employees with dyslexia and their workplace challenges'.

Transcripts were then re-read for reflection and to ensure that interpretation of participants' data had been captured authentically. The data was condensed further to create five sub-categories associated with the two main categories. Direct quotations from participants were cross-checked against the categories to ensure the categories were reflective of the participants' narrative [66,67]. Although the researcher had pre-set discussion topics within the interviews, the main categories and sub-categories were created from the interview data. Finally, phase three consisted of writing up the report.

4. Results

The two main categories and five sub-categories identified from the data. The results highlight the myriad of challenges faced by employees with dyslexia, but also provide examples of how employers and managers could better support dyslexic employees.

4.1. Employees with Dyslexia and Workplace Challenges

This first main category from the interview data focused on the challenges of working with and providing leadership to dyslexic employees. Participant responses were categorised as follows: (1) employers and managers perceived dyslexic employees' workplace performance; (2) self-disclosure of disability by dyslexic employees and (3) perceived discrimination in the workplace, a manager's perspective.

4.1.1. Dyslexic Employees' Workplace Performance

All participants felt that dyslexia could be a barrier in the workplace regarding dyslexic employees executing their expected administrative and professional duties. For example, participants had observed employees with dyslexia having difficulties constructing emails, problems with spelling and grammar, delayed processing of written information and needing extra time to complete tasks that involved reading and writing. These difficulties were prominent when participants were asked to compare dyslexic employees to those without dyslexia.

Prior to knowing that employees had dyslexia, employers and managers noted they had often questioned the reasons for minor task errors and the length of time required to accomplish tasks. For example, P3 described how during a performance review, it had been noted that his employee was:

"... a little bit slower than the other staff and sort of needed to pick up the pace and she needed to work on the interpretation of briefs a little bit better ..."

During this same performance review, the employee disclosed they had dyslexia. Following their disclosure, P3 reported that his attitude towards his employee's work shifted, and strategies were put in place to allow the employee more time to complete tasks. More detailed instructions were also verbally provided for future task briefings.

Some workplace challenges described by participants were unique to the characteristics of the workplace and sector. Within the hospitality industry, these challenges included; matching invoices to product numbers, writing down phone numbers and people's names, interpreting written information and communicating with individuals who had English as a second language.

"Sometimes we've got these big numbers, which are product codes or item numbers for reference. And then if the box says 'food', and the food item is written in its long form, but the box perhaps has the short form, they can't determine that that is that item, because ... you know, it doesn't match." [P1]

In the not-for-profit sector, challenges included writing briefs, preparing tenders, and preparing government documents. In the construction and manufacturing industry, performance challenges were evidence for dyslexic employees in management roles, particularly when these managers were required to provide instructions for team members in written format (such as step-by-step instruction manuals) or when they were required to work at a fast pace.

4.1.2. Self-Disclosure of Disability by Dyslexic Employees

Of the four participants, two had worked with multiple dyslexic employees, whilst the other two had only worked with one staff member who had disclosed dyslexia. Participants identified several barriers for employees to disclose in the workplace.

In most instances, they reported that employees disclosed only once a manager identified areas of difficulty, poor performance or a failure to meet expectations. In other instances,

disclosure occurred when employees had passed their probation period or following a good performance review.

“... One team member had joined us, and had passed their probation period, [but needed to] develop their written communication [skills]. When he came to me, he was quite open and said ‘Look, I do have a lot of difficulties in this area and this is my concern, which is my problem, my disability ...’ [P1]

Participants perceived those employees with dyslexia may fear discrimination following disclosure. In most cases, participants reported that their employees appeared embarrassed, anxious, ashamed, and lacked the confidence to self-advocate following disclosure. Some felt that employees might have had previous negative experiences when they disclosed their dyslexia to a manager and feared possible repercussions.

“... [They] told me after a very good review that [they] had dyslexia. They just said there’s something else that they need to tell me, and I could see them start to tremble, and the anxiety in their face and fear. Judging from that, I would expect employers may have discriminated against people with a learning disability, or possibly managed it in a way that wasn’t so proactive and positive for the employee ...” [P3]

Even after employees had disclosed their dyslexia, workplace policies and procedures were not adjusted to make the workplace more inclusive.

“... We do have a non-discriminatory policy, obviously. It’s more geared towards ‘this is the legislation, and this is what you need to be aware of.’ It’s not an individual sort of ‘this is the way we want you to handle it if (sic) [it’s] brought up, or if you become aware of it.’ So, no, there isn’t a specific policy that deals with it at all ...” [P1]

Participants 1, 2 and 3 all felt another barrier to disclosure was when managers and employers were unskilled in dealing with disclosure. The participants also felt that due to a lack of understanding of dyslexia across organisations, other managers would not necessarily have the skills to support dyslexic employees, which could lead to discrimination and conflict. In two instances, staff members had not disclosed their dyslexia until performance management was put into effect.

“... In two instances the employee was brought to HR. These people had got along [with their teams], they had worked out ways of working that worked [for them] the people that knew them well, knew their contribution, and valued them highly. However, then somebody came along and asked for something different of them, that wasn’t their core-strength, and they weren’t able to do it. They just weren’t confident to either disclose the dyslexia or manage the situation in a way to get the other person off their back. And it turned into a conflict ...” [P4]

4.1.3. Discrimination in the Workplace, a Manager’s Perspective

Participants felt there was a considerable lack of awareness and understanding of how to manage and support individuals with learning disabilities at an organisational and leadership level, which they felt could impede an employee’s ability to succeed in the workplace. They felt this lack of awareness and understanding could also possibly explain an employee’s fear of discrimination from work colleagues and organisations.

Overall, participants thought there should be a better understanding of dyslexia in the workplace, including both the strengths and weaknesses of individuals with dyslexia and ways to reduce the stigma and discrimination that dyslexic employees could experience. Participants felt this might prevent situations like the following example provided by P4, who spoke of an employee in the role of team leader:

“... The team leader would not provide the information that they [their staff] required in a written format. The staff felt the team leader was deliberately holding them up from progressing in their career. The team leader was about to be stood down pending further investigation. He broke down, and disclosed he had dyslexia, which he had been able to

keep undisclosed from the company. He said he didn't want anyone to know. He felt [a lot of] shame and was willing to take the disciplinary action as a choice over disclosing the dyslexia. That's how strongly he felt about it ... "

Participants observed a mix of attitudes between non-dyslexic work colleagues and work colleagues with dyslexia. Some observed positive responses such as informal support between team members and constructive responses of team members to the disclosure of dyslexia. However, some participants described seeing "direct discrimination" [P1, P2, P3] against those with dyslexia in the workplace, including dyslexics being called "dumb" [P4] and "stupid" [P4] and colleagues "sniggering" [P4] about people's spelling mistakes. They described how they could imagine employees being undermined and their contributions not valued because of their poor written communication skills.

"... If you get a document that you can tell is just not up to a standard, I can imagine in an environment where no one knows anything [about dyslexia] ... , I could imagine very easily that you'd get bullied because a person would just say you're not doing your job, you're doing a crap job, what is this work, it's not enough, it's not what I expect, and you've got to do better ... " [P2]

P1 described a view that there was still a stigma attached to the term *dyslexia*, which prevented people from disclosing their dyslexia or disclosing dyslexia as a disability.

"... There needs to be the stigma removal of dyslexia because I think they're very cautious about sharing with others in case they're treated differently ... " [P1]

Participants also believed that dyslexia awareness training was needed at both a team and leadership level.

"... I think we could always do with education of others. If you've got team members that are dyslexic, there are obviously concerns, there are considerations, and this is what we should and shouldn't do. But I think we need to educate the rest of the team first. Because otherwise you'll have some people that will think that, you know, they're getting a better run or they don't have to do all of this, and we're all getting paid the same money. There's always going to be that aspect ... " [P4]

4.1.4. Organisational Practices, Policies and Processes

Three participants felt that poor workplace practices and organisational processes could lead to unintentional discrimination of dyslexic employees. They described barriers to employees accessing appropriate support across the employment life cycle, from the early stages of recruitment through to retention of staff. Recruitment and induction procedures such as addressing selection criteria and pre-employment tests were seen as barriers to employment where those with dyslexia could not openly disclose their dyslexia and/or request access to the support they were entitled to. Additionally, participants observed that onboarding processes requiring large amounts of reading could alienate potential or new employees, leaving them at risk of not understanding workplace roles and responsibilities while also exposing companies to liability.

"... Shortlisted candidates have to do psychometric testing, which is online testing. There's a lot of reading in the tests. It's not easy. I can imagine that is a barrier for someone with severe dyslexia. And then there's quite a lot of reading [going forward]. There are heaps of policies, there's heaps of documents to read, heaps of readings, essentially. So that's also not that helpful ... " [P2]

Participants identified a lack of experience of organisational leaders to manage and support individuals with disabilities and differing staff attitudes towards those with disabilities. They described a need for workplaces to be more inclusive. Suggestions as to what measures could be adopted included employing more people with disabilities and employing more neurodiverse individuals. Participants felt this would progress the implementation of inclusion and diversity committees, clear policies, and qualified human

resources managers adequately trained to deal with various disabilities in a more diverse staff. However, for the organisations represented through our interviews, only two organisations had implemented strategies to support staff with disabilities, with little focus on dyslexic individuals.

“... I think there is a growing awareness in our society about neurodiversity and all the value that brings. Personally, I think in the last five years, maybe even 10, there’s a heap more awareness. It’s an opportune time for there to be a rethink in terms of what we mean by inclusion ...” [P2]

4.2. Workplace Enablers That Support Dyslexic Employees

The second main category from the interview data focused on the workplace enablers that can support employees with dyslexia to work to their full potential and meet employer expectations. Results from this category were sorted into two sub-categories: (1) inclusive leadership, and (2) workplace training.

4.2.1. Inclusive Leadership in Action to Support Individuals with Dyslexia in the Workplace

Participants indicated that even with limited workplace policies and procedures in place, those with dyslexia could thrive if their employers and managers are responsive, empathetic, and upskilled to work with them. Those participants with a personal connection to dyslexia, and an awareness of the strengths that a dyslexic individual can possess, expressed a sense of positivity in working with dyslexic colleagues. They also expressed that implementing reasonable adjustments to support employees with dyslexia was no more burdensome than meeting the requirements of other non-disabled or non-dyslexic staff. Further, they noted that most adjustments they perceived to be effective were free, or low cost.

All participants felt equipped and confident to support their staff and to make accommodations, despite there being no formal procedures in place in their organisation, due to their personal encounters with dyslexia *“...It was just giving her more time to be able to clearly go through things, rather than trying to go at a pace that wasn’t beneficial to her understanding or checking or doing everything correctly...” [P3]*.

Participants reported that some accommodations were made in collaboration with their dyslexic employees, while other accommodations were implemented based on role requirements. Accommodations included a buddy system, meeting more frequently for one-on-one informal support, allowing more time to complete tasks, providing instructions in a verbal format, encouraging open communication, and providing ongoing verbal feedback.

“... I always think about who she [the employee] should work with when we’re doing big pieces of work, like big reports, in that I know that if I assign her a project officer to work alongside her to check everything and to do the editing and all of that stuff, then I know it’s going to be a good end result ...” [P2]

4.2.2. Workplace Training to Increase Understanding and Awareness of Dyslexia

Our participants identified that leading and managing teams of people with different needs can be complex, especially for leaders that have a limited understanding of these needs. Participants suggested that a barrier to effectively leading a diverse team could be the little understanding and lack of training that managers and leaders have about dyslexia.

“... I think that managers see it [dyslexia] as something that’s difficult to deal with. It makes their job harder. Everyone’s time is precious, so unless they’ve got an open mind, I think sometimes it’s seen as something that’s a little bit hard to deal with, and that’s going to add another element to their already busy day. Workplaces don’t have enough knowledge of [dyslexia]. Having to stretch your mind to trying to understand LGBTQ, then multifaith, multicultural. Now we’ve got neurodiverse thinking and then you’ve got dyslexia, autism, anxiety, depression, mental health. It’s like “I don’t have a psychology degree, how am I meant to manage all of this?” [P4]

Therefore, workplace training was identified as an enabler for better supporting employees with dyslexia, their teams, their managers, and organisations. It was noted that workplace training was a way of reducing the stigma attached to dyslexia and discrimination within the workplace. Only one of the four participants had received formal training that had included information about dyslexia.

All participants noted that when a staff member disclosed their dyslexia, there were no resources available inside their organisations to support them as managers, and they also had difficulty locating appropriate resources outside of their organisations. They felt Australian-led dyslexic organisations provided support targeted at children rather than adults. All participants felt that training on awareness and available resources was imperative to improve how individuals with dyslexia were supported and general workplace culture.

“... I think it would be good for people to have more awareness around the link between reasonable adjustments [in the workplace] and dyslexia. Because that is sort of an advocacy movement. So, it potentially could be an awareness program that would be very helpful for people that have dyslexia ...” [P4]

5. Discussion

In this study, we adopted a deductive content analysis approach to explore employers' and managers' perspectives and experiences of leading and managing diverse teams, particularly employees with dyslexia. Currently, there is minimal literature investigating how best to manage a diverse workforce, particularly with a focus on dyslexia. This was surprising given the high proportion of people with dyslexia in the population. However, we do know there is a significant amount of international literature on the workplace experiences of dyslexic employees [26,34,37,68] and these outcomes align with and support the employer and managers' experiences and perceptions described and represented in our findings. Local [27,69] and international studies [25,26,28] suggest that individuals with dyslexia work across a variety of occupations and roles. Therefore, people in leadership roles across all industries will most likely encounter and manage dyslexic individuals at some point in their careers.

5.1. Workplace Performance of Dyslexic Employees

Although based on a small sample, our findings suggest that the nature of dyslexia may pose unique challenges for employers and managers. Our participants identified several literacy-based difficulties at a task level faced by dyslexic employees, including errors with spelling and grammar, length of time to complete work tasks, poor organisation and time management, and difficulties with reading comprehension and speed. These findings correlate with several international studies focusing on the experiences of dyslexic employees. Sumner and Brown (2015) [41] found that employees with dyslexia face unique challenges because the nature of their disability directly affects various work practices. In addition to the challenges that are common to all people, such as increased cognitive demand and an ability to respond in fast-paced work environments, employees with dyslexia must also contend with their literacy-based difficulties and this has the potential to put employees with dyslexia at a considerable disadvantage within the workplace [41,70–72].

Our findings also suggested that the impact of dyslexia may not become apparent until work performance drops. Although our results are based on a small sample size, they do support the work of De Beer et al. (2014) [26] and Winters (2020) [73], who found that managers may only suspect a problem when they see employees unable to keep up with speed of completing tasks or not coping with significant changes (e.g., new work procedures, managers, team or equipment). This suggests that workplaces are currently reactive, rather than proactive, in their awareness and support of disabilities such as dyslexia.

The participants in our study described how supportive performance reviews could lead to performance improvement for employees with dyslexia, particularly when employ-

ees felt safe to disclose. This aligns with work undertaken by von Scharder et al. (2014) [74] that suggested workplace improvements occurred when employees could identify that their difficulties were linked to their disability, could discuss this during their performance reviews, and felt supported to request reasonable accommodations in response to their disability.

5.2. Disclosure of Dyslexia by Employees

Disclosure of dyslexia in the workplace was a key issue explored in this research. Consistent with the literature, we found that disability disclosure in the workplace could also be met with negative consequences for employees, such as low supervisor expectations, isolation and exclusion from co-workers, stigmatisation, discrimination, impact on career progression and termination of employment [74–77].

The literature suggests that workplace culture plays a critical role in disclosure decision-making [74,77]. Our study confirmed that when managers were empathetic and understanding, staff felt safe to disclose their dyslexia, and this resulted in positive outcomes for both the employee and the employer. However, in our study, it was to the responsibility of the employee to self-identify or disclose to their managers that they had dyslexia. This reflects the findings of O'Dwyer and Thorpe (2013) [38]. To counter this, workplaces need to be upskilled to support employees with dyslexia so they can feel psychologically safe to disclose and then access the reasonable adjustments needed to perform at their best.

The participants in our study identified several barriers that might prevent employees from disclosing dyslexia. At the organisation level, these barriers included a lack of awareness of dyslexia, minimal or no training opportunities to manage and support dyslexic workers, and an absence of workplace disability policies and/or procedures. This was a similar finding to O'Dwyer and Thorpe (2013) [38], who found that within the Further Education sector, there was a focus on supporting the student who has dyslexia directly, rather than supporting or upskilling teachers to work effectively with dyslexic students. In addition, Further Education policies and procedures and consultants and external training bodies did not appear to inform employees or guide managers on how to support any teacher who was dyslexic.

All participants in this study had prior experience of dyslexia through family members or managing previous staff. However, participants noted there was a possibility that managers and employers without this prior experience might feel ill-equipped, overwhelmed, or susceptible to inadvertent discrimination when working with dyslexic staff. This supported the findings of O'Dwyer and Thorpe (2013) [38], who identified that managers might feel ill-prepared to provide the necessary support to a staff member who disclosed it. In light of more inclusive and diverse employee profiles within the workplace and the emergence of initiatives designed to increase the number of people with disabilities in the labour market, employers would be well-advised to foster a workplace that encourages disclosure and reduce the likelihood of negative consequences for the employee with dyslexia.

