THE EXPERIENCES OF PARENTS OF CHILDREN WHO HAVE DYSLEXIA IN VICTORIA, AUSTRALIA: A SOCIAL JUSTICE PERSPECTIVE

Katherine Sarah Levi

Submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy

December 2017

Department of Social Work
Melbourne School of Health Sciences
Faculty of Medicine, Dentistry & Health Sciences
The University of Melbourne
ABSTRACT

This study aimed to shed light on the experiences of parents in Victoria, Australia with a school-aged child diagnosed with dyslexia. Utilising a mixed method research design, the study examined the experiences of parents as they navigated the pathway to their child’s diagnosis and attempted to gain support for their child’s learning disability post diagnosis. Applying a social work, social justice lens, this study examined the impact of the current social policy status of dyslexia on parents and their children as they sought recognition and support within the education system. Nancy Fraser’s theory of need recognition (1989) was utilised to provide a theoretical lens with which to analyse parents’ experiences and provide insight into the current status of the recognition of dyslexia in Victoria.

The findings provided insight into the struggle by parents for the recognition of the needs of children who have dyslexia. The experiences of parents presented in the findings of this study illustrated the complex terrain parents traversed in order to have their child’s dyslexia identified and to obtain support for their child’s learning needs. The findings demonstrated that parents of children with dyslexia in Victoria navigated, largely unsupported, the domain of the educational system and were predominantly responsible for identifying early signs of their child’s dyslexia and funding resources to meet their additional learning needs. As parents encountered this landscape, they negotiated many professional terrains in a largely unregulated marketplace of services and resources. Despite the existence of the Disability Discrimination Act 1992 (Cwlth) and the Disability Standards for Education 2005, the findings demonstrate that neither the state, nor the Catholic nor the independent school sectors consistently recognised or addressed the needs of children with dyslexia. This was largely a consequence of the absence of a mandated overarching educational policy framework and the consequent lack of comprehensive provision of pre-service and in-service teacher training in relation to dyslexia and resources for the identification and remediation of dyslexia. The failure of the state to provide resources resulted in an over-reliance on parents to support their child’s learning
needs. This contributed to social injustice in the form of inequity for children, as the provision of resources was dependent on factors associated with children’s family of origin, economic context and the extent to which the child’s school was prepared and able to allocate resources to children with dyslexia.

This study demonstrates that the lack of structural recognition of dyslexia results in a paucity of knowledge relating to dyslexia which is exacerbated by the lack of allocation of consistent and comprehensive provisions and resources to accommodate the learning needs of children with dyslexia. These deficits lead to discrimination in relation to the provision of education to children with dyslexia. Recommendations from this study include policy recognition of dyslexia, mandated teacher education relating to dyslexia and the allocation of resources for the identification, remediation and accommodation of students with dyslexia in the education system.
DECLARATION

This is to certify that:

• the thesis comprises only my original work towards the PhD;

• due acknowledgement has been made in the text to all other material used; and

• the thesis is fewer than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Signed:

Katherine Sarah Levi
ACKNOWLEDGMENTS

I would like to acknowledge with deep gratitude my supervisors from the University of Melbourne. I have been privileged over the past seven years to have experienced the support, guidance, and encouragement of three remarkable supervisors, Professor Cathy Humphreys, Dr Nola Firth and Dr David Rose. I sincerely thank them all for their patience, good humour and their provision of excellent academic supervision. I also wish to thank Emeritus Professor Bruce Lagay for his provision of additional supervisory support, expertise and encouragement. Also, my sincere thanks to Dr Winsome Roberts from the Department of Social Work at the University of Melbourne for first encouraging me to undertake this intellectually rewarding path.

I particularly want to thank all the research participants who generously shared their experiences via interview and survey. Your poignant stories inspired me to persevere through the challenges presented by this research project. Your wish to be heard and your hope that this study may contribute to change was a strong motivator. I am grateful to SPELD Victoria for publicising this research and for the use of your rooms to conduct interviews. I also wish to thank the many community organisations, schools, parent support networks and individuals who publicised the call for research participants.

I would especially like to thank my son, Joshua Sylvan. Joshua good naturedly tolerated my focus on this topic, a topic he would probably rather not dwell on or discuss. Thanks are also due to Josh for his technological skills which ensured that this thesis remained safe and secure in cyberspace and on numerous hard drives. Thank you also to my beloved daughter, Amy Sylvan, for her patience as I juggled this research while simultaneously trying to be the best parent I could be. At 14 years of age, she has put up with this study impinging on her time with me for half her life.

I would like to thank my parents, Robyn and John Levi, for easing the path and understanding the importance of this work to me.
A heartfelt thanks to all my tolerant and cherished friends. Particular thanks to Dr Kate Grosser for her wisdom, advice and support. Thanks to Michelle Schwarz for walk talk therapy over countless laps around the park over the last seven years.

My gratitude extends also to the many others who supported this study in their own unique way, particularly Alisoun Robertson, Jewel Topsfield, Kerri Walker-Staalkjaer and Marian Steele.

This research was undertaken with the financial support of an Australian Postgraduate Award (APA) Scholarship, for which I am most grateful.

I am very grateful for the generosity of heart of those named above and others whom I have encountered along the path. I feel privileged to have had the opportunity to undertake this study. I will be forever grateful to everyone involved in enabling me to undertake and complete it.
# CONTENTS

Abstract .................................................................................................................. ii 
Declaration ........................................................................................................... iv 
Acknowledgments ................................................................................................. v 
List of Tables ......................................................................................................... xiii 

**INTRODUCTION** ................................................................................................. 1 

**PART A: CONTEXT AND METHODOLOGY** ......................................................... 7 

**CHAPTER 1: CONTEXTUALISING THE STATUS OF DYSLEXIA** ......................... 8 
 Introduction ........................................................................................................ 8 
 Definition and Incidence of Dyslexia: Contested Territory .............................. 9 
 The Plurality of Perspectives on Dyslexia ....................................................... 15 
 Consequences of Dyslexia ............................................................................. 18 
 Studies of Parents of Children with Dyslexia ............................................. 20 
 Dyslexia in the Australian Legislative and Political Landscape .................. 23 
 Dyslexia in the Victorian Legislative and Political Landscape .................... 26 
 Dyslexia through the Social Justice Lens ................................................... 27 
 Summary ......................................................................................................... 32 

**CHAPTER 2: METHODOLOGY** ........................................................................... 34 
 Introduction ..................................................................................................... 34 
 Rationale for a Mixed Method Approach .................................................... 35 
 Research Aims and Questions ................................................................... 36 
 A Convergence of Methods: The Research Structure ................................ 37 
 Criteria for Study Participation ................................................................ 38 
 Qualitative Approach .................................................................................... 41 
  Semi-structured Interviews ................................................................... 41 
  Recruitment and Participation: Interview Participants .......................... 43 
  Interviews .................................................................................................... 48 
  Data Analysis ............................................................................................... 49 
 Quantitative Data Collection .................................................................... 51 
  Recruitment Strategy for Survey Participants ...................................... 52
The Use of Internet Survey Tool ................................................................. 53
Data Analysis .......................................................................................... 55
Demographic Profile of Survey Respondents........................................... 57
Demographic Profile of the Children Referred to in the Survey .............. 64
Ethical Considerations ............................................................................ 67
Ethical Processes: Interviews ................................................................. 67
Ethical Processes: Survey ...................................................................... 67
Ethical Considerations for All Research Participants.............................. 68
Summary ................................................................................................. 69

PART B: FINDINGS .................................................................................. 71

CHAPTER 3: QUALITATIVE FINDINGS – PARENT’S EXPERIENCES ON
THE ROUTE TO DYSLEXIA ...................................................................... 72
Introduction ............................................................................................. 72
Section 1: Initial Recognition of Children’s Difficulties: Educational and
Psychosocial Factors ........................................................................... 73
  Early Indicators of a Learning Disability ............................................... 73
  Section 1: Summary .............................................................................. 78
Section 2: Responses to Seeking Initial Advice and Support .................... 79
  Cognitive and Emotional Dissonance: a Prelude to Diagnosis ............. 85
  Section 2: Summary .............................................................................. 88
Section 3: Parents’ Perceptions and Experiences of the Pathway to Diagnosis....89
  A Lack of Support and Guidance .......................................................... 90
  A Lack of Funding .................................................................................. 92
  The Route to Diagnosis: A Relative with Dyslexia ................................ 96
  The Route to Diagnosis: A Second or Third Child with Dyslexia ........... 99
  Section 3: Summary .............................................................................. 101
Chapter Summary .................................................................................. 102

CHAPTER 4: QUALITATIVE FINDINGS – PARENT’S EXPERIENCES OF
SUPPORT POST DIAGNOSIS .................................................................. 103
Introduction ............................................................................................. 103
Section 1: Resources and Support in the Catholic and State Education Systems104
  Parents’ Reflections on the Relegation of Responsibility from School to
  Parent ..................................................................................................... 110
Navigating a Labyrinth of Remediation Programs .............................................. 112
Parents’ Perceptions and Experiences of the Independent School Sector ... 114
The Impact of Caring for a Child with Dyslexia on Parents’ Workforce Participation .................................................................................................. 118
Section 1: Summary .......................................................................................... 120
Section 2: Lack of Teachers’ Knowledge in Relation to Dyslexia .............. 121
Parents’ Reflections on Lack of Teacher Training in Relation to Dyslexia 121
The Impact of Teacher Training on Dyslexia ................................................. 125
Parents’ Hopes for Policy Change in Relation to Teacher Training .......... 129
Implementation of Remediation Strategies in the Classroom ................. 130
Implementation of Remediation Strategies in the Independent School Sector .................................................................................................... 135
Use of the Word “Dyslexia” ............................................................................. 136
Section 2: Summary .......................................................................................... 140
Section 3: Parental Advocacy .......................................................................... 141
Balancing the Advocacy Role and the Relationship with the School .... 147
The Scope of the Advocacy Role ................................................................. 150
Peer Support and Advocacy ........................................................................ 153
Section 3: Summary .......................................................................................... 156
Section 4: Children’s and Parents’ Wellbeing .............................................. 157
Parental Concern about their Child’s Self-Esteem and Wellbeing ........ 157
Parents’ Emotional Journey .......................................................................... 163
Section 4: Summary .......................................................................................... 169
Chapter Summary ............................................................................................ 170
CHAPTER 5: QUANTITATIVE FINDINGS – NAVIGATING THE JOURNEY PRE AND POST DIAGNOSIS ................................................................. 171
Introduction ...................................................................................................... 171
Section 1: The Route to Diagnosis ................................................................. 172
The Prevalence of Dyslexia in the Family of the Respondent ................. 182
Section 2: Navigating the Journey Post Diagnosis ..................................... 185
Section 3: Resources ....................................................................................... 197
Summary .......................................................................................................... 205
Section 2: Parental Agency: Power, Gender and Advocacy ........................................... 264
  Structural Challenges for Parents in the Advocacy Role .......................................... 266
  Gender and Advocacy ................................................................................................... 268
Section 3: Hidden Economic Consequences of Dyslexia .............................................. 271
  Constraints and Barriers in Relation to Remediation .................................................. 274
Summary .......................................................................................................................... 275
CHAPTER 9: INEQUITY AND THE RIGHT TO AN EDUCATION .................................... 276
  Introduction .................................................................................................................. 276
  Inequity and Systemic Failure to Recognise Dyslexia .................................................. 277
  A Two-Tier Educational System of Discrimination ...................................................... 281
  Applying Fraser’s Theory to the De-politicisation of Inequity ....................................... 282
  Marginalisation of the Most Vulnerable ....................................................................... 284
  A Key to Systemic Reform: Teacher Education and Training ...................................... 286
  The Status of Dyslexia and Recognition of Needs ....................................................... 290
  Parental Perceptions of the Status of Dyslexia ............................................................ 292
  The Agenda for Change: The Social Work Role .......................................................... 293
  An Investment in Recognition and Change .................................................................... 295
CONCLUSION .................................................................................................................. 299
CHAPTER 10: CONCLUSION .......................................................................................... 300
  Limitations of this Study .............................................................................................. 301
  Further Research Directions ....................................................................................... 302
  Concluding Reflections ................................................................................................. 304
REFERENCES .................................................................................................................. 307
APPENDICES .................................................................................................................. 327
  APPENDIX A: Survey – Plain Language Statement ...................................................... 328
  APPENDIX B: Interview Guide .................................................................................... 332
  APPENDIX C: Agreement with SPELD Victoria ........................................................... 337
  APPENDIX D: Interview – Flyer .................................................................................. 338
  APPENDIX E: Survey – Flyer ....................................................................................... 340
  APPENDIX F: Survey Questions ................................................................................... 341
  APPENDIX G: Interview – Plain Language Statement .................................................. 355
LIST OF TABLES

Table 1: Gender of Interviewees ................................................................. 46
Table 2: Identifiers, Occupations and Locations of Interviewees – Female ........ 47
Table 3: Identifiers, Occupations and Locations of Interviewees – Male .......... 47
Table 4: Gender of the Children of Interviewees ........................................... 48
Table 5: School Sector Enrolment Pre Diagnosis ......................................... 49
Table 6: Gender of Respondents ................................................................. 57
Table 7: Relationship of Respondent to Child ............................................... 58
Table 8: Respondent’s Age ...................................................................... 58
Table 9: Respondents Born in Australia ....................................................... 59
Table 10: English Spoken at Home ............................................................ 59
Table 11: Aboriginal or Torres Strait Islander Background .......................... 60
Table 12: Respondent’s Highest Level of Education ..................................... 61
Table 13: Employment Status of Respondent by Gender .............................. 62
Table 14: Family Income of Respondent ..................................................... 63
Table 15: Gender of Child ........................................................................ 64
Table 16: Birth Year of Child ..................................................................... 65
Table 17: Type of School the Child Currently Attends ................................. 66
Table 18: Initial Signs of Dyslexia Before Diagnosis ................................. 173
Table 19: Person Who First Noticed Child was Experiencing Difficulties in Relation to Literacy .......................................................... 175
Table 20: Professionals that Parents or Carers Sought Help or Advice from Before Diagnosis .......................................................... 178
Table 21: Child’s Age at Appearance of First Signs of Dyslexia and Age at Diagnosis .......................................................... 182
Table 22: Child’s Family Members with Suspected or Diagnosed Dyslexia..... 183
Table 23: Feelings of Respondents Post Diagnosis ....................................... 185
Table 24: Level of Ease and Difficulty in Finding Help for Child Post Diagnosis .......................................................... 190
Table 25: Respondent’s Feeling of Being Able to Assist their Child ............. 191
Table 26: Seeking Support Post Diagnosis .................................................. 193
Table 27: Challenges Parents or Carers Experienced in Dealing with Child’s Dyslexia

Table 28: Amount Spent on Assessment Services

Table 29: Cost of Support Purchased to Assist Child with Needs

Table 30: Annual Ongoing Costs of Respondent

Table 31: Types of Resources that Parents Want for Child but Unable to Obtain

Table 32: Economic Repercussions on Respondents and their Families

Table 33: Number of Schools Attended by Child

Table 34: School Moves due to Previous School’s Response to Dyslexia

Table 35: Overall Confidence in Teachers’ Understanding of Dyslexia

Table 36: Perceptions of Child’s Current Teachers’ Understanding of Dyslexia and its Impact

Table 37: Respondents’ Perceptions of School Helpfulness in Addressing Learning Needs

Table 38: Parents’ Perceptions of Support Provided by School According to Sector

Table 39: Terminology Current School Uses to Describe Dyslexia

Table 40: Rationale for Objections to Use of the Word “Dyslexia”

Table 41: Labels Used by a Teacher, Psychologist or other Professional According to Gender of Child

Table 42: Level of Satisfaction with Support provided by State and Federal Government

Table 43: Policy Changes Parents or Carers would Like to See at the State or Federal Government Levels

Table 44: Respondent’s Preference for Government Level Policy Changes

Table 45: Parental Advocacy
ABBREVIATIONS

AASW     Australian Association of Social Work
ABS      Australian Bureau of Statistics
ADA      Australian Dyslexia Association
ADD      attention deficit disorder
ADHD     attention deficit hyperactivity disorder
BDA      British Dyslexia Association
CRPD     Convention of the Rights of Persons with a Disability
CRT      casual relief teacher
DDA 1992 Disability Discrimination Act 1992 (Cwlth)
DETYA    Department of Education, Training and Youth Affairs
DSE      disability studies in education
LD       learning difficulties
LDA      Learning Difficulties Australia
LDAC     Learning Disabilities Association of Canada
MIC      means of interpretation and communication
NAPLAN   National Assessment Program – Literacy and Numeracy
NDIS     National Disability Insurance Scheme
NHMRC    National Health and Medical Research Council
OECD     Organisation for Economic Co-operation and Development
OT       occupational therapist
VCAA     Victorian Curriculum and Assessment Authority
VCAL     Victorian Certificate of Applied Learning
VCE      Victorian Certificate of Education
VEOHRC   Victorian Equal Opportunity and Human Rights Commission
WIAT     Wechsler Individual Achievement Test
WISC     Wechsler Intelligence Scale for Children
INTRODUCTION
INTRODUCTION

In an interview about her work, the eminent feminist philosopher and scholar Nancy Fraser was asked how she has managed to negotiate the tension between activism and scholarship (Fraser & Naples, 2004). Fraser responded:

throughout my adult life I have cared passionately about two different things: the intellectual project of understanding the world and the political project of changing it. To paraphrase Marx, I would say the point is both to interpret and to change the world. For me, in other words, it’s not an either/or (Fraser & Naples, 2004, p. 1106).

This study of the experiences of parents of children with dyslexia utilises Fraser’s model of need recognition (1989) as a theoretical framework and shares Fraser’s objectives. It is exploratory research with an agenda “both to interpret and to change the world” (Fraser & Naples, 2004). The study is designed to give voice to the experiences of parents and to gain a depth and breadth of insight into and understanding of their world. It aims to interpret and contextualise the findings of the study through theory and a social justice lens and thereby contribute a social work perspective to the discourse on the needs of parents of children with dyslexia. This exploration of parents’ experiences and analysis of the status of the recognition of their needs will contribute to Fraser’s theory.
The genesis of this thesis is located in personal experience. After years of struggle with literacy and accompanying low self-esteem, in 2007 my eldest child was diagnosed by an educational psychologist with moderately severe dyslexia. In response, I initiated a meeting with his school to discuss a plan to address his learning needs. At this meeting, with several teachers and a psychologist in attendance, I was informed that dyslexia did not exist and that the issue that needed addressing was my anxiety about my son’s difficulty with reading and slow academic progress. My curiosity and concern were sparked. Over the next few months my mind raced with questions. Why, despite a diagnosis of dyslexia, did the school psychologist inform me that dyslexia does not exist? What was the status of dyslexia in Australia compared to other countries? Why, when other English-speaking countries such as the United Kingdom were investing in teacher education in relation to dyslexia, was I being told it did not exist? What were the experiences of other parents? How does the status of dyslexia affect a child’s trajectory through school? What happens to a child with dyslexia when they have no advocate? What happens if a parent lacks the confidence to negotiate with their child’s school? What happens if they lack the financial resources to fund the initial diagnosis? What changes in the policy landscape do parents require to enable their children to reach their full potential? What are the social justice implications of the status of dyslexia? There were no clear answers. Thus began the journey which resulted in this study.

The story of the origin of this thesis is important as it adds to the understanding of my status both as a mother of a child with dyslexia and therefore an “insider” and as a researcher and therefore an “outsider”. Insights from my own journey contributed to a profound engagement with this topic and provided a catalyst to delve deeply into this unexplored territory. Both the “insider” and “outsider” positions add valuable perspectives to research (Patton, 2002, p. 268). Although there is an inherent tension in being both a mother of a child with dyslexia and a researcher, the dual role brings increased depth and rigour to this study. Whilst the researcher role affords me the privilege of gaining access to the stories of parents and a formal mechanism and authority to record and analyse these stories, being a mother of a child with dyslexia humanises the researcher...
role. Parents’ knowledge of my insider role and their sense of my empathy benefitted the interview process, allowing participants to feel comfortable to share information. Additionally, this insider role demanded that the methodological approach utilised for this study be devised and applied with exceptional rigour and reflexivity. Triangulation via a mixed method research process and a scrupulous supervision process to facilitate a high level of rigour are essential to this study. Darling (2016) contends that the conceptualisation of researchers as either emic or etic is a false dichotomy and these categories are best thought of as a continuum. Darling’s perspective on the etic–emic continuum resonates for me, particularly, as my status as a researcher is inextricably related to my professional social work identity. Social work is unwavering in its commitment to social justice. My commitment to social justice arises from both personal and professional values, ethics and identity. This research was undertaken rigorously and reflexively within the framework of a social justice orientation. The mixed method approach was chosen to facilitate the gathering of deep and quantifiable data which shed light on the experience of parents with children with dyslexia in Victoria.

The structure of this thesis is as follows. This introductory chapter provides a context and background for the study. Chapter 1 of this thesis contextualises the discourse on dyslexia. It delves into the contested territory of definitions and incidence of, and beliefs about, dyslexia. It explores the impact of dyslexia. It also discusses the political and legislative landscape of dyslexia in Victoria. The literature on studies of parents of children with dyslexia is explored. The social justice orientation, which includes a social work lens and Fraser’s theory of need recognition which is utilised in this study, is presented.

Chapter 2 outlines the methodology and the rationale for the mixed method approach utilised in the study. It presents the research questions which underpin the study. The chapter describes the methods used to select and recruit research participants for the online survey and the interviews. The approach and the tools utilised for the data analysis of both the quantitative and qualitative research are discussed. The minor and major themes and the way they emerged from the qualitative results are presented.
The findings from the qualitative research are presented in Chapters 3 and 4. Chapter 3 contains the findings in relation to the experiences, reflections and feelings of research participants as their child’s difficulties began to emerge prior to the diagnosis of dyslexia. It contains findings in relation to the initial recognition of their child’s difficulties, teachers’ responses to parental concerns and parents’ perceptions and experiences of the pathway to diagnosis. It presents parents’ experiences and thoughts in relation to access to resources and the provision of resources by the education system, the state and the private market.

Chapter 4 continues with the presentation of the qualitative findings. This chapter contains findings in relation to parents’ experiences of support post diagnosis. It presents parents’ thoughts and reflections on their experiences within the Catholic, state and independent school sectors. Parents’ feelings about their responsibility for their children’s learning needs and their perceptions of navigating the education sector and private market to find support for their children are presented. Findings in relation to parents’ perceptions of teachers’ knowledge and training in relation to dyslexia and the remediation of dyslexia within the school context are also presented. This chapter contains findings in relation to terminology used to refer to dyslexia and resistance to the use of the term “dyslexia”. Findings related to parents’ advocacy role are also contained in this chapter. Finally, parent reflections on their child’s self-esteem and wellbeing, as well as parents’ emotional journey, are presented in this chapter.

Chapters 5 and 6 contain the quantitative and qualitative findings derived from the online survey. Chapter 5 provides demographic information about each survey participant and their child. It presents findings in relation to the signs that led parents to their child’s diagnosis as well as the professionals consulted along the journey to diagnosis. Issues associated with finding support pre- and post-diagnosis are also presented. Challenges inherent in identifying and accessing a diagnosis, obtaining support, meeting the cost of resources and managing their economic impact conclude this chapter.

Chapter 6 continues with parents’ thoughts and experiences in relation to their engagement with the Catholic, state and independent school sectors. Parents’
experiences of the use of terminology and the resistance to use of the term “dyslexia” and the concept of dyslexia are presented. Insights into parents’ experience of advocacy and parents’ thoughts and reflections on policy recommendations are contained in this chapter.

Chapter 7, Chapter 8 and Chapter 9 present a discussion drawing on the findings from the interviews and the online survey. These chapters are divided according to the themes which emerged from the qualitative research. These chapters locate the discussion within a social justice framework, drawing on Fraser’s (1989) model of need recognition and contributing new perspectives to Fraser’s model. These chapters address the research questions drawing on the findings, relevant literature and Fraser’s model of need recognition. Insights are provided into the status of dyslexia in Victoria and recommendations for a future social work focus on this topic are presented in these chapters.

Chapter 10 presents the conclusions which can be drawn from this study. It outlines the contributions of this study to social work, to Fraser’s theoretical model of need recognition and to Australian research in the field of dyslexia. It highlights the limitations of this study and provides reflections in relation to areas for future research. This chapter also contains the researcher’s concluding reflections.
PART A:

CONTEXT AND METHODOLOGY
CHAPTER 1:
CONTEXTUALISING THE STATUS OF DYSLEXIA

Introduction

This thesis aims to explore and understand the experiences of parents with a child who has dyslexia. This approach sheds light on the status of the recognition of dyslexia in Victoria and its impact on parents with children with dyslexia. Drawing on Australian and international research, this initial chapter explores the discourse surrounding dyslexia. It examines the current status of dyslexia within the Victorian landscape, and the gaps in the research literature in relation to the experience of parents with a child with dyslexia in the Australian context are highlighted. The relevance of this topic to social work is introduced. Then, the legislative and social policy recognition of dyslexia in Victoria is explored from a social justice perspective. Finally, the relevance of Nancy Fraser’s theory of need recognition (1989) is introduced. This chapter provides the background to the exploration of parents’ experiences contained within this mixed method study.
Definition and Incidence of Dyslexia: Contested Territory

Australia is lagging behind most English-speaking countries in relation to developing a national definition of dyslexia, recognising and screening for dyslexia and remediating and providing funding for students with dyslexia (Firth, 2010a; Firth 2010b; Skues & Cunningham, 2011). Estimates of the prevalence of dyslexia vary significantly within countries and across the world. This variance is due to factors such as differences in definitions, terminology used to describe dyslexia, awareness of dyslexia and access to clinical testing; a lack of universally mandated screening; comorbidity with other disorders; and orthographical features of language (Barbiero, Lonciari, Montico, Monasta & Penge et al., 2012; Prior, Sanson, Smart & Oberklaid, 1995; Riddick, 2010; Skues & Cunningham, 2011; Stegemann, 2016; Vellutino, Fletcher, Snowling & Scanlon, 2004). These constraints make it difficult to ascertain the incidence of dyslexia in Australia. The lack of universal mandated screening for dyslexia results in Australian schoolchildren being identified for testing for dyslexia in response to academic failure or challenging behaviour (Elkins, 2000; Skues & Cunningham, 2011). This ad hoc testing selection implies that some children with dyslexia will remain undiagnosed, with their potential underestimated or their failure blamed on bad behaviour (MacCalluagh, 2014). There are also differences in terminology and the categorisation of students with learning disabilities between states and between school sectors, which makes incidence very hard to ascertain (Al-Yagon, Cavendish, Cornoldi, Fawcett, Grünke & Hung et al., 2013; Louden, Chan, Elkins, Greaves, House & Milton et al., 2000; Skues & Cunningham, 2011). A large-scale general population based study in the United States found that dyslexia affected 5% to 12% of the population (Katusic, Colligan, Barbaresi, Schaid & Jacobson, 2001). The British Dyslexia Association (BDA) estimates that approximately 10% of the population has dyslexia, with 4% being affected by a severe form of dyslexia and the remaining 6% having a moderate to mild form (BDA cited by Riddick, 1996). In Australia, prevalence rates (reflecting the constraints in data) currently include a wide range of figures from 2% to 15% of Australians (Coltheart & Prior, 2007; Firth & Frydenberg, 2011; Louden et al., 2000; Prior et al., 1995; Skues & Cunningham, 2011). Recent research produced
Defining dyslexia is fraught with complexity and contention (Firth, 1992; Hammond, 2002). Swann claims: “Dyslexia is a professional battlefield. Nothing is more likely to induce apoplexy among the combatants, and confusion among the spectators” (1985 cited by Riddick, 1996, p. 21). A scan of the historical and current literature suggests that Swann’s vividly illustrative analogy is as accurate in the present day as it was when the claim was made over three decades ago. Neither the term “dyslexia” nor the term “learning disability” has a universally recognised or accepted definition or criteria for clinical diagnosis (Andrist & Lynman, 2015; Prior et al., 1995; Yingling, 2011). The lack of clarity around definition and terminology and the criteria for inclusion in the diagnosis results in people with dyslexia being incorrectly categorised by a wide range of labels including, but not limited to, categories such as “reading disability”, “learning difficulty”, “specific learning difficulty”, “specific learning disability” and “at educational risk” (Prior et al., 1995; Serry & Hammond, 2015; Skues & Cunningham, 2011). The origin of the confusion in the Australian context has been attributed to a House of Representatives Select Committee on Specific Learning Difficulties in the 1970s (Cadman, 1976) which Firth (2011) reflects reached the “erroneous conclusion that failure to acquire literacy skills is a reflection of bad teaching rather than a neurological disability” (Mitchell, 2011).

Consequently, the Committee’s findings failed to differentiate students with dyslexia from students with mild intellectual disabilities, slow learners, students suffering from economic disadvantage, students subjected to inadequate teaching, students from culturally and linguistically diverse backgrounds and students with behavioural or other disorders. The Committee recommended that a blanket term of “learning difficulties” be extended to all students who struggled with reading, spelling, writing and/or mathematics (Elkins 2002; Skues & Cunningham, 2011).
This lack of nuance and clustering of diverse problems under the generic heading of “learning difficulties” was highlighted as problematic as recently as 2010 (Dyslexia Working Party, 2010). The Dyslexia Working Party was a committee of literacy experts whose work culminated in a report entitled the “Australian National Action Agenda” (Dyslexia Working Party, 2010). This report contains 19 recommendations for change. The first of these is a nationally recognised working definition of dyslexia. The definition proposed by this panel is consistent with definitions utilised by the British Dyslexia Association, the International Dyslexia Association, the National Institute of Child Health and Development (based in the United States), the International Reading Association and the UK Government commissioned Rose Report on Dyslexia (Dyslexia Working Party, 2010). The definition recommended by the Dyslexia Working Party (2010) is utilised in this study:

Dyslexia is a language-based learning disability of neurological origin. It primarily affects the skills involved in accurate and fluent word reading and spelling. It is frequently associated with difficulties in phonological processing. It occurs across the range of intellectual abilities with no distinct cut-off points. It is viewed as a lifelong disability that often does not respond as expected to best-practice, evidence-based classroom methods for teaching reading (Dyslexia Working Party, 2010, p. 8).

The choice of a definition of dyslexia is an inherently political act. The definition and terminology used to describe dyslexia are not simply practical; they influence the status and recognition of dyslexia, which has policy, legal, economic and educational ramifications. The Dyslexia Working Party’s proposal of a national definition of dyslexia was both political and pragmatic. As Riddick (1996) suggests, the problems associated with the lack of a single accepted definition of dyslexia may prevent educationalists from recognising the existence of dyslexia; therefore, it has implications for the identification of children with dyslexia as well as the allocation of suitable resources to assist these children. Additionally, the lack of a consistent national definition of dyslexia makes it difficult to gain a clear understanding of how children with learning difficulties such as dyslexia are faring in our school systems (Rivalland, 2000). The Australian Government, however, has thus far sidestepped the recommendation
for a national agreed definition. Whilst agreeing in principle that a nationally-agreed definition would be useful, the federal government sidestepped endorsing the proposed definition, claiming “there is still a degree of debate, both nationally and internationally, regarding the definition of dyslexia” (Australian Government, 2012, p. 1). This is true, however it has not impeded other English-speaking countries such as Canada, the United Kingdom, New Zealand and the United States from adopting state- or nationally-endorsed definitions (Klassen, Neufeld & Munro, 2005; Rowan, 2010; Stegemann, 2016). Additionally, the Australian Government’s response to the Dyslexia Working Party claimed that Australia does not “have a national body responsible for determining universal definitions. Instead, definitions are adopted or developed by different departments of statutory bodies for distinctive purposes for example, for eligibility for a program, intervention or payment” (Australian Government, 2012, p. 1). The federal government has, therefore, relegated the definition of dyslexia to statutory departments. In Australia, education is the domain of the state and territory governments. Therefore, the Commonwealth Government has essentially relegated the definition of dyslexia to an array of statutory bodies at state and territory government levels rather than adopting a national definition. This results in national inconsistency and a lack of federal leadership on this issue.

Hammond (2002) contends that “there are as many definitions” of dyslexia “as there are researchers in the field” (p. 11). There are a vast and diverse range of disciplines involved in the study of dyslexia including education, disability studies, special needs teaching, medicine, neuroscience, ophthalmology, optometry, audiology, speech pathology, psychology (both educational and cognitive), linguistics, psycholinguistics and sociology (Buttner & Hasselhorn, 2011; Riddick, 1996; Stein, 2002; Vogel & Holt, 2003; Wolf, 2008). Stein (2002) refers to the study of dyslexia as being characterised by “competitive viciousness” (p. 178). The quagmire of worldwide debate surrounding the definition of dyslexia is exacerbated by this disputed professional territory (Frith, 1999; Miles, 1999; Vellutino et al., 2004). However these other research disciplines in specialist fields such as ophthalmology, optometry, neuroscience and audiology are outside the
scope of this thesis. This thesis incorporates the debates relevant to a social justice paradigm.

Of note to this study is that definitions of dyslexia differ depending on whether one approaches the task from a medical or an educational orientation (Gaddes, 1976). Definitions are often focused on the underlying cause of the condition, the manifestation of symptoms or the treatment of dyslexia (Gaddes, 1976, p. 12). Generally, those who ascribe to the medical and educational models concur that the aetiology of developmental dyslexia has an underlying genetic and/or neurobiological cause (Macdonald, 2009). Despite divisions between adherents to the medical and educational models and debate and contention between and within disciplines, dyslexia has been successfully defined and incorporated into legislation in many countries and jurisdictions around the world. In the United States dyslexia is often referred to as a “learning disability” or a “reading difficulty”, while in the United Kingdom dyslexia is referred to as “dyslexia” or “specific learning disability” (Alexander-Passe, 2007). Irrespective of the terminology used, there are legislative requirements to recognise dyslexia as a disability and to fund remediation for students with dyslexia in both the United States and the United Kingdom (MacCullagh, 2014).