5.3. Discrimination of Dyslexic Employees

Despite the high global prevalence, there is still a profound lack of awareness and understanding of dyslexia at a societal level [30,31,78–80]. This lack of awareness can have a flow-on effect within the workplace, leading to dyslexia discrimination. In this study, participants acknowledged that those with dyslexia could be discriminated against across the employment lifecycle, starting at recruitment (e.g., during psychometric assessments and interview processes) and leading into onboarding and retention. This correlates with the literature, which describe perceived discrimination or unfair treatment during screening and recruitment process as those with dyslexia may not fit the job-profiles advertised. Additionally, the tools used to screen potential candidate may not accurately and equitably evaluate the capabilities and abilities of people with dyslexia [30,41,81,82]. Rao's work demonstrated concerns raised by employers when looking to recruit individuals with

disabilities such as neurodiverse people including the need to have in depth knowledge of multiple disabilities, the skills to manage mental health illnesses and training of staff in these disabilities [82]. Although research shows that neurodiverse employees are manageable and the return on invest (ROI) within this cohort is significant [82–84].

The participants in this study had clear, informal support systems in place to support their dyslexic employees. Yet, participants in some cases still felt that discrimination and stigma remained attached to the term ‘dyslexia’. This correlates with other studies that have found those with disabilities, including dyslexia, are often subjected to negative perceptions and stigmatisation or disparate treatment, including wage disparities [31,85–90]. Local research has shown that when employees with dyslexia feel they have insecure employment and unsupportive working conditions, they are at risk of poor mental health, well-being and early job burnout [30].

5.4. Creating Inclusive Workplaces

Despite the high prevalence rates of dyslexia in the workforce, our findings support the literature that indicates workplaces appear to lack the skills to support the dyslexic population as they transition from education into the workforce [38,39,41,91]. Our work adds to previous research by O’Dwyer and Thorpe (2013) [38] and Thorpe and Burns (2016) [39], who investigated managers’ understanding of dyslexia within the teaching population. Together, their work identified there was a lack of awareness, training, and support for managers of dyslexic staff and that dyslexia was still an invisible disability in the workforce. In these studies, it was reported that it was the responsibility of dyslexic employees to disclose and self-advocate for what they needed to survive in the workplace [31,38,39]. Due to the complex nature of dyslexia, employers and managers can face unique challenges and tension in the workplace that they may not be adequately prepared for or skilled to manage.

These concerns are corroborated in a qualitative case study by Feggins (2022) [92], which concluded that managers, supervisors, and HR professionals need dyslexia awareness and education training, to better understand and support employees with disabilities. Feggins acknowledged the necessity for disability training tailored to Human Resource (HR) professionals and those who have responsibilities in the recruitment process. Alongside HR training, Feggins suggested disability awareness training for organisations emphasising diversity and inclusion [92]. Similarly, research undertaken by Wissell et al. (2022) [30] highlighted the need for dyslexia awareness training across the whole of an organisation, with specific training for HR and those in leadership roles (managers, team leaders and/or supervisors).

Our study indicated that managers believed reasonable adjustments were a key enabler to empowering their employees with dyslexia to succeed. However, formalised reasonable adjustments were not readily available to our sample, rather, this process was left to the discretion of managers. This reflects work by Wissell et al. (2022) [30], who also found that access to reasonable adjustments was the responsibility of managers and that managers often felt ill-equipped to support such requests. As Sumner and Brown (2015) [41] indicated, employers and managers require training to understand the possible accommodations that dyslexics may need and to determine whether these accommodations are reasonable, fair, justified, and of reasonable cost to the organisation.

Finally, and most importantly, our study indicates that when employers and managers have been previously exposed to, or had experience with dyslexia, they are more likely to make workplace adjustments for dyslexic employees, leading to more inclusive working environments. This emphasises the need for organisations to be proactive rather than reactive in their approach to supporting the specific needs of dyslexic staff, by facilitating awareness training for managers, leaders and HR staff, creating workplaces that feel psychologically safe to disclose, and providing access to reasonable work adjustments.

5.5. Implementation of International and National Policy Change That Can Create Workplace Inclusion

As signatories of the UNCRPD and Article 27 in particular, Australia has a responsibility to actively raising awareness, reduce discrimination and ensure the rights of those with dyslexia. Australia must adhere to the UNCRPD, as a signatory as we have set goals and targets to reach, a process that is monitored and reported on every four years [42]. Yet, international research in relation to dyslexia in the workplace has revealed a tension between the development of a policy and the real-life application of that policy [38,90,93]. In Australia in recent years, several initiatives have been launched to increase employment of people with disabilities, such as the 'Employ My Ability' Disability Employment Strategy, which support employment of people with a disability-Inclusive workplace cultures were people with disability thrive in their careers [94]. Nevertheless, as is the case with other similar initiatives, the 'Employ My Ability' strategy seems to excludes the needs of individuals with 'hidden' learning disabilities such as dyslexia [94]. Our work illustrates that the exclusion of dyslexia from national strategies may contribute to employers and managers lacking the skills required to support dyslexic employees and lead diverse teams.

At a micro level the employment sector must adhere to and meet the requirements under the Discrimination, Human Rights and Fair Work Acts [46–48], through policies and policy enactment that raise awareness and disability awareness training, reduces discrimination through the adaptations to recruitment, onboarding and retention practices, ease of access to reasonable adjustments and psychologically safe workplaces could all help reduce the perceived risk of discrimination occurring and lend themselves to improving workplace practices. These strategies are enablers of a cultural movement of inclusion and diversity which is truly embraced in practical terms across the employment sector.

After observing the impact of the COVID-19 pandemic in Australia, we now know that workplaces can be adaptive and flexible. We also know that societal changes and challenges to workplace norms have led to a greater focus on inclusion and diversity within the workplace. These positive changes are a great start, but they now need to be broadened to embrace those with dyslexia and other 'invisible' disabilities so that all employees can be effective and productive contributors in the workplace.

6. Limitations

This preliminary study had several drawbacks that must be recognised. First, the cohort was very small, and the results cannot therefore be generalised with any confidence. This preliminary study could only recruit four participants, it could be assumed that uptake was low because employers and managers are not coming across employees with dyslexia because workplaces are not providing psychologically safe environment to disclose. Employers and managers may feel vulnerable to be open about how they are managing employees with dyslexia, and it may shine a light on gaps in their workplaces that they do not want to disclose, or alternatively workplaces just have such little understanding and awareness of dyslexia that employers do not believe they have dyslexic employees, and they are performance managing those with dyslexia out.

Further, our participants were weighted towards those with previous lived experiences of dyslexia, which may bias the results. The challenges and achievements presented here may not signify the wider experiences of leaders who have worked with dyslexic employees. The personal experiences and knowledge of Author One, who is dyslexic, may have influenced data collection. Future research should consider involving a broader range of leaders that work with dyslexic employees.

7. Conclusions

Currently there is limited research of a similar nature that has investigated the experiences of employers and managers of dyslexic employees. In this preliminary study although the sample size was small, we found that our participants' workplaces appeared to be ill-equipped to support dyslexic employees across the workplace ecosystem; it was only when leaders had pre-exposure to dyslexia that they knew how to effectively influence

support to assist their dyslexic employees. Overwhelmingly, leaders felt that when dyslexic employees had access to appropriate reasonable adjustments, they made a significant and positive contribution to their workplaces which could lead to improved economic outcomes for employers and society in general.

Generally, the literature on dyslexia in the workplace is weighted to the experiences reported by employees with dyslexia. Further research from a management point of view would assist in developing support strategies for dyslexic employees across various industries and roles. Discouragingly, there is a lack of awareness of dyslexia within workplaces and society. Yet, we found that when empathy was paired with an awareness and understanding of dyslexia as part of the workplace culture, those with dyslexia were not only surviving, but also thriving.

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Data Availability Statement: The data that support the findings of this study are available from the corresponding author upon satisfactory request.

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Appendix A. Interview Guide: Looking from the Outside In-Dyslexia and the Workplace

Group 2—Employers or managers who have worked with staff with dyslexia.

The following interview guide has been developed as part of the Looking from the Outside In-Dyslexia and the Workplace research project. This guide will be used to collect participants views and experiences of working with and or managing employees with dyslexia in the workplace.

Hi XXXXX Thank you for meeting with me today and for agreeing to participate in this interview and for completing the online survey. Did you have any questions about that before we begin? Do you have any questions about the PICF?

As the recruitment flyer mentioned, this is the first time in Australia that there has been the opportunity for employers to discuss their experiences and perspectives of working with and managing employees that have dyslexia and associated learning disabilities. So, I am going to start by asking you some background information and then some questions about your current or previous work experiences.

The information you provided today will be tape recorded and everything you say is confidential. Can I confirm that you are still happy for our interview to be audio-recorded?

Once we are finished, it will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information which means it will be deidentified, so no one will be able to tell who provided which answer. Does that make sense?

Do you have any questions before we start?

Ok let us get started

Section 1: Background questions

- How long have you been employed in your current job?
- Role within organisation
- Do you work in a metro or regional/rural location?
- Can you briefly tell me about your workplace/business?
- How many staff
- What state do you live in

Section 2: About your work

The next few questions are about learning disabilities (LD). For the purpose of this interview when we talk about learning disabilities we mean dyslexia, dysgraphia and dyscalculia.

- When did you first come across the term LDs within the workplace?
- What is your understanding of what these terms meant?
- In your view, how do you think others would perceive what dyslexia is

Section 3: About dyslexia at work

The next few questions are about your current or previous workplaces

Thinking about your work place (now or previous):

- Can you tell me about any employees that have had dyslexia?
- Do you think that a Dyslexia impacts on an employee's ability to carry out their day to day work tasks?
 - Could you tell me more about that?

Possible probes:

- Do you think LDs can have positive and negative effects on employees' work?
- Do you think LDs ever effect employees' mental health and wellbeing at work?
- Do you LDs effect employees work performance?
- Have you every noted that employees with LDs have higher rates of absenteeism?
- Do you think employees with LDs need special consideration to ensure they complete tasks and complete work on time?
- Could you tell me about any HR processes in your workplace for employees with dyslexia.
- How would you manage inclusion and Diversity policies?
- In your view, what are the attitudes of other staff towards employees that have dyslexia?
 - Do you think dyslexia can have positive and negative effects at work?
 - Have you hear of the term neurodiversity?

If no, interviewer to explain that neurodiversity is a term used to look at people with learning disabilities as a difference rather than a disability and a strength.

If yes, what is your perception of the term, do you see your dyslexia as a strength/s? Some people say that dyslexia is a super power, do you think dyslexia is a super power or a disability?

If yes what superpowers do you think they bring to the workplace?

- Do you feel that if a staff member discloses they have a Dyslexia within the workplace that they could be discriminated against?
 - Have you seen this happen?
 - Would it be their peers or line manager who would be more likely to discriminate against them?
- If an employee has disclosed, they have dyslexia and need assistance would you know where to get help and resources?
- Are there any changes you would make within the workplace to better support people who have dyslexia?
- Are there any resources or supports you would like to see developed to support staff with dyslexia?

- Budget to support employees with adaptations
- I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know or that you'd like to add?
- I should have all the information I need. Would it be alright to call you if I have any more questions?

As mentioned above your it will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information which means it will be deidentified, so no one will be able to tell who provided which answer.

Thanks again for your time and for your invaluable feedback for this research project.

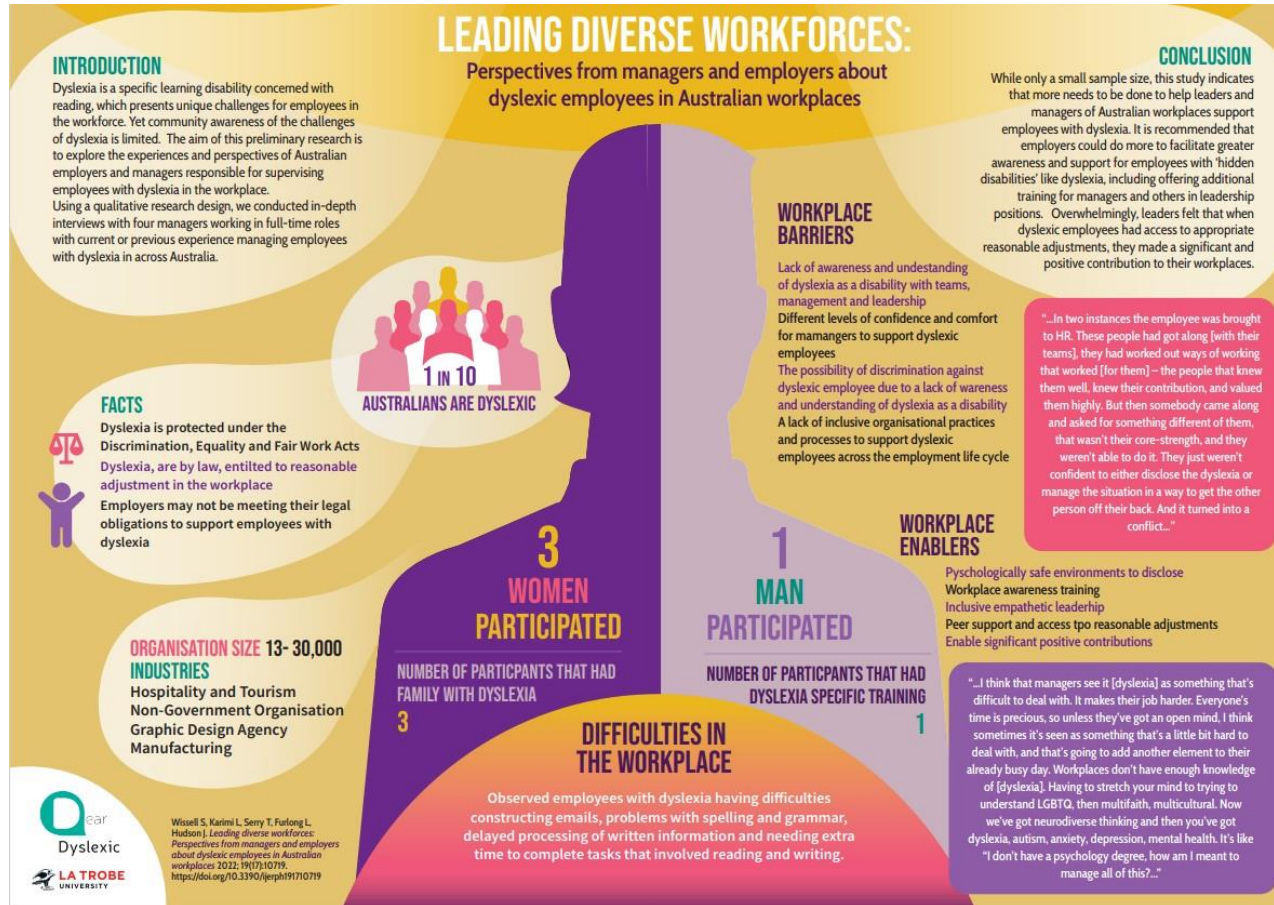
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6.3 Infographic 3. Leading Diverse Workforces: Perspectives from managers and employers about dyslexic employees in Australian Workplaces



Chapter 7

Discussion

"In the middle of difficulty lies opportunity."

- Albert Einstein

7.1 Understanding the full impact of dyslexia

The available research on dyslexia in adulthood is limited in scope and depth within the Australian context. Therefore, this thesis aimed to provide a comprehensive exploration of the lived experiences of Australian adults with dyslexia. This inquiry into dyslexia moved beyond the scope of the traditional medical model. Specifically, in addition to investigating dyslexia's physiological differences, predominantly manifesting as difficulties in reading, writing, and spelling, this research explored its broader ramifications on an individual's self-concept, academic achievement, occupational choices, and professional experiences throughout adulthood.

The novelty of this research is that it is grounded in the utilisation of standardised tools and the application of the ecological model, which provides a more comprehensive understanding of the universal difficulties encountered by individuals with dyslexia. When considering the three studies from an ecological perspective, it becomes evident that the factors that impact the experiences of adults with dyslexia span multiple systems, from the microsystem to the macrosystem. Within this context, it is apparent that there are multiple systemic barriers for those with dyslexia to achieving success. For example, a decision made at the level of the macrosystem to include dyslexia as a disability in anti-discrimination legislation might raise more awareness of dyslexia in the workplace and encourage people with dyslexia to seek support, with the potential to foster career progression. Alternatively, a decision to exclude dyslexia from NDIS funding may discourage people with dyslexia from identifying with the label 'disabled' and might prevent disclosure and assistance-seeking behaviour. In either scenario, what appear to be quite 'distant' decision-making processes can have a profound impact at an individual level as highlighted in [Figure 6](#).

Findings from Studies A.1, B.1 and B.2 ([Figure 1.](#)) largely depict the influence of factors from the mesosystem and the microsystem on adults with dyslexia (e.g., access to

diagnosis and interventions, educational systems and practices, employment and workplace experiences, and the social and emotional wellbeing of dyslexic individuals). This chapter looks at those factors in more detail. Included in this discussion are the voices of study participants, who speak of the pain, suffering, and perpetual barriers they have personally experienced.

7.2 Diagnosis and access to interventions

International research shows great inconsistency in what constitutes dyslexia, how it is assessed, diagnosed and the age of diagnosis for individuals (Andresen & Monsrud, 2022; Barbiero et al., 2019; Bazen et al., 2020; Major & Tetley, 2019; Torppa et al., 2015; Yang et al., 2022). This doctoral research reflects and reinforces the current global ambiguity surrounding the definition of dyslexia, which may result in inconsistencies in dyslexia assessment and the risk of being diagnosed later in life. A large proportion of participants across Study A (57%) and Study B (43%) were diagnosed in adulthood. This research demonstrates that for many Australians, from the outset, the ability to access and gain a diagnosis of dyslexia and then access follow-up interventions can be an ongoing challenge for children, young people and adults (Al-Yagon et al., 2013; Waring & Knight, 2013).