In the 1990s the Australian Government made progress towards endorsing the term “learning disability”, albeit in a limited way. The Australian National Health and Medical Research Council (NHMRC), an independent statutory body reporting to the federal government Department for Health and Ageing, attempted to clarify terminology and definitions. It clearly distinguished “learning difficulty” from “learning disability”, pointing out that the term “learning difficulties” refers “to a relatively large group of children who need extra assistance with schooling for reasons such as intellectual or physical disability or lack of educational opportunities” (NHMRC, 1990, p. 2).

This is distinct from children with a specific learning disability (dyslexia) whom they define as a:

much smaller proportion (2–4%) of children and adolescents who exhibit problems in developmental and academic skills which are significantly below expectation for their age and general ability. The disabilities,
which often include severe and prolonged directional confusion, sequencing and short-term retention difficulties, are presumed to be intrinsic to the individual, but they are not considered to be the direct result of intellectual disability, physical and sensory deficits or emotional difficulties. Neither do they appear to derive directly from inadequate environmental experiences, or lack of appropriate educational experiences. (NHMRC, 1990, p. 2)

However, the NHMRC clarification and differentiation between dyslexia and learning difficulties and impediments seem to have had minimal impact on the use of terminology by dyslexia organisations or educational institutions. A decade later, evidence from a study commissioned by the federal Department of Education, Training and Youth Affairs (DETYA) exploring school policies and practices and the private provision of services in relation to children’s learning disabilities nationwide highlighted that the term “learning disability” has not been widely accepted in practice (Louden et al., 2000). In the year 2000, few Australian school systems or school sectors used the term “learning disabilities” (Louden et al., 2000, p. 4). Rather, multiple terms were used such as “learning difficulties”, “at educational risk”, “special needs” and “needing support” (Louden et al., 2000, p. 3). Louden found that in Victoria, government schools most often used the vague and amorphous terms “at risk” and “at educational risk” to describe a variety of learning disabilities and difficulties. However, from a national perspective at that time across school sectors (state, independent and Catholic), approximately half of the government schools and independent schools and more than a third of the Catholic schools used the term “learning difficulties” (Louden et al., 2000). “Learning difficulties” is neither specific nor descriptive; it includes a heterogeneous group of students including those with dyslexia, those with low-functioning cognitive ability, those displaying challenging behaviour, children whose first language or language spoken at home is not English and children who live in impoverished home environments (Louden et al., 2000, p. 23). The 2000 study of Louden et al. is evidence that despite the passing of approximately 25 years since the release of Cadman’s 1976 House of Representatives Report and the clarification by the NHMRC (Cadman, 1990), students with dyslexia were not
being distinguished from those with learning difficulties arising from other sources.

Differences of opinion in relation to the use of terminology are not limited to schools and government. An examination of the community sector also reveals a disputed and contested arena. SPELD Victoria is a community organisation in Victoria which defines itself as “the Peak body for Specific Learning Difficulties [emphasis added] in Victoria” (https://www.speldvic.org.au). The tagline of the national federation of SPELD associations, AUSPELD, reads “supporting people with learning disabilities [emphasis added]” (http://auspeld.org.au), however text on the website refers to dyslexia as a learning “difficulty”, demonstrating a confusing inconsistency. The Australian Dyslexia Association (ADA), an association for professionals concerned with “well-being, identification, treatment” of dyslexia refers to dyslexia as “learning disability-(sic) difference” (http://dyslexiaassociation.org.au). This perhaps reflects the ADA’s stance which takes a strengths-based approach to dyslexia, incorporating the cognitive strengths of individuals in addition to the weaknesses caused by the condition (http://dyslexiaassociation.org.au). Learning Difficulties Australia (LDA), an association of teachers and other professionals, refers to dyslexia as a “specific or significant learning difficulty” and states that dyslexia is “generally considered to be a learning disability or specific learning difficulty” (https://www.ldaustralia.org). The different use of terminology and the lack of cohesion in relation to definitions represents a contested landscape. This provides insight into one dimension of the backdrop which impacts on parents’ experiences of navigating the complex terrain of dyslexia in Victoria.

**The Plurality of Perspectives on Dyslexia**

Amidst the professional jousting around causation, definition, diagnosis, prevalence and appropriate remediation strategies, there is a small group of theorists who argue that dyslexia does not exist. Elliot and Grigorenko (2014) contend that a diagnosis of dyslexia is unscientific and unhelpful to individuals categorised in this subgroup as well as to others with related difficulties that are
not classified in this grouping and also require literacy support. Elliot and Grigorenko (2014) and Elliot and Gibbs (2008) are controversial in the academy in the current day, but similar views were more common in the 1950s and 1960s in the United Kingdom (Riddick, 2001) and in the 1970s in Australia, as evident in findings of the House of Representatives Select Committee on Specific Learning Difficulties (Cadman, 1976).

Difficulty is caused by dyslexia deniers in the teaching profession who, due to a lack of instruction, perceive dyslexia as “a figment of imagination in the neurotic minds of ambitious middle class parents who cannot come to terms with their child’s poor academic performance” (Riddick, 2009, p. 92). Others perceive children struggling with the challenges of acquiring literacy skills as “lazy children” (Riddick, Sterling, Farmer & Morgan, 1999, p. 97; Gwernan-Jones & Burden, 2010). Those who do not believe in the existence of dyslexia (or have insight into its existence) label children as “dumb” or “stubborn” (Wolf, 2008, p. 194). A correlate of dyslexia denial is, on occasion, the attribution of blame for symptoms of dyslexia to neglectful parents and poor home environments (Pumfrey & Reason, 1991). Others point the finger at poor pedagogical practice, finding fault in teachers and teaching methods rather than acknowledging that the difficulties may be intrinsic to the child. Whittaker states that “we do not have a medical condition called dyslexia. We have an educational problem about how to teach more effectively” (1981 cited by Pumfrey & Reason, 1991, p. 6). Theorists such as Feuerstein (1989) and Whittaker (1981) consider the dyslexia label an “alibi” for teacher “ineffectiveness” (Feuerstein, 1989 cited by Pumfrey & Reason, 1991). In their argument against the existence of dyslexia, Elliot and Gibbs (2008) expound many theories including one suggesting that government policy rewards schools for students achieving high literacy standards. They contend that this encourages schools to relegate children with poor literacy skills to a box labelled “dyslexic”, thereby shifting blame onto the purported cognitive weaknesses of the child rather than the failure of the school to teach (Elliot & Gibbs, 2008). In perhaps their most controversial argument, Elliot and Gibbs (2008) suggest that dyslexia is socially constructed to create a group who can be deemed “other”. This group of “other” who struggle with literacy can be
categorised as “unsuccessful”. They suggest that it is only by contrast with the “unsuccessful” that there can be another group considered “successful”. Elliot and Gibbs (2008) therefore conclude that government rhetoric to eliminate illiteracy is an insincere, hollow claim as there is a paradoxical political need to maintain illiteracy to retain “power and position” amongst the literate segments of society (Elliot & Gibb, 2008, p. 486). This is a unique argument perhaps leaning more towards conspiracy theory than academic theory.

Divisions amongst disability scholars and educationalists are more traditionally focused on the divide between the social model of disability and the medical model. Baglieri, Valle, Connor and Gallagher (2011) highlight this divide amongst disability scholars in education. Baglieri et al. (2011) contend that there is a divide between the incrementalist perspective and the reconceptualist framework. The incrementalist perspective draws on the medical model of disability which locates the deficit within the individual and perceives it as something that requires fixing or curing (Baglieri et al. 2011). By contrast, the reconceptualists draw on the social model of disability (Oliver & Barnes, 1998) which, while not denying the existence of the person’s impairment, frames the disability as a social construction (Baglieri et al., 2011). Applying this lens to students with dyslexia would suggest that the constraints associated with the manifestation of dyslexia will be problematic if schools fail to institute pedagogical practices that cater for the learning needs of children with dyslexia.

Baglieri et al. (2011) identify as researchers in the emerging field of disability studies in education (DSE) and contend that disability is “a product of social, political, economic, and cultural practice” (p. 270). They ascribe to the view that “variations that exist in human behaviour, appearance, functioning, sensory acuity, and cognitive processing” can best be described as an “impairment” (Baglieri et al., 2011, p. 270). Riddick (2001) highlights that in the case of hidden disabilities such as dyslexia, people often have to fight hard to have their disability recognised before they can challenge the structural constraints that “disable” the social, political, economic and cultural practices around them. Riddick draws on the work of Goffman (1968) and makes a distinction between “evident” and “not evident” disabilities (Goffman, 1968 cited
by Riddick, 2001, p. 231). Riddick (2001) contends that in order to protect an individual with dyslexia from negative stereotypes which attribute their disability erroneously to negative personality attributes such as laziness, it is important to identify and label dyslexia.

**Consequences of Dyslexia**

Dyslexia has a lifelong, negative impact on an individual’s ability to process language resulting in difficulty acquiring and possessing reading, spelling and writing skills and can also be evidenced in reading comprehension and speaking (Shaywitz, 2003; Washburn, Binks-Cantrell & Joshi, 2013, p. 2). International data demonstrate that children with dyslexia are at increased risk of school failure and drop-out as well as anxiety, low self-esteem, depressive disorders and suicidal ideation (Alexander-Passe, 2007; Daniel, Walsh, Goldston, Arnold, Reboussin & Wood, 2006; Long, S. MacBlain & M. MacBalain, 2007; Mugnaini, Lassi, Malfa & Albertini, 2009; Willcutt & Pennington, 2000).

Children with dyslexia require adjustments to the curriculum and teaching styles to accommodate their learning needs and provide them with equal opportunity to succeed in an academic environment (Lindgren, Jensen, Dalteg, Wirsén Meurling, Ingvar & Levander, 2002). Without such adjustments, intervention and remediation, children with dyslexia are at risk of acquiring only low-level literacy skills. Literacy skills are inarguably of central importance to successfully gaining and maintaining employment in industrialised countries. Burden (2008) describes literacy as “a highly valued skill or commodity” (p. 188). In an overview of the literature on negative self-worth and dyslexia from 1988 to 2008, Burden highlights the fact that a person’s feelings of self-worth will be influenced by what is “valued within their society and culture” (Burden, 2008, p. 188). Perri (2007) highlights the importance of reading, suggesting it has “powerful and far-reaching effects” (p. 36). Those who are excluded from the workforce or marginalised in low-paying jobs within the workforce risk poverty and societal alienation (Oliver & Barnes, 2012). It can be argued that the dominant economic paradigm of the industrialised world is neoliberalism which
promulgates key values such as “consumerism”, “individualism”, “competition” and “laissez faire” policies (Fenna, 2004, p. 53). The globalised and competitive nature of capitalist society under a neoliberal regime translates a struggle with literacy into a risk of exclusion from the workforce resulting in potentially serious material disadvantage (Pumfrey & Reason, 1991).

In a 2003 study, Vogel and Holt focused on an examination of the policy context of dyslexia and its impact on outcomes for people with dyslexia. Their study was comparative in scope providing an examination of adults with learning disabilities in six English-speaking populations (Canada, Great Britain, Republic of Ireland, New Zealand, Northern Ireland and the United States). Findings demonstrated that those populations which lacked mandated screening and remediation for dyslexia (and other learning disabilities) showed indicators suggesting that in adulthood people with dyslexia showed the lowest level of reading and maths literacy, “lower educational attainment, lower occupational status and income and higher percent of unemployment than adults with dyslexia in those countries with mandated screening and remediation programs for dyslexia or those with very “proactive parent/professional dyslexia organisations (Vogel & Holt, 2003, p. 222).

International prevalence studies of the participation of students with dyslexia in higher education demonstrate that students with dyslexia are highly under-represented (MacCullagh, 2014). Although there are currently no prevalence studies in the Australian context, MacCullagh refers to international data which indicates that although 4–12% of the population (Katusic et al., 2001 cited by MacCullagh, 2014, p. 93) are thought to be affected by dyslexia, students with a diagnosis of dyslexia represent approximately 0.2–0.4% of students enrolled in higher education (MacCullagh, 2014, p. 93). Evidence from the Organisation for Economic Cooperation and Development (OECD) indicates that students who disengage from education are less likely to gain employment and more likely to be unemployed during times of economic downturn (Craven & Dillon, 2013). This indicates that adults with dyslexia who experience barriers to higher education are at ongoing risk of marginalisation from the workforce and poverty.
Worldwide there is a substantial amount of research evidence demonstrating that adults with dyslexia are over-represented in the prison population (Lindgren et al., 2002). A study which utilised interviews, tests and psychological assessments conducted in Sweden found that 41% of the prison population in an area of Sweden had dyslexia using the clinical definition contained in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* Version IV (DSM-IV) (Jensen, Lindgren, Wirsén Meurling, Ingvar & Levander, 1999). The results of this study were similar to others conducted in other contexts (Jensen et al., 1999).

Multiple studies have shown that parents play a central role in improving and influencing children’s academic achievement, attitudes, behaviour and self-esteem and in building resilience in children (Chan & Dally, 2000; Kaplan, Liu & Kaplan, 2001). Shaywitz, a leading American neuroscientist, dyslexia expert and professor of paediatrics, states “All dyslexics who have become successful by any account share in common the unfailing love and support of their parent(s) or, occasionally, a teacher or spouse” (2003, p. 309). Long-term studies on adults with dyslexia correlate positive life outcomes with external and intrinsic factors. Extrinsic factors include support and guidance from significant people in their lives such as family members, mentors, friends and therapist.

Intrinsic factors include personal qualities such as “self-awareness”, “proactivity”, “goal setting”, “perseverance” and “emotional stability” (Raskind, Goldberg, Higgins & Herman, 2002, p. 204). The study does not note the importance of the policy context and the educational environment in which the person with dyslexia is situated. Nevertheless, it highlights the importance of a supportive family as a factor which mitigates against negative life outcomes.

**Studies of Parents of Children with Dyslexia**

There is a paucity of Australian literature on the experiences of parents with children with dyslexia. There is also currently very little worldwide literature on parental perspectives and experiences of their children’s dyslexia (Buswell, Griffiths, Norwich & Burden, 2004, p. 428). A search of the database Web of
Science using the search terms “dyslexia and Australian parents” located 14 records. None of these studies relates directly to the experiences of parents of children with dyslexia. A search of the database Scopus V.4 located no Australian articles relating specifically to this topic. However, this search did locate a paper by Nichols (2000) contained within a wider project “Mapping the Territory” by Louden et al. (2000). This study, entitled “Parental Involvement in Supporting Children with Learning Difficulties”, draws on case studies of between three and six parents with a focus on developing strategies for parental involvement in schools (Nichols, 2000). Nichols and Read (2002) delve into the issue of parent–school communication in the case of children with learning difficulties in the Australian context. This study uses a case study to illustrate and expand the models of understanding the complex web of interaction between home and school with an aim to create models for improved communication flow in the context of children with learning difficulties or disabilities. Mothers have traditionally held responsibility for caring roles within the family and today remain over-represented in this role (Home, 2002). Ryan and Runswick-Cole (2008) observe that mothers of children with disability are marginalised within disability studies and within the disability movement.

An Australian case study (van Krayeennord, 2017) is included in two volumes of a compilation of international case studies of the psychosocial development of children with dyslexia and the challenges their parents face in supporting them, edited by Anderson and Meier-Hedde (2011, 2017). This informative longitudinal study provides insights into the Australian experience of one child and his parents in one jurisdiction (van Krayeennord, 2017). To date, there are no other identified studies in Australia with a specific focus on parents of children with dyslexia in the Australian context.

Internationally, Riddick (1996, 2010) has been at the forefront of research into the experiences of parents of children with dyslexia and the wellbeing of children with dyslexia. Her research examines the experiences of parents and children within the United Kingdom’s policy context. International studies provide important information that may contain universal themes that have relevance to the Australian context. Transposing Riddick’s findings to the
Australian context is risky, as the recognition, identification and remediation of dyslexia in the United Kingdom occurs in a vastly different policy environment. In response to the Rose Report, entitled “Identifying and Teaching Children and Young People with Dyslexia and Literacy Difficulties” (2009), the British Government allocated £10 million over an initial two-year period to screen children for dyslexia, increase the skill level and knowledge base of teachers and establish a significant and complex remediation program. Additionally, the government funded the provision of guidance for parents of children with dyslexia (Rose, 2009).

Other studies which focus on aspects of parent experiences in dealing with dyslexia are also located and framed within political contexts which differ from the Australian experience. Internationally, studies which focus on parents of children with dyslexia contain a variety of foci. In some cases, research into the experiences of parents of children with dyslexia are contained within broader, themed studies which focus on disabilities other than dyslexia (intellectual and physical disabilities and other neurological conditions), but make reference to parents of children with dyslexia. Buswell et al. (2004), making reference to the policy context of dyslexia in the United Kingdom, focus on problems in communication that arise between parents and professionals. Crozier and Reay (2004) present a study with a focus on home–school relationships in the context of the United Kingdom which takes into account the socio-political context of dyslexia in the United Kingdom. In a similar vein, Power and Clark (2000) focus on communication flows between schools and parents of children with learning disabilities in the United Kingdom’s social policy regime. Rogers (2007) examines the experiences of parents in the United Kingdom with children with a wide variety of disabilities (including dyslexia) and delves into issues relating to diagnosis, parents’ responses, labelling, mothering children with disabilities, the political context and parental partnership with schools. Leiter & Krauss (2004), writing in the United States context, focus on the parents of children with disabilities more broadly (but including a cohort of students with learning disabilities) and examine their experiences of requests for additional special education services. Their study reflects on the socio-political and legal context of

Theorists contend that a supportive parent of a child with dyslexia can be described as a parent who seeks an accurate diagnosis, enables suitable and effective remediation, liaises with the child’s school to ensure that the child experiences school in a positive manner, reads with the child, exposes them to many experiences of the world and encourage their feelings of self-worth (Shaywitz, 2003). In light of this knowledge, it is surprising how few studies focus on parental experiences of children with dyslexia to better understand the hurdles created by the educational and political landscape. In acknowledging the crucial importance of parents in supporting their child’s development and facilitating their pathway through the education system, it is also imperative to understand the social, political, legislative and educational context of the child and the parent.

**Dyslexia in the Australian Legislative and Political Landscape**

The critically important role that parents play in supporting their children to develop socially, emotionally and academically needs to be understood in the political and social context in which it occurs. Policy, legislation and institutions impact on the experiences of parents. This section provides a backdrop to experiences of parents of children with dyslexia by locating the treatment of dyslexia in the political and legislative environment.

Australia is a signatory to the United Nations Convention on the Rights of Persons with a Disability (CRPD). The convention was released on 13 December 2006 and Australia officially became a signatory on 30 March 2007. The Commonwealth of Australia is therefore committed to the guiding principles of
the CRPD which contain statements outlining non-discrimination, full and effective participation and inclusion in society for people with disabilities, equal opportunity, accessibility measures and respect for the evolving capacities of children with disabilities (https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/optional-protocol-to-the-convention-on-the-rights-of-persons-with-disabilities.html). In addition to Australia’s commitment to this international convention, there is Commonwealth legislation in the form of the Disability Discrimination Act 1992 (Cwlth) (DDA 1992). This federal Act enshrines in legislation principles which are designed to “eliminate, as far as possible, discrimination against persons on the ground of disability” (DDA 1992, section 4). The DDA 1992 does not specifically refer to any syndrome or type of disability by name; rather, section 4(1) lists broad categories of “disability” including “A disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction”. This lack of categorisation is designed to be inclusive of all disabilities (Burdekin, 1991). Dyslexia clearly falls within the scope of this Act. (If there was any doubt about this fact, it was laid to rest by the federal government’s response to the Dyslexia Working Party’s recommendations, discussed below.)

Additionally, the DDA 1992 contains a statement which outlines the intention to prevent discrimination in areas such as work and education. It also specifically seeks to ensure that people with disabilities have “the same fundamental rights as the rest of the community” (DDA 1992, section 3(c)). Marshal (2005) explains that the legislation is focused on the protection of people with disabilities from discrimination, with a focus on determining whether discrimination has occurred rather than a focus on which category of disability a person is classified within. This suggests a divergence from the medical model of disability in which the categorisation of disability is of central importance. It points to an understanding that adherence to classifications of disability with strict but arbitrary cut-off points and definitions may not be conducive to ensuring that the rights of all citizens are upheld. For this, the thinking behind the legislation should be commended. As a further protection for children with disabilities, the Commonwealth legislated the Disability Standards for Education 2005. This
additional safety net for the protection for children and young people with disabilities in the educational context is a subset of the DDA 1992 and as such has the same objectives. It is therefore clear that dyslexia fits within the criteria for the Disability Standards for Education 2005.

The national Dyslexia Working Party’s (2010) second recommendation was that “there should be legislative recognition at both State and Commonwealth level of dyslexia as a disability as determined under the Disability Discrimination Act 1992” (Dyslexia Working Party, 2010, p. 2). The recommendation also contained the statement that dyslexia should be included under the special needs section of the Education Act in each state in order that funding and provisions be made for remediation. The Commonwealth Government “partially agreed” with this recommendation. In its response, the government clearly stated that the definition of disability in the DDA 1992 was “sufficiently broad to include dyslexia” (Australian Government, 2012, p. 2). Whilst not determining it was necessary to amend legislation, the response clearly determined that dyslexia is and should be considered a “disability” under the DDA 1992 and the Disability Standards for Education 2005. This leaves no doubt that the federal government considers dyslexia to be a disability. However, while the federal government clearly “prohibits active discrimination” (MacCullagh, 2014, p.101 ), it falls short of the proactive stance evident in countries such as the United Kingdom and the United States (see, for example, the US Individuals with Disability Education Act 2006) which enshrine equity and educational inclusion in law (Yingling, 2011; MacCullagh, 2014). In other words, in the Australian context there is legislation to deter discrimination but no national framework to stipulate how children with dyslexia should be treated and no policy framework regarding how students with dyslexia should be accommodated in the classroom and how their remediation and other support needs should be funded. The federal government’s response to the recommendation regarding funding was to relegate responsibility to state and territory government consideration. Students with dyslexia are not eligible for federal government funding (Hammond, 2002) and the federal government does not direct the states on how to direct their funding for the special needs of students with dyslexia.
Dyslexia in the Victorian Legislative and Political Landscape

The federal government’s decentralised approach to the definition of dyslexia and provision of funding for students with dyslexia to the state governments relegates the response and responsibility within Victoria to the Department of Education and Training. A search of the department’s website provides a description of dyslexia rather than a definition of dyslexia. It describes dyslexia as a “language based difficulty [emphasis added] of neurological origin” (http://www.education.vic.gov.au). The department’s avoidance of the word “disability” in its description of dyslexia and reference to dyslexia as a “difficulty” highlights a fundamental tension between the Commonwealth Government’s intention and the state of play on the ground in Victoria. In addition, historically there has been no separate, specific funding allocation by the state government for the remediation of students with dyslexia (Skues & Cunningham, 2011). This is not the case for children with sensory, physical and intellectual disabilities, who receive funding from a Commonwealth Government funding program (Australian Senate, 2002). A Senate report, “Education of Students with Disabilities” (2002), highlights the failure of the Australian states (including Victoria) to provide equal opportunity to students with disabilities. The report reflects on the failure of school education authorities to differentiate between students with a diagnosed learning disability such as dyslexia and those grappling with a more general learning difficulty, in their approach to remediation (Australian Senate, 2002). A decade later, in 2012, a report by the Victorian Equal Opportunity and Human Rights Commission (VEOHRC), entitled “Held Back: The Experiences of Children with Disabilities in Victoria”, highlighted the concerning fact that in Victoria, while all students are protected from discrimination by the Equal Opportunities Act 2010 (Vic), there are students who are not eligible for specific funding for their support needs (VEOHRC, 2012). This includes children with dyslexia. The report also found that those students with disabilities who did not qualify for funding were also least likely to have adjustments and accommodations to suit their learning needs (VEOHRC, 2012).
The 2012 report by the VEOHRC highlights the concern that, despite the *Charter of Human Rights and Responsibilities Act 2006* (Vic), the inclusion and treatment of children with disabilities in Victoria is inconsistent. Whilst acknowledging pockets of good practice, the report suggests that despite legislative frameworks designed to promote equity and inclusion, whether these actions occur or not is largely dependent on individual principals, schools and teachers. The report suggests that there is a lack of structural accountability and oversight by the Department of Education and Early Childhood, now known as the Department of Education and Training (VEOHRC, 2012).

Whilst the federal government delegates responsibility to the States and Territories, the current model in place in Victoria devolves responsibility for the direction of funds to individual schools (VEOHRC, 2012). The VEOHRC’s study highlights that this devolution of oversight to schools results in inconsistency, with almost all accountability for the allocation of funds and the elimination of discrimination remaining at school level (VEOHRC, 2012, p. 187).

**Dyslexia through the Social Justice Lens**

The vast array of literature relating to dyslexia worldwide has emerged from multiple disciplines including psychology, educational psychology, education, medicine and speech therapy and from the field of disability studies. These studies have a wide scope and contribute significantly to our understanding of dyslexia on topics which include (but are not limited to) aetiology, definition, categories, prevalence, co-morbidity, treatment, remediation and impact on educational achievement and an individual’s self-esteem, self-concept and relationships with peers and family. These studies largely focused on the manifestation and impact of the condition of dyslexia on the individual and its impact on the individual’s context rather than the social policy context and recognition of dyslexia. Oliver and Zarb (1989) writing in the context of the United Kingdom contend “it is only in recent years that the issue of disability has been transformed from a purely medical problem to a political one” (p. 221). In Western countries such as the United Kingdom, Canada, New Zealand and the
United States, dyslexia has gained recognition as a disability that requires remediation and funding by government (Klassen et al., 2005; Rowan, 2010; Stegemann, 2016). Therefore, the relative absence of discussion of dyslexia from a social justice perspective in the academy in other Western countries is unsurprising. In the Australian context, however—where this is not the case—it is contentious. Australian writers on the politics of education, Cranston, Kimber, Mulford, Reid and Keating (2010), observe that there is a current and evolving shift in the ideology which underpins the education sector from social equity to marketisation. Cranston et al. contend that this transformation, which has impacted on all school sectors, reflects a shift in emphasis from the importance of values such as equity and social justice to one of education for the purposes of social mobility (2010). Therefore, at the same time that there has been growing awareness of disability as a political issue, the neoliberalisation of the education system in Australia is operating in a political environment that has relegated social equity to a submerged status and elevated market forces. It can be argued that social work is well placed to observe these conflicting agendas, to frame dyslexia within a social justice lens, and to advocate for its recognition to ensure equity and social justice within a social policy context.

Internationally, social work’s mandate, values and underlying tenets as a profession are aligned with social justice and human rights (Dudziak, 2002; Werkmeister Rozas & Garran, 2016). The Australian Association of Social Work (AASW) Code of Ethics includes in its definition of social work that it is a profession which:

promotes social change … utilising theories of human behavior and social systems social work intervenes at the point where people interact with their environments. Principles of human rights and social justice are fundamental to social work. (AASW, 2010)

Yet to date worldwide, social work as a discipline is largely silent on the topic of dyslexia. Featuring amongst the few voices in social work on the topic of dyslexia are Nalavany, Carawan and Sauber (2015) in their work from a social work perspective which focuses on dyslexia, family support and self-esteem. Social work’s focus on individual wellbeing is important, and in the context of the
United States in which dyslexia is recognised as a disability, it is fitting and useful. In the Australian context, in light of the submerged position of dyslexia in the social policy landscape, social work could contribute to the study of dyslexia from a human rights and social justice perspective. McKinnon, Kearns and Crockett (2004), in an article examining the nature of educational barriers and the role of school social workers, highlight key tenets of the United Nations Convention on the Rights of the Child, to which Australia is a signatory (p. 239). Under the UN convention, every child has a right to an education that assists the child to develop to their full potential and prepares the child for “responsible life in a free society” (McKinnon et al., 2004, p. 239). The role of the social worker can be useful in mitigating against individual social and educational barriers faced by the child and their family. Arguably, it can also be useful to mitigate against structural silent oppressive injustice that act as a barrier to limit the individual. Yet, as noted by Gilligan (1998), worldwide there is very little attention paid by social work to educational policies in research or in the education of social workers (p. 13).

In 2015, Nalavany et al. critically noted that, despite the fact that dyslexia fits with the social work mandate, they could identify no articles on the topic of dyslexia in the eminent social work journal, the British Journal of Social Work. A search of the British Journal of Social Work in 2017 using the term “dyslexia” yielded only one result which referred to Nalavany et al.’s 2015 article. There were five articles focused on diversity and disability within social work courses (not specifically related to dyslexia), as well as two articles relating to disability more broadly. A further search of this journal using the search terms “specific learning difficulty”—which is often used in the United Kingdom as an umbrella term for learning disabilities including dyslexia (Riddick, 2010)—yielded no results. A search of the Australian Journal of Social Work from its emergence in 1948 to the present day found no responses to the search term “dyslexia”. A further search of the journal with the search term “specific learning difficulty” found zero results relevant to dyslexia or other learning disabilities. Searches carried out using the terms “specific learning disability” and “learning disability” also yielded no results in the Australian Journal of Social Work. Congruent with
this finding is the observation by Moyle (2016) which highlights that core social work curriculum, stipulated by the AASW as a requirement for accreditation by the AASW, lacks a targeted focus on disability. Moyle (2016) reflects on the inadequacy of a curriculum that fails to address “disability theory, knowledge, policies and practice deficits” within its core curriculum (p. 504). Moyle notes that, in light of the changes in the disability sector with the introduction of the new National Disability Insurance Scheme (NDIS), social work courses urgently need to address disability-specific knowledge and theories in their core curriculum. There is an importance and urgency for this to change in light of the changing conditions for people with disabilities and the need for social workers to assist them to navigate, advocate and access services in the new policy environment (Moyle 2016).

A search of the US social work journal Child and Family Studies yielded one study from the Norwegian context which focuses on the learning difficulties of children in the welfare system (Iverson, Hetland, Havik & Stormark, 2010). The education of children in the child welfare system is a matter of social justice. The focus of the paper is, however, on the nexus between the education system and child welfare. Gilligan (1998), critiquing the lack of social work attention on education in schools, sets out an agenda for change. This agenda, whilst encompassing many important social work values, does not specifically include students with a disability (learning or other) (Gilligan, 1998).

Macdonald (2009), writing from a sociological perspective, applies the lens of C. Wright Mills, author of “The Sociological Imagination” (1959) and explores the social model of disability in relation to dyslexia. He contends that it is the social class and institutional barriers that discriminate and cause disabling barriers, rather than dyslexia itself (Macdonald, 2009, p. 348). Similarly, Kinsella and Senior (2008), writing in the Irish context and discussing the debate around inclusive education versus special education for children with special needs such

---

At the time of writing, it is unclear how the rollout of the NDIS scheme in Victoria will impact on children and adults with dyslexia.
as dyslexia, recommend a cultural shift from the focus on “individual pathology” to a focus on “organisational pathology” (p. 655).

McKinnon et al. (2004) contend that social work’s “social justice perspective requires that once we identify a situation that is socially inequitable we must work to bring about equity and strive to achieve change” (p. 244). This study has a social justice orientation. As such it seeks to identify the experiences of parents and to give voice to their experiences in light of the current social policy regime in Australia. It aims to shift the discourse into the social work arena not with a focus on the individual pathology of a child or family but with a broadened lens, a social justice perspective. It attempts to achieve this aim by utilising Fraser’s (1989) framework for the recognition of needs as a tool to examine the experiences of parents.

Fraser developed the needs recognition framework in the tradition of critical social theory which she describes as a school with a “practical intent” (Fraser & Naples, 2004). As such, Fraser’s framework provides a mechanism with which to analyse the emergence of the recognition of dyslexia in the Australian landscape. Fraser’s model contextualises “talk about people’s needs” (Fraser, 1989, p. 291) within a political discourse, claiming that this need discourse is a distinctive hallmark of “late capitalist political culture” (1989, p. 292). She identifies the importance of applying a critical lens to the “politics of need interpretation” (1989, p. 292). Fraser differentiates her model from those of other theorists who focus on the discourse about a particular need or highlight a particular “needs satisfaction” (1989, p. 293). Fraser’s model, by contrast, focuses on the politics of the interpretation of the need within the politics of the state. It contains three distinct phases. The first stage consists of the “struggle to establish or deny the political status of a need” (1989, p. 294). This is the arena in which a struggle occurs between the politicisation and the counteraction to depoliticise the need. Once the need is successfully politicised, it moves to the second stage of Fraser’s model which is “the struggle over the interpretation of the need” (1989, p. 294). This stage consists of debate regarding the definition of the need, the understanding of the need, the language used to define it and therefore the professional domain or political arena in which it belongs. This categorisation and
classification determine what measures will be taken to rectify the unmet need in society. The third stage of Fraser’s model is the struggle over the satisfaction of the need” (1989, p. 294). In this phase, opposing parties struggle over the determination of what measures will be taken to meet the need, what resources will be distributed to meet the need, and by whom (Fraser, 1989, p. 294). Each stage of the model is imbued with struggle and contestation by competing interests. Dominant and subordinate groups with unequal resources engage in battles in a variety of arenas such as the media, the courts, universities, parliament and through public activities such as protests and other activist activities (Fraser, 1989, p. 296). Fraser’s model, which stems from her critical realist approach to theory, recognises the structural inequalities in society taking into account factors such as race, class, gender, ethnicity and age (1989, p. 296). Fraser’s model hypothesises how claims for need recognition break out of the domestic sphere and become successfully politicised and dealt with in the context of policy and legislation (1989, p. 299). This makes Fraser’s model particularly relevant for this study. Chapter 6 of this thesis uses Fraser’s needs analysis framework to examine and test its applicability to the needs of parents of children with dyslexia. Through the prism of Fraser’s model, this research seeks to locate the current status of needs recognition of parents with children with dyslexia within Fraser’s framework. Questions are asked such as: what lessons can be drawn from this study of parents’ experiences that are incongruent with Fraser’s framework? And can Fraser’s theoretical model be expanded in light of the findings of this study?