This research ascertains that in Australia there is a lack of uniformity in the way individuals are assessed with a broad range of health professionals providing a dyslexia assessment. These professionals include educational psychologists, clinical and neuropsychologists, speech pathologists, and general practitioners (GPs). Al-Yagon's work also found variability by practitioners (e.g., psychologists, speech pathologists and general practitioners used different methods/criteria to make a diagnosis), and between Australian states and territories (Al-Yagon et al., 2013). Furthermore, there is no clear position across

different disciplines about how dyslexia should be classified (e.g., learning difficulty, reading disorder, etc.) and little consistency in the application of diagnostic criteria found in the DSM-5. Further, while dyslexia is a complex bio-psychosocial condition, it is most often identified using psychometric assessments (Al-Yagon et al., 2013; Sadusky, Freeman, et al., 2021) and some adults have been assessed for dyslexia using diagnostic tools designed for children. The results of the current research confirmed this unclear pathway to diagnosis, with participants across Study A and Study B reporting different practitioners involved in their diagnosis. Further, several independent organisations and agencies in Australia also claim to provide dyslexia assessments, including pre-assessments and online self-diagnosis (Australian Dyslexia Association, 2022). This lack of consistency in classification and identification can be costly, confusing and misleading and makes access to an accurate assessment even more difficult, highlighting fragmentation and gaps across the education and health sectors. Timely diagnosis and intervention are critical to enabling people with dyslexia to complete their education and to gain and retain employment (Bond et al., 2010). A diagnosis of dyslexia later in life and missed opportunities for intervention has the potential to impact a person's sense of self and leave them vulnerable to poor mental health and wellbeing over their life's trajectory (Major & Tetley, 2019).

7.3 Educational attainment

Reading difficulties have been found to be a unique risk factor for poorer educational outcomes, with co-occurring problems highlighted in Chapter 3.5 (such as ADHD, dyscalculia and dysgraphia) significantly increasing this risk (Smart et al., 2017). It is therefore anticipated that participants in this research would have lower than average educational attainment compared to the general population. Contrary to this assumption, the

participants in both Study A.1 and Study B.1 were highly educated, more so than the national population average. Most participants (79.74%) had attained an education level of Year 12 and above, compared to only 68% of the general population (Australian Bureau of Statistics, 2019). One explanation could be that these co-occurring difficulties are less well understood and diagnosed and researched in Australia. There is also a lack of awareness between the high correlation rates between dyslexia and these neurodevelopmental disorders.

Another explanation for this discrepancy in results could be that educational opportunities have increased across the education and higher education sectors over the past two decades as a better understanding of dyslexia as a disability has emerged (de Beer et al., 2014; Maxwell, 2019; Serry & Hammond, 2015; Serry & Oberklaid, 2015; Tanner, 2009). Reasonable adjustments for people with disability in the education and higher education sectors are now mandated globally through laws and legislations (Commonwealth of Australia, 1992; Gerber et al., 2012; Kornblau, 1995) although this is fraught with difficulties due to funding and diagnostic issues in Australia.

People with dyslexia in education and higher education can now access assistive technology, have additional time to complete assignments and sit exams, and use other adaptations, like audiobooks and speech to text, and text to speech software (de Beer et al., 2014; King, 2019; Lauder, 2020). These adjustments may explain why most of our cohort had completed secondary school and gone on to undertake vocational training and higher education. However, this does not explain how a considerable number of participants in Study A.1 (57%) and B.1 (40%) who were diagnosed with dyslexia as adults were still able to gain vocational training and post-graduate qualifications. Without a diagnosis of dyslexia in their formative years, these participants would not have had access to early interventions and/or reasonable adjustments to support their learning disability.

7.4 Employment and workplace experiences

“...I'd just like the understanding of diversity to be more inclusive, if someone says, "Is it possible that someone can check your writing or support you with a document?" that there's no guilt related to that and that they'll say, "Yeah, Mary's free, she can help you with that" and there was no underlying feeling that you were incompetent related to that. Just the same as someone would say, "I need to do an interview, can you help me understand how to articulate an interview question?", whereas a lot of people will come to you about that but they won't come to you because they can't write. It's just that whole acceptance like mental health. Let's not talk about it, it's a feeling of inadequacy and incompetence of being able to achieve and people won't want to employ you. It might be just Australian high expectations, but that's a strong feeling for me...” [P2]

Participants in Study B.1 were employed across a range of sectors and settings, including service industries, the arts, administration, education, health, public service, commercial enterprises and self-employment. These findings are consistent with international research that shows people with dyslexia are employed in a variety of sectors and roles across blue-collar and white-collar industries, and with a cross-section of low-level occupations from low-level/unskilled roles through to middle management, senior management and executive levels (Beetham & Okhai, 2017; Burns et al., 2013; de Beer et al., 2014; Macdonald & Deacon, 2019; Maughan et al., 2009).

However, we did find that some of our participants were working at levels lower than they were qualified for, though further investigation is necessary to determine whether this is significantly different from the general population. This finding is also backed by international research (de Beer et al., 2014; Winters, 2020) and suggests that career progression may be more difficult for employees with dyslexia.

7.4.1 Workplace experiences

“...There wasn't a lot of understanding that someone of my position would not have those skills, so I felt I couldn't say anything. It's a feeling of inadequacy and incompetence in being able to achieve and [a fear that] people won't want to employ you...” [P2]

Despite progress over recent decades, workplaces are still predominantly designed for people without disabilities (Santuzzi et al., 2014; Telwatte et al., 2017). From the outset (during the job-seeking process), our research found that people with dyslexia faced perceived discrimination, unfair judgments, and lack of access to reasonable supports or adjustments during the screening and recruitment process.

Difficulties occurred during the recruitment process, particularly during interviews and in the completion of psychometric assessments, where participants from Study B expressed a reluctance to disclose their disability. For those who did disclose, there was a lack of access to appropriate reasonable adjustments. This adds to a growing body of international research suggesting that dyslexics are on an uneven footing when applying for and gaining employment compared to their non-dyslexic peers (Gerber et al., 2012; Madaus, 2008; Madaus et al., 2008; McLoughlin, 2015; Sumner & Brown, 2015), despite laws that are in place designed to protect them. To overcome these fundamental obstacles, numerous changes could be made. For example, trialling more inclusive interview practices or allowing job applicants access to alternative psychometric assessments that do not rely solely upon the measurement of conventional academic skills (Goldstein, 2011).

Once employed, the participants in our studies faced substantial and ongoing impediments to meeting their workplace demands. These impediments stemmed from systematic organisational barriers (such as a lack of formal policies and procedures on

managing dyslexia in the workplace), which contributed to low levels of understanding and awareness of dyslexia as a disability by managers, human resources, and colleagues; this is despite dyslexia having the highest prevalence of all disabilities in the workplace.

It is apparent from the literature that few people with dyslexia have been able to access readily available reasonable adjustments in the workplace (Leveroy, 2013; Major & Tetley, 2019; Winters, 2020). Likewise, the participants in our studies reported that receiving approval for reasonable adjustments was often not timely or forthcoming and was at the discretion of managers rather than outlined in a policy. This suggests that policies are not sufficient to create changes in the working environment. This aligns with the work of Deacon et al. (2020), who found that having an unsupportive line manager could lead to job strain and individuals being fearful of seeking support.

Participants in this study also noted that internal workplace policies were not sufficiently sensitive to the distinctive experiences of employees with dyslexia, and that employers rarely attempted to foster an inclusive working environment. This is despite the attempts of policy and legislation to increase the participation of workers with disabilities (Commonwealth of Australia, 1992, 2009, 2010). In workplaces where employees fear discrimination and stigma, they are forced to execute their own strategies to manage and keep up with workplace demands, and this can lead to mental exhaustion, stress, and anxiety, leading to job burnout, as illustrated in Figure 10. Workplaces must develop an understanding

Figure 8. Adaptation of the Job Demands-Resources Model of Burn Out



about what constitutes a ‘reasonable adjustment’ or a workplace concession to provide appropriate support to employees with dyslexia. This might include access to assistive technologies, which participants in Study B.1 noted were currently lacking. Assistive technologies have been found to play a crucial role in supporting work performance for dyslexic employees. However, as these technologies are not consistently available across Australian workplaces, significant barriers still remain for many individuals (Deacon et al., 2020).

Finally, collegial relationships and supportive working environments are integral to managing job demands and encouraging people with dyslexia to undertake self-advocacy and help-seeking behaviours (Weziak-Bialowolska et al., 2020). Yet the experience of our participants was that there was a considerable lack of awareness and understanding of dyslexia and its impact on workplace performance. This research is consistent with the conclusion drawn by Morris and Turnbull (2007), which identified an absence of understanding and comprehension concerning the impact of dyslexia's attributes on occupational efficacy, specifically within the medical field. Overall, evidence from this work and international studies suggests that professional development and awareness-raising strategies are needed to address current knowledge deficits, and that meaningful effort is necessary for organisations to meet policy and legislative objectives of workplace inclusion (Evans, 2014; Major & Tetley, 2019; Ryan, 2011).

7.4.2 Workplace wellbeing

“...I’ve been in a few meetings where you have them doing a PowerPoint presentation, they’re explaining things and they – a few numbers come up – I’ve had – I remember because

I felt like walking out of a meeting – one guy said “If you’re dyslexic this won’t make any sense to you”, make it a joke of it like you’re stupid or something...” [P3]

The cost of excessive work stress, such as feeling overwhelmed and emotionally exhausted, may have significant consequences for individuals and their organisations (Wallace & Lemaire, 2013). Employee wellbeing plays a crucial role in how an organisation performs. When employees experience autonomy at work, have supportive colleagues and managers, and have access to receive reasonable adjustments, they are intrinsically motivated to achieve their work goals (de Beer et al., 2014; Livingston et al., 2018).

Our research substantiates the findings of local studies (Smart et al., 2017) and international investigations (de Beer et al., 2014; Locke et al., 2017; Locke et al., 2015; Shrewsbury, 2016) that have uncovered how the enduring and recurrent challenges encountered by individuals with dyslexia can provoke adverse emotional states. These mental health issues can impact their ability to acquire a job and once acquired, can impact their ability to stay in employment. To compensate for their difficulties, employees with dyslexia often apply considerable coping strategies (Gerber et al., 2004; Newlands et al., 2015; Price et al., 2003), such as working longer hours, using templates or check lists, colour coding, and using assistive technology (Kreider et al., 2019; Major & Tetley, 2019; McBride, 2019; Newlands et al., 2015; Wallace & Lemaire, 2013). Like our findings, the research tells us that people with dyslexia often feel they have no choice but to develop their own strategies and coping mechanisms when in a working environment that feels unsafe for disclosing disability. This can lead to higher rates of workplace stress and significant mental fatigue, feelings of isolation, lack of support, and high anxiety (Locke et al., 2017; McNulty, 2003; Nalavany et al., 2011; Newlands et al., 2015).

Failing to address the additional stressors that people with dyslexia are often placed under in the work context is a disservice, not only to the employees themselves, but to employers and organisations. We know that people with dyslexia make a significant contribution to the community and have many strengths (Earnest and Young, 2019; Eide & Eide, 2011). Making small but reasonable adjustments within the workplace gives organisations an opportunity to better harness those strengths, and to mitigate some of the mental health issues experienced by people with dyslexia.

7.4.3 The role of the employer and manager

“...[They] told me after a very good review that (they) had dyslexia. They just said there’s something else that they need to tell me, and I could see them start to tremble, and the anxiety in their face, and fear. Judging from that, I would expect employers may have discriminated against people with a learning disability, or possibly managed it in a way that wasn’t so proactive and positive for the employee...” [P3]

In addition to exploring the workplace experiences of people with dyslexia, we also wanted to look at the culture of workplaces from the perspective of employers and managers working with dyslexic employees. There is little international research on managing a diverse workforce, and none within the Australian context. Given the high percentage of people with dyslexia across the population (Beetham & Okhai, 2017; Bell, 2009; de Beer et al., 2014; Macdonald & Deacon, 2019; Morris & Turnbull, 2007b), this was surprising. Whilst some management and support of individuals with dyslexia may need to be industry or role

specific, our work identified some common underlying principles for inclusive workplace practices that could be applied to all settings.

Despite the limited size of the sample, an important outcome from Study B.2 was the finding of an absence of comprehensive policies and procedures to promote inclusivity for individuals with dyslexia in organisations. Instead, employers and managers tended to approach each situation on an ad hoc basis, resulting in a lack of preparedness and competency in handling such disclosures. Study participants reported an overall absence of awareness, understanding, and training opportunities at the organisational level to manage and support employees with dyslexia. The absence of explicit and precise workplace policies and procedures further compounded this issue.

This research found that when employers and managers were sympathetic and understanding, their staff felt safe to disclose their dyslexia, and there were positive outcomes for the employee and their employer when they did so. While it was fortunate that the participants in this study had prior experience of dyslexia with family members and previous staff, this will not be the case for all managers. It is therefore likely that, without the right training and organisational supports, many managers could feel ill-equipped, overwhelmed, and susceptible to inadvertent discrimination when working with dyslexic staff.

Our work indicated that for some individuals, the impact of their dyslexia did not become apparent until their work performance dropped. This often arose from changes to job structure, such as the introduction of new work processes, management, groups, or equipment. This finding is also supported in work undertaken by Winters (2020) and De Beer et al. (2014). Conversely, our findings also found that supportive performance reviews could encourage disclosure of dyslexia and lead to performance improvement, particularly when employers and managers felt able to implement reasonable adjustments for the dyslexic employee.

One of our most important findings was that education, training and access to dyslexic resources were perceived to be crucial to ensure managers and employees possessed the knowledge needed to perform their duties in the workplace effectively. Equally, education and training were considered essential for developing an understanding of workplace policies in relation to disabilities, reasonable adjustments and equal opportunity. A key enabler for supporting employees with dyslexia is to ensure workplaces understand dyslexia as a disability and develop a comprehensive awareness of the needs, strengths and weaknesses of dyslexic employees. Furthermore, employers have a responsibility to adhere to and understand the legal demands specified in the DDA, equality laws and the Fair Work Act. Employers and organisations are in a unique and exciting position to be able to provide truly inclusive and diverse workplaces by embracing those with dyslexia and harnessing the strengths and qualities they bring to the workplace.

7.5 The decision to disclose

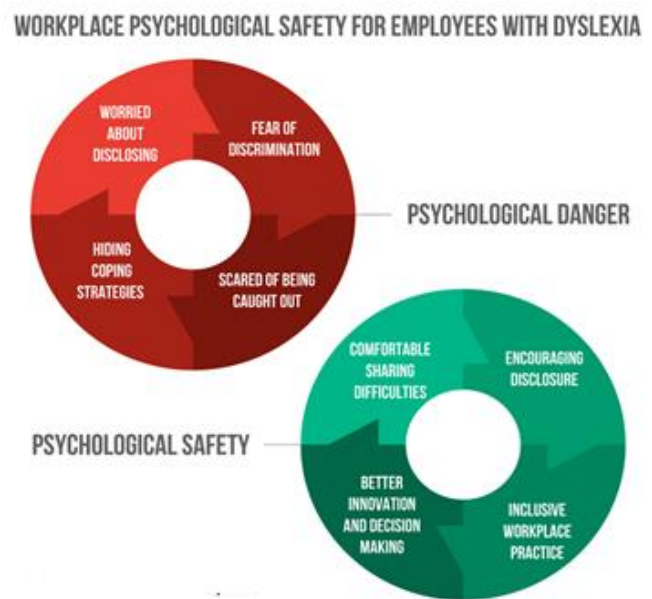
“...I kept it very much a secret because people thought it was some form of intellectual limitation, and I saw so much judgment and prejudice about dyslexic people that, given the jobs I did, at the very centre of them was being clever. I wasn't going to create a prejudice around it towards me on it, so I never shared that...” [P1]

The decision to disclose one's dyslexia is a multifaceted and a deeply personal choice. Previous research has revealed that individuals with dyslexia may perceive a potential disadvantage if they opt to disclose their condition, which can contribute to their reluctance to identify their "disability" (Rose, 2006). Beetham and Okhai (2017) found that individuals'

apprehension about disclosing their dyslexia stemmed from concerns regarding possible victimisation by their employer or bullying by colleagues. However, other studies have reported that disclosure of a disability can lead to positive outcomes, including decreased feelings of isolation and improved job performance (Sabat et al., 2014; Santuzzi et al., 2014).

Both Study A and Study B identified high rates of disclosure. Participants in Study A were more inclined to disclose to people close to them, including friends and family, rather than to people at work (90% v. 57%). This supports the work of Alexander-Passe (2015) who found that individuals are only inclined to disclose their learning disability if they feel comfortable or psychologically safe as

Figure 9. Workplace psychological safety



illustrated in Figure 11. However, some Study B participants also indicated they may disclose their dyslexia if they felt psychological danger or felt threatened (for example, if their performance was being questioned). Disclosure in this scenario is unlikely to produce the positive effects associated with disclosure in a working environment that is accepting and supportive of dyslexia.