The current status of dyslexia in Victoria is unique and idiosyncratic. Fraser’s 1989 model of need recognition theory is a useful tool to facilitate understanding of the current status of recognition of dyslexia in Australia. The utilisation of Fraser’s theory in this context provides an opportunity to add a social work voice to the mélange of voices utilising and critiquing Fraser’s work.

Summary

This chapter has provided insight into the contested nature of the definition of dyslexia and has defined dyslexia for the purposes of this study. As a
backdrop to the study, it has introduced the discourse on the manifestation of
dyslexia, language used to describe dyslexia and its prevalence. It has highlighted
the contested status of dyslexia. The position of dyslexia within the Australian
context, and more specifically the Victorian educational and legislative arena, has
been introduced. The impact of dyslexia on children with dyslexia has been
referred to, highlighting the importance of this issue at the centre of this study.

The paucity of studies in relation to parents of children with dyslexia
internationally and within the Australian context has been illustrated. The
marginalised status of disability and dyslexia within the field of social work
nationally and internationally has been explored. The contextualisation of dyslexia
as an important issue of social justice has been presented. The opportunity for
social work to make a unique contribution to the discourse using Fraser’s (1989)
theory of needs analysis has been presented. Chapter 2 will focus on the
methodological approach utilised by this study.
CHAPTER 2:
METHODOLOGY

Introduction

This chapter outlines the methodological approach utilised in this study. The rationale for choosing a mixed method approach is discussed. The chapter articulates the research aims and questions which form the basis of this study. The structure of the research is outlined. The steps undertaken in the qualitative and quantitative methodology are described. The rationale for the criteria for participation in this study is explored, along with an analysis of and insights into issues associated with participation criteria. The strategies utilised for the recruitment of research participants and issues associated with their selection and recruitment are also presented. The process and measures undertaken in the qualitative data analysis are described in this chapter. This is followed by an explanation of the quantitative data collection, recruitment of participants for the survey and the rationale for the use of a survey hosted on the internet. Quantitative data analysis measures are outlined and finally the demographics of participants who participated in the survey are presented. This section is followed by a discussion of the ethical considerations involved in undertaking this study,
the importance of the reflexive approach utilised by the researcher, and an exposition of the qualitative approach and methodology.

**Rationale for a Mixed Method Approach**

This study was conducted utilising both qualitative and quantitative techniques in a mixed method approach. Mixed method research, which emerged in the late 1980s (Creswell, 2014, p. 217), is also referred to as the “third methodological movement” (Creswell & Plano Clark, 2007, p. 1) or “the third research paradigm” (Johnson & Onwuegbuzie, 2004, p.15). It provides answers to research questions in both “narrative and numerical forms” (Teddlie & Tashakkori, 2009, p. 8). Johnson and Onwuegbuzie (2004) suggest that mixed method studies ensure that the end product of the research will be “superior to mono-method studies” (p. 17). This is a contentious view which is debated by dogmatists and purists from both quantitative and qualitative research camps (Johnson & Onwuegbuzie, 2004). The constraints of this study do not allow for an in-depth analysis of one technique’s superiority over the other. Furthermore, mixed method research “rejects traditional dualism” (Johnson & Onwuegbuzie, 2004, p. 18) and can be used to measure “different facets of a phenomenon, yielding an enriched, elaborated understanding” of a subject (Green, Caracelli & Graham, 1989, p. 258). The rationale for choosing a mixed method approach for this study was not a belief in its superiority as a method, but rather a pragmatic decision based on the aims of the research. Tashakkori and Teddlie (2003) encourage researchers to adopt a pragmatic approach, instructing them to study “what is of interest and value to you” and to consider the research questions as more important than the method or paradigm utilised (p. 21). Quantitative and qualitative methods combine to complement each other by expanding and enhancing understanding of the subject (Johnson & Onwuegbuzie, 2004, p. 9). One reason a mixed method design has been chosen for this study is that it best suits the aims and research questions of the study as it provides an expansive breadth, depth and richness of information (Tashakkori & Teddlie, 2003). This is an important objective in light of the paucity of studies on the experience of parents with a child with dyslexia.
Johnson and Onwuegbuzie (2004) argue that mixed method research “draws from the strengths and minimizes the weaknesses” of each technique. One of the inherent weaknesses of qualitative research is that “results may be impacted by the researcher’s personal biases and idiosyncrasies” (Johnson & Onwuegbuzie, 2004, p. 20). The researcher’s dual role of “insider” and “outsider” and the need to ensure rigour strengthened the decision to select a mixed method research design. Additionally, the accessibility and use of the research findings for a variety of key stakeholders was important (Hesse-Biber, 2010, p. 33). Adopting a pluralistic mixed method approach enables the communication of results to a broader range of stakeholders than one research method alone (Johnson & Onwuegbuzie, 2004). This is a particularly salient point as the study of dyslexia is a contested arena with multiple professional and political stakeholders (Hammond, 2002).

Combining a web survey method with an interview process allowed for “multiple perspectives, positions and standpoints” (Johnson, Onwuegbuzie & Turner, 2007, p. 113). The collection of data through an online survey ($n = 413$) provided a mechanism to uncover a greater diversity of experiences than would have been possible within the confines of the small qualitative sample ($n = 21$). The interviews provided a depth of information into phenomena that could not have been gleaned from the survey data on its own. A sequential mixed method model enabled the researcher to explore research questions more broadly than one method would have permitted, and facilitated data triangulation (Patton, 2002, p. 247). The study therefore benefited from the strengths associated with the combination of methods.

**Research Aims and Questions**

This research aimed to gain insight into the experiences of parents with school-aged children with dyslexia in Victoria under the current policy regime. It sought to uncover and understand the experiences of parents who were identifying their child’s learning challenges, gaining a diagnosis of dyslexia and navigating the educational landscape to find support for their child’s additional learning needs. It sought to learn from their (negative and positive) experiences and to hear
and document their ideas for policy change with the aims of furthering the discourse on dyslexia in Australia.

The research questions underpinning this study are:

RQ1. What are the experiences of parents who live in Victoria, Australia who have a child with dyslexia with regard to:

(a) the pathway to the diagnosis of their child with dyslexia; and
(b) gaining recognition and support for their child’s learning needs arising from dyslexia.

RQ2. What is the status of dyslexia in Victoria and how does it impact on parents?

RQ3. What policy recommendations regarding dyslexia arise from this study?

A Convergence of Methods: The Research Structure

Morse (1991) contends that if the questions being examined lack previous theory and research, then they lend themselves to a qualitative examination in the first instance in order to inductively develop theory which can then be complemented with quantitative data (Morse, 1991, p. 121). The lack of previous research in this field informed the study design, with qualitative data being gathered in the first instance and quantitative data collected in the second phase. Creswell & Plano Clark (2007) describe this type of study design as an “exploratory design” (p. 75). The rationale for choosing this type of study was the lack of previous exploration of the subject.

The qualitative research component of this study provided deep and valuable insights into the experiences, feelings, challenges and actions of parents. The survey provided detailed and descriptive data that added strength and measurement to the insights gained at the qualitative stage of the research. Although it is legitimate to decide to place greater importance on either the qualitative or quantitative components of a study, in some instances equal importance is given to both sets of data (Creswell & Plano Clark, 2007). This
study falls into the latter category which considers data gleaned from both techniques as complementary and important for the purpose of expanding the discourse on dyslexia.

This study was carried out using a multi-level model (Tashakkori & Teddlie, 1998, p. 48). The interview schedule was designed and the interviews proceeded. The data emerging from the interviews helped to inform the question design of the survey instrument. The questions contained in the survey were designed to quantify and test the extent of the emerging themes as well as explore the detail of the phenomena in question. In conducting a mixed method research study, there are points where the different strands of the research converge (Creswell & Plano Clark, 2007, p. 66). In this study, while qualitative data were collected in the interviews, the survey instrument collected both quantitative and qualitative data. This is referred to by Creswell & Plano Clark (2007) as an “embedded design” (p. 67). The qualitative data from the interviews were analysed separately from the qualitative and quantitative data collected via the survey tool. (The method of analysis will be discussed later in this chapter.) The qualitative and quantitative findings from the interviews and the survey were combined and synthesised in the interpretation and discussion of findings.

Criteria for Study Participation

Participants of this study (both interview and survey participants) were required to meet the following criteria:

- The participants were parents or guardians of children (aged between 7 and 18 years) having a sole diagnosis of dyslexia from a practitioner with medical or behavioural sciences qualifications obtained from a recognised tertiary institution.
- The diagnosis of their child’s dyslexia was made when the interview participants resided within the state of Victoria.
- At the time of participation in the study, the participants resided in Victoria.
The rationale for the qualifying criteria was based on several considerations. It was important that the participants were parents of children with dyslexia and not another syndrome. The age range of children was contained within the 7–18-year age group as this group encompasses children who are of school age. The inclusion of parents of children aged from seven years rather than the legal school commencement age of five years was selected in order to gain a sense of the pathways and experiences of parents over time. Although children in Victoria are able to commence school from five years of age, some do not commence until they are six years old. Targeting the study at parents with children aged seven and older provided a buffer of time for factors such as professional consultation, diagnosis, advice, responses from school personnel and pathways to services and feelings about policy to evolve and emerge.

The qualifications of the diagnosing practitioner were specified because these are the qualifications which allow them to confirm that the student has a disability under the DDA 1992. Additionally, a sole diagnosis of dyslexia was required, so that the focus would remain on the impact of dyslexia and not be a result of a mixture of additional neurological or physical conditions. The reason for this was the belief that a combination of conditions might make it difficult to single out and focus on the implications of dyslexia. However, in practice, confining the requirement to a sole diagnosis of dyslexia was not straightforward. There are numerous learning disorders which are not currently well defined (Colker, S. Shaywitz, B. Shaywitz & Simon, 2013, p. 2). Additionally, comorbidity of learning disorders is common (Pennington, 2009). Dyslexia and other learning disabilities possess “partially shared etiological and cognitive risk factors” (Pennington, 2009, p. 5). Both the interviews and the survey relied on the participants’ interpretation of the qualifying criteria, their honesty and their psychological acceptance or rejection of a practitioner’s diagnosis. To some extent it also relied on the quality of information provided by the diagnosing practitioner as well as the parent’s understanding of learning difficulties (dyslexia in particular). A quarter of the way through Interview no. 16, the interviewee noted that her son also had a diagnosis of motor dyspraxia. Gray and Gibbons (2007) contend that “Ethical decisions are subjective and relational and depend on the
situations in which they occur” (p. 225). Immediate critical reflection informed me that it would not have been ethical, respectful, compassionate or in the interests of the research participant to terminate the interview at this point. Instead, I attempted to inquire deeply into her experiences to understand how the dual diagnosis affected her experience and distinguished it from those of other research participants.

In another instance (Interview no. 8), the interviewee’s son had been diagnosed with dyslexia by one psychologist and been deemed “one point below the cut-off mark” for a diagnosis of attention deficit disorder (ADD) by another psychologist. The interviewee accepted the diagnosis of dyslexia and rejected the borderline diagnosis of ADD, and hence interpreted that the child had a single diagnosis of dyslexia. Pennington (2009) states that some diagnoses are “fuzzy sets” memberships (p. 39). It is not always the case that learning difficulties can be categorised into neat and discrete categories (Pennington, 2009, p. 6). Additionally, there is evidence of cognitive deficits that are shared by different disorders (Pennington, 2009, p. 6). For example, deficits in processing speed appear both in people with dyslexia and with attention deficit hyperactivity disorder (ADHD) (Shanahan et al., 2006 cited by Pennington, 2009, p. 8). This leads to a murkiness and confusion around diagnoses. Whilst interview participants were required to show the researcher a written diagnosis of dyslexia from a qualified practitioner, it is possible that some participants’ children had undiagnosed comorbidity. In the case of the survey participants, the same issues apply, however those participants were not required to provide evidence of their child’s diagnosis and participation relied on each participant’s integrity when answering the screening question regarding their child’s sole diagnosis of dyslexia. The Plain Language Statement for the survey (see Appendix A (which all participants were required to confirm they had read before proceeding) specifies that eligibility is conditional on their child’s “single diagnosis of dyslexia” and points out that this means that the child “does not have other conditions such as Attention Deficit Disorder or acquired brain injury”. Whilst all participants confirmed this was the case, there is no way to verify this information. It would be reasonable to assume that some participants who filled out the survey had children
with a dual diagnosis of dyslexia and another condition or another undiagnosed syndrome.

An unexpected difficulty that arose in relation to qualifying criteria for the study and the comorbidity of dyslexia and other learning disorders or disabilities was the researcher’s sense of unease at excluding those with multiple syndromes. It resulted in feelings of guilt over marginalising the parents of some of the most marginalised children, silencing the silenced. This marginalisation was acknowledged by the researcher to two potential interview participants who called to check their eligibility to participate, and to three parents who contacted the researcher via email about their eligibility to participate in the survey. It was hoped that this acknowledgement would ease their sense of injustice at the exclusion of their voices.

**Qualitative Approach**

Qualitative research “privileges no single methodological practice over another” (Denzin & Lincoln, 2000, p. 6). This bestows on the researcher the latitude, the scope and the challenge of finding a methodological practice best suited to their inquiry—a blessing and a curse for a novice researcher. This study draws upon Braun and Clark’s (2006) qualitative thematic analysis model, chosen for its utility for this type of exploratory study.

**Semi-structured Interviews**

Creswell (2007) contends that qualitative research methods have the potential to empower and give voice to the silent (p. 40). A key intention of this research was to give a voice to Victorian parents of children with dyslexia. Twenty-one semi-structured interviews were conducted. Twenty interviews were conducted face to face and one interview was conducted via the telephone (Interviewee no. 13) due to the limited time that this particular participant had available for a face-to-face meeting.\(^2\) Interviews allowed the researcher to

\(^2\) Interviewee no. 13 is the mother of three children with diagnosed dyslexia.
examine the “essence of the lived experiences” (Creswell, 2007, p. 93) of parents participating in this study. Semi-structured interviews were chosen to gain insights into parents’ experiences, feelings, thoughts and reflections, decisions, actions and wishes in relation to this complex and sensitive issue. (See Appendix B for the interview guide.)

The interviews explored parents’ experiences in relation to their:

- understanding, experience and response to the initial identification of dyslexia;
- pathway to their child’s diagnosis;
- navigation of the education and policy environment to gain information;
- support and recognition of their child’s learning needs;
- feelings, hopes and concerns in relation to their child in the short term and long term; and
- reflections and key messages for policymakers in relation to dyslexia.

Interviews allowed the interviewees to speak privately and naturally with the interviewer. The duration of each interview was 60–90 mins. While focus groups also create a space for discussion, it was determined that interviews would provide each research participant with exclusive time and space to express themselves anonymously and confidentially. Ritchie and Lewis (2003) suggest that the key feature of interviews is their “ability to provide an undiluted focus on the individual” (p. 36). Additionally, interviews enabled the researcher to tailor the time and location of the interview around the individual participant’s schedule, availability and location. No tangible incentives to participate in this research were offered. This strengthened the importance of ensuring that interviews occurred at the most convenient times and locations possible for the interviewees.

The decision to engage participants in a semi-structured interview as opposed to a “structured standardized interview” or “unstructured interview” (Patton, 2002, p. 342) was based on the need for exploration of specific experiences in order to address the research questions. An unstructured interview risks the possibility of meandering into aspects of the phenomenon that are
perhaps not under inquiry in this study, while a standardised interview does not provide the researcher with the flexibility to explore topics or issues that are novel or unanticipated (Patton, 2002, p. 347; Smith 2004, p. 56). In the context of this study, in which there is a dearth of literature, it was important to allow the interviewee the latitude to raise unanticipated issues of importance.

Recruitment and Participation: Interview Participants

Parents of children with dyslexia are a relatively hidden group (Riddick, 2001). Interview participants were recruited using “purposive” or “criterion based” sampling (Mason, 2002, p. 78; Creswell & Plano Clark, 2007, p. 173). It is important that the “sample strategy support the study’s purpose” (Patton, 2002, p. 245). Therefore, a stratified purposive sampling strategy (Patton, 2002, p. 224) involving targeted advertising of the research project was utilised to ensure that the experiences of parents of children with dyslexia from diverse locations in Melbourne, as well as rural and regional settings, were included in the sample. There was also an attempt to target parents of children from the state, independent and Catholic sectors and to include participants from diverse socio-economic groups. The objective was to try to obtain insights into areas of congruence and difference in the experiences of parents with children in different school sectors, geographical locations and socio-economic groups.

Prior to the recruitment of participants for the study, an informal agreement with SPELD Victoria was established (see Appendix C). The agreement involved the expression of support for this study from SPELD Victoria and its willingness to promote the interviews (and the survey) to its client group. In addition, SPELD Victoria granted permission for the interviews to be conducted on its premises when the venue was deemed suitable by research participants.

---

3 SPELD Victoria has approximately 300 members and is a leading not-for-profit service and advocacy organisation for people with dyslexia in Victoria. It provides support, information and services for children and adults with dyslexia and other learning difficulties.

4 The agreement also contains an understanding that the results of the study will be shared with SPELD Victoria and a summary of the research will be posted on its website.
In addition to SPELD Victoria, which has a state-wide reach, publicity for the recruitment of participants was distributed via:

- the website of an educational consultant who provides fee-for-service consultancy;
- a notice in the online newsletter of a state school in the northern suburbs of Melbourne;
- the email newsletter of an urban volunteer-run support group for parents of children with dyslexia located in the western suburbs of Melbourne;
- an email distributed by two regional parent-run support groups for parents of children with dyslexia located in regional Victoria;
- a flyer placed in the waiting area at an Irlen clinic;
- a flyer included in a kit at a state-wide conference for parents of children with dyslexia which had been promoted through an informal alliance of geographically diverse parent-run support groups; and
- word of mouth via interview participants.

The recruitment strategy was implemented quickly and successfully. Within three weeks of distribution of flyers, emails and website posts, interviews in metropolitan Melbourne \((n = 13)\) and interviews in regional Victoria \((n = 8)\) were secured.

The respondents from the email distribution in regional Victoria were diverse in socio-economic background, employment status, affiliation with the support group, school type and location. The rapid uptake from participants reflected the thirst of parents to share their experiences and be heard. An ethics-based decision was made not to publicise the research more widely in regional Victoria to avoid disappointing potential participants who may have needed to be turned away. The knowledge that parents in other regional areas of Victoria would have the opportunity to participate via the online survey assisted with this decision to cease publicity.

Recruitment of participants ceased when it was felt that the data reached a saturation level; this occurred at Interview no. 21. The concept of saturation arises from grounded theory (Charmaz, 2006 cited by Creswell, 2014, p. 189). It is the
quality of the data gathered that is important—not the quantity (Smith, Flowers & Larkin, 2009, p. 51). Although each of the final three interviews were different and interesting, the interviews were confirming patterns, experiences, feelings and themes which had already emerged. Darlington and Scott (2002) confirm that when this occurs, it “can be safe to stop” gathering data (p. 53).

There were two striking features of the recruitment strategy for the interviews. First was the fact that it took very little publicity to elicit a substantial and speedy response from potential research candidates. Second, news about the interviews spread via word of mouth and potential new candidates emailed the researcher and made contact via phone as a result of this unplanned, unexpected quasi “snowball” type response. Patton (2002) refers to this type of sampling as “opportunistic or emergent sampling” (p. 244). Parents who made contact with the researcher as a result of word of mouth referrals were also included in the interviews.

All candidates for interviews were asked if their child had a formal diagnosis of dyslexia and were sent the Plain Language Statement and Consent Form to preview. All participants confirmed the diagnosis and provided consent. One potential interviewee in Bendigo withdrew from the interview prior to attending as she felt over-burdened by family issues regarding ill health. No participants were screened out as they all fitted the criteria for participation.

The invitation to participate in the interviews was extended to “parents and carers” of children with dyslexia. The flyer (see Appendix D) was not prescriptive in relation to whether one parent or both parents (in the case of couples) were invited to attend, and it was left open for interpretation and flexibility in relation to whether both parents attended or one parent attended. In all cases, interviewees were in fact parents rather than carers.

Table 1 summarises the genders of the interview participants.
Table 1: Gender of Interviewees

<table>
<thead>
<tr>
<th>Gender</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>20</td>
<td>83.3</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>16.7</td>
</tr>
</tbody>
</table>

In total, there were 21 interviews conducted with 24 participants. Interviewees included 17 mothers, 1 father and 3 couples, all of whom were parents of at least one child with diagnosed dyslexia. Although there were 4 males who participated in the interviews, all but one attended with their female partner (the mother of the child). The only male interviewee who attended an interview on his own was a sole parent who had raised his child from six weeks of age on his own. The over-representation of females in the interview cohort and the survey demographics is discussed in the findings and the discussion chapters.

In Table 2, interviews with females are identified by a randomly assigned interview number (to maintain anonymity). Each interviewee’s current occupation is provided along with a general descriptor of their residential location.¹

¹ Note that Interview 10 did not include a female and is therefore not represented in this table.
Table 2: Identifiers, Occupations and Locations of Interviewees – Female

<table>
<thead>
<tr>
<th>Interviewee no.</th>
<th>Occupation</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Disability support teacher</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>2</td>
<td>Manager, public service</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>3</td>
<td>Garment technologist</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>4</td>
<td>Social worker</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>5</td>
<td>Corporate lawyer</td>
<td>Regional Victoria</td>
</tr>
<tr>
<td>6</td>
<td>Creative arts therapist</td>
<td>Regional Victoria</td>
</tr>
<tr>
<td>7</td>
<td>Nurse</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>8</td>
<td>Librarian</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>9</td>
<td>Botanist</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>11</td>
<td>Integration aide</td>
<td>Rural Victoria</td>
</tr>
<tr>
<td>12</td>
<td>Senior public servant</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>13</td>
<td>Teacher</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>14</td>
<td>Manager of a not-for-profit</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>15</td>
<td>Teacher</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>16</td>
<td>Sales and marketing manager</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>17</td>
<td>Home duties</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>18</td>
<td>Home duties</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>19</td>
<td>Teacher</td>
<td>Regional Victoria</td>
</tr>
<tr>
<td>20</td>
<td>Teacher</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>21</td>
<td>Personal shopper</td>
<td>Metropolitan Melbourne</td>
</tr>
</tbody>
</table>

In Table 3, interviews with males are identified by a randomly assigned interview number. Each interviewee’s current occupation is provided along with a general descriptor of their residential location.

Table 3: Identifiers, Occupations and Locations of Interviewees – Male

<table>
<thead>
<tr>
<th>Interviewee no.</th>
<th>Occupation</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Self-employed consultant</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>9</td>
<td>Biochemist</td>
<td>Metropolitan Melbourne</td>
</tr>
<tr>
<td>10</td>
<td>Technician</td>
<td>Regional Victoria</td>
</tr>
<tr>
<td>21</td>
<td>Quality control (manufacturing)</td>
<td>Metropolitan Melbourne</td>
</tr>
</tbody>
</table>
Interviews

Interviews were held in metropolitan Melbourne and in Bendigo, a regional city in Victoria. Interviewee no. 11 resided in rural Victoria and elected to travel several hours to Bendigo to participate in an interview. The remaining five interviewees resided in Bendigo and Castlemaine.

All 21 interviews were conducted over a three-month period, which reflected the researcher’s scheduling and need for reflection between interviews rather than the time required to recruit volunteer participants. Interviewees who contacted the researcher were selected on a first-come first-serve basis. Three potential candidates for interviews who did not meet the selection criteria were rejected. The reasons for rejection were lack of a formal diagnosis of dyslexia, and co-morbidity of dyslexia with autism. The numbers of participants in regional Victoria versus metropolitan Melbourne reflects response from participants rather than control by the researcher. The speed of the uptake to participate in this research is considered in Chapter 7.

Table 4 identifies the gender of children referred to by parents in this study.

Table 4: Gender of the Children of Interviewees

<table>
<thead>
<tr>
<th>Gender</th>
<th>( n )</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>12</td>
<td>48.0</td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>52.0</td>
</tr>
</tbody>
</table>

Amongst the 21 interviewees, there were three cases with more than one child with dyslexia in the family; hence, the total number of children referred to in the 21 interviews was 25. In the sample, the numbers of male and female children with dyslexia (represented by their parents) is almost equal. This gender ratio of the children represented by their parents in the interviews is unintended and coincidental. No quota was set regarding the gender of children referred to in this study. Pseudonyms are used for children (and parents who are named) in the findings and discussion chapters.
Table 5 identifies the school sector in which the children referred to in the interviews are currently enrolled.

<table>
<thead>
<tr>
<th>Type of school</th>
<th>n</th>
<th>%</th>
<th>ABS %</th>
</tr>
</thead>
<tbody>
<tr>
<td>State school</td>
<td>22</td>
<td>88</td>
<td>62.5</td>
</tr>
<tr>
<td>Independent school</td>
<td>—</td>
<td></td>
<td>14.3</td>
</tr>
<tr>
<td>Catholic school</td>
<td>3</td>
<td>12</td>
<td>20.5</td>
</tr>
</tbody>
</table>

Note. ABS = Australian Bureau of Statistics.

Interviews in the Melbourne region were conducted at several locations. These sites included the offices of SPELD Victoria, school offices, interviewees’ work sites, Melbourne University and La Trobe University campus in Bendigo. It should be noted that when interviews were conducted on site at SPELD Victoria, the nature of the agreement regarding cooperation for publicity and office space was made clear, so that participants would not feel inhibited in expressing any views or feelings they might have in relation to their experiences of SPELD Victoria. Locations of the interviews were chosen on the basis of ease of access for the interviewee. One interviewee (Interviewee no. 11), who resided in rural Victoria, chose to make a four-hour round trip to Bendigo to participate in an interview. Sites that provided a quiet, comfortable space and privacy were chosen over public spaces that lacked these conditions. All interviewees consented to being recorded, and two digital recording devices were used so that if one technology failed, information from the interview was backed up on the second recording device. The recordings were outsourced for professional transcription.

Data Analysis

This study used thematic analysis to analyse the data. Braun and Clarke (2006) contend that “thematic analysis should be considered a method in its own right” (p. 78). Their framework provides a clear guide for conducting thematic
analysis which is pragmatic and rigorous whilst also allowing for flexibility in its application.

Using an inductive approach (Braun & Clarke, 2006), the whole data set was coded using the software NVivo. Memos and summary notes containing observations and feelings emerging from the interviews were written immediately post interview and were used to help inform the creation of codes. As implied by an inductive approach, the codes emerged from the data (Braun & Clarke, 2006, p. 83) from both semantic and latent content (pp. 84, 88). Whilst some researchers who take an inductive approach construct the literature review following the analysis of data, in this study the literature review was compiled prior to developing the interview schedule (and the survey). This step was deemed important as it allowed an exploration of the topic and familiarisation with existing data. The literature review provided a depth of understanding and a context which informed the construction of the research questions. Awareness of the current gaps in knowledge was useful. The paucity of Australian data in this space meant there was no danger of a reduction of the “analytical field of vision” (Braun & Clarke, 1996, p. 86) as a result of engaging with the literature. The challenge to emerge was the attempt to narrow the study focus, as the research gap in this field is large.

As the first step in data analysis, each interview recording was listened to while simultaneously reading the transcript and correcting any transcription errors. Replaying the recordings added tone of voice, nuances, emphasis and emotions such as tears and laughter, adding depth and bringing the interview to life again. Listening carefully was very helpful at this point, and additional memos, observations, reflections and emerging ideas were produced. Braun and Clarke suggest that checking the original audio recordings against the transcripts for accuracy is an essential step pre-coding (2006, p. 88). Using NVivo software meant that coding one extract of text in several different code categories was easily achievable, and this occurred often in the construction of the initial codes. Once the codes were identified and all data distributed according to each code, coded data was re-read within each category and some codes were merged as they overlapped or were inaccurately labelled. Some data extracts were regrouped, and
some codes renamed to more accurately reflect the content within the code. Following this stage, mind maps with the initial codes identified were produced and then honed into thematic maps. In creating multiple and different versions of these mind maps, examining the key ideas, feelings, thoughts and experiences of the research participants enabled the development of thematic maps identifying how the codes interacted with each other (Braun & Clarke, 2006, p. 89). As noted by Ryan and Bernard (2000), questions such as “when, why, and under what conditions do these themes occur in the text” (p. 783) were asked. This was a slow iterative process of analysis that resulted in the emergence of sub-themes and themes.

Throughout the coding process, caution was taken in relation to the application of researcher bias and this included application of reflexivity and reflection. This resulted in an ongoing checking of process: a “review and evaluation of … the interplay of assumptions and beliefs” (Jude, 2017, p. 12). For the first three years of the research process, supervision meetings were held with three research supervisors on a fortnightly basis. Discussion regarding reflexivity occurred within these supervision meetings on a regular basis. Reflexivity is described as a way of examining “being in the world with self and others” (Pearce, 2014 cited by Jude, 2017, p. 2). In its application in this research process, it included double-checking with the supervision team the phrasing of questions, the interpretation and understanding of emerging findings and the literature as well as the reflection on and interpretation of the literature. In-depth discussions occurred during this process.

**Quantitative Data Collection**

An online survey was chosen as the quantitative data collection instrument. The survey sample used a nonprobability convenience sampling design (Hesse-Biber, 2010; Faulkner & Faulkner, 2009). This was chosen as it was not the intention of the researcher to make statistical generalisations about the sample group, but rather to explore new as well as emerging phenomena arising
from the qualitative part of the study. This type of nonprobability sample is best suited to exploratory studies of this kind (Grinnell, 1988, p. 251).

Descriptive data were gathered via the survey. The survey included open-ended qualitative questions that elicited additional descriptive data and explanations of responses. These data were manually coded using thematic analysis techniques (Braun & Clarke, 2006). Open-ended questions generated data and themes which enriched the quantitative data produced in the survey by adding details, contexts and explanations. Meaning was drawn from the respondents’ thoughts, comments, opinions and stories and emerging themes were noted, categorised and reflected in themes referred to in the findings from the survey.

The online survey was designed using the SurveyMonkey tool. SurveyMonkey was chosen as it is a convenient user-friendly tool (Vanderstoep & Johnston, 2009, p. 87). The survey was piloted using eight testers. The testers included two of the researcher’s supervisors, three parents of children with dyslexia and three people who had excellent literacy skills and who were unfamiliar with the research. Testers were instructed to provide feedback on any technical glitches, English language errors, ambiguity or lack of clarity, use of technical language or jargon, oversights, negative experiences and/or positive feedback as well as how long the survey took to complete. Minor changes to wording of questions in the survey were made in response to the feedback. A concern that was expressed by those who piloted the survey was that it took 30–40 mins to complete and that this could deter some potential respondents. This criticism was noted, however changes were not made as it was decided that all the information being gathered was of importance to the study. This decision was justified in light of the fact that the final number of survey respondents was 403, which exceeded the study target of 250 participants at the outset of the study.

Recruitment Strategy for Survey Participants

The initial recruitment strategy for the online survey involved strategically posting a flyer (Appendix E) with a link to the survey on dyslexia related websites and dyslexia related social media sites (including Facebook), as well as including
notes in online and hardcopy newsletters of target organisations and schools. The strategy involved targeting dyslexia-specific, disability-specific and general parenting sites and newsletters. Examples included the VEOHRC newsletter, SPELD Victoria and LDA. The organisations that were approached to publicise the interviews agreed to advertise the flier with an embedded link to the online survey.

Articles on this research were also published in state-wide newspapers in June 2014, nine months after the survey went live. Following publication in a daily state-wide newspaper (both hardcopy and digital formats) and a subsequent appearance by the researcher on the Australian Broadcasting Commission’s local Melbourne radio station, ABC 774, respondent numbers for the survey increased rapidly over a two-week period, from 140 to 331 (537 attempted surveys).

The Use of Internet Survey Tool

The rationale for using a web survey was based on multiple factors. A web survey provides a cost-effective means of distribution (Couper & Miller, 2008) as compared to a mail-out, telephone survey or delivery of the survey to suitable sites (Reips, 2007, p. 376). The population of parents of children with diagnosed dyslexia is generally a hidden population (Riddick, 2001). The placement of a link to the web survey on strategic websites and in newsletters and via email distribution sites was effective in terms of accessing participants residing in diverse geographical locations simultaneously and was therefore time effective (Reips, 2007, p. 376). The web survey enabled a large cohort of parents to access the survey simultaneously following the embedded link in the online newspaper article or navigating there from the prompt in the print copy of the newspaper article. Additionally, the nature of the internet means that the data collection did not have to occur at a particular time or date or place (Couper & Miller, 2008). The survey could be accessed at any time, from any geographic location (Mansoldo Dainesi & Goldbaum, 2014). This is an advantage for parents who are frequently time poor, juggling the needs of their children, household and other key priorities such as paid work.
All research methodologies have strengths and weaknesses (Couper & Miller, 2008). One of the constraints of using an online survey is that, although filtering questions were provided to specify the target group, it was not possible for the researcher to view evidence confirming eligibility. For example, evidence of the child’s diagnosis of dyslexia was not obtainable. However, this constraint is also associated with traditional survey methods, such as telephone surveys or the distribution of hard copy surveys. An additional constraint of an online survey is that it is theoretically possible for a participant to log in to the survey and complete it more than once. While the SurveyMonkey tool does enable researchers to identify a unique, identifying meta-data code for each survey respondent, this is not a safeguard against a respondent logging in from two different locations, such as home and work. However, a review of the codes demonstrated no duplication of meta-data and there were no identical survey results which appeared in the data analysis of surveys. Therefore it is highly unlikely that a respondent completed the survey more than once.

The online status of the survey created a buffer between the researcher and the survey participants. The anonymity provided by de-identified online surveys offered privacy and assured confidentiality, which can be considered a strength of the methodological approach. The lack of personal interaction between the researcher and the survey participants negates researcher influence on the respondent’s responses, which is not the case with telephone surveys or face-to-face interviews (Mansoldo Dainesi & Goldbaum, 2014). This is an important element to take into account when reflecting on the researcher’s “insider” status. According to the Australian Bureau of Statistics (ABS), 86% of Australian households have access to the internet (ABS, 2016). Despite this relatively high figure and the availability of the internet in public locations such as libraries and internet cafes, it is recognised that some people in the survey target group may not have access to the internet, particularly people from lower socio-economic groups and culturally and linguistically diverse backgrounds.

The survey was administered via the SurveyMonkey tool, which is a tool to enable researchers to design and store data on a web-based platform (Murray, 2014). SurveyMonkey is an off-the-shelf tool which was chosen for its user-
friendly interface and the assurance of anonymity for participants. An inherent weakness of the web survey utilised for this target group is that, as dyslexia runs in families, a written survey tool may have deterred some participants from completing the survey. However, it is possible that parents or carers with literacy challenges may have installed computer software which enables voice reading and voice recognition technology on their devices to assist with accessing and completing the survey. It should also be noted that the distribution of a handwritten survey would also have presented a barrier for those with learning disabilities.

The SurveyMonkey platform enabled the research questions to include a variety of question types including the options to indicate ratings on a Likert scale, select multiple responses to a question, select a yes or no answer, and write free form in the space provided.

Survey respondents were directed through a series of questions consisting of the following categories:

- General non-identifying background information;
- Information relating to the pathway to the identification and diagnosis of child’s dyslexia;
- Experience of gaining support for child;
- Expenditure relating to assessment and support for child;
- Experience of the recognition of child’s learning and support needs in school environment;
- Policy views; and
- Demographics of respondent.

(See Appendix F for the web survey questions.)

**Data Analysis**

The survey was online from 5 September 2013 and ceased to collect data on 1 August 2016. The length of time the survey was online reflects the intention to gather a large quantity of data for the required sample. There were no
significant changes in policy during the three-year period which might have influenced how participants responded. Quantitative data from the survey were downloaded from SurveyMonkey into an Excel spreadsheet and cleaned. The data were then transferred into the statistical program, IBM SPSS Statistics, and analysed primarily through descriptive statistics which included frequencies, the mean and standard deviation, confidence intervals and cross-tabulations.

In the first instance, all respondents who did not match the selection criteria were screened out of the survey and their responses were deleted. The first five filtering questions to ensure qualification for the survey were:

- the participant had read and understood the Plain Language Statement;
- the participant consented to participation;
- the participant was the parent or carer of a child with dyslexia which had been diagnosed by a qualified practitioner;
- the child had been diagnosed in Victoria; and
- the respondent currently resided in Victoria.

These qualifying questions reduced the number of respondents from 790 to 419. Additionally, four respondents stopped completing the survey at question 6 which is the first question post the screening and selection questions and requests information from participants in relation to the exact nature of their relationship to the child. This was deemed not to be useful data without the context of the rest of the survey. A further eight participants ceased participation at question 8. This meant that, in addition to the screening questions, they had answered three questions out of a total of 73. These three questions related to their relationship to the child, their own gender and the gender of the child. This was not deemed useful information in the absence of additional completed survey questions. The total number of participants remaining after this data cleaning process was \( n = 403 \). The option for survey respondents to skip questions resulted in a fluctuation of respondent numbers throughout the survey. Some survey questions permitted multiple responses. This is indicated in the findings when it occurs.
Demographic Profile of Survey Respondents

This section provides context to the sample group by comparing demographic details of the respondents to the general Australian population. It outlines information relating to the gender of the respondent, familial relationship of the respondent to the child, the country of birth of the respondent, Aboriginal and Torres Strait Islander status and the language respondents speak in the home. Also included is information relating to the respondent’s education, employment status and their household income.

Table 6: Gender of Respondents

<table>
<thead>
<tr>
<th>Gender</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>385</td>
<td>95.5</td>
</tr>
<tr>
<td>Male</td>
<td>18</td>
<td>4.5</td>
</tr>
</tbody>
</table>

Table 6 indicates that respondents to the online survey (n = 403) were overwhelmingly and disproportionately female, with 95.5% of respondents being female and 4.5% male. Although there is literature on the influence of gender in relation to participation in online surveys, including preliminary evidence that females are more likely to respond to online surveys than males (Smith, 2008), it does not account for the disproportionate response rates from females (mothers, stepmothers, foster mothers and grandmothers) who elected to undertake this survey. The stark contrast in the number of female versus number of male respondents is far greater than can be accounted for by differing gender response rates to surveys online or other. It is probable that an underlying cause for this high representation of females is related to broader societal factors relating to gender roles. Literature suggests that women are more likely to be carers and advocates for children in the education sphere (Golden & Erdreich, 2014; Ryan & Runswick-Cole, 2008). A more in-depth analysis of the predominance of female respondents to the survey will be addressed in Chapter 6.
Table 7: Relationship of Respondent to Child

<table>
<thead>
<tr>
<th>Relationship</th>
<th>n (n = 403)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>400</td>
<td>99.3</td>
</tr>
<tr>
<td>Step-parent</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Foster parent</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Grandparent</td>
<td>1</td>
<td>0.2</td>
</tr>
</tbody>
</table>

Table 7 highlights that 99.3% of survey respondents (n = 403) were the biological parents of the child they referred to in the survey. The figures demonstrate that amongst respondents there was one step-parent, one foster parent and one grandparent with caring responsibilities for their grandchild with dyslexia.6

Table 8: Respondent’s Age

<table>
<thead>
<tr>
<th>Age range</th>
<th>n (n = 362)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>18–19</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>20–29</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>30–39</td>
<td>54</td>
<td>14.9</td>
</tr>
<tr>
<td>40–49</td>
<td>257</td>
<td>71.0</td>
</tr>
<tr>
<td>50–59</td>
<td>44</td>
<td>12.2</td>
</tr>
<tr>
<td>60–69</td>
<td>4</td>
<td>1.1</td>
</tr>
</tbody>
</table>

Table 8 shows that, of the 403 survey respondents, only 362 reported their age. The majority of respondents were aged in the 40 to 49 age group categories. The average age of survey respondents was 44.

---

6 In light of the fact that there is only one grandparent represented in the sample group and that the grandparent acts in loco parentis for the child, the term “survey respondents” is used interchangeably with the term “parent” in the discussion chapter.
Table 9: Respondents Born in Australia

<table>
<thead>
<tr>
<th>Response</th>
<th>n (n = 368)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>321</td>
<td>87.2</td>
</tr>
<tr>
<td>No</td>
<td>47</td>
<td>12.8</td>
</tr>
</tbody>
</table>

Table 9 indicates that survey respondents born in Australia constitute 87.2% of this sample with the remaining 12.8% of respondents born overseas. The 2011 Australian population Census data reports that 68.6% of Victoria’s population were born in Australia (ABS, 2011). Therefore, the views and experiences of parents of children with dyslexia who were born overseas are under-represented in this survey. The reason for the under-representation of overseas-born parents of children with dyslexia in this sample is unknown. A possible explanation is that immigrants from non-English speaking countries may be less likely to fill out an online survey in English than native English speakers. Congruent with this hypothesis is the evidence from data displayed in Table 10 which demonstrate that the majority of respondents speak English at home. This implies a substantial degree of proficiency in the use of spoken English.

Table 10: English Spoken at Home

<table>
<thead>
<tr>
<th>Response</th>
<th>n (n = 368)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>360</td>
<td>97.8</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Data represented in Table 10 demonstrate that 97.8% of respondents speak English at home. In Victoria, data from the ABS demonstrates that in 72.4% of households, English is spoken in the home, with languages other than English being the norm in 23.0% of homes (ABS, 2011). Therefore, parents who speak languages other than English in the home are under-represented in this survey. There were no significant patterns amongst the eight respondents that spoke

---

7 At the time of writing, the 2011 Census data was the latest data available.
languages other than English in the home. These languages were Serbian \((n = 1)\), Korean and Hokkien \((n = 1)\), German \((n = 1)\), Cantonese \((n = 1)\), Italian \((n = 2)\), Danish \((n = 1)\) and Greek \((n = 1)\).

It is possible that the English language presented as a hurdle for potential respondents from non-English speaking countries. Additionally, it should be noted that dyslexia has a genetic heritability component (Snowling, Gallagher & Frith, 2003). Wood and Grigorenko (2001) point out that approximately one third of parents of children with dyslexia have dyslexia themselves (p. 504). Parents of children with dyslexia who also have dyslexia and do not speak English as a first language would encounter an even greater level of difficulty in filling out an online survey in English. This may have deterred their participation in greater numbers.

Table 11: Aboriginal or Torres Strait Islander Background

<table>
<thead>
<tr>
<th>Response</th>
<th>(n = 368)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>365</td>
<td>99.2</td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>0.8</td>
</tr>
</tbody>
</table>

Table 11 contains information in relation to Aboriginal or Torres Strait Islander background. In Australia, the Aboriginal and Torres Strait Islander population is 2.5% of the general population. In Victoria this figure is lower, with 0.7% of the population identifying as having an Aboriginal or Torres Strait Islander background (ABS, 2011). Table 11 contains demographic data which indicates that 0.8% of respondents (representing three respondents) identify as Aboriginal or Torres Strait Islander. Therefore, the sample distribution can be considered congruent with and representative of the percentage of people with an Aboriginal and Torres Strait Islander background in the general population in Victoria. However, from such a small number of people representing Aboriginal and Torres Strait Islander background, meaningful observations and conclusions cannot be drawn.
Table 12: Respondent’s Highest Level of Education

<table>
<thead>
<tr>
<th>Level of education completed</th>
<th>n</th>
<th>(%)</th>
<th>ABS %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Postgraduate studies</td>
<td>140</td>
<td>38.0</td>
<td>5.6</td>
</tr>
<tr>
<td>Undergraduate studies</td>
<td>96</td>
<td>26.1</td>
<td>38.0</td>
</tr>
<tr>
<td>Technical or further education</td>
<td>75</td>
<td>20.4</td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>42</td>
<td>11.4</td>
<td></td>
</tr>
<tr>
<td>Secondary (part)</td>
<td>14</td>
<td>3.8</td>
<td></td>
</tr>
<tr>
<td>Primary school</td>
<td>1</td>
<td>0.3</td>
<td></td>
</tr>
</tbody>
</table>

Note. ABS = Australian Bureau of Statistics.

Table 12 indicates that respondents who answered the question about education (n = 368) have a significantly higher percentage of postgraduate qualification than the Victorian population. Amongst Victorians 5.6% of the population holds postgraduate qualifications compared to 38.0% of the survey respondents (ABS, 2011). Amongst the general population of Victoria, the highest level of education is an undergraduate degree held by 38.0% (ABS, 2011). Amongst survey respondents, the percentage who ceased their studies upon completion of an undergraduate degree is 26.1%. In total 64.1% of respondents have completed both undergraduate and postgraduate qualifications, as compared to 43.6% of the Victorian population as measured by the 2011 Census (ABS, 2011). Conversely, the general Victorian population has a higher percentage of people (56.4%) with technical and further education (TAFE) qualifications or lower compared to the survey population of 35.9% (ABS, 2011).
Table 13: Employment Status of Respondent by Gender

<table>
<thead>
<tr>
<th>Employment status (multiple response)</th>
<th>Female</th>
<th></th>
<th>Male</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>118</td>
<td>33.3</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Employed full-time</td>
<td>78</td>
<td>22.0</td>
<td>9</td>
<td>64.3</td>
</tr>
<tr>
<td>Self-employed</td>
<td>74</td>
<td>20.9</td>
<td>6</td>
<td>42.9</td>
</tr>
<tr>
<td>Home duties</td>
<td>64</td>
<td>18.1</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Employed casual</td>
<td>20</td>
<td>5.6</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Disability pension</td>
<td>7</td>
<td>2.0</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Student</td>
<td>6</td>
<td>1.7</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5</td>
<td>1.4</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Single parent pension</td>
<td>4</td>
<td>1.1</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
<td>0.3</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Note. Multiple responses were permitted in this question; therefore, frequencies do not add up to 100%.

The emergence of the gender of the respondents as a matter of significance determined that it would be of interest to analyse the respondents’ employment status according to gender. Table 13 indicates that female responses (n = 354) to the question about employment demonstrate that a third of females (33.3%) are employed part time and a further 5.6% are employed in casual employment, equating to 38.9% of female respondents. This compares to the lower rate of 24.3% of females employed on a part-time and casual basis in the general population (ABS, 2011). Female respondents are also self-employed at a much higher rate (20.9%) than the general female population (9.6%) (ABS, 2011). Additionally, female respondents are employed in a full-time capacity (22.0%) at a lower rate than females in the workforce in the general population (ABS, 2011). There are 18.1% of females in the survey sample who are engaged solely in home duties. The ABS data does not reflect data on people engaged solely in home duties.

Of note is that a high percentage of males are self-employed (42.9%) and no males are employed part time or on a casual basis, engaged in home duties.
studying, on a pension, retired or unemployed. However, due to the low number of male participants \((n = 14)\), observations need to be made with caution.

Table 14: Family Income of Respondent

<table>
<thead>
<tr>
<th>Income range $</th>
<th>(n = 369)</th>
<th>%</th>
<th>ABS %</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–12,000</td>
<td>—</td>
<td>—</td>
<td>4.1</td>
</tr>
<tr>
<td>12,000–35,999</td>
<td>21</td>
<td>5.7</td>
<td>12.5</td>
</tr>
<tr>
<td>36,000–65,999</td>
<td>34</td>
<td>9.2</td>
<td>18.8</td>
</tr>
<tr>
<td>66,000–105,999</td>
<td>91</td>
<td>24.7</td>
<td>22.4</td>
</tr>
<tr>
<td>106,000–145,999</td>
<td>74</td>
<td>20.1</td>
<td>18.3</td>
</tr>
<tr>
<td>146,000–185,999</td>
<td>55</td>
<td>14.9</td>
<td>13.1</td>
</tr>
<tr>
<td>186,000–249,999</td>
<td>30</td>
<td>8.1</td>
<td>5.3</td>
</tr>
<tr>
<td>250,000 or more</td>
<td>27</td>
<td>7.3</td>
<td>2.2</td>
</tr>
<tr>
<td>Undisclosed</td>
<td>37</td>
<td>10.0</td>
<td>3.3</td>
</tr>
</tbody>
</table>

*Note. ABS = Australian Bureau of Statistics.*

In comparing the household incomes of survey respondents to the general population of Victoria, respondents have higher income levels than the Victorian population. The Census data of 2011 reflects that 4.1% of the Victorian population have an income of below $12,000 (ABS, 2011). Table 14 shows that there were no survey respondents \((n = 369)\) within this lowest income bracket. Of the Victorian population, 12.5% have a household income of between $12,000 and $35,999 (ABS, 2011) compared with 5.6% of survey respondents. Similar levels of difference are reflected in the next relatively low income bracket, with 9.2% of the respondents indicating that their household income is between $36,000 and $65,000 as compared to 18.8% of the Victorian population (ABS, 2011). The difference between the survey sample group and the general population is also evident at the other extreme of income bracket, with 7.3% of the sample group earning $250,000 or more per annum compared to 2.2% of the general population, and 8.4% of the sample earning between $186,000 and $249,000 compared to 5.3% of the general population (ABS, 2011).
There is less difference between those earning in the middle categories of between $66,000 and $105,000, with 24.6% of respondents fitting this category compared to the slightly lower 22.4% of the general population (ABS, 2011). With each increasing income bracket, the gap between survey respondents and the general population increases, with survey respondents having a higher income than the norm.

Of the survey population, 10.0% chose not to disclose their income compared to 3.3% of respondents to the Census. Perhaps this reflects a higher level of comfort in revealing income levels in response to a government survey.

**Demographic Profile of the Children Referred to in the Survey**

Following is demographic material collected in relation to the child. It outlines the breakdown of the children referred to by respondents to the survey by gender, age and school sector in which the child is enrolled.

Table 15: Gender of Child

<table>
<thead>
<tr>
<th>Gender</th>
<th>$n$ (n = 403)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>232</td>
<td>57.6</td>
</tr>
<tr>
<td>Female</td>
<td>171</td>
<td>42.4</td>
</tr>
</tbody>
</table>

Survey participants ($n = 402$) were asked to indicate the gender of the child of whom they were thinking about when completing this survey. Table 15 indicates that 42.4% of children were female and 57.6% children were male.

There is controversy and unresolved debate in the literature regarding the prevalence of dyslexia in males and females (Wheldall & Limbrick, 2010; Jimenez et al., 2009; Berninger, Nielsen, Abbott, Wijsman & Raskind, 2008). The difficulty of determining the prevalence of dyslexia in males and females is compounded by issues such as differing definitions of dyslexia, research sampling structures, cross-cultural issues in cross-national studies, language differences, gender role bias, referral for testing and the child’s environment (Jimenez et al., 2009). Jimenez et al. (2009) conducted a study which concluded there were no
significant gender differences in prevalence; but other studies suggest the frequency in males is higher, being slightly above the one-to-one ratio (Chan, Suk-han Ho, Tsang, Lee & Chung, 2007; Flannery, Liederman, Daly & Schultz, 2000; S. Shaywitz, B. Shaywitz, Fletcher & Escobar, 1990; Wadsworth, DeFries, Stevenson, Gilger & Pennington, 1992). Others conclude the ratio for boys is several times higher (Miles, Haslum & Wheeler, 1998; Quinn & Wagner, 2015; Vogel, 1990; Wheldall & Limbrick, 2010). Others contest that developmental dyslexia is equally common in females, claiming that figures for females with diagnosed dyslexia are under-represented due to referral bias for males for diagnosis (Siegel & Smythe, 2005; Shaywitz et al., 1990). While the debate remains controversial, the cause of the higher representation of males than females in this study is unknown.

Table 16: Birth Year of Child

<table>
<thead>
<tr>
<th>Birth year</th>
<th>Frequency %</th>
<th>$(n = 403)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>2.0</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>2.7</td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>5.0</td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>6.7</td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>8.7</td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>9.9</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>8.7</td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>13.4</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>15.6</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>8.2</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>11.2</td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>4.0</td>
<td></td>
</tr>
</tbody>
</table>

Table 16 contains data regarding the year of birth of children of respondents $(n = 403)$ referred to in this survey. Links to the survey were available on the internet from October 2013 to August 2016. The majority of responses was
collected in July 2014 in response to an article in The Age newspaper in relation to dyslexia and containing a link to this survey (The Age, 5 July 2014). Therefore, when this date is taken as the reference point, 52.4% of children referred to by parents in this survey are aged 13 or under. Children in Victoria complete primary school at approximately 12–13 years of age and commence secondary school. This suggests that an approximately equal number of primary and secondary school children were identified by their parents in this survey.

Table 17: Type of School the Child Currently Attends

<table>
<thead>
<tr>
<th>Type of school</th>
<th>n (n = 376)</th>
<th>%</th>
<th>ABS %</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
<td>194</td>
<td>51.6</td>
<td>62.5</td>
</tr>
<tr>
<td>Independent</td>
<td>91</td>
<td>24.2</td>
<td>14.3</td>
</tr>
<tr>
<td>Catholic</td>
<td>81</td>
<td>21.5</td>
<td>20.5</td>
</tr>
<tr>
<td>Home</td>
<td>7</td>
<td>1.9</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>0.8</td>
<td></td>
</tr>
</tbody>
</table>

Table 17 displays the school sector in which respondents’ children (n = 376) were enrolled at the time of the survey. Responses indicate that 51.6% of participants’ children are enrolled in the state school sector compared to 65.2% of children in the general population (ABS, 2013). Of the survey sample, 21.5% are enrolled in the Catholic education sector, reflecting a marginally higher percent than the general population in which 20.5% of children attend a Catholic school (ABS, 2013). The percentage of respondents’ children enrolled in the independent school sector is 24.2 compared to 14.3% of the general population (ABS, 2013). There are 1.9% of respondents who indicated that their children are home schooled. Possible reasons for the differences between the survey sample group and the general population in relation to over-representation of children in the independent school sector is addressed in explored in Chapter 9.
Ethical Considerations

The study was granted ethics approval by The University of Melbourne Human Research Ethics Committee (Approval number 1238564.1).

Ethical Processes: Interviews

All participation in this research was voluntary with no incentive or reward offered in exchange for participation. All participants were adults over 18 years of age. Emails were sent to potential interview candidates with the Plain Language Statement (Appendix G) and the Consent Form (Appendix H) before interview times were arranged. Signed consent forms were returned to the interviewer preceding the interview. No information about the research was concealed from participants. The contact details (email addresses and telephone numbers) of the researcher and the supervisory team were provided to participants to enable further enquiries about the research. Participants were free to withdraw from the research at any point, including following the signing of consent forms and collection of data. No interviewee withdrew from the research process once the consent forms were signed. Records of interviews were kept securely under lock and key in a filing cabinet and in password protected computer files. Interview transcripts were de-identified and pseudonyms are used when quotes are given in this thesis. Following transcription of the interviews, the recordings of the interviews were wiped from the two recording devices to ensure privacy. One voice recording of each interview has been retained by the researcher on a password protected computer.

Ethical Processes: Survey

Survey respondents were provided with a link to the Plain Language Statement (see Appendix A) and the Consent Form (see Appendix I) and were required to read these forms and provide consent via a tick box system before they could progress to the survey content. Some survey respondents requested in the text boxes of the survey that the researcher make contact with them when a summary of the research results was made available. These details were collected
and added to a securely stored password-protected list for future reference in order to comply with the respondents’ wishes. No links between their email addresses and the data they supplied in the survey have been retained.

The survey mechanics were designed in such a way that the survey content could not be accessed without acknowledgement by participants that they had read and understood the Plain Language Statement and agreed to the consent form by ticking the online box. The survey software exited participants prior to the start of the survey if they did not consent to the survey. Survey participants were able to download the Plain Language Statement and the consent form and print these for future reference.

Survey participants remained anonymous. The SurveyMonkey tool used enables this to occur. No data was collected by which participants could be traced via technical or personal information.

**Ethical Considerations for All Research Participants**

Due consideration was given to the question of whether participation in this research would cause distress. It was deemed possible that in reflecting on past experiences relating to their child’s dyslexia, some emotional distress may be experienced. As a precaution, the interviewees and the survey participants were provided with a list of support services should the interview or survey raise any issues that may cause distress. The support list included psychosocial support services as well as dyslexia specific organisations (see Appendix J). Participants could download and print the support list for future reference. Additionally, if distress was caused by questions in the survey, participants had the option of exiting the survey and discontinuing their involvement.

In the course of the interview process, the distress of interview participants in telling their stories was often a factor. It was rare for an interviewee not to cry at some point during their interview. One of the ethical challenges this presented was how to navigate the boundaries between the researcher role and the social work role, as it was not a therapeutic space. The researcher’s role is not to offer counselling and counselling did not occur. However, participants were offered a
break from the interview, and provided with an empathetic response and reminded of the supports available. Compassion was integral to the tone of the interview. Finding the balance between compassion and empathy while not stepping into the therapeutic social work role required the researcher to exercise reflexivity during the interview. For many of the participants, the interview was the first time they had been afforded an opportunity to speak of their experiences and this was reflected by interviewees who thanked the researcher for providing the opportunity to reflect on their journey and contribute to this research. Many survey participants also expressed their thanks for the opportunity to participate and to be heard, and to the researcher for undertaking this project. Whilst it was not unexpected that interview participants would feel heard and valued, it was surprising that survey participants who had no direct interaction with the researcher would also feel heard. Whilst no direct incentive was provided for contributing to this research and the plain language statements directly articulated that there would be no benefit to participants for participating in the research process, the feedback from some participants was that there was a perceived benefit associated with having their stories heard.

Summary

This chapter outlined the methodology utilised in this study. It described the rationale for the methodological decisions and the ethical considerations. It demonstrated the utilisation of reflective decision-making in choosing the methodology and engaging in decision-making during the undertaking of the study. The demographics of the participants and to a lesser extent their children in both the interviews and the online survey were presented. Criteria for inclusion in the study and recruitment of participants, discussion relating to methodological constraints and strengths of the methodological approach concluded the chapter.

Chapters 3 and 4 present the findings from the interviews. Chapters 5 and 6 present the findings from the survey. A discussion of minor and major themes is included in the summary sections of each of the chapters. These themes provide
insights into the research questions and inform the discussion to be presented in Chapters 7, 8 and 9.
PART B:
FINDINGS
CHAPTER 3:
QUALITATIVE FINDINGS – PARENT’S EXPERIENCES ON THE ROUTE TO DYSLEXIA

Introduction

The qualitative findings from this study are presented in two chapters. Chapter 3 focuses on the experiences, reflections and feelings of research participants prior to their child’s diagnosis of dyslexia. Chapter 4 contains parents’ experiences of support post diagnosis; it also contains parents’ policy recommendations, reflections and concerns regarding their children’s self-esteem and wellbeing, insights into parental advocacy and the emotional journey of parents.

The structural division of the chapters, which is largely chronological, was chosen as it reflects one of the key aims of this research which is to explore the journey of parents with a school aged child with dyslexia in Victoria. A key theme to emerge from the findings was parents’ desire for their stories to be told and their voices heard. Both the content and form of these chapters reflect and respect the wishes of participating parents to achieve this objective.
Chapter 3 is in three sections. In the first section, parents’ reflections are presented on the process of recognising the educational and psychosocial indicators that alerted them to their child’s learning difficulty. The second section contains parents’ reflections on the initial responses they encountered as they voiced their concerns about their child’s academic challenges. This section concludes with the presentation of findings regarding the emotional and cognitive dissonance which responses from teachers and others to children’s learning difficulties evoked for parents. Section three of this chapter presents parents’ reflections on their experiences of the journey to obtaining a diagnosis of their child’s dyslexia with regard to challenges such as emotional and financial burdens experienced by parents. It also focuses on the impact of diagnosed and suspected cases of dyslexia in the nuclear and extended family and how this influenced the journey to uncover the underlying cause of their child’s difficulties.

Section 1: Initial Recognition of Children’s Difficulties: Educational and Psychosocial Factors

At the beginning of each interview, participants were asked to reflect on how they embarked on the pathway to the knowledge that their child has dyslexia. A strong and clear pattern emerged, demonstrating that within this cohort the journey to identifying dyslexia began with parental concern for their child’s achievement and/or sense of wellbeing at school. Whilst each situation was unique, initial parental concern for their child was traced to a cluster of factors reflecting poor or slow educational progress and negative psychosocial indicators, such as a decrease in self-esteem levels, anxiety, depression and resistance to attending school. The following section contains the presentation of factors which foretold the children’s undiagnosed neurological difficulties.

Early Indicators of a Learning Disability

In the following example, despite a substantial amount of assistance and support with reading and writing from the child’s parents, the child’s progress with these skills remained slow and laborious. This raised concern for the parents:
He was just so slow at picking up reading and writing, even though we’d put in a great deal of effort to teach him. (Mother, Interview no. 9)

In the majority of cases, parents cited multiple factors which alerted them to the fact that there was a cause for concern:

Being a primary teacher myself, I realised after – it was after prep grade one, I started to think, oh, she’s not good at learning. Her reading was quite weak. I’d gone to the school to help out and I could see she was in the bottom group. I could see at home as her mum looking at her readers that she wasn’t picking up on words. (Interviewee no. 20)

This mother’s professional background and her observation of her child’s progress in comparison to her peers was part of the initial picture that sparked concern for the child. She also compared her with her sibling’s mastery of literacy skills:

It was hard not to compare her to the other daughter that was just flying through and reading chapter after chapter. (Interviewee no. 20)

Additionally, the mother recalls:

By the end of prep, she didn’t want to go to school. She told me she’s learnt enough and that she was happy to stay at home and just make me cups of tea. She wanted to live on a farm and we’d just have animals on a farm. (Interviewee no. 20)

Adding to this parent’s growing sense of concern was her child’s unhappiness and lack of desire to return to school after completing prep. This case demonstrates a confluence of factors which triggered the parent’s initial concern for her child. These factors included the child’s academic progress in comparison with her peers and sibling, the child’s expression of resistance to school attendance and the parent’s professional experience.

Of note is that, although this mother is a trained primary school teacher, she was not equipped by any pre-service or in-service teacher training with knowledge regarding specific learning disabilities broadly or dyslexia specifically.

---

8 Prep in Victoria is the first formal year of schooling. It is referred to using different terminology in other states and territories.
Her experience as a teacher informed her that her child was not progressing in an expected manner with literacy skills, but did not provide her with insights into why this might be the case. The issue of pre-service and in-service teacher training is a theme that is explored more thoroughly in Chapter 4.

Many parents revealed that comparing their child with other children (their own or their child’s peers) alerted them to the fact that their child’s progress acquiring literacy was outside the norm. In cases in which there was an older child or children in the family (without dyslexia), it was not uncommon for parents to realise quite quickly that the younger child’s grasp of literacy skills was unusual and indicative of a problem:

When he came to primary school prep it was immediately obvious, especially since he is my third child, that it just wasn’t clicking. (Interviewee no. 18)

In the case of a couple with two daughters four years apart, the mother states in relation to the second child:

We had a sense that things weren’t right in regard to reading and particularly her reading and writing. (Interviewee no. 7)

In addition to this sense that something was not “right” this mother reflects that it was really the comparison between the two children’s grasp of literacy skills that alerted her to the problem:

Like I say, it was really that I had something else to compare it to in my elder daughter, because I wouldn’t have picked it up, I don’t reckon. (Interviewee no. 7)

In some cases, comparison of a child with an older sibling with diagnosed dyslexia also occurred:

Linda’s nearly four years younger than Jona – I noticed a few similar traits … So again I thought, well, let’s get a diagnosis and understand the spectrum of her learning difficulties. (Interviewee no. 16)

However, in relation to the older child for whom she had no comparable precedent, the same parent comments that she was not sure that her son’s apparent
lack of interest in reading and difficulty with reading was representative of a problem until she had the opportunity to compare his progress with another child of the same age. She recalls:

Jona had no interest at all in reading words, in learning the words, and also would eventually read the words but then he’d go back to them within half an hour and would have no idea what the words were. So, like a problem with his short-term memory. I was just thinking you know, well, perhaps that’s what preps do but he had a friend stay over and she’s a really bright little girl but just her ability to read was amazing and I just sort of felt well wait a minute, I think we’ve got a bit of an issue here. (Interviewee no. 16)

In another case comparing one child in the family to another was initially not very helpful. In this case, the mother compared her second child (who was subsequently diagnosed with dyslexia) to her older child, who does not have dyslexia but had found it difficult to learn to read and required substantial support from her parent as well as in-school remedial support. The parent recounts that she presumed the second child’s acquisition of reading skills would occur in a similar way to the older child. However, this was not the case:

I think because I’d had an older daughter it took a long time to pick it. So when my older daughter read she was the same. I was quite patient with Rose because she was the same. (Interviewee no. 6)

Later, however, the differences between the second child’s response to intervention, in comparison to her sibling’s response, combined with factors such as the teacher’s concern and the child’s expression of frustration, to raise parental concern:

The teacher was worried. I was worried by her distress, like her frustration that was worrying me. So she was in reading recovery and we got about 18 months and it’s – and I think I knew that it wasn’t kicking in for her – you know like that it wasn’t kicking in for Rose whereas it had – you know like she wasn’t – I could see that she wasn’t improving like my other daughter had improved. (Interviewee no. 6)
This case also differs from all other cases in this cohort as the teacher was also concerned about the child’s lack of progress with literacy. In no other case in this cohort did a teacher express concern on initial presentation of the child’s difficulties with literacy.