7.6 Social and emotional wellbeing

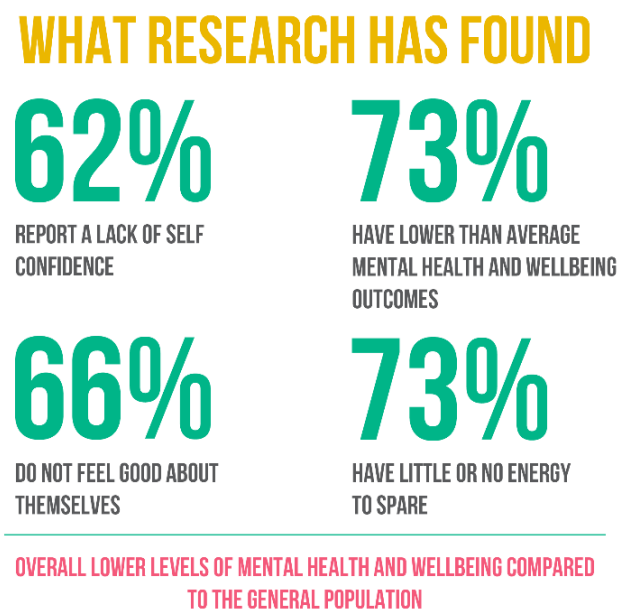
We used the Warwick-Edinburgh Mental Wellbeing Scales (WEMWBS) standardised tool in Study A to look at the overall wellbeing of adults with dyslexia, and identified that in

our sample, mental health and wellbeing was significantly compromised compared to general populations in Australia (Australian Psychology Society, 2015) and the UK (Taggart et al., 2016). Specifically, participants reported lower self-confidence, poorer self-esteem, and more mental fatigue (see Figure 10).

These scores on the WEMWBS are supported by the results we obtained in Study B.1 from the in-depth interviews. Participants expressed feeling mentally exhausted, unsafe to disclose their disability (due to potential discrimination), socially isolated, and unable to be their true authentic self in the workplace.

Considering the internalising and externalising factors highlighted in this discussion, it may be inferred that these factors are instrumental in comprehending why individuals with dyslexia, despite having achieved a high level of education and being employed, still experienced notably lower levels of mental health and wellbeing, as well as lower overall life satisfaction ratings compared to the general population. Further research is needed to unpack which of these factors, if any, play a greater role than others and the role of specific types of interventions and support that may help to buffer these stressors.

Figure 10. Snapshot of research findings from Study A.1



Chapter 8

Serendipitous findings, limitations, recommendations, and conclusion

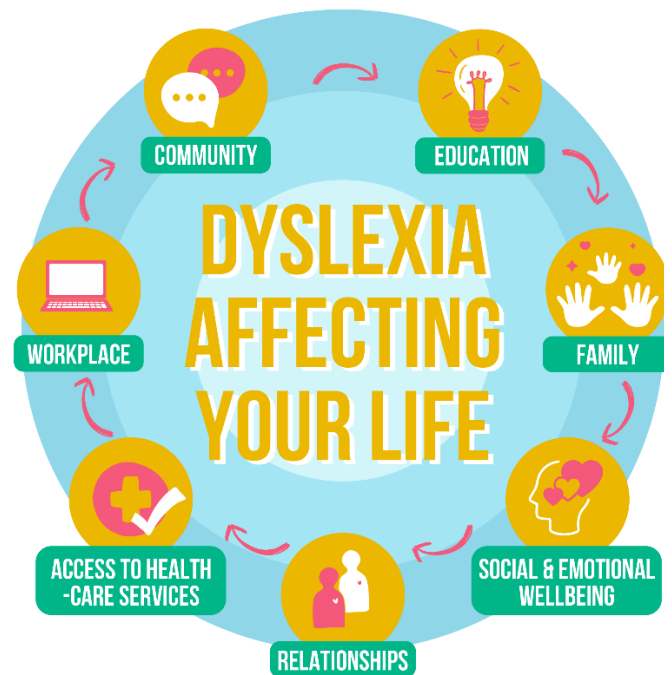
“Some of the greatest things, as I understand, they have come about by serendipity, the greatest discoveries.”

- Alan Alda

This section presents supplementary findings derived from the in-depth interviews conducted in Study B.1. Beyond employment-related matters, various other experiences were revealed during these interviews. Participants discussed the impact of dyslexia on different aspects of their lives, encompassing the social determinants of health such as early education, schooling, support networks, and mental health and wellbeing during childhood and adulthood. These incidental findings are explored in the subsequent discussion. The

quote above highlights to me the importance of these findings, which until now have never been known about adulthood dyslexia within the Australian context.

Figure 11. Dyslexia across the social determinants of health

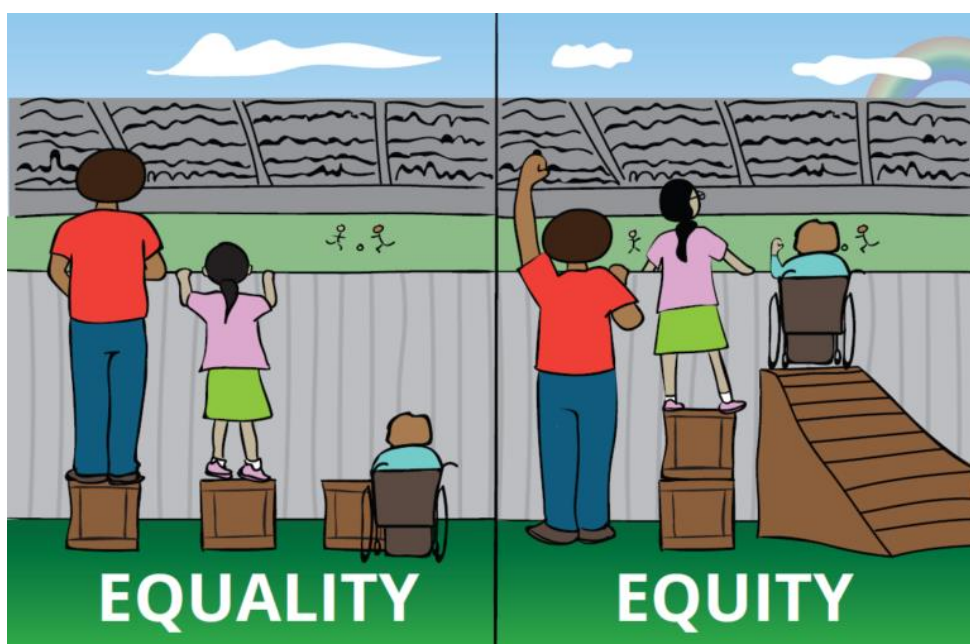


8.1 Support and funding inequality

Socio-economic status plays a role in one's ability to access an assessment and interventions. Our work highlighted an apparent inequality between neurodevelopmental disorders in relation to funding and support. Although dyslexic people make up 50% of the neurodivergent population, they receive the least amount of access to funding and support compared to other neurodevelopmental disorders such as autism, which is covered under the the National Disability Insurance Scheme (NDIS) and the Australian Medicare Benefits Scheme (MBS).

In Australia, the cost of a diagnostic assessment for dyslexia is between A\$1,500 and A\$2,000 (SPELD Victoria, 2020). Following diagnosis, access to private health professionals such as speech pathologists and educational support, such as private tutors, can be anywhere from \$60.00-\$200.00 a session. These costs may be unaffordable as dyslexia and learning disabilities are not covered under the NDIS nor the MBS. The failure of the Australian Government to provide appropriate resources under MBS and NDIS has resulted in an expectation and heavy reliance on parents or the dyslexic person themselves to be able to advocate and pay for a diagnosis and then any interventions that may be needed. This incongruent treatment of different disabilities contributes to social injustice via economic inequity. Figure 12 illustrates the concept between equity and equality. The concept of equality suggests that every individual or group is provided with the same resources or opportunities, while equity acknowledges that each person has unique circumstances and distributes resources and opportunities according to their specific needs to achieve an equal outcome. This research found that those with dyslexia are facing significant social inequities because they are not accessing the resources and opportunities needed to meet their disability.

Figure 12. Equity vs. Equality (Maguire, 2016)



8.2 Psycho-social wellbeing

“...I spent so long fighting [it]. I didn’t want anybody to pity my situation or make allowances for it. For me, it was difficult because I had spent so long being people’s equal without them knowing that I had this, what I perceived as a weakness. How embarrassing it is - it really is. As a smart person, to feel as dumb as you did, when you had to be remotely public about any work you ever did that was in written form, and there were some moments of just exquisite embarrassment along the way...” [P7]

Numerous studies have established a clear association between adverse childhood experiences and adult psychosocial wellbeing (Cohrdes & Mauz, 2020; Daniel et al., 2006; Westermair et al., 2018). The constructivist theory provides a theoretical framework for comprehending this connection. According to this theory, individuals' experiences are integrated into their existing knowledge through a continuous process of synthesis, leading to alterations in their internal paradigms (Paradice, 2001; Tom, 2012). In this study, participants' negative experiences with dyslexia appeared to strengthen their feelings of stress, shame, frustration, and embarrassment and contribute to the development of a negative self-concept associated with inadequacy, anxiety, and fear. This accords with the work of Berresford and Kjersten (2019), who found that any significant difficulty or difference, including dyslexia, was associated with distress, frustration, anxiety, and shame, resulting in negative self-beliefs, as well as studies that have found a general link between dyslexia and vulnerability to low self-esteem (Alexander-Passe, 2015a; Boetsch et al., 1996; Burden, 2008; Nalavany et al., 2018; Paradice, 2001; Riddick, 2000).

8.2.1 Negative childhood experiences

“...I was sad, I got bullied a bit as well which was really hard, so I hated primary school...”

[P4]

There is strong evidence linking negative early life experiences to poor mental health and wellbeing (Cohrdes & Mauz, 2020; Daniel et al., 2006; Westermair et al., 2018). Again, constructivist theory offers a framework for understanding how participants in this study may have developed an internal paradigm of negative self-beliefs, inadequacy, anxiety, and fear through repeated negative experiences (Paradice, 2001; Tom, 2012). However, limited Australian research has been conducted on the association between negative childhood experiences within the education system for people with dyslexia and their impact on psychosocial wellbeing into adulthood.

Despite their positive educational outcomes, participants in Study B.1 described traumatic experiences across their early education, including elevated levels of emotional distress, stress or mental fatigue relating to their dyslexia during their formative years. What this research highlights, which seems to be missing from previous literature in Australia, is that there appears to be a significant amount of chronic stress and mental fatigue experienced by people with dyslexia, particularly in their younger years, that may be over and above that experienced by the average person. Although stress is a normal human reaction affecting all people, this research highlighted that, from an early age, many people with dyslexia appear to be in a continuous state of stress.

Chronic stress has been known to negatively alter the brain’s development, particularly in relation to motivation, memory, thinking, reasoning, and emotional regulation (R. A. Thompson, 2014). Stress responses can elicit different emotions and behaviours and could contribute to the ‘fight or flight’ behaviours described by some participants (e.g., school truancy and anger). In severe cases, research has shown that people with dyslexia

exposed to chronic stress and traumatic experiences are at risk of post-traumatic stress disorder (PTSD).

While none of the participants in this study disclosed a diagnosis of PTSD, some participants appeared to be experiencing significant challenges in adulthood, including difficulties forming relationships, ongoing health problems, challenges in the workplace, and difficulty managing day-to-day activities. This research overwhelmingly supports local and international research that children, adolescents and adults face considerable mental health resulting from their dyslexia that commences in childhood.

There are numerous factors to adverse experiences in early childhood that may contribute to stress and negative self-concept for people with dyslexia, including educational trauma, adverse relationships with peers, adverse comments from teachers, being 'labelled', and a lack of support within the family unit. Researchers have found that adverse comments from teachers can have a particularly devastating impact on the way students perceive themselves and their academic self-concept, and that the impact on self-esteem can be carried into middle age as those with dyslexia continue to compare themselves with others even if they are comparatively 'successful' (Glazzard & Dale, 2013; McNulty, 2003; Terras et al., 2009).

Our study found that, as adults, most participants sought informal emotional support from friends and family, while some sought professional support. Seven participants had seen or were currently seeing a psychologist, and two disclosed the use of medication to support their mental health and wellbeing. Although participants could see the benefits in accessing professional support such as a psychologist or counsellor at different points in their adult lives, not all participants sought professional support specifically for their dyslexia difficulties. Some had looked for support for other reasons, such as a marriage breakdown.

There were mixed reactions from people who sought professional help for their dyslexia-related difficulties; some found it very useful, while others were concerned that their dyslexia wasn't well understood as a disability and therefore wasn't treated. Finally, participants in Study B.1 also expressed frustration and disappointment at the lack of understanding by psychologists around a dual diagnosis of dyslexia and mental health. Participants felt psychologists and mental health practitioners lacked the skills and knowledge of dyslexia as a disability and how their disability could be linked to past traumatic experiences and current anxiety and depression and self-concept. This could possibly explain why Study A participants had overall lower levels of mental health and wellbeing on the WEMWBS assessment.

8.3 Dyslexic strengths and personal resources

'...I think I have strengths from having dyslexia. I learnt to be resilient, to be strong in myself, to build confidence. I don't need to always write, and in the situation of not being able to write, that's a disability for me...' [P2].

The results of Study B.1 indicate most participants were consistently exposed to stressful difficulties that had to be overcome by drawing on personal resources, including resilience, lateral thinking, self-awareness, perseverance, coping strategies, growth mindset and support systems to manage and succeed in the workplace. Those who could employ these traits seemed to do better in life overall, which is in line with other research showing that successful adaptation can improve overall quality of life (Goldberg et al., 2003; McNulty, 2003).

The concept of 'eudaimonia' in relation to wellbeing suggests there are six characteristics that can enable positive mental health; including positive relationships,

meaning and purpose, autonomy, self-acceptance, personal growth and environmental mastery (Tulip et al., 2020). Study B.1 demonstrates that participants with higher levels of positive psychosocial wellbeing were more likely to demonstrate these six characteristics. This suggests that individuals with dyslexia could be better supported by the education, employment, and health sectors by encouraging a focus on building or developing these six characteristics.

As the prevalence of Artificial Intelligence (AI) continues to increase, the significance of soft skills, in addition to technical skills, is becoming increasingly apparent. Such skills include problem-solving, communication, adaptability, critical thinking, interpersonal skills, emotional intelligence, and empathy. This research supports empirical evidence that suggests that individuals with dyslexia often demonstrate remarkable levels of self-efficacy, knowing that they possess specific strengths that they can bring to a job, such as their capacity for empathy, excellent oral communication skills, creative thinking and problem-solving abilities, as well as aptitude in the delegation of tasks (Logan, 2009; Nalavany et al., 2018; Reid & Kirk, 2001; West, 2020). It has been demonstrated that dyslexia need not be an impediment to their success. It is worth noting that, while research has suggested that dyslexics possess strengths in these areas, there are some individuals who may not exhibit such characteristics. Nonetheless, it is evident that these skills are crucial in fostering success in a constantly evolving work environment.

8.4 Relationships and social connectedness

“...It affects my parenting. One of the things I've really struggled with is teaching my kids how to read. When I had to start teaching them phonetics and how to break down a word and chunking, I can't do that, and being a single parent as well, that's absolutely impacted their

reading ability. My anxiety over them being able to cope at school [has] impacted them... ”

[P12]

Social competence refers to the skills required to initiate and maintain social relationships, encompassing cooperation, trust, and communication (Friborg et al., 2005). Several scholars, including Gerber et al. (1992), Greenbaum et al. (1995), Goldberg et al. (2003), Hellendoorn and Ruijsenaars (2000), and Litner et al. (2005), have explored the social interactions of adults with learning disabilities/difficulties. These studies have identified a subgroup of dyslexic individuals who demonstrate successful social interactions, whereas others encounter challenges in developing and maintaining relationships. Despite some successful social interactions among certain dyslexic adults, others may experience social and emotional difficulties throughout their lives due to the impact of dyslexia on their communication skills, self-esteem, and overall psychological well-being (Greenbaum et al., 1995; Hellendoorn & Ruijsenaars, 2000; Litner et al., 2005; H. L. Stack-Cutler et al., 2015)

Some of the Study B participants noted that the trauma of past humiliations and their fear of making mistakes contributed to feelings of social embarrassment and isolation. One participant spoke of struggling to manage and follow conversations and understand jokes, leading them to feel they were socially awkward.

Several participants noted that their dyslexia created complications when trying to communicate with friends, family and work colleagues using different types of written tools such as social media, online dating forums, emailing and text messaging. Two participants spoke of feeling they would be shamed online because of their spelling mistakes, including one participant who emphasised the trials of dating in an online environment and the requirement to communicate in the written form leading to distress and fear. Other participants disclosed that communicating through text messages between family and friends left them feeling vulnerable and worried about being misinterpreted or misconstrued. Four

participants spoke of the impact of their dyslexia on parenting, including the trials of communication using technology, feelings of inadequacy when they couldn't read to their children and help them with their homework, and how they perceived the impact of their own anxieties about their dyslexia and educational trauma impacted on their children's academic success.

Most participants in Study B.2 reported relying heavily on their parents, particularly mothers, who played a major role in facilitating their educational progression, by helping them complete academic tasks, advocating for their needs, and seeking alternative support when they felt the school system had let them down. As they transitioned into adulthood there was a tendency to rely heavily on peers, friends and intimate partners to support their day-to-day activities and their job roles. Kjersten (2017) found that people with dyslexia tend to gravitate towards partners that are high functioning individuals and who can complete tasks that dyslexics may struggle to undertake. Non-dyslexic partners tend to be relied on more to complete day-to-day activities such as managing paperwork, planning, staying on time, and managing finances and housework (Kjersten, 2017). Our work also found that as those with dyslexia transitioned into adulthood, their reliance on family was reduced as they became more dependent on intimate partners and peers to support day-to-day activities and to manage in the workplace.

According to international research, individuals with dyslexia may encounter challenges in building close relationships with peers and establishing intimate relationships. (Alexander-Passe, 2015b; Carawan et al., 2016; Moore & Carey, 2005; Nalavany & Carawan, 2012; Stack-Cutler, 2017), and our findings support this research. Research now strongly supports the notion that friendships and positive relationships are protective factors in reducing the risk of poor mental health and wellbeing for all people. However, several studies have highlighted that those with dyslexia can have difficulties developing friendships

and intimate and collegial relationships (Alexander-Passe, 2015a; Moore & Carey, 2005; Stack-Cutler, 2017; Weigel et al., 2006). As friendships and positive relationships are protective factors for reducing the risk of poor mental health and wellbeing, this is cause for concern and warrants further investigation.

The literature acknowledges that those with dyslexia can struggle to communicate with their partner, due to difficulties processing information that they hear or in finding the right words to express themselves. During stressful times, problems can be heightened. As the dyslexic partner struggles to regulate their emotions, their verbal expression can become impaired, and they may withdraw. This can cause a communication breakdown within relationships (Kjersten, 2017). If a non-dyslexic partner becomes critical of a partner with dyslexia, this can lead to self-criticism, anxiety, and depression, leading to poor overall mental health and wellbeing (Kjersten, 2017). All these factors can contribute to difficulties maintaining positive friendships, and intimate and collegial relationships.

The additional findings in this section, including experiences of support and funding inequities, adverse childhood experiences, the personal resources/strengths needed to overcome dyslexia-related challenges, the impact on personal relationships and worries about communicating in a digital era – are impacts that would not necessarily be identified under the traditional medical model of health. However, research shows that these ecological systems factors play a huge, often detrimental role in the lives of people with dyslexia, and ought to be considered as significant as any physiological challenges.

8.5 Limitations

This research project had several limitations. The sample sizes were small (Study A n= 65, Study B.1 n=14 and B.2 n=4) and therefore, generalisability of the findings

needs to be treated with some caution. The author's own diagnosis of dyslexia, personal experiences and knowledge of dyslexia may have influenced data collection and analysis.

There was a reliance on social media to recruit for Study A and Study B, which may have limited the number of people who saw the recruitment flyer. The online survey used in Study A required a certain level of digital literacy and general literacy skills, which may have excluded those with limited access or capacity to use technology and those with reading difficulties.

In addition, the following limitations apply to each of our analyses:

The recruitment process for Study A and Study B heavily relied on social media, potentially limiting the visibility of the recruitment flyer and potentially excluding individuals who have limited access or proficiency in using technology, as well as those with reading difficulties. Furthermore, the online survey utilized in Study A required a certain level of digital literacy and general literacy skills, further excluding certain individuals.

Study A.1 was predominantly composed of female participants, thus limiting the generalisability of the data to the broader population of Australian adults with dyslexia. Additionally, there was no means of verifying whether survey respondents had received a formal diagnosis of dyslexia. Regarding the Wellbeing Measure for Adults (WEMWBS), our findings assume comparability of wellbeing between the Australian and UK populations, which served as our comparison group. Furthermore, the WEMWBS questionnaire was originally designed to assess individuals' feelings over the past two weeks, while our study asked participants to reflect on their feelings and coping over the last six months.

In Study B.1, it is important to note that the Job Demands-Resources (JD-R) Model has not been validated specifically for the sub-population of individuals with dyslexia. This limitation may impact the interpretation of the results obtained.

In Study B.2, participants (managers and employers) were skewed towards those who had previous personal experiences with dyslexia, such as having family members with dyslexia. This potential bias in the sample may limit the generalisability of the challenges and successes presented, as the experiences may not accurately represent those of leaders who have no prior encounters with dyslexia. Future research should aim to include a broader range of leaders to enhance the comprehensiveness of the findings.

8.6 Recommendations for further research and policy change opportunities

“ The seeds of great discoveries are constantly floating around us, but they only take root in minds well-prepared to receive them.”

- Joseph Henry

Although sample sizes were small, the following set of recommendations have been drawn from findings to inform further research or for consideration of future evidence-based practices.

1. Community awareness and public health messaging

Dyslexia is a public health issue and as such Australian federal and state governments need to improve public awareness of dyslexia and its effects on individuals, their families and the broader community. Public awareness campaigns have been known to reduce smoking, enforce seatbelt wearing in cars, and reduce the uptake of alcohol and other drugs. We are now seeing campaigns supporting autistic people and there is a place for increasing awareness and understanding of dyslexics, their needs and abilities.

2. Taxonomy, appropriate diagnosis pathways and early intervention

It is important to create a nationally accepted standard for the operational definition of dyslexia that is developmentally sensitive and can create a uniform and age-appropriate approach for all. This will reduce stigma, misunderstanding and poor community awareness of dyslexia, especially amongst health professionals and educational institutions.

National guidelines and standards should be implemented for the assessment of dyslexia that enable a variety of age-appropriate, evidence-based assessment strategies. This

would enable accurate diagnosis, regardless of age or developmental stage. National standards would provide health professionals with the confidence and skills needed to accurately assess and diagnose adults. This would also align dyslexia with other neurodivergent conditions such as autism and would ensure improved assessment and access to early interventions.

It is paramount that those in our community, especially children, can access timely diagnosis. The Australian Federal Government has a significant role to play in reducing societal inequalities faced by those with dyslexia. Policy and legislation must change if we are going to create equality for those with dyslexia. This could be improved by allocating an assessment item number for learning disabilities under the Medicare Benefits Scheme.

To support diagnosis, early interventions and supports for individuals with dyslexia must be added to the National Disability Insurance Scheme (NDIS). Research tells us that when early interventions are put in place, the impact of dyslexic difficulties can be reduced. This, combined with improved education and employment outcomes, can reduce the cost on the mental health system. Although dyslexia is the largest disability population, we also know that there will be a sizeable percentage of dyslexics who do not require NDIS support. Dyslexia is a broad ranging spectrum disorder and only those at the lower end would need ongoing support through the scheme. However, this support could increase success opportunities for dyslexic individuals by removing barriers, raising awareness of their strengths and weaknesses, and educating employers and educators about their needs.

3. Improved social and emotional wellbeing of dyslexic adults

Currently there is a lack of training for psychologists and mental health practitioners on dyslexia as a disability and the ongoing deep mental health difficulties that dyslexics can

face. Training on dual diagnosis should be embedded into educational practices within university courses and supported by ongoing professional development training.

4. Improve workplace practices through training.

Workplaces must take a proactive approach in better understanding the needs of their dyslexic employees. Change must occur across the employment lifecycle and include policy changes, improved inclusive practices and, most of all, training; especially for managers, those in leadership roles, such as people in human resources (HR) managers and inclusion and diversity role. Training must occur to help better understand the needs and strengths of dyslexic employees. Also, effective HR and retention activities, and ensuring organisations adhere to and comply with federal laws and legislation, are a necessity.

5. Align federal and state governments in relation to access to health care, education and employment for people with dyslexia.

According to the Organisation for Economic Cooperation and Development (OECD) in 2017, Australia faces the risk of lagging behind other countries in terms of innovation and economic growth if it fails to invest in enhancing the literacy and numeracy skills of its population. This risk is particularly significant as other nations have made substantial investments in improving their citizens' literacy skills. Over the past three decades the Federal Government has taken steps to streamline education standards, road safety and licensing, and aspects of the criminal code across the various states. It is recommended the same is done in relation to dyslexia as a disability. There is a pressing need for leadership that can guide and streamline dyslexia across education, employment and health with the states and territories to improve overall outcomes for individuals with dyslexia.

6. Increase in data collection and surveillance.

Given the relatively high prevalence of dyslexia in comparison to other hidden disabilities, such as autism spectrum disorder, it is crucial to collect data and implement surveillance measures that accurately capture the substantial impact of dyslexia on individuals. This can be achieved through comprehensive data collection efforts, including the incorporation of dyslexia-related questions in the Australian Census and the initiatives undertaken by the Australian Bureau of Statistics. By gathering reliable data, policymakers and stakeholders can develop appropriate policies and programs tailored to support individuals with dyslexia effectively.

7. Future research

In light of the findings from this research, it is recommended that funding be provided for further research to be undertaken to better understand the barriers and needs of adults with dyslexia and to improve quality of life outcomes for all Australians living with dyslexia.

8.7 Conclusion

This new Australian research endeavours to advance understanding of the lived experiences of adults with dyslexia, with a focus on workplace environments and social and emotional wellbeing. This novel and ground-breaking study challenges established paradigms that suggest dyslexia has limited (purely physiological) bearing on adults. Rather, this thesis exposes incontestable disadvantages and impediments enshrined in societal constructs and systems that obstruct the capacity of individuals with dyslexia to enjoy fulfilling and healthy lifestyles.

The creation of this thesis arose from the author's persistent frustration with the discrimination and lack of awareness that has characterised her personal and professional life. This work endeavoured to explore the author's own lived experiences through empirical analysis. The findings validate the author's own personal struggles, and the challenges articulated by each participant. While more research is necessary, there is a pressing need for societal change towards a more accepting attitude towards neurodivergent disabilities such as dyslexia. Raising awareness is critical, and this research endeavours to make a significant contribution.

Supplementary Materials

Contribution to publications

I am the primary author of all publications within this thesis. As the primary author, I carried out the majority of work relating to study design, ethics applications, recruitment of participants, data collection, data analysis and interpretation, manuscript drafting, manuscript editing and supervision of research assistants involved in the project, with support from my supervisors: Professor Leila Karimi, Associate Professor Dr Tanya Serry, Dr Lisa Furlong and Dr Judith Hudson.

Author contributions to publications

This thesis contains four published manuscripts and one submitted manuscript under review.

Author contributions to each manuscript are described below:

Wissell, S., Karimi, L., & Serry, T. (2021). Adults with dyslexia: A snapshot of the demands on adulthood in Australia. *Australian Article of Learning Difficulties*, 26(2), 153–166. <https://doi.org/10.1080/19404158.2021.1991965>

SW: study design, data collection, data analysis and interpretation, manuscript drafting, manuscript and editing.

LE: study design, data analysis and interpretation, manuscript drafting and editing.

TS: study design and manuscript editing.

Wissell, S., Karimi, L., Serry, T. Furlong, L., Hudson, J. (2022). “You don’t look dyslexic”: Using the JD-R Model to explore workplace experiences of Australian adults with dyslexia.

SW: study design, data collection, data analysis and interpretation, manuscript drafting, manuscript and editing.

LE: study design, data analysis and interpretation, manuscript drafting and editing.

TS: study design and manuscript editing.

LF: data analysis and interpretation, manuscript drafting and editing.

JH: manuscript drafting and editing.

Wissell, S., Karimi, L., Serry, T. Furlong, L., Hudson, J. (2022). Leading diverse workforces: Perspectives from managers and employers about dyslexic employees in Australian workplaces

SW: study design, data collection, data analysis and interpretation, manuscript drafting, manuscript and editing.

LE: study design, manuscript drafting and editing.

TS: study design data analysis and interpretation and manuscript editing.

LF: data analysis and interpretation, manuscript drafting and editing.

JH: manuscript drafting and editing.

Research Dissemination

Submitted publications

Wissell, S., Karimi, L., & Serry, T. (2021). Adults with dyslexia: A snapshot of the demands on adulthood in Australia. *Australian Article of Learning Difficulties*, 26(2), 153–166.

<https://doi.org/10.1080/19404158.2021.1991965>

Wissell S, Karimi L, Serry T, Furlong L, Hudson J. "You Don't Look Dyslexic": Using the Job Demands-Resource Model of Burnout to Explore Employment Experiences of Australian Adults with Dyslexia. *Int J Environ Res Public Health*. 2022 Aug 28;19(17):10719. doi: 10.3390/ijerph191710719.

Wissell, S.; Karimi, L.; Serry, T.; Furlong, L.; Hudson, J. Leading Diverse Workforces: Perspectives from Managers and Employers about Dyslexic Employees in Australian Workplaces. *Int. J. Environ. Res. Public Health* 2022, 19, 11991.

<https://doi.org/10.3390/ijerph191911991>

Oral presentations

Wissell, S., Karimi, L., Serry, T. Furlong, L., & Hudson, J. (2023) *Creating Inclusive Workplace Practices to Support Individuals with Dyslexia Across the Employment Lifecycle: Perspectives from Employers, Managers, and Employees with Dyslexia*.

Presenting at the International Conference on Equality, Diversity and Inclusion, Paris (Virtual).

Wissell, S., Karimi, L., Serry, T. Furlong, L., & Hudson, J. (2023) *Creating Inclusive Workplace Practices to Support Individuals with Dyslexia across the Employment Lifecycle*. 23rd International Conference on Diversity in Organizations, Communities & Nations, Toronto (Virtual).

Wissell, S., Karimi, L., Serry, T. Furlong, L., & Hudson, J. (2023). *Impact of dyslexia on mental health and wellbeing*. National Education Summit, Melbourne - Diverse Learners Symposium.

Wissell, S., Karimi, L., Serry, T. Furlong, L., & Hudson, J. (2022) *Creating Inclusive Workplace Practices: Support Individuals with Dyslexia Across the Employment Lifecycle*. Paper presented at the European Public Health Webinar (Virtual).

Wissell, S., Karimi, L., & Serry, T. (2021) *You don't look dyslexic, the lived experiences of adults with dyslexia in Australian workplaces*. Paper presented at the Living Successfully with Dyslexia in Australia Conference (Virtual).

Wissell, S., Karimi, L., & Serry, T. (March 2020). *Adults with dyslexia: A snapshot of the demands on adulthood in Australia*. Paper presented at the International British Dyslexia Conference: U.K (Virtual).

Wissell, S., Karimi, L., & Serry, T. (May 2019). *The Mental Wellbeing of Adults with Dyslexia Living in Australia*. Neurodiversity Conference, Brisbane, Australia.

Wissell, S., Karimi, L., & Serry, T. (March 2019). *The Mental Wellbeing of Adults with Dyslexia living in Australia*, International Mental Health Conference, Gold Coast, Australia (Virtual)

Wissell, S., Karimi, L., & Serry, T. (2018). *Living successfully with dyslexia in Australia: Adults with dyslexia: A snapshot of the demands on adulthood in Australia*. La Trobe University, Bundoora, Australia.

Appendices

Study A: Impacts of living with dyslexia in adulthood

1. Ethics Application



Research Office

To	Leila Karimi
From	SHE College Subcommittee
HEC Number	HEC18233
Project title	Impacts of living with Dyslexia in adulthood
Subject	Notification of Ethics Review Outcome
Date	30 June 2018

Thank you for submitting the above research project to the SHE College Subcommittee for ethical review.

Before the project can be approved, the SHE College Subcommittee asks for the following points to be responded to:

Application form

- Section 1.6:** please update the project conclusion date.
This has been completed.
30/06/2020
- Section 2.23 and PICF:** the student researcher's involvement with the Dear Dyslexic Foundation could be understood as a potential conflict of interest in this project. Please select yes to this section, provide an answer and declare this potential COI in the PICF.
This has been completed
The student researcher is involved with the Dear Dyslexic Foundation which could be understood as a potential conflict of interest in this project. This is outlined in the PICF.
- Section 2.3:** please include information about the methods of data analysis and how it will be interpreted in such a way that it will address the aims of the project outlined in Section 2.1.
This has been completed.
The survey will be an online, anonymous tool that has two main parts.
In part one, some brief demographic questions will be asked. In part two, we will use the Warwick-Edinburgh Mental Well-being Scale, 2008, which is a validated tool. The survey should take approximately 15 minutes to complete.

Recruitment of approximately 40 participants will occur by using a targeted awareness campaign via social media. including:

- promoting the study through Dear Dyslexic Foundation Website (www.deardyslexic.com), networks, newsletter. The Dear Dyslexic Foundation is a not-for-profit organisation. Their vision is for all those 16 and over with dyslexia are empowered to reach their full potential. The student researcher is the CEO and Founder of the Dear Dyslexic Foundation. The Foundation will use this research to develop evidence-based workplace training program and resources.
- posting on social media on the Dear Dyslexic Foundation Facebook, Twitter, LinkedIn and Instagram pages, Dyslexic Specific Facebook Pages such as Dyslexia Support Victoria, Dyslexia Support Australia Facebook Pages (the third author is a member of these closed Facebook groups and will seek permission), through national dyslexia-specific organisations such as SPELDVic (after seeking permission). In addition, we will seek permission to advertise on the La Trobe University Facebook page and twitter feed.

Section 2.4: please select 'No' to ensure consistency with section 4.1.
This has been completed.

4. **Section 2.5:** please select 'no' as the study does not involve use of information for an existing data base.
This has been completed.
5. **Section 2.6:** Please amend to 'yes' as Section 2.1 states that the proposed study is preliminary to a larger PhD project.
This has been completed.
6. **Section 2.23:** Please amend to 'yes'.
This has been completed.
7. **Section 3.4:** please update this section to clearly reference the aim when justifying your proposed participant numbers.
This has been completed.
8. **Section 3.9:** The Committee ask the researchers to use Qualtrics instead of using Survey Monkey.
This has been completed.
Survey has been changed to Qualtrics and uploaded into Research Master Application.
9. **Section 5.2:** Please select 'direct electronic data entry' as another answer
This has been completed.
10. **Section 5.10:** Please select 'research report to collaborating organisations'.
This has been completed.
11. **Section 5.13:** Please select 'no' to this questions as data will be collected anonymously.
This has been completed.