In some cases, parents reported that indicators of their child’s academic struggle were accompanied by signs of anxiety:

I just realised that he wasn’t enjoying school. He didn’t seem to be progressing. He was very anxious. Even though other parents would say don’t compare him, it was obvious that he wasn’t achieving the way that other kids were. (Interviewee no. 3)

In another example, a mother recalls that it was her daughter’s distress, drop in self-esteem and negativity about school that alerted them to the depths of her struggle with literacy:

No one had detected that she was really struggling quite as much as what she was. Grade 3 is when it really started to show, but by Grade 4, certainly, that’s when things really took a downward slide, that she – probably by the end of Grade 3, beginning of Grade 4 she’d become aware of her own deficiencies and that she wasn’t up to the speed of her peers. I think probably they’d – that had been recognised in the classroom, as well, so we started having every morning tears and, I hate school and I’m stupid. It really impacted her self-esteem. (Interviewee no. 2)

Similarly, in the following example it was the child’s (aged 10) feelings of frustration, sense of failure and realisation that his difficulties made him unlike his peers which caused him distress. The child’s distress and his ability to articulate the cause of this distress was the trigger that alerted the parent to his literacy difficulty. The mother recalls:

He got off the bus and he threw his school bag at me, burst into tears, just absolute – he was absolutely traumatised, and he ran all the way home. I was thinking, what is going on? I picked up his school bag. I started bolting home. I thought, oh my God, he’s being bullied, somebody’s sexually abusing him, I had all these things going through my head because it was such a strange reaction for him. Anyway I got home and
he was lying on his bed, sobbing his little heart out. I said to him, what’s wrong? He goes, “I just can’t do it. I’ve had enough”. I said, “what do you mean?” He said, “today we had to write a story about dragons”. He said, “I wrote three words”. He said, “I had a whole story in my head and I couldn’t get past three words”. He said, everybody else had written whole pages, “I had this great story and I couldn’t get it on the page”. He was just completely traumatised. (Interviewee no. 13)

Of note is that this child is the second child in a family of three children with dyslexia and his mother is a teacher by profession. However, it is not the symptoms of dyslexia (which differed from the symptoms of the older child with dyslexia) but rather the child’s articulation of the cause of his distress, which alerted the parent to a potential problem. This child’s ability to articulate the underlying cause of his distress was unique.

In another example which varied from other experiences, a child (aged 10) who was being raised solely by her father at the time, expressed feelings of distress at home and during a parent–teacher interview at school:

My daughter (aged 10) was crying a lot. You’d ask her how she went in school, and she’d sort of break into tears. When we went to the parents and teachers interviews sort of thing, and they told me about how good she’s going and she breaks into tears and …. (Interviewee no. 10)

In this instance, it was the child’s sadness at home and the teacher’s praise for her academic progress which triggered the child’s distress which concerned the parent. In this case, the parent took action to address his concerns for his daughter’s wellbeing, referring the matter to the principal:

I consequently spoke to him [the principal] and I thought he was going to look at her in relation to her emotions and getting on with other kids at school, that sort of thing. But what he actually did was observe her work, and he gave her cognitive tests (Interviewee no. 10).

**Section 1: Summary**

Strong and distinct patterns emerged from the findings, demonstrating that in this sample a majority of parents noted a combination of academic and
psychosocial factors which alerted them to their child’s difficulties in mastering literacy skills, later diagnosed as dyslexia. Amongst this cohort there was only one case in which a parent and a teacher concurred from the initial presentation of the child’s difficulty with literacy that this was a reason for concern. Significantly, there was no instance in which a teacher approached a parent to raise concern for the child’s slow progress with literacy or the manifestation of symptoms of anxiety or low self-esteem. Added insight into this issue was provided by the narrative of two parents who are trained teachers. One of these parents identified that her child’s progress in reading, writing and spelling was unexpectedly poor. While her teaching experience equipped her with this knowledge, she appeared to be no more qualified to identify the cause of the problem than the other parents without teacher training. In the other example in which the parent is also a trained teacher, this was also the case. It was the child’s ability to articulate his distress at his difficulty with literacy that raised the alarm that further investigation into a possible learning disability was required. Parents did not make direct reference to teacher training at this early stage in their narratives. However, the impact of the lack of teacher training and awareness of dyslexia clearly shaped their experiences.

**Section 2: Responses to Seeking Initial Advice and Support**

Parents were asked to reflect on the responses they received when they first investigated the issue of their child’s unexplained and unexpected difficulties with literacy. In some instances, rather than considering potential learning disabilities, teachers attributed the child’s difficulties to negative factors intrinsic to the child. These negative factors were diverse. Examples of these factors are provided in the following teachers’ comments to parents, attributing the child’s difficulties to: “it’s a maturity thing” (Interview no. 8), possible “developmental delay” (Interview no. 2), “the child’s lack of intelligence” (Interview no. 3), “low intelligence” (Interview no. 12), “not being very good at learning” (Interview no. 17), a “lack of effort and lack of risk taking” and the “child not trying” (Interview no. 14), the child “just having a little bit of difficulty putting sounds together”
Less common, but of significance, are the instances of teachers’ misattribution of children’s difficulties to negative factors relating to the parents or the home environment. In a small number of cases, mothers felt that teachers subtly blamed them or implied that the child’s home environment was a causal factor in a slow development of literacy skills. A parent described this subtle blame as “a strong impression” that “the teacher felt you’re not doing enough at home with him” (Interviewee no. 17).

In another example, a single mother sensed that the school attributed her daughter’s difficulties to her parent’s single status:

I also think I fell into that whole category of the single parent, and they maybe thought well, that’s because she’s from a single parent household — probably uneducated — blah, blah, blah. I’m not — I’ve got a Melbourne University degree – I’ve now got a law degree. So we didn’t fit in that profile, but we were categorised. (Interviewee no. 5)

This interviewee suggested that her child was at increased risk of additional barriers to the identification of dyslexia as a result of underlying negative stereotypes of the functionality of her family status. In another case, a mother reflected that she had a sense that the school dismissed her worries, relegating her concern to parental anxiety. The mother in this instance felt that the school was labelling her as anxious, rather than recognising her child’s problem:

Every time I tried to tell the teachers, look I think there is something wrong, I’m sure they started labelling, so that’s why I started backing off. I didn’t know how to work the system. So, you could see them thinking that you’re just worrying too much, they would say. (Interviewee no. 4)

Similarly, another mother who expressed concern to her child’s Grade 3 teacher about the child’s reading difficulties was told:

that in class she was fine, that I was reading too much into it. They knew she wasn’t the most academic kid and she was in the lower spelling
groups and reading groups, but they didn’t think that there was a problem. (Interviewee no. 18)

Inherent in this assessment that the child’s poor achievement in spelling and reading is “fine” is an underlying assumption that the child’s lack of achievement is due to her not being an “academic kid”, which may be interpreted as a euphemism for possessing low intelligence. The parent “reading too much into it” implies that the parent is overly anxious. In a similar vein, another parent recounted that when expressing concern for her son’s progress with reading and writing, she was told by his Grade 6 teacher that she should “get out of his face” (Interviewee no. 12). The implication is that the parent’s concern for her child’s progress was unhelpful. The mother revealed how she felt deeply affected by this hostility:

and I’m still slightly traumatised by that meeting. … it is something I almost have never recovered from. (Interviewee no. 12)

Another parent recounted a scenario in which a teacher, who up until this point had rejected the idea that the child was experiencing any kind of learning difficulties, began to acknowledge the child’s literacy difficulties. However, whilst acknowledging this, the teacher began to question the mother about the quality of the child’s home environment:

Then the grade 2 the teacher said, “oh, something’s not right”. She said, sometimes she seems to know something and then she doesn’t a week later. She actually said to me, has she had any trauma in her life? I’m thinking, you know, the guilty mother. (Interviewee no. 14)

In a few instances, teachers relegated children’s undiagnosed difficulties with literacy to syndromes other than dyslexia. In two instances, children’s difficulties were attributed to “the child’s anxiety” (Interview no. 11 and Interview no. 12). In one of these cases, the parent’s concerns about difficulty with literacy for her fourth child (and her only child with dyslexia) were directly dismissed by the school psychologist as an expression of the child’s anxiety. The psychologist suggested that if the child’s anxiety were “fixed” then he would learn to read and write. However, the parent’s instinct told her that the reverse was true:
I don’t know, midway through Grade 2 and they got the school psychologist to come in and she just said, he is an anxious kid, fix the anxiety and he’ll learn to read and write. I said, no, you’ve got it wrong, you’re backwards. Fix his reading and writing and spelling and he’ll learn – and the anxiety will subside. No, you’re just a mummy, you don’t know what you’re talking about, I’m the professional. She was lovely, she was really nice, but I just said, you’re wrong, and she said, no, I know what I’m doing. (Interviewee no. 12)

In another case, concerned by the child’s lack of academic progress and achievement, the school debated, without a formal assessment of the child, whether he had attention deficit hyperactivity disorder (ADHD):

So what happened was the school went in and they made a quick assessment of his behaviour and the teacher had – his other part-time teacher had suggested that he had ADHD and the assistant principal went in there and said “no he doesn’t”. (Interviewee no. 8)

In some cases, teachers and principals suggested directly to parents that they should dismiss their concerns for their children’s difficulties. This was evident in teacher’s comments such as “don’t worry about it. Forget it” (Interview no. 11) or “it [the child’s difficulty] wasn’t an issue” (Interview no. 4) and “no she’s fine … she blends in with the average” (Interview no. 21). In another example, a parent was told:

that’s fine, everyone is different. You can’t compare between siblings.

(Interview no. 17)

There were a few exceptional cases in which parents encountered teachers who did not in the first instance refute, misattribute or dismiss parents’ concerns about their children’s progress with literacy. In the first exceptional case, the parent noted that her daughter’s prep teacher observed her child’s struggle to master basic literacy skills and expressed concern:

Anyway, she was really struggling picking up the alphabet and so by midway through prep I started making alphabet cards and playing memory games and stuff with her thinking oh, we need to work on this. The teacher was starting to get worried …. and she [the child] was starting to get very unhappy at school because she could see that other
people were doing stuff – I’m assuming that she couldn’t. (Interviewee no. 6)

In this case, there was no period of dissonance between the parent’s perception of the child’s difficulty and the teacher’s perception. Both the parent and the teacher were concerned about the child and swift action to support the child was taken by both parties. The child was referred to a remedial reading program (“Reading Recovery”):

So she went into reading recovery at the start – right at the start of Grade 1. The reading recovery teacher, at the end of reading recovery she hadn’t – she responded really, really well to reading recovery. But at the end of that she was still well behind and he said I think actually that she’s dyslexic (Interviewee no. 6).

The Reading Recovery teacher’s observation that despite the provision of assistance the child was not making sufficient or expected progress led him to refer the parents to have the child tested for dyslexia:

He’d [the teacher] done a fair bit of training in the area. But, he said I recommend you go and get an assessment to work out whether that’s true because he’s also good at knowing that he doesn’t actually have skills to diagnose it. (Interviewee no. 6)

This child was the youngest first or only child in the family to be diagnosed with dyslexia in this cohort. The key to the early diagnosis for this child was a combination of factors which included the parent’s concern for the child which resonated with the teacher’s observations of the child. Contributing to this picture of collaboration was the quick referral of the child to remedial intervention and the observation of this failed intervention by a teacher who had received training in understanding the signs of dyslexia.

Within this cohort of interviewees there were two other cases in which a teacher suggested to a parent that a child might have dyslexia. However, only one of these cases involved early identification of dyslexia. A parent who had struggled for many years to identify the cause of her first child’s learning difficulties and low self-esteem had successfully lobbied the child’s school to
introduce in-service training about dyslexia. Consequently, when this parent’s second child was in prep, a teacher with specific training in awareness of the signs of dyslexia alerted her to her second child’s difficulties:

So I was hoping that he wouldn’t have the same struggles. But then when the teacher alerted to me and, again, this is such a different – on one hand I was so grateful, because I thought, isn’t this amazing, the difference years later. By term 2 in prep I’m getting, we have concerns, instead of me two or three years later having to (Interviewee no. 14).

The other exceptional case in which a teacher directly named “dyslexia” as a probable cause of the child’s learning difficulties occurred when the child was aged 14 and in year 8 at school:

Her English teacher rang me, I think, and said, oh, look, I just want to talk about your daughter. I said, yeah. I was just so relieved that somebody actually came to me and said there’s something wrong here and let’s find out what it is. She actually said, she presents like a couple of other previous students I’ve had who are dyslexic. I went, oh my God. I was so relieved. I said, what do you want me to do? Where do I take her? They said take her to [name of dyslexia support agency] (Interviewee no. 20).

The parent had experienced years of denial and misattribution of her daughter’s problems before encountering this teacher. Of particular note is the fact that the teacher acknowledged that she does not have specialist training in dyslexia but had acquired knowledge about dyslexia through her teaching experience over the years.

There was one other exceptional case: although the child’s prep teacher thought the child was “slow to learn”, later his more “experienced” Grade 1 teacher was concerned with the child’s academic progress and relayed her concerns to the parent. The teacher set the parent on a trajectory of exploration in relation to the child’s learning challenges:

So then in Grade 1 he had a very experienced teacher and she said, “no, I think there’s an issue that we need to get to the bottom of.” She was great. So she really pushed me to get some help or get his hearing tested
first of all, and we do have hearing loss in the family history, eyesight, all of that. So we did all of that and they were all fine. Then we organised through the school a speech therapist to look at Jona and she said, “look, I think everything’s fine except I think maybe there are some learning difficulties or a learning difficulty.” I suppose I wasn’t even aware of what that could be. Then I asked the school. I said, “look, where do we go from here?” They had no idea, absolutely no idea. (Interviewee no. 16)

This case contrasts with the other exceptional cases. Although the teacher did not suggest or name dyslexia as a possible cause of the child’s difficulties, she acknowledged and confirmed there was an “issue”. This was perceived as helpful by the parent. However, the teacher’s subsequent lack of knowledge in relation to dyslexia and possible avenues to investigate learning difficulties left the family without direction and support.

Cognitive and Emotional Dissonance: a Prelude to Diagnosis

The negation of parental concerns and the misattribution of the cause of children’s difficulties gave rise, in the majority of cases, to a deep sense of uncertainty and cognitive and emotional dissonance for parents. This occurred as parents continued to observe their child’s struggle and emotional distress and grappled with the negation of their observations by children’s teachers. In the following example, the parent describes the mismatch between her perception of the child’s intelligence and the child’s achievement in relation to literacy. The parent also reveals that her gut feeling tells her something is wrong but this is tempered by a sense of uncertainty and self-doubt about the validity of her own perceptions in light of the teacher’s view:

She was … a very, very bright little girl before school. Very happy, very shy, but had this amazing creative imagination … . When I went in to school to help, she was at the bottom group of everything and she hated being with all the boys, as a little girl. I couldn’t quite – because my gut feeling was that she was smart. Then I thought, well, I’m not a teacher. Maybe I’m just wrong. Maybe all parents think their kids are smart and I’ve just got to accept that she’s not. (Interviewee no. 14)
Exacerbating this dissonance is the teacher’s dismissal or attribution of the child’s difficulty to behaviour or factors which do not resonate with the parent. In this case, the parent was informed that her child was demonstrating a “lack of effort” and “lack of risk taking” and was “not trying” (Interview no. 14).

A sense of limbo prevailed for many parents over various lengths of time in which there was uncertainty as to the cause of the child’s difficulty. During this time parents grappled with whether to trust the teacher’s view and dismiss their own instincts about their child or take further action. One mother recounted a sense of self-reproach and self-derision for elevating the school’s expertise over her own insights for as long as she did:

But, because in my ignorance I deferred to the school as the expert and so, going into Grade 2, again …. Again it’s the same response, she’s fine, just some kids are a bit slower, blah blah blah. I did, I deferred to the school’s judgement. (Interviewee no. 2)

In another case a parent reflected on how important it is for parents to pursue their own “gut feelings” about their child rather than rely on school reports:

If you’ve got any doubt, because if we had not pursued it, we wouldn’t have found out, because we’d keep getting this report that says everything is fine. If any parents have got that gut feeling, you just know something’s going on, you have to try and pursue it. (Mother, interview no. 21)

Commonly, it was this dissonance and a pervading sense of “something going on” that led parents to embark upon a route to further investigate their child’s difficulties which resulted in a diagnosis of dyslexia.

In one exceptional case, the parent noted her child’s difficulty with reading and her distress when engaging in school work, however she erroneously interpreted her child’s lack of progress as oppositional behaviour and poor motivation:

In the period that she was at primary school, initially Evelyn had a great deal of difficulty reading, and it was really quite traumatic. She’d come
home of an evening and we’d sit down and try and do her reader, and she couldn’t read it, and she’d become extremely distressed, and she wouldn’t want to continue on with the reader, and I’d be trying to force her to read. I thought that the lack of wanting to read was a motivational thing, more than an ability type sort of thing. (Interviewee no. 5)

This case is exceptional as this is the only case in this cohort of research participants in which the parent misattributed the cause of the child’s difficulty to behavioural issues. Additionally, the parent accepted a teacher’s advice that her daughter:

comes from an articulate educated home clearly she’ll catch up at some point. (Interviewee no. 5)

Later in the interview the parent commented that:

I had no idea what was normal and what wasn’t. So I was kind of relying on the teachers to guide me, to say that something was wrong. (Interviewee no. 5)

In all other cases, without exception, when a parent identified a difficulty (psychosocial or academic), it set them on a pathway of investigation which began with consultation with teachers and principals. In the case of Interviewee no. 5, although the parent did lobby for the school for support, the parent’s misattribution of the cause of the problem to the child’s behaviour, compounded by her reliance on teachers as experts in regard to literacy, combined to delay the route to diagnosis significantly. The child in this case remained undiagnosed for the longest period of time of the children of all participants in this interview cohort. She was diagnosed aged 16 in year 10. The parent refers to her disappointment regarding the lack of support from the school in identifying the teenager’s dyslexia and the school’s attribution of responsibility to the realm of the parent:

I contacted the school and I said, “I’ve just got this report – I feel really let down that nobody in the four years that we’ve been here has said anything about learning difficulties and perhaps we should go and get her tested – it’s year 10, and we’re finding out now – we could have done so
much if it had been diagnosed in year 7”. They said, “it’s not our responsibility to do that – you’re the parent”. (Interviewee no. 5)

In the majority of cases, it was the parent’s reliance on their innate feelings of unease and their unwillingness to accept the interpretation of the teacher, principal or psychologist which was the catalyst for further investigation and eventual diagnosis.

In the following example, the parent approached a teacher with the hypothesis that her daughter would benefit from clinical testing for a learning disability:

But as soon as I went to them and went to her teacher and said, “look, I think there’s something else, I want to investigate it further, we’re going to take her to [name of specialist dyslexia agency] she doesn’t understand the difference between a Y and a U”, they were flat out telling me, “no, she’s fine. There’s nothing”. It was right from the word go, they weren’t really interested in what we had to say. (Interviewee no. 18)

The parent in this example rejected the teacher’s advice and relied on her own intuition and knowledge rather than the teacher’s refutation of her insight.

I just knew that there was something that wasn’t quite right, and I wanted to do something to help her. (Interviewee no. 18)

**Section 2: Summary**

A very clear theme emerged in relation to parents’ responses to their children’s apparent learning difficulties. Without exception parents, in the first instance, approached the child’s classroom teacher or principal to seek advice and support. Parents expected and trusted that teachers and principals would be able to guide and assist them in clarifying the cause of their child’s problem. However, in the majority of cases, parents’ concerns for their children were dismissed or negated by teachers and/or principals and in one case a school psychologist. A pattern of misattribution, dismissal and negation of parental concerns emerged that can be categorised into three groups of factors: those intrinsic to the child;
those intrinsic to the child’s parents and home environment; and syndromes other than dyslexia.

It was clear that many parents were left with a sense of dissonance between their perceptions of the child’s difficulties and the teacher’s misattribution or dismissal of the child’s symptoms of struggle with literacy. This sense of dissonance, a sense of knowing or a gut feeling that there was a missing element in their child’s difficulty, was the catalyst that prompted most parents to continue on a pathway of investigation by pursuing testing of their child.

The one exception in which the parent noted the child’s difficulties with literacy but misattributed it to behavioural and motivational problems resulted in the parent expressing resentment, anger and a sense of frustration toward the child. In this case, there was no sense of dissonance for the parent. Nor did the child serendipitously encounter a teacher with insight into her difficulties. In this case, the child was diagnosed as a teenager aged 16. This was the longest period that any child in the cohort remained undiagnosed. Quantitative data on the length of time to reach a diagnosis was not collected during the interview process but a general sense was gleaned from parents’ narratives of the time from initial identification of symptoms of dyslexia to the diagnosis of dyslexia. This period ranged from approximately 18 months to 11 years.

The exceptional cases are noted in which teachers demonstrated basic knowledge of the signs and symptoms enabling them to name “dyslexia” as a probable underlying cause of children’s difficulties. This prompted parents to embark upon a direct trajectory to the diagnosis of their children with dyslexia. Parents were relieved when teachers validated their perceptions of their child’s difficulty. However, it was the naming of “dyslexia” as a possible cause and the provision of direction to appropriate agencies for testing which was of the greatest help to parents and children.

Section 3: Parents’ Perceptions and Experiences of the Pathway to Diagnosis

Parents were asked about their experience of the routes they took to reach a diagnosis of dyslexia for their child. Questions regarding the presentation of
dyslexia in other family members were posed, to ascertain how this impacted on the child’s pathway to diagnosis.

It emerged that, despite each pathway to reach the diagnosis of dyslexia being unique, there were common themes. One of the key themes identified was parents’ sense of frustration at the lack of support and direction from an authoritative source. The second key theme was the lack of financial support and perceived lack of funding for testing for dyslexia. Parents frequently referred to the burden of cost relating to testing as well as the burden resulting from a lack of support and guidance. These interrelated themes are a subset of a larger theme which emerges throughout each and every interview: the lack of recognition of dyslexia in the broader political environment.

**A Lack of Support and Guidance**

Many parents expressed feelings of frustration at the difficulty they experienced as a result of a lack of expert guidance, support and clarity relating to the appropriate direction to pursue:

then I just saw that there was so much stuff out there, like you could go and have their eyes tested and Irlen, and there was just so much stuff. I thought, I don’t know which one – what do I choose to test her? Because I didn’t really know what the problem was. (Interviewee no. 18)

This lack of clarity around the source of the problem, coupled with the lack of guidance, made it difficult for many parents to decide which professionals to consult. Parents grappled with this issue, describing their frustration with the route to diagnosis:

a journey full of frustrations and lack of clear information. (Interviewee no. 4)

a maze; it’s a real maze of stuff out there. (Interviewees no. 7)

a patchwork discovery of what it was (Interviewee no. 12).
Parents reflected on how they wished for assistance from experts or an authority on dyslexia:

Some assistance to make sense of all this stuff and to get your way through the mire would be handy. Now, we’ve done that ourselves but I’m sure other people would be – earlier on in the pathway would be finding oh hell, where do you go, what do you do? (Father, interview no. 7)

A similar sentiment was expressed by this parent:

It is an extremely frustrating journey without someone taking – it needs to be a professional organisation taking control of this … there has never been a clear course and where do you start? How much should this actually cost? Where do you go to for assistance? (Interviewee no. 8)

Parents commonly referred to doing their own “research” in relation to their child’s difficulties, generally referring to internet searches.

I just didn’t know where to go, when I first started doing that research, you’d sort of – it was like a rabbit down a hole, you follow a particular trajectory thinking, is this going to solve my problem? Then it would end up being some sort of weird hocus pocus. Or just – there’s no authoritative forum (Interviewee no. 2).

In this example, the parent’s words also convey a strong sense of the lack of support and guidance, feeling— with allusion to an “Alice in Wonderland” sense of being like a “rabbit down a hole”— in a frightening, unfamiliar world containing “hocus pocus”, not really able to make sense of the new and unfamiliar domain on their own. In some cases, the route to diagnosis was not linear. In the following case, despite pursuing early testing, the dissonance and uncertainty relating to the underlying cause of the child’s difficulties persisted:

about that time we got hearing checked, vision checked, all those sorts of things. I think I took him to, I think it would have been in prep, I think it was later in prep and I took him to a paediatrician and he had an educational psych assessment done, but because he was young, the psychologist wouldn’t put any diagnosis to it.
So that was not particularly helpful. She did tell me he’s just not very good at learning. I’m thinking oh my gosh, that’s actually not right. He’s just not very good at learning some things because clearly he was learning a lot, life skills and so on. (Interviewee no. 17)

The parent had consulted an audiologist, an optometrist, a paediatrician and an educational psychologist, but no clear diagnosis had emerged from this first round of testing. Although the child had undergone psychological testing at a very early age (approximately five years), the reticence to provide the parent with a diagnosis and the alternative explanation that the child was “not being very good at learning” created dissonance for the parent:

Yeah, well it didn’t make sense. So I didn’t know what to make of it really (Interviewee no. 17).

The diagnosis of dyslexia was obtained through further testing several years later when the child was in Grade 3 aged eight:

because the Grade 3 teacher actually pretty much said, “I don’t believe in dyslexia or that he’s got dyslexia” and asked for him to be reassessed, so another $1000 for another report. (Interviewee no. 17)

This reference to the costs associated with diagnostic testing will be dealt with in the next subsection. (The parent’s comment relating to the teacher’s lack of “belief” in dyslexia is also a salient issue. It arose in several other interviews and is presented in Section 2 of Chapter 4.)

A Lack of Funding

The financial costs associated with testing, as parents navigated a pathway to diagnosis, was a significant issue of concern in the majority of interviews. In all but two cases, parents were responsible for the costs associated with the diagnosis. This was the case regardless of the school sector the child attended at the time of diagnosis. In the two exceptional cases, parents were offered and accessed state funded psychological testing from a psychologist employed by the Department of Education and Training.
The majority of parents interviewed for this study accessed fee-for-service (unsubsidised) psychological testing for their children, not as a result of preference but rather from a perceived lack of choice. This is illustrated in the following quote by a mother whose child attended a Catholic school:

we had to go and spend $1300 to have it [testing] done. If we didn’t do that, we would never be able to get her diagnosed properly, because the schools don’t have any facilities. They don’t have the support, nothing. It’s crazy. It’s insane (Father, Interview no. 21).

Another parent recounts reflecting on the lack of resources for testing at her son’s primary state school:

We knew that there were no resources at school so we wanted to take things under our own steam. (Interviewee no. 8)

The mother of the child diagnosed whilst attending an independent school noted that a teacher had recommended to the parent that the child be tested by a fee-for-service specialist (not-for-profit) dyslexia organisation. The mother recalled asking her child’s year 8 English teacher:

I said, what do you want me to do? Where do I take her? They said take her to [name of specialist dyslexia agency]. (Interviewee no. 20)

Costs associated with identifying dyslexia were not limited to the costs of psychological testing. In most instances, parents engaged multiple services of a wide variety of professionals before their child was diagnosed with dyslexia. These professionals included audiologists, behavioural optometrists, speech therapists, occupational therapists, paediatricians, general practitioners and educational consultants. Many parents felt over-burdened by these costs.

A single parent recounting the theme of the costly nature of assessments and illustrating the lengthy and circuitous route it took before her son was diagnosed with dyslexia states:

So, we did auditory processing, that was expensive, trying to go to an OT [occupational therapist] was expensive, then there was the speech therapist who the OT said, “look I think he needs auditory processing and
speech” and then that was another assessment report. … They had actually recommended I do vision therapy, do that assessment, so that was another cost. Then I went to this place in Brunswick, who does vision therapy and she wanted to charge me a sweet fortune, a thousand dollars. I never did that because I couldn’t do it. (Interviewee no. 4)

Several parents expressed concern about the cost of testing for dyslexia, highlighting it as an issue of equity and social justice:

How does somebody for starters, not everyone has $1300. So if you don’t have the $1300, you’ll never know, or you’ll never have one of those. Then if you never have one of these, how do you progress? (Father, interview no. 21)

and most of it wasn’t Medicare funded. So you wonder how people who don’t have the financial resources manage. (Mother, Interview no. 7)

Another parent reflected:

I think what stops a lot of people from having children assessed would be a cost factor. (Interviewee no. 19)

This parent suggested that there needs to be policy change in this arena with government funded assessment:

some kind of policy or reimbursement, even for people that can go ahead and have that assessment done, then they’ve got the information or they’re not – that’s not a barrier to receiving an assessment and recommendations for the classroom. The whole cost factor, it’s just out of most people’s reach. (Interviewee no. 19)

Another parent, with three children with diagnosed dyslexia, reflected:

and thankfully I’m lucky I’ve got the money. I got it all [testing] done privately through an educational psychologist (Interviewee no. 13).

It was not uncommon for parents to express dissatisfaction in relation to the cost of testing and scepticism about the validity of testing providers:
I found that when you go on the internet to look for places, there’s heaps of places that supposedly do testing. But really, it’s all just about getting $800 or $1000 out of you. (Interviewee no. 10)

Another parent expressed a similar sentiment, expressing her disapproval that there are many people making money from diagnostic services. As distinct from the previously quoted parent, she did not call into question the validity of testing; rather, she observed what she views as the lack of provision of state funded testing:

I think at one end there’s a lot of people making money from it, which really annoys me. I have heard of people that have gone through the [name of a hospital] but then they still have to pay for another assessment. So I think they ended up paying about $700 anyway. I don’t think I’ve heard of anyone who’s had it done totally free. (Interviewee no. 1)

In the following case, the parents were informed by the psychologist who tested their child that they would need to have their (primary school age) child retested every two years to build a case for her to have special consideration when she completes her final year of school, the Victorian Certificate of Education:

Then again, don’t get me wrong. I’m not going to cry about the money, but $1300 every two years … So there’s 10 to 15 grand by the time she finishes her education. That’s fine, but even if it’s my money we’re talking about giving away, I’d rather be spending it on something useful than continually getting a pack that’s going to tell me the same thing. (Father, interview no. 21)

The father in this interview identified that retesting the child every two years for this lifelong condition is not the best use of resources. This use and provision of resources for children who have been diagnosed with dyslexia is another important key theme which emerged in all interviews without exception and will be expanded upon in Section 1 of Chapter 5.
The Route to Diagnosis: A Relative with Dyslexia

Parents were asked about the history of dyslexia in their family and how this impacted upon the pathway to diagnosis for their child. The evidence for the hereditability of dyslexia is strong (Wood & Gryorenko, 2001). Shaywitz, a leading dyslexia researcher, contends that between one quarter to one half of the children of a parent with dyslexia will also be dyslexic (2003, p. 99). In pursuit of rich understanding of the process of identifying dyslexia in this social policy context, interviewees were asked if a relative in their family (other than their child or children) has diagnosed or suspected undiagnosed dyslexia. The purpose of this question was to gain insight into whether knowledge of dyslexia in the family assisted these research participants with identifying dyslexia.

In all, 21 parents identified another family member with diagnosed or suspected but undiagnosed dyslexia. In one case, a mother (who has diagnosed dyslexia) believed that her own diagnosis of dyslexia had helped her to identify dyslexia in her son:

Yes, I did think that the lack of word recognition and the lack of phonetics and just not getting it, just the – and the repeatedly not getting it. The progress was so slow. I thought that that would probably be what he would have. (Interviewee no. 1)

This parent’s response demonstrates knowledge of the symptoms of dyslexia. However, also of note in this case is the fact that the mother is a trained disability support teacher. It is not clear how much this contributed to this parent’s understanding of her child’s problems and familiarity with terms such as “word recognition” and “phonetics”. In contrast to this case, Lisa, a parent with dyslexia, highlights the role that psychological processes may play in a parent’s pathway to the identification of dyslexia in their child. Her response to the question as to whether her diagnosis of dyslexia assisted in identifying dyslexia in her son demonstrates that, for her, it was more complex than simply a case of recognising the symptoms of dyslexia:

No. … Yeah I didn’t connect the two much and I suppose I’m interested in what that might be, my own pop psychology that Lisa was in some sort
of denial. My husband is very – I think at some level my husband is very capable academically and I just hoped he would be like him (Interviewee no. 12).

Lisa’s response demonstrates the role that denial played in the process of identifying her child’s dyslexia. She reflected on the hope she had harboured that her son would be like his non-dyslexic father. Adding another layer of complexity to this issue is the secret status of dyslexia in Lisa’s family of origin:

I knew it was in our family. I don’t think we’d ever used the dyslexia word much but it was there. It was talked about, forgotten about, not really understood I think and I just I think at some level probably didn’t want to think that he had it or didn’t think about it and then came to it through various diagnoses of auditory processing disorder, they said “oh it’s probably dyslexia but we can’t diagnose for that” … Then the school would say things like “well yes but I suppose his progress is not very good but that’s probably good for someone with low intelligence”, so all just – what a mess. (Interviewee no. 12)

This quote highlights the interplay of factors which combined to make it difficult for Lisa’s child to be diagnosed. These factors consisted of Lisa’s hope that dyslexia was not the cause of her son’s difficulty, the hint of stigma and taboo associated with the use of the word in her family of origin, and misunderstanding associated with dyslexia. Additionally, the misattribution of the child’s symptoms by the school to low intelligence and the apparent lack of initial referral to a psychologist by the audiologist who suspected the child had dyslexia, contributed to a delay in obtaining a diagnosis.

In the case of a family with a child whose two aunts (both sisters of the child’s father) had diagnosed dyslexia, there seemed to be no apparent impact on the child’s pathway to identification and diagnosis of dyslexia. This is a unique case in which the remedial teacher suggested to the parent that the child might have dyslexia and recommended testing:

The reading recovery teacher, at the end of reading recovery she hadn’t – she responded really, really well to reading recovery. But at the end of that she was still well behind and he said I think actually that she’s dyslexic. (Interviewee no. 6)
A strong pattern to emerge was the tendency of the diagnosis of the child with dyslexia to trigger an understanding in parents that they, or their spouse (or ex-spouse) or an aunt or uncle of the child, and in some cases grandparents, had suspected (but undiagnosed) dyslexia. This is evident in the following quote where the mother of the child with dyslexia refers to her ex-husband (the biological parent of her child) and states:

I believe that my ex-husband has dyslexia. He used to write letters backwards, can’t spell, no grammar, absolutely shocking. Yeah, no and I just thought he was dumb, to be honest with you. That’s terrible, but we were only very young, and I just – I don’t know – plus I came from a very academic family. I just thought well maybe he’s just not from an academic family. So – but now I think about it, yes he’s definitely got dyslexia and his cousin Paul had dyslexia. That was well known. (Interviewee no. 5)

This interviewee’s discovery of dyslexia in her child helped her reframe her impressions of her ex-husband’s difficulties as opposed to the father’s literacy challenges, illuminating and contextualising the child’s struggles. In another interview, a mother relayed that after her son was diagnosed it became clear that her husband had undiagnosed dyslexia:

We were able to understand some of the indicators and my husband subsequently is dyslexic. He’s a structural engineer and obviously very clever but always felt like he was really useless at English and reading and never liked to read anything that was outside his boundaries. Even now he’ll listen to audio books. (Interviewee no. 16)

In other cases, the diagnosis of the child raised the question for parents as to whether they may also have undiagnosed dyslexia. A father commented:

It probably wasn’t until I was in my late teens that I really learned to read properly, and I’m not sure if that’s just because I was a bit lazy and didn’t enjoy school and wasn’t really applying myself at that time, or whether or not I had an issue that was undiagnosed. (Father, interview no. 21)

The parent in this case (in his 40s) remains unsure as to whether he was “lazy” or if he has symptoms of dyslexia.
In a family with two children with diagnosed dyslexia, a mother reflected that she was surprised to find that her husband, the children’s biological father, also believes he has dyslexia:

I did speak to my husband, who said, “oh, yeah, well, I’m dyslexic”. I went, “well, when were you going to tell me?” (Interviewee no. 14)

This mother explained that her husband had never been assessed for or diagnosed with dyslexia or had his difficulties remediated:

Interviewer:  So he knew he was?
Interviewee:  Yeah.
Interviewee:  But he didn’t consider it relevant to what your daughter was experiencing?
Interviewee:  No, it wasn’t really when I said to him – when I read [name of social commentator] article and I said, I think Claudia’s dyslexic. He went, “yeah, well, I am”, but I don’t know if he’d – because he’d never had an assessment, he’d never got any support in school. He just hated school. (Interviewee no. 14)

The issue of hidden or undiagnosed dyslexia in parents of children with dyslexia in this study raises many important questions and warrants exploration; however, it is not the focus of this study. In relation to the current study, it is interesting to note that in most cases of children diagnosed with dyslexia there was hidden, suspected yet undiagnosed dyslexia amongst close family members. The hidden nature and lack of certainty about the diagnosis meant that, amongst these participants, it was seldom helpful in providing parents with useful information on the pathway to their children’s diagnosis.

The Route to Diagnosis: A Second or Third Child with Dyslexia

There were four families in this cohort with more than one child with diagnosed dyslexia. Although the identification of dyslexia in the second (and in one case, the third) child was slightly easier than for the first child, there were still inherent challenges in the process of discovery. One parent with three children
relates that it was easier for her to deal with the manifestation of dyslexia in her second and third children:

Their stories are a bit simpler, because I was so much more educated by the time they came around. (Interviewee no. 13)

As dyslexia presented in a different manner in each child, it was not immediately obvious to the parent that each child had dyslexia from the outset of learning to read. In relation to her second son, this mother reflects on how different the manifestation of dyslexia was in her second son compared to her first son:

Interviewer: It was obviously different from your elder son.
Interviewee: Totally different.
Interviewer: In the way that it expressed itself?
Interviewee: Yep, totally different. It really caught me unawares. I wasn’t thinking dyslexia at this stage. I was thinking reading and writing difficulty, but I wasn’t – he could remember words. He could do all the things my other son couldn’t. (Interviewee no. 13)

In another two examples, similar presentations of difficulties and traits in second child compared to first children diagnosed with dyslexia made the identification and the pathway to diagnosis and intervention quicker and more direct:

Linda’s nearly four years younger than Jona – I noticed a few similar traits. … So again, yeah, I had her diagnosed with [name of specialist dyslexia agency]. (Interviewee no. 16)

This was also the case in another example of a family with two children with dyslexia:

Then in Grade 2, again, she (second child) started doing some of the things that Sam (eldest child) would do. The alarm bells started ringing for me. (Interviewee no. 3)
Section 3: Summary

The lack of a systematic and uniform screening process for specific learning disabilities in Victorian schools resulted in each family embarking on a unique pathway to obtain a diagnosis of dyslexia. The journey to diagnosis was characterised by a sense that parents struggled in isolation, without clear guidance, to find the root cause of the problem in a generally unsupportive environment. Parents related the difficulty they encountered in determining which professionals to consult. Parents forged a pathway to diagnosis often spurred on by a sense that their child was experiencing a deep and unresolved problem. Despite the rejection of this concept by an educator, parents independently investigated the child’s issues, relying on their gut feelings that something was wrong. In most cases, parents consulted multiple experts in a variety of fields. The costs associated with testing were perceived by many parents as a financial burden. A strong sense of a yearning for moral and financial support emerged. The lack of support and direction from an authoritative source frequently made the pathway to diagnosis lengthy as parents consulted with multiple professionals.

Parents grappled with the question of whether financial responsibility should be shouldered by parents, the child’s school or, more broadly, the state. There was a clear indication from parents that they felt that having to bear the high cost of testing was a social injustice that would preclude many people in lower socio-economic groups from obtaining a diagnosis. The majority of parents with children in the state education system remained unaware that there are psychologists employed by the state within the education system who are equipped to test for dyslexia. No child in this cohort in the Catholic or independent school system was offered funded testing in-house.

Emerging from the data is a sense of complexity in relation to the impact of the presence of dyslexia in the nuclear family or extended family of a child with symptoms of dyslexia. In some cases when children presented with similar symptoms to their older siblings, this eased the pathway to identification for the younger child. Conversely, in cases when symptoms of dyslexia were dissimilar to those of the older sibling, it was not helpful for the younger child. Stigma
associated with dyslexia and levels of denial or acceptance of an adult’s own
diagnosis of dyslexia coupled with low levels of awareness of dyslexia in the
community appeared to influence the pathway to diagnosis for children.

Clearly emerging from these findings was a theme which was not the
subject of this research. That is a glimpse into the phenomenon of parents (and
other members of a child’s family) gaining insight in the possible hidden
existence of dyslexia in themselves or their close family members once a child has
been diagnosed. In the instances in which dyslexia had remained undiagnosed and
hidden in adults, it did not contribute to insights that could have been helpful for
the child’s pathway to diagnosis.

Chapter Summary

This chapter has identified from the findings parents’ experiences on the
route to their child’s diagnosis of dyslexia. It has documented numerous sub-
themes and themes providing insight into the experiences of parents on the
pathway to the identification of dyslexia. The signs and indicators of dyslexia, the
challenges associated with parents’ experiences, the difficulty of identifying
dyslexia, the isolation, the lack of support and the rejection and misattribution of
parental concerns by teachers and other school officials combine to form the first
major theme to emerge: the structural invisibility of dyslexia. In addition, the
findings highlighted in this chapter demonstrating the difficulty parents have in
exploring their child’s learning difficulties and the costs associated with this
exercise, contribute to the second major theme: the contestation over resources.
The next chapter, which focuses on parents’ experiences post diagnosis, also
contributes to these themes, in particular the theme of the contestation over
resources. The third and final major theme is also outlined in Chapter 4.
CHAPTER 4:
QUALITATIVE FINDINGS – PARENT’S EXPERIENCES OF SUPPORT POST DIAGNOSIS

Introduction

This chapter deals with parents’ experiences following their child’s diagnosis of dyslexia. The chapter is divided into four sections. Section 1 presents findings relating to the experiences of parents post diagnosis in attempting to identify and secure resources and support to assist with remediation for their child. It contains parents’ reflections on government dyslexia policy with regard to the emotional and financial cost to parents. Findings of parents’ perceptions of resources in the state, Catholic and independent school sectors are presented. Section 1 also contains findings relating to the impact of caring for a child with dyslexia on parents’ participation in the workforce.

Section 2 addresses the experiences of parents in seeking remedial support and understanding of their child’s learning needs within the school context. In exploring this topic, the central theme to emerge is the detrimental impact of the lack of teacher training in relation to dyslexia. Elements of this theme emerged in earlier sections of the findings, specifically in relation to teachers’ lack of
recognition of the early signs of dyslexia. In this section, this topic is presented as a distinct theme along with parents’ nuanced reflections on their experiences of teachers’ responses to dyslexia. It includes a focus on teacher’s views on their own training, and a focus on parents’ and children’s experiences resulting from the deficits in teacher training. The positive impact of a teacher’s knowledge of dyslexia is also presented. A central theme of this section is an interrelated finding regarding the failure of schools to implement provisions to accommodate children’s learning difficulties in the classroom. The final subsection relates to the experiences of parents who encountered a lack of recognition (or in some cases, denial) of the existence of dyslexia within the school context. Some parents attribute their experiences of these phenomena to a lack of resources to cater for dyslexic students; others believe it stems from a lack of teacher training. There is no clear resolution to this question in the findings.

Section 3 of this chapter concentrates on reflections on parents’ agency. It is divided into subsections on parental advocacy and peer support and parental recommendations for policy.

Section 4 contains findings relating to parental concerns regarding the self-esteem, mental health and wellbeing of their children. As highlighted in Chapter 3, parents indicated that their observation of their children’s unexpected low self-esteem after starting school was an indicator of a deeper underlying problem that served as the catalyst for further investigation. This section presents parents’ reflections on children’s low self-esteem, depression and school refusal post diagnosis of dyslexia.

**Section 1: Resources and Support in the Catholic and State Education Systems**

A key theme emerging from parents’ reflections on identifying and securing resources and support was parental dissatisfaction with the lack of state-funded or state-subsidised resources to support children with dyslexia. Parents considered the difficulties they encountered, and identified the lack of recognition and government support for children with dyslexia as an issue contributing to
social injustice. Diverse challenges for parents and children resulted. In the following quote, a parent who has two children with dyslexia reflects on the financial burden placed on parents:

I get no support. Every piece of tutoring that I’ve had, we’ve paid for ourselves – the assessments, the tutors, the programs. … All our money seems to be going with tutors. (Interviewee no. 8)

Another mother with two children with dyslexia reflects:

We’ve tried everything. We spent thousands and thousands of dollars on all sorts of things, on both of them. (Interviewee no. 3)

The extracts above relate to families with two children with dyslexia. It is clear that they experienced the financial burden acutely. Expenses associated with funding remediation were highlighted in the majority of interviews, with very few exceptions.

It is often difficult to distinguish between parents’ feelings in relation to a lack of support and assistance on a practical and psycho-social level and a lack of financial support. The lack of funding for remediation is significant in its own right. Its burden appears to be heightened by and interconnected with the lack of support for parents more broadly. In the following extract, the parent refers clearly to the deficit of support—practical, psychosocial and financial. But there is a deeper sense of isolation: a lack of any investment of “time” by their child’s school:

Oh, we’ve had no support at all, no funding, no time, none. (Father, interview no. 7)

There is a sense from this parent’s words that the lack of investment of time—“no time, none”—refers to the child but also to him as a parent, suggesting a sense of feeling marginalised. Similarly, in the following example, the same sense of isolation and marginalisation can be recognised. The parent details the lack of financial support within the state education system to fund remediation for her child:
You know you’re on your own. You know you have to find external resources. It’s very costly and time consuming – costs thousands of dollars. A 50-minute session costs us $95 – do it every week, and we have to pay travelling costs for that tutor. So our bill’s around $1000 every term. Then, computer programs cost us $800, because one was $600 and one was $200. So you’ve always got that every year, and quite a few hundred on top of that for extra things you might need, and you’re the only one who’s accountable. There’s no long-term accountability in the system. The Education Department should be providing some sort of resource – they advertise “every child”, but it’s not. (Mother, Interview no. 9)

The parent in this case reflects on the shift of the financial burden to the family. She highlights that the onus is on parents to search for and purchase resources without guidance or direction. She conveys a clear sense of disillusionment as she recognises the systemic failure of the state to provide her child with an appropriate education. This was not an unusual perception. Many parents questioned why the state does not provide assistance to children with dyslexia and why identification and fiscal responsibility is relegated to the domain of parents. In the following extract, in a case in which the child and the parent had not encountered a supportive attitude from the school, there is anger and a sense of injustice directed towards the school and the system as a whole:

Why aren’t they? – to me, this is their job too. They’ve got to teach these children and Zac’s not the only one that could use it, so why aren’t they learning and providing what these children – not just this school, any school. Why aren’t they providing the tools these kids need to learn?
(Interviewee no. 11)

There is no program for dyslexic kids. We’ve got bright children who don’t get support. I don’t get support, my family doesn’t get support and my children don’t get support and that’s outrageous in this country.
(Interviewee no. 8)

Responding to the deficiencies in the education system, most parents in this study felt the responsibility to provide remediation to fill the gap left by their child’s school:
The environment dictates, or the current legislation dictates that the onus is very much on the parents to fix the problem. (Father, interview 21)

but it’s like another school has to begin when we come home, because the responsibility rests on our shoulders and not the school. (Mother, interview no. 9)

The parents in this case contended that without their assistance their son would not have mastered reading skills. The implication is that not only are the parents fiscally responsible for the provision of their child’s education outside the structure of the state funded school, but they are also responsible for his acquisition of reading skills outside school hours:

Father: Yeah, if we had done nothing, he would be basically not be reading by now.
Mother: He’s just lucky that we’re committed to spend that time. We’re both well educated. I tell you, I’m not – my area’s not education, but I think I know a lot more than most of those teachers already, and he’s just lucky that we’re prepared to commit those resources, even though it’s really tough on the family. (Interview no. 9)

Inherent in the statement that their son is “lucky” is the understanding that not all children have the privilege of parents with sufficient financial resources and education to help their children remediate their difficulties. The sense of burden is also clear in the reference to the financial difficulty caused to the family by bearing the onus of the cost of remediation.

In most cases, parents recognised that the lack of support for their children was a systemic issue resulting from the lack of recognition of dyslexia as a funding category by the government:

they [the school] don’t have the funding that – like Zac’s got this learning disability, but he gets no funding, he gets nothing to get extra help, but he needs it. He’s not the only one. (Interviewee no. 11)

A strong sense of anger at the education system is evident in the following extract:
You know there’s this whole push on every kid reading, well why the fuck aren’t they helping the ones that can’t read? I just don’t think – and I think yeah my issue is not so much with specific school, I just think the education system needs a real err, like shift in terms of how to deal with it. (Interviewee no. 6)

A mother who resides in regional Victoria and whose child has had a positive experience at the local state school, with early identification of the child’s dyslexia and supportive teaching staff, was grateful for the support she receives in the context of an under-resourced environment:

but then I see this incredibly under-resourced educational environment and think I’m also incredibly grateful that they’re doing what they can do, what they are doing. (Interviewee no. 6)

This interviewee clearly identified a problematic lack of resources and acknowledged the efforts of teachers working within this constraint.

Many parents raised the issue of the inherent inequity of a lack of uniform funding for remediation for children with dyslexia. Parents pointed out that under the current policy regime, children’s opportunity to access remediation and support is dependent upon the economic status of their parents. In the following case, a parent who moved her child from the primary state system to the independent school sector for secondary school reflected on this inequality of access to resources:

But I hate to think what, yeah – that’s what I find really sad because I think not everyone’s in the same position as me to think, okay, well no, this is not going to be the end. This is not going to be the way it is; we’re going to do something. I think, well, everyone should be given that opportunity. (Interviewee no. 16)

A similar sentiment was expressed by this parent:

I mean we’re fortunate. I work and so does my husband. We can just afford to do all this stuff so it needs to be subsidised. (Interviewee no. 8)

Another parent pointed out that the costs associated with implementing report recommendations may be prohibitive for parents:
Recommendations suggest particular programs and also a laptop. So there’s quite a few thousand dollars involved in it, which sadly stops a lot of people from being able to support their kids. There’s been a whole lot of costs along the way as well, the glasses and you want to buy books. You want to go and hear people speak and they all cost hundreds and hundreds of dollars. (Interviewee no. 19)

In recognising the funding deficiency within the school, there were some parents with resources who elected to privately fund support for their child within their state school. In the following case, the child’s state school expressed resistance to this approach:

We actually had a one-to-one computing program within the school, and when I said that’s really good – we’re going to put on some software that will help Jack, the assistant principal said I’m not sure if that’s actually doable, because you lease that computer – blah, blah, blah. It’s like Stone Ages. (Interviewee no. 9)

These parents initially encountered the same resistance from the school in relation to the provision of a privately funded tutor, but were eventually successful in securing permission to have the child tutored privately on site:

So then we got him some help through getting him a private tutor, which we paid for every week, and that – we managed eventually to get that tutor to be able to go to the school. I used to, at the beginning, have to take him out of school and then take him home to get the tutoring and then take him back. (Mother, interview no. 9)

This case was not unique. In the following case, the parent states that her child’s school would not allow the child to undertake a remediation program within the school environment.

So then we had the test and, yes, we got this test. Then nobody was prepared to help us. I was just in this fog of non-information. So I spent hours and hours and hours Googling things and working out what we could do. We went down the route of promoting his visual spatial stuff. The program that we did was great but, really, it was a program that should be done for about 15 minutes every day within the school environment. The school were absolutely totally anti that. There was absolutely no way that they would allow us to do that. (Interviewee no. 3)
These scenarios describe a double-bind situation in which the school does not provide resources for remediation and yet will not allow parents to organise resources to assist the child within the school context.

The following is an exceptional case in which the culture of a state school was transformed to become one of “awareness and acceptance” as a result of advocacy by a parent. Despite this positive development for children, a parent acknowledges that difficulties are still encountered due to the lack of funding and allocation of resources:

There’s a real, real awareness and acceptance and a want to help. Again, at the same time, there’s no resources, and they’re not funded are they
(Interviewee no. 3)

Parents’ Reflections on the Relegation of Responsibility from School to Parent

Another key challenge, illustrated by the following case, is that many parents feel ill equipped to make decisions relating to appropriate remediation. They perceive that these decisions are best made by educators with specialist knowledge:

Then, but then I’m feeling like I’m a parent, I’m not a teacher. What this – what dyslexia’s left me with is needing to pick up some teaching skills or some reading – learning, reading and writing and spelling skills and also the temperament that comes with teaching. You know what I mean, like I’m not a teacher. (Interviewee no. 6)

Similarly, another mother considers the same challenge:

What’s right? What’s wrong? It’s a guessing game. It really is frustrating as well, because I’m not a teacher. I just do my best I can and try to be patient with her, and work through things every single day when I can. It’s really hard. It is disheartening. (Mother, interview no. 21)

The requirement for parents to be both parent and teacher, and the inherent difficulty this dual role presents, emerges clearly in the words of two single parents. A father states his belief that it is the responsibility of the school to
educate his child and his responsibility to provide and care for his child. He also expresses a sense of inadequacy and guilt for not being equipped to assist his daughter overcome her literacy difficulties:

I was bringing my daughter up by myself, feeding her and the whole works. I don’t think – whether, I mean that situation or a full-fledged family – I don’t think it’s the role of the parents to teach the children. That’s the role – that’s what I pay the school for. That’s what they’re meant to be doing. I feel guilty when she can’t read something, and when I try to get her to sound it out as best I understand – I haven’t been taught to teach. (Interviewee no. 10)

In the following extract, a single mother observes that the need to provide her son’s school with resources and information and support her son academically is very time consuming. She perceives the extra requirements placed on her as parent as robbing her of her time to be a mum:

Even though I’m providing him with books, I’m providing the school with the websites that might provide the good apps. I’m thinking, why don’t you know this? I want to be a mum. … I just want to be his mum, I don’t want to be his teacher and that’s the thing I think I struggle with the most is that dyslexia has robbed us a lot of just doing other things which is why I backed off a bit. (Interviewee no. 4)

A mother recounted sharing her feelings of distress regarding her son’s diagnosis of dyslexia with his art teacher. Attempting to comfort the mother, the teacher reassured the mother that her son just needed her “support”:

so you just need to support him. Yeah, but my background’s sales and marketing in wine. (Interviewee no. 16)

This parent interpreted the word “support” as academic support and, consistent with the previous two examples, intonated that she does not have the educational background and expertise required.
Navigating a Labyrinth of Remediation Programs

An additional theme to emerge from parents’ narratives in relation to remediation and resources is the challenge of navigating the labyrinth of programs on the private market:

There’s time where we looked on the internet, and there are a thousand different things, and some people claim, we can sort your dyslexia out in one lesson, and you think, how? That’s not possible, because what is it that I’m doing wrong? You start to doubt yourself and think, I’m not doing enough for her. So you think, surely it’s a gimmick, but there’s got to be some people that can help or some resource. There has to be something because we can’t do it on our own. (Mother, interview no. 21)

A parent refers to the inherent difficulty in discerning legitimate interventions from unscrupulous or non-evidence-based interventions:

A lot of parents will throw a lot of money at trying to get a result but they still can’t help their kids. They can’t help them, it’s very frustrating. (Interviewee no. 8)

In the following extract, the parent reflects on the cost rather than the bona fides of some remediation resources:

It disgusts me about this. The thing that blew me away when I realised that she was dyslexic is just how much the whole thing is big bucks for the – I mean there’s heaps of internet sites that are free. There’s stuff that’s free. But there’s also brilliant resources that are priced really high. (Interviewee no. 6)

The following extract is from an interview with a parent who is also an experienced secondary school teacher with postgraduate qualifications in special education:

It’s because it’s such a maze of what programs – I’ve been to so many places to think oh, this is going to be the magic fix. I had the [name of program] – I didn’t do that, thank God – she came to my house and told me it was about $6000 [whispers]. She wanted $3000 up front and I was like, no. (Interviewee no. 15)
Later the same parent reflects:

It’s almost rort, like it’s almost people preying on desperate parents who want to do everything for their children. They go, here’s $10,000 for the privilege. (Interviewee no. 15)

This quote highlights the difficulty this parent experienced navigating through the private market attempting to distinguish between bona fide programs and products and gimmicks without professional expertise or authoritative guidance to draw upon.

Many parents also felt challenged by the need to discern which legitimate intervention strategy would best suit their child’s learning needs. In this example, the parent describes how her child’s school encouraged her to focus on building upon the child’s strengths rather than remediating his weaknesses:

The school originally – he’s a gifted visual spatial learner, so they suggested that we work on the positives rather than what he’s not very good at. So we enrolled on a course with a lady that runs a course for visual spatial children, called [name of private agency] which was very expensive, very time consuming, very stressful. We did prism lenses because somebody suggested that would be the right thing for him. The whole time his school was very non-supportive. He wasn’t funded, so they weren’t prepared to help. (Interviewee no. 3)

It is evident that this mother experienced a sense of financial and emotional burden, a lack of support, a sense of isolation as well as a burden resulting from the investment of time required by the child and by the parent for these external remediation programs. Similarly, a father expresses a sense of difficulty and isolation in discerning what will best suit his child’s learning needs. Contained within his words is a desire for support, advice, direction and funding:

It’s a maze; it’s a real maze of stuff out there. Which one do you choose, the [program name] and the [program name] you know, all that sort of stuff? … Some assistance to make sense of all this stuff and to get your way through the mire would be handy. Now, we’ve done that ourselves but I’m sure other people would be – earlier on in the pathway would be finding oh hell, where do you go, what do you do? Also without the
resources, having to spend a lot of money to actually go to all these
different places. (Father, Interview no. 7)

The following observation from another parent once again reflects the
theme of the lack of support and guidance and sense of isolation experienced by
parents:

So there’s no one body that can take control of this and say parents, this
is what you can do at home. (Interviewee no. 8)

Parents’ Perceptions and Experiences of the Independent School Sector

At the outset of the interview process, parents were asked in which school
sector their children began their schooling. It emerged that, in 20 of the 21
interviews, children commenced their schooling career in either the state or the
Catholic education system. In the one exceptional case, a child commenced her
schooling overseas at an independent school, sponsored by the father’s Australian
employer. Upon the family’s return to Australia, the child was enrolled in a
Catholic school. (The child was diagnosed with dyslexia in Australia.)

During the interview process, seven participants highlighted that they had
moved or were planning to move their children from the state or Catholic
education sector to an independent school. The reasons for this move varied very
slightly in theme. One parent conveyed that she felt that her child would receive
greater “care” in a general sense in the independent school sector. In this case, the
child was moved from a primary state school to a secondary independent school
prior to her diagnosis of dyslexia:

She went to a girls’ private school, small one that I chose specifically
because I felt that she would be looked after. (Interviewee no. 20)

Of note is that this parent is a qualified teacher working in the state
primary school system. The new school was not chosen on the basis of its support
programs for children with dyslexia, as the child was yet to be diagnosed. Rather,
it was the perception that this child who was struggling academically would be
generally better “looked after” in the setting of an independent school
environment. In every other instance, children were moved to the independent school system following their diagnosis of dyslexia.

In contrast to the previous situation, the parent in the following example specifically chose her child’s independent school based on her assessment of its capacity to support her children to reach their potential. The selection of the school determined the family’s choice of suburb in which to live:

I chose my school very carefully. I actually chose the school, then I chose where we were going to live and the house. … I know that not every school – there’s no school that’s going to be perfect, because you can’t find perfect. I had to find the school that was going to be the closest fit for what I was expecting and what I perceived was going to be best opportunity for them to do the best they could. (Interviewee no. 13)

In this example, the parent who was interviewed was also a teacher. Emerging from this interview is an indication of the variability between independent schools in catering for children with dyslexia:

I was at this particular school that people had been raving about including teachers I knew who’d worked there. As soon as I mentioned to the registrar that – I think I might have said only one son had dyslexia and would need extra support, I literally saw the blinkers – the blinds go down on his eyes. He went from being a complete advocate of his school, you should come here because of this, this, this and this, to “there’s no guarantees he’ll get support”, that sort of thing. (Interviewee no. 13)

This lack of consistency between independent schools in relation to their treatment of and approach to dyslexia was also demonstrated in other interviews. In the following example, a parent who moved her child from a state school to an independent school reflects on the independent school’s lack of a systemic and comprehensive approach to dealing with her daughter’s dyslexia:

Yeah, it’s not perfect by any stretch of the imagination, but – and a lot of it is up to me, working out how to help her, and then talking to the teacher and trying to implement whatever we come up with. There are still some issues with communication there, especially now she’s in year 7. The specialist teachers don’t know that she has dyslexia. It hasn’t been
communicated. So, it’s up to me to communicate that sort of information.
(Interviewee no. 18)

In this case, the child was moved in upper primary school from the state system to an independent school based on the perception that both the child’s needs, and the parent’s need for effective communication, would be better catered for in that environment:

we actually moved her after her diagnosis with dyslexia, … So, after her diagnosis, we had a look into what schools might suit her best, and we decided to move her in Grade 5 to [name of independent school] … She would just let things go around her. So, we felt that we needed to be in a school, too, where we could contact the teachers and be more comfortable being up there and being involved with her school.
(Interviewee no. 18)

Juxtaposing this case is the following scenario in which a parent provides an unequivocally positive report of the management of her son’s dyslexia at an independent school. The parent describes a level of engagement by the school and support that meets the child’s learning needs:

Yeah, it’s interesting. But [independent school has] been fantastic and wanting to understand Jona’s level of dyslexia, what areas he struggles the most in and how they can support him. They have learning mentors in the year 7 and 8 as well so they have someone that goes with them for the majority of their classes in addition to the teacher. (Interviewee no. 16)

However, this positive outcome was serendipitous as the parents did not choose the child’s independent school based on prior knowledge of its ability to cater for children with dyslexia. Rather it was selected as both parents had attended that school as children:

Interviewer: Is your decision to go to that school based on the fact that he had a learning disability?
Interviewee: No. He was booked in when he was a baby. I went to [name of independent school], and my husband was a boarder at [name of independent school]. We’re lucky that when we really started looking at schools and
knowing the kids better, that it was a school that catered very well for learning difficulties (Interviewee no. 16)

In the following example, the parent attributes her decision to move her child from a state primary state school to an independent secondary school to concern for her child’s academic, physical and emotional wellbeing:

I just thought I think this [name of state high school] could be a disaster, Oscar will be disengaged, he’ll have different teachers, we’ll have trouble keeping up the lines of communication, he won’t have any remediation. He needs to have remediation and that needs to be an accepted thing and it needs to be done sensitively and stuff. … Someone had said that [name of independent school] was kind of okay and it was very late in the piece and I went and visited and had a talk to them and they said “you probably won’t get in” and I thought okay fine, but I was terrified by that stage of sending him to the high school when I thought about the lack of stability, the lack of support and I think kids who were capable will do fine there, it’s not a bad school. Then also I thought it would be nice to get away from some of the kids who were rough actually which I hadn’t thought about before. (Interviewee no. 12)

This parent expressed her perception of risk rather than experience. She believed her son may be at risk of academic disengagement due to the lack of resources in the secondary state system. The parent also expressed her belief that she may have difficulty maintaining effective communication with the staff in the state system.

In the next example, the parent explicitly frames her son’s move to the independent school sector as a direct expression of dissatisfaction with her son’s current experience at his state school rather than a future perceived risk. Her action is framed as a reaction to the state system:

I said that’s enough. We’ve had enough. The school that we’re at is not coming to the party. That’s it, we’re going to private school and I said at the outset when we had our meeting, Michael has dyslexia. We need to try and help him within the school. I know that the school has a psychologist. I know that the school provide activities like sport. Michael is quite good at sport so they can help him with his sport (Interviewee no. 8)
Inherent here, again, is the hope that the facilities and resources, both academic and extra-curricular, at this independent school would better cater for her son’s needs.

The Impact of Caring for a Child with Dyslexia on Parents’ Workforce Participation

In some instances, parents in this research cohort redesigned their work arrangements in order to support their children’s learning needs. This was manifest in a variety of ways. One mother left the paid workforce in order to provide more time and energy to support and advocate for her two children with dyslexia:

Mmm. I’m actually not working at the moment, just because I feel like I need to be available, to be around for them, to advocate. We have some terrible mornings where I can’t get – I couldn’t get to school on Monday. I wouldn’t be able to work if that was happening all the time, which it does. (Interviewee no. 3)

Similarly, another mother decided to remain working at a part-time ratio rather than resume full-time work as initially planned:

It’s affected my work this dyslexia. It’s affected my ability to go back to work full time because on Mondays and Wednesdays I spend all my time writing to people saying what’s going on. (Interviewee no. 8)

In the following example, the mother comments (without a specific question posed on this matter), that her son’s dyslexia and support needs have contributed to her decision to not return to the paid workforce:

So it does feel quite isolating and in a way it’s not the entire reason why I don’t work, but it’s had quite a big impact on why, it’s a big part of it I suppose. (Interviewee no. 17)

In all but one case, in which participation in the workforce was renegotiated to accommodate children’s extra learning and support needs, it was the mother who adjusted her working arrangements. In one exceptional case, a
father juggled his consultancy work hours to provide support and remediation for his daughter:

There’s only so many things you can fit into the day. Some of our after-school things – I take time off work to do homework with her some days, just to try and go through. … I have to work at night to catch up. (Father, interview no. 7)

A family residing in regional Victoria with one child with dyslexia and a younger child diagnosed with Asperger’s syndrome downsized their home. This decision was made to enable the mother to exit the paid workforce and to provide support for her children’s learning needs:

I’ve just resigned, actually, from my job to be a stay-at-home mum to deal with all this. … We’ve just sold our house and we’re downsizing. (Interviewee no. 18)

With the prospect of high school approaching, a single mother who is a trained teacher with qualifications in special education does not feel confident that she will find a suitable school for her son, and ruminates:

my only other option is to sell the house and move somewhere where I have no mortgage and home school (Interviewee no. 1).

There were some instances of increased strain on the family budget in relation to supporting children’s interests and hobbies with the explicit intent of boosting the child’s low self-esteem caused by their sense of failure in the school arena:

it’s costing me a fortune in time and money to find courses in computer animation for Ella to – find an art teacher that wants to do – that will do cartooning with her like she wants to. … so if I can support her in her strengths, that will keep her self-esteem intact and she will get through school (Interviewee no. 19)

My daughter’s great at dancing, so we spend an awful lot on ballet. She’s very good at it, but again it’s about that self-esteem. She needs it. (Interviewee no. 14)
Section 1: Summary

It emerged that the lack of funded resources for children with dyslexia in the state and Catholic school systems were a source of dissatisfaction and frustration for parents. This deficit contributed to a sense of financial burden, an overwhelming sense of responsibility which parents felt ill equipped to deal with and feelings of isolation.

In addition to paying for remediation, some parents also funded counselling and participation in additional extra-curricular activities to help boost their child’s self-esteem and wellbeing. In some cases, parents decreased their participation in the workforce in order to assist their child with school work at home and to take them to appointments such as counselling and other types of therapy related to the remediation of dyslexia. Therefore, there was a co-occurrence of reduced income and increased expenses in some families. In the majority of cases, it was women who reduced their participation in the workforce so they could look after their children’s learning and psychosocial support needs.

The decision to move a child from state or Catholic education to an independent school was based on the perception that an independent school would better cater for their children’s learning needs by providing more care than the other education sectors as well as increased access to academic resources, extra-curricular activities and psychosocial supports. The belief was also expressed that an independent school would facilitate communication with parents more effectively and reduce risk of harm to the child from their peers.

As highlighted by different examples, the treatment of children’s dyslexia in independent schools is variable and dependent upon the staff and leadership of the day. The absence of government funding directed towards the treatment of dyslexia contributes to this variability in the treatment of dyslexia by schools in all sectors. Consistency of management of children with dyslexia was not a feature of the state, Catholic or independent school system. In the absence of government policy, children in all sectors encounter treatment dependent on teacher training and experience and the school’s willingness and ability to cater for children’s learning differences. Although parents generally perceived that
resources and support were superior in the better funded independent school sector, and were generally more positive about the independent school sector, this was not without qualification. It was apparent from parents’ experiences that the independent school system is not homogenous in its treatment of dyslexia and its distribution of resources.