Recruitment Materials

Please update the following in the recruitment materials:

- a. Include the ethics approval reference number HEC1833
This has been completed.

New Application - Subject to letter version dated 21 February 2018

Page 2 of 2

- b. Include the nature of the research project
This has been completed.
I am currently researching the social and emotional wellbeing of adults that have dyslexia through La Trobe University, School of Public Health.
 - c. Include the School/Department hosting the study
This has been completed.
 - d. Include the name and LTU contact information of the CI
This has been completed.
 - e. remove the student investigator's personal phone number
This has been completed.
 - f. include the phone number for the Dear Dyslexic Foundation (1800 589 667)
This has been completed.
- All amended documents have been uploaded onto into Research Master Application.**

Participant information Statement & Consent Form (PICF)

- 12. Please specify the area of study (Doctor of..., or PhD).
This has been completed.
 - 13. **Personnel information box:** the Committee think it is important to declare the student's organisations as La Trobe, Department of Public Health and Dear Dyslexic Foundation. Please update the personnel information box to reflect this advice.
This has been completed.
 - 14. **Section 4:** Please update the survey completion time to reflect the application form (15 minutes).
This has been amended
 - 15. **Section 6:** Please delete student's personal phone number.
This has been amended
 - 16. **Section 10:** Please include the chief investigators LTU contact information.
This has been completed.
- All amended documents have been uploaded onto into Research Master Application.**

How to prepare a response

Please prepare the following documents as part of your response:

- 1. **Responding to comments:** in this letter, provide a response below each question in regular font
- 2. **Application Form:** make the changes via Research Master
- 3. **Attachments:** provide a marked-up copy (using tracked changes) and clean copy

How to submit your response

- 1. Email humanethics@latrobe.edu.au
- 2. Email Subject Heading should read 'Resubmission of HEC18233'

Please respond within three-months from the date of the letter, otherwise the application will be withdrawn and a new application will need to be submitted.

Should you require any further information, please contact the Human Research Ethics Team on:
T: +61 3 9479 1443 | E: humanethics@latrobe.edu.au.

Warm regards,

Agnes Hazi
Deputy Chair, SHE College Subcommittee

2. Consent Form and Participant Information Statement



Participant Information Statement and Consent Form



Impacts of living with Dyslexia in adulthood		
The research is being carried out in fulfilment of Doctorate under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researchers will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Doctoral Student	La Trobe University, Department of Public Health and Dear Dyslexic Foundation
Research funder	This research is supported by in kind support by La Trobe University.	

1. What is the study about?

You are invited to consider participating in a study of to explore the perceived impact on the social and emotional wellbeing for adults who have dyslexia. We hope to learn how dyslexia can impact on the lives of adults.

2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. Who is being asked to participate?

To be eligible for this study, you must be 18 years and over and you must have received a formal diagnosis of Dyslexia.

4. What will I be asked to do?

If you want to take part in this study, you'll be asked to complete an online survey that is anonymous. We will ask about your age, education, employment status, and how you think Dyslexia has impacted on your social and emotional wellbeing. The survey will take approximately 15 minutes.

5. What are the benefits?

We are unable to say if there will be any direct benefits to you. However, once this study is complete you will be able to learn about other people's experiences with dyslexia's in the workplace.

The expected benefits to society in general are to identify what social and emotional issues those with dyslexia are facing to consider how we can better support them.

6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Shae Wissell La Trobe University	Research Student	1800 589 667	2995513@students.latrobe.edu
Dr <u>Leila Karimi</u>	Chief Investigator	3 9479 3013	l.karimi@latrobe.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

Some of the questions may make you feel uncomfortable and you may feel upset while answering some of the questions. If this occurs, we will support you to contact your GP or other health-care provider. Please speak to the researchers for any assistance. For emergency support, you can contract Beyondblue - 1300 22 4636 or Lifeline – 13 11 14.

7. What will happen to information about me?

3. Recruitment Flyer



IMPACTS OF LIVING WITH DYSLEXIA IN ADULTHOOD

HEC1833

If you are 18 and over and have a formal diagnosis of dyslexia, then I would like to hear from you. I am currently researching the social and emotional wellbeing of adults that have dyslexia through La Trobe University, School of Public Health. So, if that's you then I would love you invite you to consider participating in this 15-minute online survey.

Why, well it's the first time anyone in Australia has asked people with dyslexia how they are feeling, what they need and how they could be better supported, can you believe that!!



4. Survey

Impacts of living with Dyslexia in adulthood

Start of Block: Default Question Block

Part 1. General information about yourself.

Q1 What is your gender?

- Female (51)
 - Male (52)
 - Transgender (53)
 - Other (54)
 - Prefer not to say (55)
-

Q2 What is your age?

- 16 - 20 (152)
 - 20 - 29 (153)
 - 30 - 39 (154)
 - 40 - 49 (155)
 - 50 - 59 (156)
 - 60 + (157)
-

Q3 How old were you when you were diagnosed with dyslexia? If you are not sure of your age please put an approximate age or write unsure.

Q4 Can you recall which professional diagnosed your dyslexia?

- Educational Psychologist (1)
- Neuropsychologist (2)
- Speech Pathologist (3)
- GP (4)
- Can't recall (5)
- Other (please specify) (6) _____

Q5 What is the highest level of education you have completed?

- Year 11 or lower (1)
- Completed Year 12 (2)
- Diploma qualification (3)
- Under-graduate degree Post-graduate degree (4)

Q6 Which of the following categories best describes your current employment status?

- Employed (1)
 - Working part-time (2)
 - Employed (3)
 - Working full-time (4)
 - Not employed, (5)
 - Looking for work (6)
 - Not employed (7)
 - Not looking for work (8)
-

Q7 If you are currently employed, can you please state what it is?

Q8 How likely are you to disclose your dyslexia to your family?

- Very likely (23)
 - Likely (24)
 - Unlikely (25)
 - Very unlikely (26)
 - Unsure (27)
-

Q9 How likely are you to disclose your dyslexia to your friends?

- Very likely (23)
 - Likely (24)
 - Unlikely (25)
 - Very unlikely (26)
 - Unsure (27)
-

Q10 If you work, how likely are you to disclose your dyslexia to your work colleagues?

- Very likely (19)
 - Likely (20)
 - Unlikely (21)
 - Very unlikely (22)
 - Unsure (23)
-

Q11 Part 2: Information on your wellbeing. Please read each question and decide how often, over the last six months you have felt the following:

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	All of the time (5)
I've been feeling optimistic about the future? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling useful? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling relaxed? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling interested in other people? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've had been dealing with problems well? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been thinking clearly? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've have the energy to spare? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling close to people? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling confident? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling good about myself? (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I've been feeling loved? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I've been able to make up my own mind about things? (12)

Become easily bored? (13)

I've been feeling cheerful? (14)

I've been interested in new things? (15)

Thank you for taking this survey.

End of Block: Default Question Block

Study B: Looking from the Outside In - Dyslexia and the Workplace

1. Ethics Application



Research Office

Research and Graduate Studies Committee
University Human Ethics Committee
College Human Ethics Sub-Committees

LOW RISK PROJECT – HUMAN RESEARCH ETHICS

1. Project Title	Impacts of Dyslexia a hidden disability with Dyslexia in adulthood
2. Chief Investigator / Supervisor: <small>(academic staff members only)</small>	Name: Dr. Leila Karimi Email address: L.karimi@latrobe.edu.au Department: College of Science, Health and Engineering
3. Student Investigator <small>(if applicable)</small>	Shae Wissell B.App. Sc (Speech Path) MHA/MPH

4. Provide a description of the project in plain language including:

- ***Aims of the research (Including a brief background to the research)***

Development Dyslexia (DD) is a neurological-learning disability, which causes significant processing difficulties in read comprehension, fluency, speed and can impact on grammar, punctuation and spelling. It is usually genetic and lifelong, unaffected by educational level or exceptional teaching (Lyon, Shaywitz & Shaywitz, 2003). DD can have mathematics and associated language processing deficits, such as difficulty with phonic analysis or working memory. (Low, B.J, & Low, D.M I, 2006). It is estimated that one in ten people have dyslexia (Moody, 2009). Like many other learning disabilities such as Autism, dyslexia exists on a spectrum and can fluctuate from day- to-day depending on a person's mental health, fatigue and daily stressors. It is not uncommon for dyslexia to co-occur with other learning difficulties including dyscalculia (mathematics and numeracy literacy, dyspraxia (fine motor coordination such as hand-writing), dysgraphia (written expression) and attention deficit hyperactivity syndrome (Moody, 2009).

Over the years a number of countries have made significant progress in the way they identify and support people with dyslexia. However, in Australia is this not the case. Australia is significantly further behind other first world countries in regard to early identification, interventions and ongoing support from across the life spectrum from school years into the workplace and beyond (Nalavany, Carawan & Rennick, 2010). Evidence suggests that without functional literacy skills to read signs, fill in forms, write emails and social integration is beyond the reach of young people and adults with DD who have no choice but to remain socially isolated and dependent on society (Dyslexia International, 2016).

DD and associated poor literacy and numeracy skills can lead to lesser life outcomes across the social determinates of health including education, employment opportunities, economic status, health literacy, and most distressing an over-representation in the justice system (Walt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P., 2004 & Grigorenko, E. L., Macomber, D., Hart, L., Naples, A., Chapman, J., Gelb, C. F., Wagner, R. 2015).

Not just impacting on the individual but society as illustrated in diagram 1.

The growing complication of the modern workplaces and modern life means that we are increasing needing to improve our literacy skills to match the changing environment.

Diagram 1. Dyslexia and the Social Determinants of Health



Australia’s current economic forte provides exceptional opportunities for more people than ever before to participate in the workforce ensuring that economic prosperity can be by all in society (Commonwealth Government, 2011). However, there are many Australians of working age that have poor literacy and numeracy skills. In fact, between 2 and 3 of every 10 Australian adults is officially below the level required to meet all the complex demands of modern work and life (Dyslexia Working Party, 2010). Minimal research exists that evaluates the risk of discrimination in the workplace based on low literacy skills caused by DD. Effective communication through different written mediums is an essential criterion in many workplace environments. When people with DD enter the workforce, they must adapt to a complex environment with numerous demands and little support (Beer et al, 2014). Some people with DD may not feel comfortable disclosing their difficulties due to fear of discrimination and loss of employment. Some examples of problems that those with DD may face include complex tasks that increase workload, a reliance on support from colleagues or family members at home, the physical working environment may present challenges such as background noise and other distractions (Beer et al, 2014). This can be further exacerbated by the mismatch between the employees’ abilities and the employer’s expectations (Miles and Varma, 1995). This can all lead to employees feeling undue stress and anxiety, not meeting performance expectations and having lower career prospects resulting in poorer social and emotional wellbeing and it could be argued that discrimination would occur.

Research into the impacts of DD in the workplace have been undertaken several European Countries as well as America, Canada and as close as New Zealand however, nothing of its kind has been undertaken in Australia. Leading to a gap in the workforce for those with DD to perform their jobs to the best of their abilities and improve their economic and social status. This leaves Australia with a subset of the population with have poor life outcomes and reduced productivity to grow our own within Australia.

In this research project, we will interview adults who have a lived experience of the DD and associated learning disabilities dyscalculia and dysgraphia within the workplace.

The second part of the research project will survey employers in the workplace to identify if they have an awareness and understanding of dyslexia within the workplace setting.

The specific aim of this project is to gain an understanding in dyslexia and associated learning disabilities within the Australia context from a dyslexic perspective and from an employer's perspective. This research will be the first of its kind in Australia looking at the impact of dyslexia and associated learning disabilities in the workplace and how we can better improve outcomes for those with dyslexia in the workplace, so they can have healthier, happier more connected lives.

- **Methods (if recruiting participants please include specific detailed step-by-step recruitment methods)**

Survey

A survey will be sent out anonymous using an online tool and should take approximately 15 minutes to complete.

Recruitment of 30 – 40 participants will occur by using a random sampling of organisation across blue and white-collar sectors.

Interview

Recruitment of 10 – 15 participants will occur by using a targeted awareness campaign via social media. Recruitment for interview participants will be through the following:

- promoting the study through Dear Dyslexic Foundation Website (www.deardyslexic.com), networks, newsletter. The Dear Dyslexic Foundation is a not-for-profit organisation. Their vision is for all those 16 and over with dyslexia are empowered to reach their full potential. The student researcher is the CEO and Founder of the Dear Dyslexic Foundation. The Foundation will use this research to develop evidence-based workplace training program and resources.
- posting on social media on the Dear Dyslexic Foundation Facebook, Twitter, LinkedIn and Instagram pages, Dyslexic Specific Facebook Pages such as Dyslexia Support Victoria, Dyslexia Support Australia Facebook Pages (the third author is a member of these closed Facebook groups), through national dyslexia-specific organisations such as SPELDVic. In addition, we will seek permission to advertise on the La Trobe University Facebook page.
- Dear Dyslexic Foundation Assessment Clinic, 842 Nicholson St North Fitzroy

- **Nature of participants and participation (if any).**

To be eligible for this study participants must:

- aged 18 and over
- have had a self-disclosed formal diagnosis of dyslexia by a medical and/or allied health professional at any time in their life

Although participants have dyslexia, it is anticipated that they will be able to complete this task as they are presumed to have functional literacy skills. A Participant Information Statement (PIS) is attached.

5. Specify the precise location/s where recruitment and data collection will occur.

Recruitment will occur online. Self-reported anonymous survey data will be collected online via the SurveyMonkey program (Research Electronic Data Capture) at a time and location suitable to individual participants.

6. Specify the precise location/s data will be stored (both electronic and hard copy data)

During the study, data will be stored on a password protected computer that belongs to the student researcher. After the study, data will be stored for five years on the La Trobe University's Research Data Storage system and destroy in line with La Trobe University's Research Data Management policy.

7. Type of Project (indicate whichever is applicable)

- | | |
|--|--|
| <input type="checkbox"/> Research by Academic Staff Member | <input checked="" type="checkbox"/> Postgraduate Research |
| <input type="checkbox"/> Contract Research | <input type="checkbox"/> Masters Research/Coursework |
| <input type="checkbox"/> Undergraduate Research | <input type="checkbox"/> Honours Research |
| <input type="checkbox"/> Clinical Trial | <input type="checkbox"/> Funded by external grant (please specify funding body and title of project) |
- [Click here to enter text.](#)

8. Please provide evidence for why the study should be classified as negligible risk (not low risk) as defined by the National Statement (as per sections [2.1.7](#), [5.1.6-8](#) and [5.1.22-23](#))

We do not anticipate any risks to participants arising from the research activities. This research does not target any groups with vulnerabilities nor include sensitive or potentially distressing questions.

9. RESEARCH USING EXISTING DATABASES

If research involves access to existing data bases provided by an institution/s, please indicate:

- a) / Where the data is held, source/s and number of records
N/A
- b) Whether data to be used will be non-identifiable, re-identifiable (e.g. coded) or identifiable
N/A
- c) Whether permission has been granted by donors to use these data for research purposes
N/A
- d) Whether formal permission/clearance has been sought or obtained from the relevant institution/s
N/A

10. Complete an Investigator Template for each La Trobe investigator involved.

CHIEF INVESTIGATOR: La Trobe University Staff Only			
For database purposes please ensure that all details are up to date and correct.			
Name	Dr Leila Karimi	Phone	Click here to enter text.
Email address	l.karimi@latrobe.edu.au	Staff/ Student No.	Click here to enter text.
Academic title /	Click here to enter text.	Signature	Click here to enter text.

Qualification / If student provide details		(electronic or scanned)	
Role on the project and experience relevant to the project.	Click here to enter text.		

INVESTIGATOR 2: Student			
For database purposes please ensure that all details are up to date and correct.			
Name	Shae Wissell	Phone	
Email address	2551773@students.latrobe.edu.au	Staff/ Student No.	
Academic title / Qualification / If student provide details	Bachelor Speech Pathology Master Public Health and Health Administration	Signature (electronic or scanned)	
Role on the project and experience relevant to the project.	Shae Wissell is the CEO and Founder of the Dear Dyslexic Foundation. Shae originally trained as a Speech Pathologist, Shae went on to complete a Master's degree in Public Health and Health Administration. Through her work as a speech pathologist, manager with the health sector, public health practitioner and her own personal experiences of having dyslexia, Shae has developed a passion for supporting young people and adults with dyslexia, and learning difficulties.		

INVESTIGATOR 2: Associate investigator			
For database purposes please ensure that all details are up to date and correct.			
Name	Tanya Serry	Phone	03 9479 1814
Email address	T.Serry.latrobe.edu.au	Staff/ Student No.	423741
Academic title / Qualification / If student provide details	PhD	Signature (electronic or scanned)	I will sign when complete
Role on the project and experience relevant to the project.	Tanya Serry is a speech pathologist and senior lecturer at La Trobe University, who has taught in speech pathology and audiology programs in for the past 18 years. Tanya's research and teaching is focused on language and literacy and learning difficulties among students from the early years through to tertiary students as well as students experiencing social disadvantage. Tanya's research and teaching centres on how to facilitate greater collaboration between educators, parents, speech pathologists and psychologists.		