Section 2: Lack of Teachers’ Knowledge in Relation to Dyslexia

A strong theme to emerge was parents’ sense of dissatisfaction with many teachers’ lack of knowledge relating to dyslexia. The implications of the lack of teacher training and knowledge of dyslexia were varied and have been categorised into subsections in the following discussion.

Subsection 1 contains parents’ experiences, feelings and insights in relation to the impact of the lack of investment in pre-service and in-service teacher training in relation to dyslexia. Parents reflect on the challenges and the negative impacts of the lack of teachers’ knowledge. Conversely, a minority of parents highlight the benefits of encountering teachers with knowledge of dyslexia. Strong views about the implementation of teacher training regarding dyslexia are voiced by parents.

Subsection 2 outlines parents’ thoughts on systemic problems associated with the failure to implement remediation strategies for children in the classroom. It presents parents’ perceptions and understanding of why the failure to implement remediation strategies occurs and the impact this has on children.

Subsection 3 contains findings relating to parents’ experiences of teachers’ denial of the existence of dyslexia as a condition as well as the refusal in some cases to use the word “dyslexia”. The impact of this negation is presented.

Parents’ Reflections on Lack of Teacher Training in Relation to Dyslexia

Challenges arising from the multifarious impacts of the lack of pre-service and in-service teacher training in relation to dyslexia were noted at many junctures throughout each interview. It emerged that in some instances the lack of
teacher training resulted in negative labelling, punitive treatment and social and academic exclusion of children with dyslexia. This was apparent in the state and Catholic school sectors but not, in this small sample, in the independent school sector. In the following excerpt, the parent points out that misunderstanding and lack of knowledge regarding the manifestation of dyslexia resulted in erroneous negative labelling of her child by his teacher:

He’s also been labelled as being lazy. Twice! Even last year’s teacher said to him, and he said me, “I’m lazy” and then he said he took it back, he said “I’m really sorry, I shouldn’t have said that”. Even Annabelle, his teacher that did the best teaching for him, she said – she never said it to him but said to me “look, I think he’s just a lazy boy”. (Interviewee no. 4)

In one example of punitive treatment resulting from a teacher’s lack of knowledge of dyslexia, a child and his (non-dyslexic) peers received collective punishment for the dyslexic child’s slow progress in class:

Sebastian has some challenges. She didn’t get it. She didn’t get it at all. She used to make him sit in the classroom if he didn’t finish his work he had to sit there and try and finish it, he couldn’t go out and play with the other kids. Other times he had kids on his table who were not allowed to go out until he finished. (Interviewee no. 4)

This suggests that the teacher attributed the child’s slow progress to behavioural factors or a lack of effort rather than a learning disability.

In another instance, parents cited a scenario in which their primary school age son was excluded from joining a student book club as a result of a teacher’s erroneous perceptions of his intelligence and ability:

Mother: The teacher said he’s not one of the gifted. He can’t read. This is for the gifted people. … The purpose at the sessions was not to read. It was to discuss the content and the setting of the book, and the characters

Interviewer: Yes.

Mother: Which he’s quite capable of doing. (Interviewees no. 9)
In another case, a principal’s lack of knowledge of dyslexia led her to advise a parent of a seven-year-old child that she should consider that literacy skills may be outside the scope of the child’s aptitude:

I said to her look, he’s struggling with literacy. He’s not recognising these words, he doesn’t have his phonetic awareness there. It’s just not making sense. I said what can we do in terms of literacy support? She said to me – it was one of those you never forget – she said have you considered that maybe it’s too late? (Interviewee no. 1)

Inherent in this comment is the belief that the child has an insurmountable deficit which no intervention will succeed in addressing. Essentially, the principal is proposing that the parent accept that her child may be subjected to lifelong societal marginalisation resulting from illiteracy. There is no offer of assistance for the child or direction to help the parent to source additional help for the child.

A lack of knowledge regarding the remediation of dyslexia was commonplace amongst teachers, however a lack of empathy was not ubiquitous. There were several examples of teachers demonstrating compassion for the child whilst acknowledging their lack of specialist training in relation to dyslexia. In these cases, the teachers expressed a desire to help the struggling child. In the following example, the parent of a child (aged 10) in Grade 4 recounts a poignant instance where she assisted a teacher to gain insight into her child’s distress. The teacher’s response was empathetic. She sought the parent’s guidance to enable her to help the child, highlighting her lack of professional expertise in dealing with dyslexia:

He [the child] was having an absolutely awful time. His teacher, who’d been teaching 32 years, said she’d never taught a dyslexic child before in her life. I showed her a picture of – we got him to draw himself and how he felt when he was feeling overwhelmed. It was a picture with all things off his head – blood rush, legs wobbling, stomach churning – all these awful negative emotions. She started crying, this lady. Tell me how I can help you. I’ve never taught a dyslexic child. She had at least four of them in the grade that year. (Interviewee no. 3)
Additionally, in other cases, teachers recognised the deficits in their knowledge and training and expressed a desire to learn more about dyslexia. In the following instance, a mother organised a dyslexia expert to present to teachers at her son’s school:

It was an eye-opener and it was packed and we had teachers from all over the area who were saying this is such an issue, what can we do tomorrow? We need help tomorrow. (Interviewee no. 12)

Again, a mother described an instance in which a teacher acknowledged her lack of knowledge regarding dyslexia and demonstrated to the mother that she was seeking to rectify this situation:

I think it was the end of last term, I was in her office and she had a book sitting on her desk that I’d noticed, about dyslexia. In conversation, she grabbed it and said, look, I’m trying. She said, we are trying to learn (Interviewee no. 11).

Parents also demonstrated empathy for teachers, acknowledging the impact of the limitations both of resources in the education system and teacher training:

so I think she was doing the best she could and I don’t think, really, that she was being supported in the echelon within the school environment itself. I think she was struggling to know what to do. (Interviewee no. 2)

Providing additional insight, all parents in this cohort who were also teachers acknowledged a deficit in relation to dyslexia in their own teacher training:

It’s not their [the teacher’s] fault for a lot of it but they do have such a lack of knowledge. I think it’s because in teacher training we don’t do anything about specific learning difficulties and we don’t know how to cater for these children. (Interviewee no. 15)
Another parent/teacher reflected:

There was one lecture on one given day where reading disabilities was mentioned, and potentially even the word dyslexia was used, but that was it. (Interviewee no. 13)

Another parent/teacher acknowledged the lack of training in relation to dyslexia and labelled it “shameful”:

Interviewee: I thought there is definitely things missing here and so I started going on the internet and looking up things – I looked up dyslexia. I can’t remember exactly what I was looking up, but it was just general – I just thought I’ve got to – I’d heard of the word. I knew of it. I just knew basically that it was children that had trouble reading, struggled with reading or spelling.

Interviewer: So in your teacher training, they never taught you ...

Interviewee: Nothing, nothing in my teacher training. It was shameful. (Interviewee no. 20)

The Impact of Teacher Training on Dyslexia

In considering her colleagues’ lack of training, a parent/teacher expressed her anger at the erroneous labelling of children with dyslexia as “lazy”:

In my work it’s frustrating because I’m trying to work with these kids and coming up against colleagues that I work with who have little understanding. It kills me when they tell me these kids are lazy. I just want to kill them. We need a lot more education on these kinds of issues. (Interviewee no. 15)

An important finding to emerge from parent’s narratives is the inconsistency of teachers’ knowledge of dyslexia:

It’s very hard. That’s quite rare to find someone. I really feel two teachers have had the ability to see the picture, and to understand and to be able to talk on a certain level with that knowledge, but most teachers have no idea (Mother, interview no. 9).
Inherent in this observation is that, in this parent’s experience, teachers with an understanding of dyslexia are the exception, not the rule. A similar sentiment is reflected in the following quote:

I feel that at the start of every year you have to go [to the school] and introduce everything again, absolutely everything. There are different levels of understanding of dyslexia. Some people understand a lot and others understand nothing. It’s like we’re educating them. (Interviewee no. 16)

This extract highlights the serendipitous nature of encountering teachers with knowledge of dyslexia. Additionally, it provides insight into the responsibility this parent feels in relation to equipping her children’s teachers with the knowledge to support them learn.

In another example, a parent referred to her daughter’s experience of a teacher who was exceptional because he was dyslexic:

Funnily enough, Jessica had an English teacher last year who was dyslexic. Well, that was the best year of her life. She excelled. I went to the parent–teacher interview. He said “she is amazing”. Instead of getting the, “oh, yes, and she struggles with this and oh, I see where she goes wrong and we really have to do that with her”, he just thought she was fantastic. I came away the proudest mother of all. Unfortunately he left – I think it was third term. (Interviewee no. 20)

This observation is particularly informative as it indicates that the child thrives in an environment in which her strengths are recognised. The teacher’s empathy and understanding of dyslexia and praise for the child are of great significance for the parent. This is not unique. Another parent presented similar evidence regarding the benefits of a teacher with dyslexia, and highlighted the positives of having a teacher, even for a very short period, who did understand her child’s learning needs:

His teacher was actually dyslexic but she was a grant teacher so she was only there for one year. ... she catered to his needs so much so that if she wasn’t going to be there, she would let us know. Because having a CRT [casual relief teacher] for one day would just – that would lose all the
good that she’d done. But he was only secure in that classroom with her and he actually had a good group of friends that year, too. Then the following year, within pretty much days it all went back to no good again. (Interviewee no. 11)

It is clear from this description that the child’s sense of security and the positive experience with a teacher who understood his learning needs also had a positive impact on his psychosocial wellbeing.

The temporary nature of a casual relief teacher provides us with a microcosmic glimpse of children’s experiences of teachers from year to year:

CRTs are always – the teachers, when they come in – they’re always a nightmare for both of the children because they don’t know that – there is a book – the communication book – but it definitely has Sam’s information in it now. I don’t know whether it gets looked at, but yes, that’s always a stress for the kids, the CRT. (Interviewee no. 3)

This parent’s perception highlights the difficulty for children of experiencing a teacher who does not understand their learning needs, capabilities and weaknesses, even for one day. In contrast, the exceptional cases in which a teacher understands the needs of children with dyslexia are very informative, illustrating the benefits of in-service teacher training even when it is not accompanied by significant funds and resources. The following quote is from a parent who moved her child from one state primary school to another. The child’s new school had trained its teachers in dyslexia awareness (as a result of lobbying by another parent in this study, identified as Interviewee no. 14):

There’s a much greater awareness at the school but, at the end of the day, they don’t get extra funding to help these kids. They just have an awareness. Last year his teacher was phenomenal. (Interviewee no. 3)

As this school transformed its practices, it became known as a dyslexia-friendly school; other parents within this research cohort heard of it through informal channels (external to this study) and moved their children there. (Positive comments attributable to Interviewee no. 2, Interviewee no. 3, and Interviewee no. 14 in this section relate to the same dyslexic-friendly metropolitan state primary school.)
The importance and value of a supportive school culture, collaborative relationships and good communication channels between teachers and parents are highlighted as significant by parents:

At the beginning of Grade 5 we moved to this other local primary school and it’s just been amazing that it could be such a difference, both in the culture of the school. The principal has since moved on, but I think the legacy of his work remains. We struck gold with an amazing teacher who worked very closely with us and it was just the whole, I think the – the environment we’ve been in, which was very much, we are the experts, to, we’re both in this together, open door policy, how can we best work together? It has been extraordinary. (Interviewee no. 2)

Another parent with children at the same school praises the school for its nurturing and supportive environment which has assisted her daughter to develop writing skills:

I think we’ve had some gorgeous teachers in the last two years. She’s been so lucky, because they have nurtured her and been gorgeous and understanding and supportive and really brought out some of her strengths in her – she writes! (Interviewee no. 14)

Of significance is that the whole school approach to dyslexia awareness means that children’s positive experiences are not time limited or based upon on an individual teacher’s or principal’s tenure. However, it was clear that despite in-service teacher training there were still occasions when teachers displayed a lack of knowledge and understanding of the manifestations of dyslexia:

I did have a bit of an issue in Grade 1 with the teacher and had to then go firing down at the school again. Because the teacher said to me, “Jackie you know, he’s really, really smart. I think he’s just lazy”. After all this training. I lost it a little bit and had to go down to the vice principal and I got very cross. … So there’s still – you still have to be this mum that goes down to the school, even when you’ve got a fairly good school, that’s had the training and had the advocacy. (Interviewee no. 14)
Parents’ Hopes for Policy Change in Relation to Teacher Training

A very strong finding to emerge was the expressed desire and hope of parents for a policy change in relation to teacher training:

Even if they [teachers] all just had some knowledge, but for the fact that they do training and they are not – it’s not even talked about, I wish that they all – when they do their teaching or they have the opportunity to do refreshers or something, it would come up, but it just doesn’t. (Mother, interview no. 21)

I think for pre-service teachers to be trained in supporting students with dyslexia is paramount, from my own experience … I think there has to be something introduced into teacher training, so that would-be teachers – most of them don’t even really know what dyslexia is, let alone how to support students. (Interviewee no. 2)

We still have teachers, lots and lots of teachers, good teachers, not knowing about dyslexia. So it’s paramount that their training is mandatory (Interviewee no. 14).

Well, the main, like from my point of view, the main problem is the lack of understanding of dyslexia by teachers. They don’t know what to do about it and the lack of resources I suppose for teachers. (Interviewee no. 17)

I’d like them to have the understanding – teachers to have the training and the understanding. They have no training. They do not understand. It can be very insulting what they say about your child, because they do not have the knowledge. So they don’t know how to deal with it. (Mother, Interview no. 9)

A parent who is also a teacher reflects on the importance of teacher training in relation to dyslexia:

I would love to see it embedded in teacher training – throughout your whole four years of teacher training a subject on learning difficulties, a subject on dyslexia (Interviewee no. 15)
Another parent–teacher, when asked what policy initiatives she would like to see implemented, highlighted teacher training as the single most important factor that she would like changed:

I think teacher training is number one. I think having a special needs teacher in your school at least that can pick up on children with special needs to support them, to support their parents. (Interviewee no. 20)

**Implementation of Remediation Strategies in the Classroom**

In the majority of cases, diagnostic reports from psychologists contained strategies for teachers to implement to help children manage workload, maintain pace with their peers and learn more effectively in a classroom environment. The key issue of great concern to parents was the lack of implementation of these remediation strategies.

Parents identified several factors which contributed to the lack of implementation. One of these issues was teachers’ lack of training and expertise in decoding psychologists’ reports. The implication is that teachers do not have the necessary training to understand the content of a psychologist’s report:

but then even after having a formal assessment done, and then going and presenting it to the school, not only were they really not equipped to understand it, I could tell during the interview that they didn’t understand what the report was (Father, interview no. 21).

This observation is echoed by a mother who is also a teacher by profession:

I had sent them [the school] all the reports. Also people at school aren’t trained to read a WISC [Wechsler Intelligence Scale for Children] and to decode a [name of specialist dyslexia agency] report, so that’s not what you get in teacher training. It wasn’t when I went through, and I doubt they’ve changed it [laughs]. (Interviewee no. 1)

In all but one case, psychologists’ diagnostic reports contained recommendations for remediation based on the child’s diagnosis and specific areas of difficulties. There was one exceptional case:
Interviewer: So you would have had the diagnosis and recommendations, I’m assuming?

Father: Well, diagnosis, but not recommendations and that’s the …

Interviewer: Really?

Mother: Really.

Father: That’s the problem. It got to a point they test and another test and another test but what are we going to do about it? … So I’m starting to make some – we have to do some action on this. So I’ve been doing [name of dyslexia remediation program] for a while on the online stuff. (Interviewees no. 7)

Lacking expert advice in regard to remediation, these parents took the initiative and sourced a program via the internet. While it was not uncommon for parents to seek programs online, it was highly unusual for reports to lack suitable strategies to assist the child in the classroom.

In the following case, a parent refers to the lack of communication between the diagnosing psychologist and the child’s school:

I thought, that doesn’t help me, that doesn’t give me the strategies I was looking for. I thought you [the psychologist] were going to come and speak to the school, I wanted someone to be an advocate to help me and I didn’t have it. (Interviewee no. 4)

This was a theme echoed by other parents. In the following quotes, a mother describes receiving her son’s diagnosis and the void between the assessing agency and the school:

Yes, you walk out the door and you hear the cash register ring, and that’s it. … There’s no connection. There doesn’t seem to be any connection.

Yes, they’ll do recommendations, but who follows them up? (Interviewee no. 1)

In the following example, the parent also describes the lack of cooperation and linkages between the psychologist and the school. She notes that the school implemented a remediation program for her son which was not recommended in
the psychologist’s report, and did not implement the strategies contained within
the report:

He’ll [her son] go off to this reading [Reading Recovery] but there’s no
relation from that reading to his dyslexic report. That’s not linked either.
Whatever happens to that – the $1000 of recommendations I have
[laughs]. That’s why I keep coming back to that $1000, because it’s
really phenomenal [laughs]. There’s no one to – yes. So he’s in some
generic thing. So there’s just no linkage. (Interviewee no. 1)

This parent’s perception of the waste of money spent on a report not
utilised by the school is not an isolated view. In another example, the parent’s
frustration at the systemic failure to identify dyslexia and to implement report
recommendations is exacerbated by the sense that the school is not capitalising on
his expenditure on the report:

Think about it – first of all we’ve got a scenario where we’ve got kids
like Estelle out there, we’ve got no process for diagnosing – one issue.
Second thing, when we have somebody go and get that diagnosis done,
the school isn’t – equipped is not really the word – the school isn’t
prepared to then lunge off that and go and reap the benefits of someone
paying the $1300. Then that’s really – we haven’t gone any further.
(Father, interview no. 21)

The majority of parents with children in the state and Catholic education
system expressed concern that report recommendations for remediation strategies
and accommodation within the classroom were not implemented. This was the
case even where there was liaison between the professional who diagnosed the
child and the school:

it [the report] came back confirming her dyslexia, but also some really
important things that could be implemented in the classroom. Part of the
service that [name of agency] provided was a follow-up discussion with
the school. Well, six months after the report having been provided, they
[the school] still hadn’t made – hadn’t done any follow-up. (Interviewee
no. 2)
In this case, the mother acknowledges a teacher’s difficulty in juggling the variety of special needs of children in the classroom, and acknowledges that the teacher was unsupported and did not have specialist knowledge:

To her [the teacher’s] credit, she was in a classroom of 28 students, two of them had intellectual disabilities, there was a full-time aide working with those other kids, she had at least two with a diagnosis of dyslexia and from my observations I’d suggest there’s probably at least another two, then she also had some kids who were needing extension. So it’s – it was a really broad spectrum, so I think she was doing the best she could and I don’t think, really, that she was being supported in the echelon within the school environment itself. I think she was struggling to know what to do. (Interviewee no. 2)

In the following extract, the parent also notes the impediment of the under-resourced school environment:

I think sometimes though, their hands are tied, like you know, the teacher is good but he’s obviously working within the system and working with the constraints and what resourcing is available and how we can manipulate his timetable. So he’s not working as a free agent, as it were. He’s got lots of constraints; he’s got 25 other kids. (Father, Interview no. 7)

Parents frequently testified to the constraints of the school system, the lack of resources, lack of support for teachers and lack of training. However, this acknowledgement of systemic issues often coexisted with a sense of frustration and despair at the perceived lack of commitment to assisting their child:

because often kids won’t put their hand up and say they don’t understand. So we [another parent of a dyslexic child and this parent] made these cards, well they were never used. In the end they were – I’d see them sort of – she [the teacher] must have distributed them, but they’d sit in the kids’ drawers and were never actually implemented properly in the classroom. It’s just – there was a lack of commitment, I suppose, to following through. By the end of Grade 4, really Iris was just – she was really depressed, she’d say horrible things about herself and reflect where she was against her peers and it was just – it was – yeah, I was really very concerned about her. (Interviewee no. 2)
they [the teachers] didn’t know what to do with it and they didn’t want to support it. No funding, no resources. It was really hard. It was really hard on my son. (Interviewee no. 3)

The impact of the learning disability combined with the lack of implementation of measures to assist children contributed to a sense of academic failure resulting in low self-esteem and, in some cases, depression. (Section 4 of this chapter presents parental concerns regarding children’s self-esteem and wellbeing.)

In the following instance, the parent links the school’s lack of implementation of her daughter’s report recommendations to a general lack of understanding of the nature and impact of dyslexia:

Yeah, but they didn’t know what dyslexia – just don’t know what dyslexia is I think. Maybe I’m assuming that but the way they managed it wasn’t, yeah, it wasn’t just demonstrating any understanding of the recommendations that came from the report and how Jody learns. (Interviewee no. 19)

Some parents explained that although the school agreed to take action to support their child’s learning, that did not translate into action in the classroom:

We went to the school and tried to get as much help as we could and the principal mouthed the right things but I didn’t really see it coming out in action. (Father, interview no. 7)

I’d set up student support group meetings at the school. We would put things in – well, propose things – and they would be agreed upon. Then at the end of the year they would apologise for not doing anything. (Interviewee no. 3)

Other schools were explicit about their inability or unwillingness to provide the required assistance to support the child:

They were like, there’s nothing we can do with her. That was basically it. There’s nothing we can do. (Interviewee no. 18)
In the following example, the parent reports that the child’s state school clearly refuses to assist her child as her learning difficulties were not sufficiently extreme to warrant funding:

So they [the school] had no interest at all in learning about her dyslexia. They then told me that because she wasn’t viewed as an extreme case of dyslexia, there would be no support for her at all, and we would have to go to a different school if we wanted to find that, because they didn’t have the funding to provide any help (Interviewee no. 5)

In the following extract, the parent notes that even though the diagnosis of dyslexia was obtained through an educational psychologist employed by the Department of Education, the school did not implement the recommendations:

ts they don’t get any extra support or help even if they’ve got that diagnosis through the education system anyway (Interviewee no. 17).

In contrast, a state school in regional Victoria which had worked cooperatively with the parent and assisted in the early identification of dyslexia was responsive to implementing the recommendations contained within the report:

Interviewer: Did the report make any recommendations about adapting things in the classroom for her?
Interviewee: Yeah.
Interviewer: How responsive are the school to doing it?
Interviewee: They’re good. I think they’re – they’re having – actually they’re having a training session. The whole school is having a training session with [specialist dyslexia teacher trainer] at the end of this month. (Interviewee no. 6)

This was a rare occurrence outside of the independent school sector.

Implementation of Remediation Strategies in the Independent School Sector

Children in the independent school sector had the benefit of the implementation of report recommendations:
Interviewee: I think there was recommendations [sic]. Yeah, there was definitely a page of recommendations.

Interviewer: They followed them?

Interviewee: I pretty much feel that they did. So I showed them the recommendations page. I met with the house dean and a special needs teacher support person. I sometimes meet with the counsellor and I’ve met with the head of senior school. (Interviewee no. 20)

Again, for a child attending an independent school the parent notes:

But [name of independent school has] been fantastic and wanting to understand Jona’s level of dyslexia, what areas he struggles the most in and how they can support him. (Interviewee no. 16)

There were varying degrees of parental satisfaction in relation to the implementation of report recommendations:

[Name of independent school] is not the be all and end all by any means, but they keep an eye on him. He won’t see the psychologist there but she keeps an eye on him but that’s a real – there’s a psychologist. There’s an individual needs teacher who keeps an eye on him. All the teachers are briefed. We still have occasion – or we still have problems from time to time, but I just feel that it’s managed and he had remediation in year 7 (Interviewee no. 12)

The mother’s assessment of the school’s resources and remediation is positive but not as glowing as the previous cases presented.

**Use of the Word “Dyslexia”**

A key theme that arose was the negation by teachers of the existence of dyslexia, and the controversy surrounding the use of the word “dyslexia”. There were several instances in which the use of the term dyslexia was directly challenged by teachers:

I continued with my own research and when I read this profile of a dyslexic child, I thought, my God, it’s just like reading my daughter. I said to the school, could she be dyslexic? They [the school] literally said, “we don’t use that term, we don’t believe – that’s a high-level term to
describe a whole range of disorders”. I sort of felt a bit, I suppose, disenfranchised (Interviewee 2)

The parent felt disempowered by this encounter. Similarly, another parent recounted that the teaching staff at her daughter’s primary school refused to acknowledge the existence of dyslexia and also negated the parent’s use of the word.

The school actually wouldn’t acknowledge that dyslexia actually existed. For about three years that was the case. We would go in there. We’d have meetings. We’d use the word “dyslexia”. They would contradict the word “dyslexia”. (Interviewee no. 3)

In exploring this issue further, this parent interpreted the school’s lack of willingness to acknowledge the existence of dyslexia and to name it as a lack of knowledge combined with a scarcity of resources:

Interviewer: Do you have a sense of why they didn’t want to use the word?
Interviewee: Yes, because they didn’t know what to do with it and they didn’t want to support it. No funding, no resources. It was really hard (Interviewee no. 3)

Similarly, a mother with a child in the Catholic education system (who is also a teacher in that system) hypothesised that the reluctance of teachers to use the word “dyslexia” was related to funding:

Interviewee: No, they didn’t say dyslexia at all. He also had – there’s this one – early in Grade 4 we had an audiological assessment, saying that he has auditory processing difficulties – not huge ones but for your ground issues. So we’d keep going back to his teachers and saying all of these things – on my mind I’m thinking that it was but no one would say the word. Also, I teach in the Catholic Education system ...

Interviewer: Oh, you’re a teacher?
Interviewee: Yes. They don’t recognise dyslexia. It’s almost a dirty word. It’s almost like they don’t recognise it because I think if they did they’d have to therefore put funding towards it. (Interviewee no. 15)
Below, another parent refers to her son’s primary school’s rejection of the word “dyslexia”:

Even though I’m quite knowledgeable, I’m not – do not accept – like, I’ve had to endure academic arguments about whether to call it dyslexia or not. It’s like I’m not here about the word – I’m here about ... doing something (Mother, Interview no. 9)

This parent imputes the school’s unwillingness to use the word “dyslexia” as the school’s reluctance to label children with a syndrome. She attributes this to education department policy:

Well, it’s getting back to that argument that you shouldn’t label children. I think it’s probably an issue at the Victorian education department. (Mother, interview no. 9)

In the next quote, the parent recalls that her child’s teacher dismissed the existence of dyslexia:

So yeah, the teacher just said, there’s no such thing as dyslexia. They didn’t know anything about dyslexia. She just needed to try. She’ll be right. (Interviewee no. 14)

In the following extract, a parent recalls that the teacher negated the child’s diagnosed dyslexia, reframing the child’s challenges as a temporary problem:

If I used the word “dyslexia” they would say, “oh look, the way that we look at it is that some children have problems reading; some have problems spelling. It’ll just click, it’ll just click.” I’m saying “you’re not getting it here”. (Interviewee no. 3)

Another parent with a child in the state school system acknowledged the problem but was mystified as to the reasons for the school’s aversion to using the word dyslexia:

Interviewee: it seemed to be almost like an aversion to using the word by any professional. So I just thought no one else is doing anything, I have got to do something.

Interviewer: What did you make of that aversion?
Interviewee: I couldn’t understand it. I don’t know whether there was a reluctance to use that as a label because the child would be stigmatised or because they didn’t understand it. I don’t know because it wasn’t really helpful because we all know it’s going to be a lifelong condition or maybe they don’t. I don’t know. Maybe there’s not enough awareness amongst the professionals. I’m really not sure why there was a real reluctance. (Interviewee no. 17)

The controversy surrounding the word “dyslexia” and the syndrome itself is not limited to schools and teacher. In the following instance, a parent disclosed that the word “dyslexia” is taboo in her family of origin:

I knew it was in our family. I don’t think we’d ever used the “dyslexia” word much but it was there. It was talked about, forgotten about, not really understood I think (Interviewee no. 12)

This parent also affirmed that this reluctance to acknowledge dyslexia had been transmitted to her son who also has a diagnosis of dyslexia. Throughout this interview, the parent referred to dyslexia as the “D word”:

actually I was locking horns a lot with Oscar and I thought he didn’t want to talk about the fact that he has some of these issues and hates the D word. (Interviewee no. 12)

The reluctance to use the word “dyslexia” extends to a psychologist from the Victorian Department of Education who diagnosed her son, Oscar:

The school, the primary school, were saying – a school psychologist saying – we think – oh sorry doing some assessments the WISC and the WIAT [Wechsler Individual Achievement Test] or whatever it’s called and then saying “we don’t actually use that word but it’s probably that, but he’s got this” … she was leaving and she said “look you really need to stay on the case with this”, but that’s probably the Education Department psychologist not wanting to use that word for whatever reason. (Interviewee no. 12)

This parent also referred to teachers at her son’s school who also do not wish to acknowledge dyslexia:
I’m dyslexic, my son has issues and I needed to help – I wanted to push the issue because there was a teacher there who said it doesn’t exist and they’re completely in denial in many ways and we wanted to start them on the journey. (Interviewee no. 12)

In contemplating the denial of dyslexia by her child’s school, another parent expressed her wish to be believed, acknowledged, understood and assisted:

What I would have liked is just to be believed, just to be understood, to say – just for them [the school] to say, “thank you for going and looking into that. Here’s what we know about dyslexia. Here’s what we can do”. (Interviewee no. 18)

Section 2: Summary

Parents identified that the lack of teacher training (pre-service and in-service) in relation to dyslexia resulted in a myriad of negative outcomes for children and their parents. Conversely, encountering teachers with training and an understanding of dyslexia was a positive experience for children and their parents.

Parents’ descriptions of their experiences indicated that a lack of teacher training in relation to dyslexia contributed to a range of deleterious consequences for children. These included negative labelling of children, punitive treatment, problems in understanding psychologists’ reports and a failure to implement strategies to assist with remediation. Additionally, the lack of teacher training was understood even more acutely by some parents who experienced teachers’ negation of the existence of dyslexia and the refusal to use the word “dyslexia”. In some instances, teachers expressed great sadness and frustration at their lack of knowledge in relation to dyslexia and expressed a desire to learn more about dyslexia in order to support students. The lack of teacher training, therefore, in some cases, appeared to disappoint teachers as well as children and their parents.

It was generally perceived by parents that the lack of teacher knowledge was compounded by a lack of resources in the state and Catholic school sectors. Parents responded very positively to the state school that had adopted a whole school approach by providing in-service dyslexia training to all its staff. This exceptional school illustrated the positive impact of greater awareness around
dyslexia and collaboration with parents. On the other hand, there were schools which demonstrated a lack of school leadership in relation to the treatment of children with dyslexia. In these cases, children’s experiences, both negative and positive, were largely dependent on an individual teacher’s experience, knowledge, training and beliefs about dyslexia. This means that children’s educational experiences and sense of wellbeing in the classroom varies, not only from year to year, but also from class to class, and even from one day to the next. In the absence of remediation provided by schools, the responsibility to support children’s learning needs and to determine pathways for remediation defaults to parents. Many parents felt that they were ill equipped to deal with this responsibility.

The pre-service and in-service training of teachers in relation to the signs of dyslexia, its various impacts and classroom remediation strategies, emerges strongly as a parental policy recommendation.

**Section 3: Parental Advocacy**

Advocacy was a strong theme that underpinned parents’ stories beginning in the pre-diagnosis phase of dyslexia and extending to many years post diagnosis. In every interview, parents made reference to their role in advocating for their child or children with dyslexia within the school environment. Parents’ experiences and feelings relating to their advocacy most commonly emerged unprompted by the interviewer as an integral part of parents’ stories. In the majority of cases it was mothers who assumed the advocacy role for their child.

A sense of the scope of the parental advocacy role is captured in this quote from a mother:

I mean it is the responsibility of the parent to care for their child and provide for them, but they shouldn’t have to find their own individual chaotic path through everything from diagnosis to support to then dealing with a system, say the education system, which has no proper ways for dealing with it, whether that be from policy at the school through to how they might educate their teachers, the whole thing. (Interviewee no. 12)
This illustrates the advocacy and leadership role this mother has taken in seeking a diagnosis, and advocating to negotiate supports for her son within the school environment. It also contains a reference to her role in assisting teachers to understand dyslexia and its implications and provides insight into the ongoing nature of the advocacy role of parents. Inherent in the quote above is a sense of injustice at the perception of the deficits inherent in the education system and the resultant responsibility this has placed on parents.

Parents’ advocacy activities arose from a sense of the injustice of the inequity and discrimination experienced by their children in the school system. A parent who moved her child from the state to the independent school system reflects on the state education system and the need for parents of children with differences to “fight for a right to an education”:

in that public forum in the primary school, I don’t know, there are amazing teachers, individuals, but I think the overarching culture is almost that you need to fight for your right for an education. Or that if you’re not the norm, forget it. So I feel like there’s some prejudice and it makes me really angry. (Interviewee no. 16)

The anger the mother expresses is clearly directed at the system rather than at an individual teacher or school.

The theme of “fighting for the right to an education” and the subsequent toll this takes on families arose in the narratives of other interview participants. A sense of burden and exhaustion is frequently conveyed in parents’ narratives in relation to their advocacy role:

the frustration of trying to get the kids assessed and then get the help that they need. Even when we had him finally found out, they said, this is only the beginning; you’re going to have to fight every day for him. I thought, oh yeah, once you get things in place it’ll be fine. But it’s so tiring and it’s so draining and it’s so unfair on the rest of the family (Interviewee no. 11).