The form must be submitted electronically by the Chief investigator from the La Trobe University staff email account. Please ensure you also submit:

- A completed Human Ethics Risk Assessment Checklist [PDF 1.7 MB]
- Any permissions obtained or indicate when permissions will be obtained from the applicable institutions.
- Participant Information Statements (if collecting data from participants).
- Surveys, questionnaires and/or interview sample questions (if applicable)
- Recruitment material such as posters, draft emails, drafts for a facebook page or website etc. (if applicable)

Please submit all forms to humanethics@latrobe.edu.au

Website: <http://www.latrobe.edu.au/researchers/research-office/ethics/human-ethics>

Reference

Beer, J.D., Engles, J., Heerkens, Y & Van Der Klink, J. (2014) *Factors Influencing Work Participation of Adults with Developmental Dyslexia: A Systematic Review*. BMC Public Health 2014, 14:77

Bond, J., Coltheart, M., Connell, T., Firth, N., Hardy, M., Nayton, M., . . . Weeks, A. (2010). Helping people with dyslexia: A national action agenda: Report to the Hon Bill Shorten, Parliamentary Secretary For Disabilities And Children's Services. Retrieved from <http://www.dyslexiaaustralia.com.au/DYSWP.pdf>

Boyes, M., Leitao, S., Claessen, M., Badcock, N., & Nayton, M. (2015) Why Are Reading Difficulties Associated with Mental Health Problems? *Reading Difficulties and Child Mental Health, Dyslexia* 22: 263–266 (2016)

Fuller-Thomson, E., Carroll, S. Z., & Yang, W. (2018). Suicide Attempts Among Individuals With Specific Learning Disorders: An Underrecognized Issue. *Journal of Learning Disabilities*, 51(3), 283-292. doi:10.1177/0022219417714776

Lyon, G. R., Shaywitz, S. E., & Shaywitz, B. A. (2003). *A definition of dyslexia, Annals of dyslexia*, 53(1), 1-14. *Medical Association J of Ethics*, 8 (11): 756-761. Accessed on 17 January 2016 retrieved from <http://journalofethics.ama-assn.org/2006/11/pfor1-0611.html>

Snow, P. C. (2016). Elizabeth Usher Memorial Lecture: Language is literacy is language-Positioning speech-language pathology in education policy, practice, paradigms and polemics. *International Journal of Speech-Language Pathology*, 18(3), 216-228.

2. Research Data Management Plan

Research Data Management Plan blank template supplied by Research Data team, Library

Research Data Management Plan

This tool will guide you through the creation of a Research Data Management Plan. It will prompt you to think about how you will manage data generated and used in your research project, both during the project and afterwards.

The tool aims to introduce researchers to good data management practice, in line with La Trobe's Research Data Management Policy and Procedure.

On completion, you can generate a PDF document that you can use in grant applications or ethics submissions.

As you use the tool:

- click on [?] for more information
- * indicates a mandatory field

Information gathered from the research data management planning tool will be used to support ongoing review of La Trobe's research data management policy and procedure, and planning for data management support services.

Please note that a research data management plan does not replace the following institutional requirements for ethics and other legal compliance:

- Human ethics
- Animal ethics
- Biosafety
- Defence export control

For further information regarding research integrity, biosafety and ethics approvals, please refer to [Ethics, Biosafety and Integrity](#).

For further queries or assistance please contact libraryresearchsupport@latrobe.edu.au.

Overview

Project title: Looking from the Outside In - Dyslexia and the Workplace

Project Description:

Dyslexia is estimated to affect some 10% of the population¹. This may be a conservative estimate as many individuals are left unidentified in the Australian population. Over the years, a number of countries such as England and Europe, have recognised Dyslexia as a learning disability and have made significant progress in policy development and practices for identifying and supporting children and adults with Dyslexia. However, in Australia this not the case². Dyslexia impacts on a person throughout his/her life from school years to the workplace and beyond³.

The purpose of this study is twofold. Firstly, we will seek to better understand a person's experience with Dyslexia in the workplace. Data will be collected through interviews conducted with adults who have Dyslexia working or have previously held employment. Secondly, this research will seek the views and experiences of employers who work or manage staff with Dyslexia. This data will also be collected through interviews. In this way, we are seeking to capture both perspectives of the workforce.

Outcomes of this research will contribute to improving, and or, establishing preliminary strategies and processes around how to best accommodate the needs of individuals with Dyslexia in the workplace, whilst also meeting the expectations of employers.

Project Type

Research project Higher degree by research project

Is this research externally funded?

Yes No

Grants: *If applicable*

¹ Moody, S., (2009) *Dyslexia and Employment: A guide for Assessors, Trainers and Managers*, Wiley-Blackwell, United Kingdom

² Bond, J., Coltheart, M., Connell, T., Firth, N., Hardy, M., Nayton, M., . . . Weeks, A. (2010). *Helping people with dyslexia: A national action agenda: Report to the Hon Bill Shorten, Parliamentary Secretary For Disabilities And Children's Services*. Retrieved from <http://www.dyslexiaaustralia.com.au/DYSWP.pdf>

³ Nalavany B. A, Williams Carawan. L, Rennick, R. A., (2010) *Psychosocial Experiences Associated with Confirmed and Self-Identified Dyslexia: A Participant-Driven Concept Map of Adult Perspectives*, *Journal Learning Disabilities* vol. 44 no. 1 63-79

Grant number	Grant description	Funding source

Project start date:

01.06.2019

Project end date:

01.12.2020

Personnel

Contributor	Email	Role
Leila Karimi	l.karimi@latrobe.edu.au	Chief Investigator
Tanya Serry	t.serry@latrobe.edu.au	Associate Investigator
Shae Wissell	s.wissell@latrobe.edu.au	Student Investigator

Will you be working with external collaborators (non-La Trobe University)?

Yes – The Dear Dyslexic Foundation

PLEASE LIST EXTERNAL COLLABORATORS IF APPLICABLE

Contributor	Email	Institution
Shae Wissell	ceo@deardyslexic.com	Dear Dyslexic Foundation

Data Overview

In your Research project, will you be generating or reusing data:

Yes

How will you generate the data?

Data will be collected using semi-structured individual interviews which will be conducted face-to-face (in person, via zoom or telephone) . Data will be captured using a digital recorder or inbuilt audio recording functionality in ZOOM, with the permission of the participants.

***If applicable* What is the source of the data you will re-use?**

N/A

How will you ensure the data is accurate, complete, authentic and reliable?

Data will be transcribed and thematically analysed. Monthly meetings with supervisors will occur to ensure the integrity of the analysis of the data and thematic codes generated are reliable, which will

Research Data Management Plan blank template supplied by Research Data team, Library

also be reviewed by the Chief Investigator on a regular basis. The data will also be reviewed by my Graduate Research Committee for review.

If a transcription service provider is engaged, the relevant confidentiality agreement form will be executed and signed.

During your project, how will you provide access to the data to others outside La Trobe who require it for collaboration, commercial, contractual or other reasons?

N/A

Data Storage

Where will the data be stored?

During the study, data will be stored on a password-protected computer that belongs to the student researcher within a data storage system in line with La Trobe University's Research Data Management policy.

Will you store any research data on personal equipment?

Yes – see above

How will you back up your data or make secure copies and how often?

Data will be backed up on the data storage system on OneDrive in line with La Trobe University's Research Data Management policy.

Will you require storage for physical research data and primary research materials?

No physical data; all electronic. Electronic research data will be collected through audio recording via Zoom. This data will be stored will be stored on a password-protected computer that belongs to the student researcher within a data storage system in line with La Trobe University's Research Data Management policy.

How will the security of your research data be ensured?

- Use of Research Data File Storage
- Codes and data kept separately
- Lockable filing cabinets
- Locked room
- Digital password protection
- Other: please describe:

Sensitive Data

In the context of Research Data Management, sensitive data is data that can be used to identify an individual, species, object, or location that introduces risk of discrimination, harm, or unwanted attention.

Information on human data privacy is available in the Australian Privacy Principles and Statutory Guidelines on Research.

Are you working with sensitive or identifiable data?

Yes

What extra security measures will you take to protect your sensitive research data?

All identifiable information in written transcripts of interviews will be deidentified with participants given a unique ID number. Data will then be coded and thematically analysed for reporting.

Post Project

How long will you retain your research data after the project concludes?

- Indefinitely
- 5 years
- 7 years
- 15 years
- 25 years
- Not retained
- Other: please specify:

How will the data be organised after the project concludes?

After the study, data will be stored for five years on the La Trobe University's Research Data Storage system and destroy in line with La Trobe University's Research Data Management policy.

If it is necessary to destroy your data, how will the data be destroyed?

All data will be deleted from the server where it has been stored, in line with La Trobe University's Research Data Management policy.

Will a metadata record (descriptive record) be created to describe the research data?

No

If applicable **Where will the metadata record be published?**

- Research Online
- Other archive or repository: please specify:

If applicable **Reason for not creating metadata:**

It is a small sample and not applicable.

Will there be physical research data and primary materials to be archived at the end of the project?

No

Can the research data be shared with other researchers once the project is complete?

No access (the research data and/or metadata cannot be shared).

B.1 Study: Dyslexia in the workplace: Looking outside in

1. Consent Form



Consent Form

LOOKING FROM THE OUTSIDE IN - DYSLEXIA AND THE WORKPLACE		
Employee Interview		
This research is being carried out in fulfilment of a PhD under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researcher will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Graduate Researcher	La Trobe University, Department of Public Health, and the Dear Dyslexic Foundation
Research funder	This research is supported by in-kind support from La Trobe University.	

Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understand the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study. I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, in presentations and in journal articles, on the condition that I cannot be identified.

I would like my information collected for this research study to be:

- only used for this specific study.
- I agree to have my interview audio and/or video recorded.

Please put your name and email address below, so the student researcher can send your transcription to review.

Name	Email (optional)	Postal address (optional)

Participant Signature

- I have received a signed copy of the Participant Information Statement and Consent Form to keep.

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

- I have given a verbal explanation of the study, what it involves, and the risks, and I believe the participant has understood.
- I am a person qualified to explain the study and the risks and to answer questions.

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature.

Consent Form

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University of any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group

***If you have consented for your contact details to be included in a participant registry you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data

- Destroyed and not used for any analysis
- Used for analysis

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

CI Name	[INSERT - CI Name]
Email	[INSERT - work email address]
Phone	[INSERT - work phone]
Postal Address	[INSERT - work postal address]

2. Withdrawal Consent Form



Withdrawal of Consent for Use of Data Form



LOOKING FROM THE OUTSIDE IN - DYSLEXIA AND THE WORKPLACE		
Employee Interview		
This research is being carried out in fulfilment of a PhD under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researcher will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Graduate Researcher	La Trobe University, Department of Public Health, and the Dear Dyslexic Foundation
Research funder	This research is supported by in-kind support from La Trobe University.	

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University or any other organisation or professional listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study.
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in future studies, unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

*** If you have consented for your contact details to be included in a participant registry, you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data:

- destroyed and not used for any analysis
- used for analysis.

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Withdrawal of Consent for Use of Data Form

Please forward this form to:

CI Name	Shae Wissell
Email	swissell@latrobe.edu.au
Phone	1800 589 667
Postal Address	Shae Wissell P.O. Box 5123 Moreland West 3055 VIC

3. Participant information statement



DYSLEXIA EMPLOYEE Participant Information Statement



LOOKING FROM THE OUTSIDE IN - DYSLEXIA AND THE WORKPLACE		
EMPLOYEE INTERVIEW		
This research is being carried out in fulfilment of a PhD under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researcher will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Graduate Researcher	La Trobe University, Department of Public Health, and the Dear Dyslexic Foundation
Research funder	This research is supported by in-kind support from La Trobe University.	

1. What is the study about?

You are invited to participate in a study exploring your experience of dyslexia within the workplace.

2. Do I have to participate?

Being part of this study is voluntary. If you wish to take part in the study, please carefully read (or have read to you, where appropriate) the information below.

If, after reading the information below, you decide not to participate in this study, your relationship with La Trobe University, Dear Dyslexic Foundation or any other listed organisation will not be affected.

3. Who is being asked to participate?

To be eligible for this study you must:

- be 18 years or over
- live in Australia
- have a formal diagnosis of dyslexia
- have participated in the workforce for a minimum of three years.

4. What will I be asked to do?

If you wish to take part in this study, you will be asked to complete an interview with Shae Wissell (student researcher), which will be conducted at your convenience, via videoconference through Zoom.

You will be asked about your experiences in the workplace, and about your employer's understanding of and attitudes towards you and dyslexia within the workplace.

The interview will take approximately one hour to complete and will be audio recorded via zoom.

5. What are the benefits of participation?

We are unable to say if there will be any direct benefit to you. However, once this study is complete you will be able to learn about other people's experiences of dyslexia in the workplace. You will also gain access to employer perspectives on working with and managing employees with dyslexia.

The study will benefit society in general through examining workplace understandings and knowledges of dyslexia and identifying how employees with dyslexia might be better supported. This is likely to enhance employee experiences within the workplace, leading them to be healthier and happier individuals, with more connected lives. Consequently, employers may find that these staff perform at a higher level and are more productive.

The Dear Dyslexic Foundation offers a variety of workplace resources and services that you can access at any time.

6. What are the potential conflicts of interest?

A potential conflict of interest for this research project is that the student researcher is the founder of the Dear Dyslexic Foundation (DDF). DDF provides services and support for young people and adults with dyslexia, particularly those who are trying to finish school or start at university or TAFE, and those who are in the workplace. DDF has partnered with La Trobe University to undertake this research and will use the results to promote the development of services and supports that empower those with dyslexia to reach their full potential and live healthier, happier and more connected lives.

7. What are the risks?

With any study there are (1) risks that can be predicted, (2) risks that cannot be predicted, and (3) risks that are unexpected. If you experience something that you are not sure about, please contact us immediately, so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Shae Wissell La Trobe University	Graduate Researcher	1800 589 667 Direct line	s.wissell@latrobe.edu.au
Dr Leila Karimi La Trobe University	Chief Investigator	03 9479 3013	l.karimi@latrobe.edu.au

\We have listed the risks we know about below. This will help you decide if you want to be part of the study.

Some of the questions may make you feel uncomfortable and you may feel upset while answering them. If this occurs, you can stop the interview at any time.

The student researcher will provide you with a debriefing about any issues and/or distress. Depending on the matter causing the distress you may be referred to the following:

- your GP or another health-care provider
- your Employer Assist Program
- Beyondblue (1300 22 4636) or Lifeline (13 11 14)
- the Dear Dyslexic Facebook group, for peer support.

8. What will happen to information about me?

We will collect and store information about you in ways that will not reveal who you are. This means you can not be identified in any type of publication arising from this study.

We will keep your information for a length of five years after the project is completed. After this time, we will destroy all of your data.

We will collect, store and destroy your data in accordance with La Trobe University's Research Data Management Policy, which can be viewed online using the following link:

<https://policies.latrobe.edu.au/document/view.php?id=106/>.

The information you provide is personal information for the purposes of the Privacy and Protection Act 2014 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

9. What happens to the data that I provide?

A transcript of your interview will be provided to you so that you may confirm that the information recorded in the transcript is accurate. It is your choice whether to review your transcript. If you would like any changes made to your transcript, you can contact the student researcher by email or phone to discuss what you would like amended. Your transcript will then be combined with all the other participants' transcripts and the aggregate data analysed.

10. Will I hear about the results of the study?

A summary of the results will be available to you on request. Please email the graduate researcher (Shae Wissell) to receive a copy of these.

Results will be published in the following places:

- a thesis

- journal papers
- a book
- conference presentations.

11. What if I change my mind?

If you no longer wish to take part in the study, you may withdraw for any reason. Your decision to withdraw at any point will **not** affect your relationship with La Trobe University, the Dear Dyslexic Foundation or any other organisation listed. After your interview you have up to four weeks to withdraw from the study.

You can let us know by:

- completing the 'Withdrawal of Consent Form' (provided at the end of this document)
- calling us
- emailing us.

If you choose to withdraw during the interview, we will stop asking you for information. Any identifiable information about you will be removed from the research study. However, once the four-week period following your interview has passed, your transcript will be deidentified and it will no longer be possible to withdraw your data.

12. Who can I contact with questions or if I want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Shae Wissell La Trobe University	Graduate Researcher	1800 589 667 direct line	Swissell@latrobe.edu.au
Dr <u>Leila Karimi</u>	Chief Investigator	03 9479 3013	lkarimi@latrobe.edu.au

13. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC19254	Senior Research Ethics Officer	03 9479 1443	humanethics@latrobe.edu.au

4. Recruitment flyer

Dear
Dyslexic



LOOKING OUTSIDE IN – LIVING AND WORKING WITH DYSLEXIA IN ADULTHOOD



Ethics ID: HEC19254

If you are 18 or over and have a formal diagnosis of dyslexia, I would like to hear from you.

I am a research student in the School of Psychology and Public Health at La Trobe University, and I am investigating the impact of living and working with dyslexia in adulthood. This is the first time anyone in Australia has conducted research to gain a better understanding of lived experiences within the workplace for adults with dyslexia.

If you live in Australia, have a formal diagnosis of dyslexia, and have disclosed that you have dyslexia to an employer, I invite you to participate in an interview with me exploring your views and your experiences within the workplace.

The interview will take up to one hour and can be done at a time that is convenient for you, through Zoom (which is like Skype), by phone, or face-to-face. Your privacy will always be respected and the information you provide will be treated with strict confidentiality.

Please contact Shae Wissell at s.wissell@latrobe.edu.au or on 1800 589 667 to find out more about how you can participate in this exciting, first-of-its-kind research in Australia.

This research project is under the supervision of Dr Leila Karimi and Dr Tanya Serry from La Trobe University.

5. Interview guide



INTERVIEW GUIDE: LOOKING FROM THE OUTSIDE IN DYSLEXIA AND THE WORKPLACE

Group 1 - Adults who have a formal diagnosis of dyslexia and are currently employed or have previously been employed

The following interview guide has been developed as part of the Looking from the Outside In - Dyslexia and the Workplace research project. This guide will be used to collect dyslexic participants' views of and experiences with their involvement in the workforce.

Hi XXXXX,

Thank you for meeting with me today and for agreeing to participate in this interview. Do you have any questions before we begin? Do you have any questions about the PICF?

As the recruitment flyer mentioned, this is the first time in Australia that there has been the opportunity for those with dyslexia to discuss what it is like for them in the workplace. I am going to start by asking you some background information and then I will move on to some questions about your current or previous work experiences.

The information you provide today will be recorded and everything you say is confidential. Can I confirm that you are still happy for our interview to be audio-recorded?

Once we are finished, your interview will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information, which means it will be deidentified, so no one will be able to tell who provided which answer. Does that make sense?

Do you have any questions before we start?

OK, let's get started.

Section 1: Background questions

Q1 What is your gender?

- Female (51)
 - Male (52)
 - Transgender (53)
 - Other (54)
 - Prefer not to say (55)
-

Q2 What is your age?

- 18 - 20
 - 20 - 29
 - 30 - 39
 - 40 - 49
 - 50 - 59
 - 60 +
-
-

Q5 What is the highest level of education you have completed?

- Year 11 or lower (1)
 - Year 12 (2)
 - Diploma qualification (3)
 - Under-graduate degree/Post-graduate degree (4)
 - PH
-

General Questions

- Throughout your education, what type of support, if any, did you receive?
 - OT support year 11 and 12, provided strategies
 - No help
 - After finishing undergraduate, he was disagnosed, was assessed in Germany by dyslexia specialist then assessed in Australia, specific learning disability,
 - Accommodation in Oxford University
- Do you have any other learning disabilities? What word would you like me to use?
- Do you remember what type of professional made the diagnosis, if one was made?

No

If needed, the following prompts can be used: Educational Psychologist, Neuropsychologist, Speech Pathologist, GP, etc.

- Do you recall how you came to be assessed?
- Does your family know about your dyslexia?
Dad, bad speeling by writing messaily
- Does anyone else in your family have dyslexia?
- Sistet, two daughters

Based on the response: Could you tell me more about that?

- Have you told any friends about having dyslexia?

Based on the response: Could you tell me more about that?

Intellectul limitation, presdicous,

Section 2: About your work

The next few questions are about work.

- Are you employed at the moment?

If yes:

- Can you tell me a bit about your work? (*Prompts as needed*)
- Is that casual work? Full time? Part time?

- *If no:* Is there a previous job that you could tell me about?

Thinking about your current or previous workplace and their HR systems and processes, did they have any policies and procedures to support you with your dyslexia?

- Did they support people with learning disabilities?
- Could you access reasonable adjustments?
- Could you access the Employer Assistance Program?
- Did your workplace have an inclusion and diversity program?

If not, what types of HR systems and processes for those with dyslexia would you have liked to have seen?

Section 3: About Dyslexia at work

IF RELEVANT:

- Thinking about your workplace (now or previous):
 - Do you think that your dyslexia impacts your day-to-day work?
 - Could you tell me more about that?

Possible probes:

- Do you think dyslexia can have positive and negative effects at work?
- Have you hear of the term neurodiversity?

If no, interviewer to explain that neurodiversity is a term used to look at people with learning disabilities as a difference rather than a disability and a strength.

If yes, what is your perception of the term, do you see your dyslexia as a strength/s?

Some people use the term that dyslexia is a super power, do you think dyslexia is a super power or a disability?

If yes what super powers has it given you?

- Does dyslexia ever affect your mental health and wellbeing at work or outside of work?
 - If yes how do you manage this:
 - If yes, have you ever sort an help for this, such as a psychologist, counsellor, peer support, family and or friends?
- Disclosure about having dyslexia.
 - Could you tell me more about that? *Depending on response:*

Why/Why not?

Explore responses of colleagues/line managers etc. In your view, what are the attitudes of other staff towards employees who have dyslexia?

Is there someone you can go to at work, like n mentor/dyslexia supporter?

- *Your experiences of telling colleagues and line managers.*
- *Your perception about how much/little line managers knew about dyslexia.*
- Are there any resources or supports you would like to see developed to support assist you in the workplace?
- In a perfect world, is there an ideal scenario in the workplace for people with dyslexia?
- I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know or that you'd like to add?

- I should have all the information I need. Would it be all right to call you if I have any more questions?

As mentioned above, your interview will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information, which means it will be deidentified, so no one will be able to tell who provided which answer.

Thanks again for your time and for your invaluable feedback for this research project.

B.2 Study: Learning Disabilities in the workplace: Looking outside in

1. Consent Form



Consent Form



LOOKING FROM THE OUTSIDE IN - DYSLEXIA AND THE WORKPLACE		
Employer Interview		
This research is being carried out in fulfilment of a PhD under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researcher will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Graduate Researcher	La Trobe University, Department of Public Health, and the Dear Dyslexic Foundation
Research funder	This research is supported by in-kind support from La Trobe University.	

CONSENT FORM – DECLARATION BY PARTICIPANT

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study. I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, in presentations, and in journal articles, on the condition that I cannot be identified.

I would like my information collected for this research study to be:

- only used for this specific study.
- I agree to have my interview audio and/or video recorded.

Please put your name and email address below, so the student researcher can send your transcription to review.

Name	Email	Postal address (optional)

Participant Signature

- I have received a signed copy of the Participant Information Statement and Consent Form to keep.

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

- I have given a verbal explanation of the study, what it involves, and the risks, and I believe the participant has understood.
- I am a person qualified to explain the study and the risks and to answer questions.

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature.

2. Withdrawal Consent Form



Withdrawal of for Use of Data Form



LOOKING FROM THE OUTSIDE IN - DYSLLEXIA AND THE WORKPLACE		
Employer Interview		
This research is being carried out in fulfilment of a PhD under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researcher will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Graduate Researcher	La Trobe University, Department of Public Health, and the Dear Dyslexic Foundation
Research funder	This research is supported by in-kind support from La Trobe University.	

WITHDRAWAL OF CONSENT

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University or any other organisation or professional listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study.
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in future studies, unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

*** If you have consented for your contact details to be included in a participant registry, you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data:

- destroyed and not used for any analysis
- used for analysis.

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

CI Name	Shae Wissell
Email	swissell@latrobe.edu.au
Phone	1800 589 667
Postal Address	Shae Wissell P.O. Box 5123 Moreland West 3055 VIC

3. Participant information statement



Employer Participant Information Statement



LOOKING FROM THE OUTSIDE IN - DYSLEXIA AND THE WORKPLACE		
Employer Interview		
This research is being carried out in fulfilment of a PhD under the supervision of Dr. Leila Karimi and Dr. Tanya Serry. The following researcher will be conducting the study:		
Name	Role	Organisation
Shae Wissell	Graduate Researcher	La Trobe University, Department of Public Health, and the Dear Dyslexic Foundation
Research funder	This research is supported by in-kind support from La Trobe University.	

1. What is the study about?

You are invited to participate in a study that aims to gain a deeper understanding of employer knowledge of dyslexia and associated learning disabilities within the workplace, and of the impact these disabilities have on employees that have them.

2. Do I have to participate?

Being part of this study is voluntary. If you wish to take part in the study, please carefully read the information below.

If, after reading the information below, you decide not to participate in this study, your relationship with La Trobe University or any other listed organisation will not be affected.

3. Who is being asked to participate?

To be eligible for this study you must:

- be 18 years and over
- have a minimum of 10 employees working for you
- have worked with or managed staff within the workplace with dyslexia and associated learning disabilities
- work for an organisation based in Australia.

4. What will I be asked to do?

If you wish to take part in this study, you will be asked to complete an interview, which will be conducted face-to-face, via videoconference using Zoom, or over the phone.

You will be asked about your experiences of working with and managing people within the workplace with

dyslexia and associated learning disabilities.

The interview will take up to one hour to complete.

5. What are the benefits of participation?

We are unable to say if there will be any direct benefit to you. However, once this study is complete you will be able to learn about other employers' experiences working with people who have dyslexia. You will also gain access to employee perspectives on their workplace experiences with dyslexia.

The study will benefit society in general through examining workplace understanding and knowledges of dyslexia and identifying how employees with dyslexia might be better supported. This is likely to enhance employee experiences within the workplace, leading them to become healthier and happier individuals, with more connected lives. Consequently, employers may find that these staff perform at a higher level and are more productive.

The Dear Dyslexic Foundation offers a variety of workplace resources and services that you or your staff may access at any time.

6. What are the potential conflicts of interest?

A potential conflict of interest for this research project is that the student research is the founder of the Dear Dyslexic Foundation (DDF). DDF provides services and support for young people and adults with dyslexia, particularly those who are trying to finish school or start at university or TAFE, and those who are in the workplace. DDF has partnered with La Trobe University to undertake this research and will use the results to promote the development of services and supports that empower those with dyslexia to reach their full potential and live healthier, happier and more connected lives.

7. What are the risks?

With any study there are (1) risks that can be predicted, (2) risks that cannot be predicted, and (3) risks that are unexpected. If you experience something that you are not sure about, please contact us immediately, so we can discuss the best way to manage your concerns.

Name/Organisation	Position	Telephone	Email
Shae Wissell La Trobe University	Graduate Researcher	1800 589 667 Direct line	s.wissell@latrobe.edu.au
Dr Leila Karimi La Trobe University	Chief Investigator	03 9479 3013	l.karimi@latrobe.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

Some of the questions may make you feel uncomfortable and you may feel upset while answering them. If this occurs, you can stop the interview at any time. The student researcher will provide you with a debriefing about any issues and/or distress. Depending on the matter causing the distress, you may be referred to the following:

- your GP or another health-care provider
- your Employer Assist Program
- Beyondblue (1300 22 4636) or Lifeline (13 11 14)
- the Dear Dyslexic Facebook group, for peer support.

8. What will happen to information about me?

We will collect and store information about you in ways that will not reveal who you are. This means you cannot be identified in any type of publication arising from this study.

We will keep your information for a length of five years after the project is completed. After this time, we will destroy all of your data.

We will collect, store and destroy your data in accordance with La Trobe University's Research Data Management Policy, which can be viewed online using the following link:
<https://policies.latrobe.edu.au/document/view.php?id=106/>.

The information you provide is personal information for the purposes of the Privacy and Protection Act 2014 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

9. What happens to the data that I provide?

A transcript of your interview will be provided to you so that you may confirm that the information recorded in the transcript is accurate. If you would like any changes made to your transcript, you can contact the student researcher by phone or email to discuss what you would like amended. Your transcript will then be combined with all the other participants' transcripts and the aggregate data analysed.

10. Will I hear about the results of the study?

A summary of the results will be available to you on request. Please email the graduate researcher (Shae Wissell) to receive a copy of these.

Results will be published in the following places:

- a thesis
- journal papers
- a book
- conference presentations.

11. What if I change my mind?

If you no longer wish to take part in the study, you may withdraw for any reason. Your decision to withdraw at any point will **not** affect your relationship with La Trobe University, the Dear Dyslexic Foundation or any other organisation listed. After your interview you have up to four weeks to withdraw from the study.

You can let us know by:

- completing the 'Withdrawal of Consent Form' (provided at the end of this document)
- calling us
- emailing us.

If you choose to withdraw during the interview, we will stop asking you for information. Any identifiable information about you will be removed from the research study. However, once the four-week period following your interview has passed, your transcript will be deidentified and it will no longer be possible to withdraw your data.

12. Who can I contact if I have questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Shae Wissell La Trobe University	Graduate Researcher	1800 589 667 direct line	s.wissell@latrobe.edu.au
Dr Leila Karimi La Trobe University	Chief Investigator	03 9479 3013	l.karimi@latrobe.edu.au

13. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC19254	Senior Research Ethics Officer	03 9479 1443	humanethics@latrobe.edu.au

4. Recruitment flyer



LEARNING DISABILITIES IN THE WORKPLACE: LOOKING OUTSIDE IN

Ethics ID: HEC19254

Are you an employer with at least 10 employees?

Have you been running an organisation for more than three years in Australia?

Then I would love to hear from you!



I am a research student in the School of Psychology and Public Health at La Trobe University, and I am investigating the impact of dyslexia within the workplace. This is the first time anyone in Australia has conducted research to gain a better understanding of lived experiences within the workplace for adults with dyslexia and their employers.

If you have worked within HR, management and/or at the executive level in an Australian organisation with more than 10 staff, and have managed staff that have disclosed to you that they have dyslexia, then I invite you to participate in an interview exploring your views and understanding of dyslexia and its impact in the workplace.

The interview will take up to one hour to complete and it will be done online via Zoom (which is like Skype), so you can be anywhere within Australia. The interview can be undertaken during or after business hours, or on a weekend. Your responses will be collected in an anonymous format.

Participating in this study will allow you to provide a vital employer perspective on the impact of dyslexia within your workplace.

Please contact Shae Wissell at s.wissell@latrobe.edu.au or on 1800 589 667 to find out more about how you can participate in this exciting, first-of-its-kind research in Australia.

This research project is under the supervision of Dr Leila Karimi and Dr Tanya Serry from the La Trobe University.

5. Interview guide



INTERVIEW GUIDE: LOOKING FROM THE OUTSIDE IN - DYSLEXIA AND THE WORKPLACE

Group 2 - Employers who have working or managing staff with Dyslexia.

The following interview guide has been developed as part of the Looking from the Outside In - Dyslexia and the Workplace research project. This guide will be used to collect participants views and experiences of working with and or managing employees with dyslexia in the workplace.

Hi XXXXX Thank you for meeting with me today and for agreeing to participate in this interview and for completing the online survey. Did you have any questions about that before we begin? Do you have any questions about the PICF?

As the recruitment flyer mentioned, this is the first time in Australia that there has been the opportunity for employers to discuss their experiences and perspectives of working with and managing employees that have dyslexia and associated learning disabilities. So, I am going to start by asking you some background information and then some questions about your current or previous work experiences.

The information you provided today will be tape recorded and everything you say is confidential. Can I confirm that you are still happy for our interview to be audio-recorded?

Once we are finished, it will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information which means it will be deidentified, so no one will be able to tell who provided which answer. Does that make sense?

Do you have any questions before we start?

Ok let's get started

Section 1: Background questions

- How long have you been employed in your current job?
- Role within organisation
- Do you work in a metro or regional/rural location?
- Can you briefly tell me about your workplace/business?
- How many staff
- What state do you live in

Section 2: About your work

The next few questions are about learning disabilities (LD). For the purpose of this interview when we talk about learning disabilities we mean dyslexia, dysgraphia and dyscalculia.

- When did you first come across the term LDs within the workplace?
- What is your understanding of what these terms meant?
- In your view, how do you think others would perceive what Dyslexia is

Section 3: About Dyslexia at work

The next few questions are about your current or previous workplaces
Thinking about your work place (now or previous):

- *Can you tell me about any employees that have had Dyslexia.*
- Do you think that a Dyslexia impacts on an employee's ability to carry out their day to day work tasks?
 - Could you tell me more about that?

Possible probes:

- *Do you think LDs can have positive and negative effects on employees' work?*
 - *Do you think LDs ever effect employees' mental health and wellbeing at work?*
 - *Do you LDs effect employees work performance?*
 - *Have you every noted that employees with LDs have higher rates of absenteeism?*
 - *Do you think employees with LDs need special consideration to ensure they complete tasks and complete work on time?*

 - *Could you tell me about any HR processes in your workplace for employees with Dyslexia.*

 - *How would you manage inclusion and Diversity policies?*
-
- In your view, what are the attitudes of other staff towards employees that have Dyslexia?
 - Do you think dyslexia can have positive and negative effects at work?
 - Have you hear of the term neurodiversity?

If no, interviewer to explain that neurodiversity is a term used to look at people with learning disabilities as a difference rather than a disability and a strength.

If yes, what is your perception of the term, do you see your dyslexia as a strength/s?

Some people say that dyslexia is a super power, do you think dyslexia is a super power or a disability?

If yes what superpowers do you think they bring to the workplace?
-
- Do you feel that if a staff member discloses they have a Dyslexia within the workplace that they could be discriminated against?
 - Have you seen this happen?
 - Would it be their peers or line manager who would be more likely to discriminate against them?

 - If an employee has disclosed, they have Dyslexia and need assistance would you know where to get help and resources?

- Are there any changes you would make within the workplace to better support people who have Dyslexia?
- Are there any resources or supports you would like to see developed to support staff with Dyslexia?
- Budget to support employees with adaptations
- I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know or that you'd like to add?
- I should have all the information I need. Would it be alright to call you if I have any more questions?

As mentioned above your it will be transcribed and then you will receive a copy to check over. You are welcome to add, delete or change anything in the written transcript. After that, I will put your transcript together with everyone else's information which means it will be deidentified, so no one will be able to tell who provided which answer.

Thanks again for your time and for your invaluable feedback for this research project.

Thrilling

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