In this next extract from the same interview, there is a clear indication of this parent’s sense of isolation and lack of guidance:
So I don’t know what else that we can do, other than just keep at them [the school] and at them and at them. (Interviewee no. 11)

A sense of tenacity coupled with hopelessness is conveyed by these words. The tenacity, energy and effort required by parents to advocate for their children is a clear theme. Many parents refer to having to “push” for their child’s rights within the school system. Some participants describe their advocacy as “pushing”, implying by the use of this word a sense of encountering resistance. At other times the word “driving” is used, highlighting their feelings of needing to lead the school to gain traction on the child’s learning needs. There is a very clear sense of burden depicted in the following quote which contains the terms “driving “and “pushing”:

It was me who was driving it. It was me who was pushing it along the way. I have driven the whole process. (Interviewee no. 8)

In the following illustration, the parent places an emphasis on “pushing”, giving the interviewer a sense of her burden as well as a sense of the resistance she encountered from the school:

I just know in Catholic education it’s just – so I just pushed and pushed and pushed and pushed because I wanted him to be looked after and not called lazy because that’s what I was getting. “Oh, he’s lazy, he’s disorganised.” I was just like “no!” (Interviewee no. 15).

In the following extract, the mother describes her perception of her advocacy role for her child as imperative. Both parents describe their advocacy for their child as “pushing”:

Mother: I mean we’ve been proactive because we have needed to be but you know nothing would have happened, I don’t think, unless we really had pushed it and fortunately the school that we’re at are a lot more responsive but still, like I suppose we’re in the second part of the year.

Father: So actually I’m pushing, it’s only because I’m pushing (Interviewees no. 7).
Implicit above is the concern that without active engagement and parental advocacy, the school system will not cater for their son’s learning needs. The importance of parental advocacy is evident in the perceptions of other parents, but is also reinforced by the advice of teachers in some instances. In the following context, a teacher encourages a mother to “push” (the school) to have her child tested by an Education Department psychologist. The role of advocate for the child is understood by the teacher as being the domain of the parent, not the teacher. The parent takes her cue from the teacher and describes her advocacy as “pushing”:

The teacher said, “push it”, because she said, “she won’t be seen as a high priority because there’s a lot more kids, because she’s a quiet girl, she’s a good girl. She sits in the corner and doesn’t say anything, so she will not be picked up”. So I had to push and push and push and push and then she got the education psychologist in. (Interviewee no. 14)

This teacher’s views regarding the need for this mother to insist her daughter be tested are congruent with the research relating to gender and the prevalence of dyslexia. Some studies suggest that boys who are perceived as disruptive to their classmates and teacher are more likely to be referred for diagnostic testing (Shaywitz et al., 1990; Chan et al., 2007). Although this teacher did not possess specific knowledge in relation to dyslexia, she sensed the child had an underlying problem that needed investigation. Her experience informed her that a quiet, well-behaved child will slip through the system without persistent parental advocacy:

But at least I got a teacher that actually said, something’s not right. But when I said to her, I think she’s dyslexic, and she said, well, I don’t know anything about dyslexia, but if you get the education psychologist to test. So I pushed with the vice principal and then I got her done. But yes, it did take a bit of nagging. (Interviewee no. 14)

Also of note is that fact that the mother describes her advocacy as “nagging”, a pejorative term commonly used to label female rather than male behaviour. Parents also reflected on their advocacy in relation to seeking extra support within the school. In the following instance, the mother recounts how she
assertively approached the school and requested extra support for her daughter and successfully received it for a short while:

Anyway, they said to us “well we’ve got a number of kids with high needs”. This was at [name of primary school]. She doesn’t fall in the category of needing any help. I said, “I don’t care whether she falls in the category of needing help – she needs to be able to read – it’s fundamental – you need to do something about it.” So they offered me [a] part-time aide, just for a very small period of time. That was I think for six weeks (Interviewee no. 5).

In the following extract, the mother recalls how she secured her daughter a place in the remedial Reading Recovery program:

But they said, “we’ve got x amount of places, we’ve got so many kids and unfortunately it’s worked out by age and she’s the youngest”. So I continued to agitate and eventually she got into the Reading Recovery program, sadly probably at someone else’s expense. But I felt that I really had to work hard. (Interviewee no. 2)

The parent’s comments reflect on the scarce resources available to assist struggling readers. She acknowledges that her advocacy secured her daughter’s entry into the remedial program at the expense of another child in need of assistance.

At times, the parental advocacy role was around securing extra assistance and tuition; at other times, the focus was on altering the classroom environment and expectations of the teacher to meet the needs and capability of the child:

I said to the teacher, please don’t give her those spelling words because she’s just obviously not coping. (Interviewee no. 20)

In the following example, a mother/teacher in advocating for her eldest child who attends an independent school, consciously designed and implemented a strategy to communicate with her child’s school:

I have email contact with all the teachers, so at the beginning of the year I write a report for them that says this is where my son is at with his learning. There’s three things on that report that I write. One is learning
strengths, [another is] learning weaknesses, and the other is how my son likes to learn. I submit that to all of his teachers at the beginning of every school year. They know from day one how to approach him, how to communicate with me, what my expectations are. I let them know if ever he is failing a subject or a subject area, I expect to know about it via email and that I do not want any surprises on any reports. I should have been informed well before it got to that point that there was an issue with a subject area. (Interviewee no. 13)

It is clear that this mother takes a leadership role to support her child’s learning and to direct the school to cater for his needs. The knowledge and confidence of this parent is exceptional amongst this cohort. In contrast, several parents referred to the challenge of having the confidence to take on the advocacy role:

I’m not really a very confident pusher. I don’t like to be confrontational. (Interviewee no. 3)

Similarly, another parent referred to her feelings of fear in approaching the school in relation to her child’s difficulties:

By that stage I was starting to make approaches to the assistant principal, who was also the welfare coordinator, and I was like a dog with my tail between my legs. Every time I went into her office I felt quite fearful because of what her approach would be. (Interviewee no. 2)

A second interviewee also refers to the confidence required to take on the parental advocacy role:

you’ve got to be fairly resourceful and pretty confident. … generally I’ve found at this school anyway but you’ve got to jump up and down a bit. (Mother, interview no. 7)

A mother who has experience as a teacher’s aide for children with disabilities recalls her views about her son’s struggles with literacy and his subsequent anxiety dismissed by a school psychologist:

No, you’re just a mummy, you don’t know what you’re talking about, I’m the professional. She was lovely, she was really nice, but I just said,
“You’re wrong” and she said, “No, I know what I’m doing.”
(Interviewee no. 11)

Conversely, at the other end of the spectrum there was an instance in which a primary school recognised that a mother had developed knowledge as a result of her own child’s experience, and referred another parent to her for advice. This was viewed by the first mother as an inappropriate and unprofessional relegation of school responsibility:

I find it interesting the fact that we’ve had to fight quite hard for the school to – like [name of another parent in this study] rang me one day and she was recommended from the school to ring me because she had a son with learning difficulties. I’m on the phone going, “I have no problems helping you at all, but I’m not an authority. I only know this from my own experience.”

I could not believe the school would recommend that people talk to me. It’s such a personal thing as well and quite emotional. I couldn’t believe it and I was actually really pissed with them, because I just spent my own time and money finding out what was going to help us and the school couldn’t even be bothered …

I sort of felt I’ve done all of this work and you guys can’t even be bothered, you know, just attending a few seminars on dyslexia and learning difficulties, or whatever you want to call it, to point us in the right direction. I thought what a joke. I take my job really seriously but I also take my children really seriously, yeah, so interesting. I learned a lot about myself too during that time. (Interviewee no. 16)

Balancing the Advocacy Role and the Relationship with the School

In the following example, a mother/teacher considers the difficulty she experiences in taking on the advocacy role for her child within the school. She discloses that her insider’s knowledge of the teacher’s negative perceptions of parents who advocate for their children inhibits her in this arena:

Interviewee: I know what they say about parents inside the staffroom, and it’s not attractive.
Interviewer: What do they say?
Interviewee: Oh, about the parents? Oh, the teachers are horrible about parents. They really oh, “so-and-so’s too precious” or
“so-and-so’s too this”, or “that mother just gets stressed out” or “they think we can do everything”. So it’s very hard ... in special ed. as well. It’s very hard to be your own advocate, for your own child. (Interviewee no. 1)

Several other parents remarked on the difficulty of finding the balance between maintaining a positive working relationship with the school and advocating for their child’s rights:

People say it’s your human right. You should be taking them [the school] to court, doing big things. Then how do you expect your child to have any relationship with the school if you’re doing things like that? It’s gone, hasn’t it? People say you can do these things, but you can’t. (Interviewee no. 3)

In the following example the mother refers to hiding her anger, highlighting her reluctance to jeopardise her relationship with the school:

I don’t know if we’ve been too soft with the school. We’re giving them everything that we can to get them to want to do something, but whether we’ve got to go in and be a little bit firmer and just say, “what have you done this week?” , or “what’s going to be done over the next term to help her?” … So it’s just trying to get some more support from the school. Have to try… [I] Just smile when I’m really angry at them. (Mother, interview no. 21)

Also inherent in the following quote from a mother is concern about a backlash if she advocates too strongly for her son:

I don’t want to upset anyone because I’m sure if you upset one, you get the whole school offside, which is understandable. (Interviewee no. 11)

In another example, a mother grappled with the difficulty of raising the issue of discrimination and maintaining an ongoing functional working relationship with the school. This parent (who has a background as a disability support person) was the only parent in this cohort to demonstrate knowledge of the existence of the DDA 1992.

I don’t know how you get across to the school, it’s against the law. If they don’t give him the means to learn, if they don’t provide him with
what he needs, they’re breaking the law, because it’s covered by the Disability Discrimination Act. But I don’t know how you say that to them. Like, stop breaking the law, do what he needs and stop making excuses. (Interviewee no. 11)

In the following extract, another parent (also with a background in disability education) reveals that one of the difficulties in advocating for her son is her lack of clarity about legislation, policy and the rights of people with dyslexia in the current social policy regime:

The question is how much can we rock the boat without the information behind us? You can jump up and down, but if you’re jumping and down on something that’s not valid you may find yourself jumping up and down until the cows come home. (Interviewee no. 1)

Another parent acknowledges the difficulties that dyslexia poses to the school and she also feels that her voice is not being heard by the school:

This is their [the school’s] first dyslexic child, so none of them have known really anything about dyslexia, but in saying that, they’re not listening to me, either. (Interviewee no. 11)

In some instances, parents’ advocacy relates to the treatment of their children and their concern for their child’s self-esteem, rather than remediation or educational issues. In the following situation, the child (in Grade 3) had been held back a year due to his lack of progress with literacy. He was told that because of his age, if he ran races against his classmates on the school’s sports day he would not be entitled to receive any ribbons. His mother recalls:

I kicked up a stink last year because then the sports teacher said to him, you can run with them but if you win, you won’t win any ribbons. … I just yelled out, “for goodness’ sake” – she thought I was yelling at her but I didn’t, I said “for goodness’ sake just give this kid a break, it’s not about competition” (Interviewee no. 4)

In the following extract, an interviewee reflects on the difficulty of advocacy and her sense of powerlessness in the absence of a clear framework of protection of rights and a central authority responsible for the provision of resources:
I suppose it’s the time constraint and the lack of power … There’s no-one saying to us there’s a group, because we’re not a group … there’s not that umbrella protection or umbrella resource to say actually, you’re entitled to this or you should be doing that (Interviewee no. 1).

The reflections contained in this quote highlight the difficulty of fighting on an individual level against a systemic or structural problem.

**The Scope of the Advocacy Role**

In this cohort of interview participants, all assumed the role of advocate for their own children, but amongst them there were four mothers who also assumed a broader advocacy role. This occurred in a variety of forums. Advocacy ranged from arranging a lecture for teachers at a child’s school to national political advocacy:

I’d organised a dyslexia talk for our primary school trying to push them along … I wanted to push the issue because there was a teacher there who said it doesn’t exist and they’re completely in denial in many ways and we wanted to start them on the journey. (Interviewee no. 12)

In the following example, a mother facilitated in-service training of the school staff by successfully lobbying the school principal for change:

Then Grade 3 I went to the school principal with a wad of research, information from England and other countries, America, Canada, but particularly the UK and how they have – articles I found in papers, research and all that stuff about how to make a classroom dyslexic-friendly. I actually said to the principal, “look, if my daughter was the only child in this school that was dyslexic, then I’d just leave it alone. It would be a family thing that we would just work on and support her with”. I said, “but if it’s 10 per cent of the population, you’ve got an awful lot of other kids in this school who are dyslexic and you’ve got teachers saying there’s no such thing”. (Interviewee no. 14)

Two mothers in this group who extended their lobbying efforts more broadly than for their own child and school, dedicated time to lobbying politicians at state and national levels:
I’ve just become an advocate for dyslexia because there’s so many people out there who are not. They don’t know and they cannot. They are exhausted at the end of the day. They can’t speak on behalf of somebody else. They can only get frustrated about the lack of support, they need support and they’re not getting support. (Interviewee no. 8)

I mean my perception is that Australia is this country that is – we are the lucky country, as far as I’m concerned. We have everything going for us. … it was like this disparity between what was possible and what was actually happening. I wasn’t prepared in this day and age to think we’re just really isolated, therefore that’s the reason. … So I got really furious. (Interviewee no. 13)

In addition to advocating for children, some mothers also empowered their children to advocate for themselves:

If he gets a substitute teacher and the substitute teacher turns around and tells him his writing is messy, he’ll say to them, “well I have dyslexia”. So I’m really trying to empower him because of the lack of knowledge. (Interviewee no. 15)

A woman who was instrumental in transforming the culture of her children’s school recalls her daughter’s first act of self-advocacy in Grade 4, aged nine:

I remember picking up Claudia on the first day at school and she came running up to me and she said, “Mum, I told the whole class I’m dyslexic”. I went, “oh”. I said, “oh”. It was really – it still moves me so much. (Interviewee no. 14)

The child’s initiative in relation to self-advocacy and public identification of her dyslexia inspired the mother to strengthen her advocacy role and she started a parent support group:

Then because she did that, then I started the support (parent) group. (Interviewee no. 14)

In the following extract, a mother who is a social worker by profession expresses a sense of failure and self-recrimination over not being more successful in her advocacy for her young son:
I think if I start to cry [it] would be [because] that’s … my greatest sense of failure is that in my work, I advocate for everyone but as a parent I feel like I’ve failed advocating for my child (Interviewee no. 4).

The criteria this mother is using to assess her success or failure in advocating for her child is unclear, however her sadness caused by her perceived failure at this point is evident. At another point in this interview the mother refers to her desire to participate in this research in order to effect change for her son and for others:

I want to be part of this [research] and hope that this might help educate our education system to help teachers understand what dyslexia is or learning challenges are and also to eventually get some more assistance. If there’s going to be some policy change, I don’t know, I’m not really quite sure. But if enough voices speak out (Interviewee no. 4).

Several other parents stated that their motivation to participate in this research was prompted by the hope that it would contribute to change and greater policy recognition:

We’re trying to reach the policy makers the way we can – that’s why I’m sitting here, to sort of get this recognised, and I think Australia’s probably behind a bit. (Father, interview no. 9)

I think we really are in a complete pickle in Australia with this. So I’m happy to support any research which may help to create understanding and change. (Interviewee no. 12)

Enmeshed with the desire for policy change is the altruistic hope that their contribution will help to prevent others from experiencing the hardships they have encountered:

I guess from my perspective on why I’m here today, is because Kate [interviewee’s spouse] told me about what you are doing. … there doesn’t seem to be the necessary help available, so if we can do anything so that one day somebody else cannot have the issues that we have, then that would be good. (Father, interview no. 21)
Peer Support and Advocacy

A small number of participants belonged to informal peer support groups for parents of children with dyslexia. These parent-led support groups have an unwritten charter of providing peer support. Additionally, some groups engage in political advocacy on occasion. An interviewee who initiated the formation of a parent support group in her local area explained her motivation:

I wanted to get something out there to the other schools. Because these other parents were saying that their schools were not listening to them at all. … So I spoke – I said, well, the group will be to support each other and just be a thing that mums – parents can get together and have a coffee and share ideas, to advocate to politicians and try and make change, and to raise awareness in our community. So to get other schools realising that this is an issue. It was just amazing. All the parents that got involved, it just is amazing. (Interviewee no. 14)

In the following quote, the parent refers to the emotional sustenance that she has gained from belonging to a support group:

I think without a doubt [the support group] was the most – and continues to be the most useful [support.] Just being exposed to a community of people, primarily women, who were going through the same thing. Being able to share and cry on one another’s shoulder was – I think for me it just – it all happened at the right time. (Interviewee no. 2)

This parent further elaborates that, in addition to the moral support she has received from other parents, the benefit of participating in the group has been practical:

I’ve suddenly been exposed to a whole range of tools that I may not have known were there previously. (Interviewee no. 2)

On the same theme of garnering both emotional and practical support from a parent support group, a mother comments:

That [belonging to a support group] was fantastic because at the time I was floundering in the dark on my own. (Interviewee no. 3)
In the following excerpt, the same parent reveals that she enrolled her child in the dyslexic-friendly primary school as a result of her involvement in the parent support group:

because of the support group, we’d found another local school that was actually being quite proactive and quite helpful, supported. So we jumped ship and moved to the new school. (Interviewee no. 3)

In the following case, participating in a support group provided the parent with information and a perspective on her daughter’s challenges:

Our support groups often – we have speakers come in, so that’s been invaluable. A lot of the time we don’t sit around going, oh, poor us, because, I mean, I look at the next person and think, gosh, I thought my daughter was struggling, but there’s always somebody worse off than you. (Interviewee no. 20)

Amongst this group of interviewees, there were some who were part of an online support group for parents:

Someone needs to take responsibility for this because we as parents and as the 200 or odd group of people who are on this Facebook page across the world, we don’t have a direction. We bumble along and then we feel guilt. Are we doing the right thing? Is this what we are supposed to be doing? We share information. … We try and help parents whose kids refuse to go to school because they’re being picked on at school. Because like my daughter – “oh no you’re dumb, you can’t read”. (Interviewee no. 8)

One parent who did not belong to a parent support group explained her wariness about joining one:

I’m too busy and actually I want to receive support. I’m not sure that I want to give support at this point in time. … I feel – I just feel so needy. That I’m – and I want help. (Interviewee no. 6)

Distinct from the parent-run and parent-led support groups are the information seminars run by some agencies. A parent who occasionally attended seminars hosted by a specialist agency with expertise in learning difficulties was
ambivalent about the benefits. She describes attending these seminars as a “double-edged sword”:

The only time I meet similar parents is when I go to the [name of a dyslexia association] meetings and that’s been good in terms of helping know what sort of resources are available and what other people are doing, but like I said, it can be a bit of a double-edged sword in that you can come away feeling a bit depressed because maybe your child hasn’t got any special talent. They do bombard us with statistics like how many of them end up in prison and suicide rates. (Interviewee no. 17)

These comments infer that, although the parent gained information as a result of her attendance, the meetings gave raise to anxiety. There was one other negative reflection on a support group. This related to the parent’s experience and perception of a dyslexia support group being a forum which parents attend and pay to hear expert guest speakers:

You’ve got different groups, and as I say, these – like parent-type groups, support-type groups. All they’re doing is organising different ones who will come up and give a lecture, and will come – and how to control your child, how to understand dyslexia, and come and pay $50 and sit and listen to it. You go and pay the money, and you sit there, and you don’t learn anything. You just learn a slightly different perspective, and at the end of the night well, okay, I’ve – where am I now? What do I do now? (Interviewee no. 10)

This parent’s comments reflect dissatisfaction with the costs of attending a support group meeting that did not meet his need for support and desire for direction in assisting his daughter. There were no other negative comments associated with support groups.

There was one parent who did not regularly attend a support group but stated that she wished there was a support group for children with dyslexia:

What I want to do too, like I want to set up in my dream time a support group where kids can get together who have it just to go oh, I’m not alone. (Interviewee no. 15)
Section 3: Summary

All parents in this research cohort felt compelled to assume an advocacy role for their child. Commonly this role was assumed by mothers. The advocacy role described consisted of advocating for their child’s rights to access remediation programs, resources, accommodation of their learning in the classroom environment, and rights for fair treatment in the context of activities such as sport and extra-curricular activities. Parents used the language of “fighting” for their children’s rights. They were motivated to advocate by a sense of injustice, inequity and discrimination within the state and Catholic school systems.

Multiple challenges associated with advocating for children’s rights were highlighted by parents. These challenges included overcoming a general lack of clarity about rights and legislation, summoning the confidence required to assume the advocacy role, juggling this role with other family responsibilities, and managing the fear of a backlash from the school.

Parents who were members of support groups spoke in very positive terms about the benefits accrued from this membership. They described gaining a sense of community and being able to share stories and freely express grief, sadness and frustration. In addition, they perceived support groups as being a source of information regarding schools and assistive technology, and a resource from which to garner ideas and collectively advocate. Information-sharing sessions with guest speakers organised by agencies received a mixed response. They were viewed by some parents as beneficial but by others as costly; on occasion they engendered a sense of fear and concern amongst parents when speakers discussed possible long-term negative outcomes for children with dyslexia.

Some parents assumed a public advocacy role in addition to their advocacy for their own child. The parameters of the public advocacy role varied from activity at their school and in the local community to state and national campaigns.
Section 4: Children’s and Parents’ Wellbeing

This section contains the interrelated findings of parental concerns for children’s self-esteem and wellbeing, and the emotional journey of parents. Children’s self-esteem and wellbeing are reported indirectly through the lens of their parents’ perceptions. They emerged as a major issue of concern for parents, and as a theme which threaded its way through each and every interview from outset to conclusion. Parents’ emotional journeys and wellbeing were impacted by their perceptions of their children’s wellbeing, but were also influenced by other factors, such as their interactions with the school, their sense of anger at the system which they perceive to have failed their child, a sense of burden, sadness and feelings of exhaustion, regret, guilt, remorse and fear relating to their child’s future.

Parental Concern about their Child’s Self-Esteem and Wellbeing

Parental concern about children’s low levels of self-esteem was prevalent in the majority of interviews. In some cases, parents felt that in addition to low self-esteem their child was suffering from depression and anxiety. In several cases, parents referred to their child’s experiences of being bullied by peers as contributing to the child’s low self-esteem, anxiety and depression. The topic of stigma associated with dyslexia also arose. Some parents described instances of their child’s reluctance or refusal to attend school, directly related to the child’s negative academic, and in some cases social, experiences at school.

In the following example, a mother describes her child’s low sense of self-esteem resulting from her sense of academic failure:

Probably by the end of Grade 3, beginning of Grade 4 she’d become aware of her own deficiencies and that she wasn’t up to the speed of her peers. I think probably they’d – that had been recognised in the classroom, as well, so we started having every morning tears and, “I hate school”, and “I’m stupid”. It really impacted her self-esteem.

(Interviewee no. 2)
The mother describes how her daughter’s negative self-image escalated over time causing the parent great concern:

By the end of Grade 4, really Iris was just – she was really depressed, she’d say horrible things about herself and reflect where she was against her peers and it was just – it was – yeah, I was really very concerned about her. (Interviewee no. 2)

The child in this case interpreted her unremediated symptoms of dyslexia, which manifested in failure to achieve academically, as a reflection of low intelligence.

Parents commonly expressed the sentiment that the impact of dyslexia on their child’s self-esteem was of much greater importance and much more concerning than their child’s academic progress:

Oh, I’d love to be able to get out there and tell people, this is real and it’s not just about the reading, the writing and the spelling, it’s the self-esteem and that was our – it’s probably still my biggest issue. (Interviewee no. 11)

In the following extract, another parent makes it clear that she would like more support for her daughter in relation to her literacy, but she also feels that she needs support in dealing with and understanding the interplay of dyslexia, anxiety and self-esteem:

I would like more support than the reading and writing bit. The reading and writing bit, it’s tricky but we’re managing. But it’s all the other stuff that’s what really I find very challenging. … yeah so I don’t know how linked anxiety and dyslexia are and I don’t know how linked her concentration is to her dyslexia. I imagine it’s very linked and the self-esteem stuff. (Interviewee no. 6)

In some cases, children’s distress and anxiety in response to school attendance was so severe that parents believed that school attendance was not in the child’s best interests:

But our biggest issue was his self-esteem, because he would vomit to go – not every day, but he would vomit. He would – nothing for him to be
awake still at two o’clock in the morning because he’s got school the next day. He would start – depending on what was going on, it might be Saturday afternoon – he would start worrying about school Monday morning. Every single solitary day he would cry, every day he would try to get out of it and it got to the point where we’d just say – he’d cry and I’d say, not sending him today, can’t do it. It got to the point I’d ring the school and say, he’s not coming in today. (Interviewee no. 11)

The child referred to above is nine years old. Similarly, the mother of another nine-year-old described his severe anxiety, stress and suicidal ideation as a result of his negative experiences at school:

So his self-esteem was so low he was rolling on the floor crying, saying I want to die. I don’t want to be here anymore. In the end I honestly believed that I was being a bad parent by sending him there every day. So we changed schools – I’m about to cry (Interviewee no. 3)

Other parents related experiences of their child’s suicidal ideation, depression and despair directly relatable to experiences at school. A mother described her concern for her daughter (then aged 11) who, post diagnosis of dyslexia, was attending a primary school which did not accommodate her learning needs. The child became very depressed:

So then in Grade 6 she [the child] just had a dreadful time at school and just hated it, hated school. She was looking very depressed and she told me she wanted to kill herself. So I went to this paediatrician, he wanted to put her on medication that took a long time to think … to come to terms with what – we tried everything else (Interviewee no. 19).

Later this mother described the cumulative effects of negative school experiences on her daughter, who at the time of this interview was aged 15:

every day after day after day, you can’t do what people are putting in front of you… She [the child] has almost been crushed. Her spirits just – her self-esteem and spirit is just so crushed. … She tries to keep a lid on it. But lately she’s been in sick bay all day sobbing and doesn’t know why, so the counsellor has rung me twice now and said, “there’s something going on” I said, “do you think I need to get her assessed for depression?” (Interviewee no. 19)
In other cases, parents described how their child struggles through the school day and releases their feelings of pent-up distress and frustration upon reaching the sanctuary of the family home:

He [the child] did come home from school crying. Sometimes he’ll hold it together at school, but as soon as he gets home he just hits the wall. (Interviewee no. 3)

When probed by the interviewer as to the source of her son’s distress, the mother attributed it to his feelings of inadequacy in relation to academic work, and in part to his feelings of embarrassment and sense of humiliation caused by his academic struggles:

Just humiliation I think from his peers. … and just that feeling of inadequacy and overwhelming anxiety. He doesn’t know what to do sometimes. Then he feels embarrassed to ask as well. So then, if he doesn’t know what to do, he either shuts down or panics. (Interviewee no. 3)

Similarly, in the following example the parent attributes her child’s low self-esteem and feeling of unhappiness to his sense of inadequacy and poor academic progress in comparison to his peers:

he [the child] was suffering in the classroom, he’s not making progress, his self-esteem’s going down the tube. … So by this stage Oscar was 18 months behind everyone. He was miserable, he was crying a lot at night. (Interviewee no. 12)

In the following account, a parent describes her child’s plummeting self-esteem in response to academic failure:

The teacher continued to give her those words [for spelling tests] and she may get one or two out of 20 or 10 or whatever it was. I don’t think it was 20. I think it might have been only 10 at that stage. But it caused her a huge – her self-esteem just went crashing. I just watched her go crashing, crashing, crashing. It was really awful. (Interviewee no. 20)

This quote above also provides insight into the impact of the lack of early identification of dyslexia, and a lack of teacher training in this field. The child was
undiagnosed with dyslexia at this stage, and despite the parent’s requests the child’s teacher would not agree to exclude her from spelling tests.

In several instances, parents referred to their child’s experiences of being bullied and socially ostracised by peers. A mother noted that she observed her daughter upon starting school change rapidly from a confident, happy kindergarten child to a school child with low self-esteem, after being subjected to bullying by her peers:

from this bright, chirpy, little girl, as soon as she started school, it just started coming out of her. She started to get bullied. She was coming home saying, “I’m dumb, I’m stupid.” We had to ban those words at our house. (Interviewee no. 14)

Bullying sometimes took the form of mocking by peers due to a perceived lack of intelligence; at other times it involved the exclusion of children with dyslexia from play in the playground:

Poor little Adele was running around by herself in the play and there was a whole heap of other issues about her social fitting because the kids in that school were so judgemental, such a narrow worldview that anything other than the norm was shunned. (Interviewee no. 7)

Bullying by peers occurred at all stages of the age spectrum. A mother reported that her daughter in year 9 (as yet undiagnosed but suffering from dyslexia) was bullied for being perceived as “dumb” by her school peers:

Anyway, so she managed – she battled through. She managed to pass year 7, year 8. Year 9 was a struggle. We had a lot of emotional stuff going on and some bullying and a lot of the kids were saying to her “you’re dumb – you’re really dumb”. (Interviewee no. 5)

As noted in the following extract, one challenge for children with dyslexia is that intelligence in the school context is judged by children based on their perception of proficiency in reading:

because the kids who read are in the top group [for reading] and so they’re seen as the smartest kids. It’s been a real eye-opener for me too, because this whole idea that if you’re good at reading, you’re smart. So
the reverse of that is, if you’re not good at reading, you’re not smart.
(Interviewee no. 14)

Congruent with this theme, a mother expands the concept and highlights the lack of reward in the academic environment for the qualities and strengths that her child does possess:

Be good at something. That’s the sad bit, the challenge I have is as a parent, what is my child good at. I don’t know. He’s a good human being, he’s caring, he’s respectful, insightful but there’s nothing in the school that says, hey you’re good at this. Do you know what I mean?
(Interviewee no. 4)

In some cases, parents attributed their child’s unhappiness and anxiety to their experiences at school. This sometimes resulted in their child’s refusal of or reluctance to attend school. School refusal ranged from mild resistance to attending school through to physical resistance and the expression of psychosomatic complaints. Mild resistance is illustrated in the following scenario, in which the child expressed a wish to stay home with her mother, engaging in practical tasks such as making tea for her mother and taking care of animals:

By the end of prep, she didn’t want to go to school. She told me she’s learnt enough and that she was happy to stay at home and just make me cups of tea. She wanted to live on a farm and we’d just have animals on a farm. (Interviewee no. 20)

In another example of unhappiness at school, a mother recalled how her child in the early years of primary school would ask her how many more years he would need to continue attending school:

Before he went to this new school he would ask quite regularly, “how many years is it till I can leave school?” I’m like, “you’ve got forever left”. (Interviewee no. 11)

An illustration of a child resisting school attendance with a psychosomatic complaint is visible in the words of this mother:

Oh, he’ll roll around on the floor in agony with stomach pains. This week it was a headache. We fight, we cajole, we bribe [laughs]. We do
everything. I’ve always said that if he could go to school seven days a week – as much as he hates school – it’s better than having a break from it because (Interviewee no. 3).

In the following example, a mother who encountered her son’s emotional and physical resistance (pre-diagnosis) to attending school also describes her own distress in response to this:

refusing, refusing to go to school. Having to drag him out of bed or drag him into the car. At times I remember he’d be hiding behind my car seat in the car. He would not get out. I’m going, you’ve got to get into class. He was in prep and I was just – that was heart-wrenching. Having to drag him into class was heart-wrenching. (Interviewee no. 14)

Post diagnosis and with her son attending a school in which the majority of teachers had undertaken dyslexia awareness training, this parent observes:

Look we still have – last Wednesday at nine o’clock, curled up in the corner of the couch saying school was stupid, I’m not going, I wish it didn’t exist. (Interviewee no. 14)

In the following case, a parent reflects on her child’s feeling overwhelmed by the amount and content of academic work both in class and given as homework. She recalls her son’s vivid explanation of this feeling:

I feel like they’ve got a shovel load of dirt and they’ve put it on top of me. Before I can get rid of that load of dirt, they put another load of dirt on me, so I can’t get rid of that and then they’re putting more dirt on me, mum, and I can’t breathe. (Interviewee no. 11)

This primary school aged child’s metaphor of being covered in suffocating dirt carries with it connotations of being buried alive.

Parents’ Emotional Journey

Strong and painful emotions were elicited as parents relayed their experiences in relation to their child’s dyslexia. From the emergence of their child’s symptoms of dyslexia to diagnosis and their child’s experiences at school,
distress was never far from the surface. Many memories of the journey evoked tears.

Chapter 3 contained findings relating to parental concern for their child’s struggle with literacy. Section 3 of this chapter highlighted parents’ feelings of distress as a result of observing their child’s anxiety and drop in self-esteem caused by experiences at school. Less evident in the findings up until this point, but a very strong theme, is parental sadness, feelings of exhaustion, regret, guilt, remorse and fear.

Tears were often shed during the interview process. There were very few interviews in which parents did not cry while telling their stories and experiences. It is not easy to capture in print the sense of sadness that permeated the interviews. However, an indication of this sadness is relayed in the following quote from a mother in relation to the child’s father who was also present at the interview. When prompted at the beginning of the interview to share their story of the journey of uncovering their child’s dyslexia, the mother observed the child’s father and asked:

Shall I tell? – because he’s going to cry. (Mother, interview no. 9)

The father, one of only four who participated in the interview process, wept audibly for the duration of the interview. The mother said she felt that the school’s treatment of their child and them had triggered her to experience an emotional “breakdown”:

I held my ground and it make me feel sick, and I actually had a breakdown two years ago. So I just thought the pressure was terrible, and I just felt – it’s just terrible to be a parent and they [the school] force you to have to defend your position to sit a test that everyone should sit.
(Mother, interview no. 9)

Here, the mother is referring to the state primary school’s attempt to stop the child sitting the in-school NAPLAN (National Assessment Program – Literacy and Numeracy) test.
Parents’ sadness and concern for their children, and an accompanying sense of burden, was evident in most cases. In the following example, a parent of two children with dyslexia describes her feelings of exhaustion caused by concern for her children and her ongoing efforts to support them emotionally and academically:

There are days where, as a parent, I’m debilitated by their dyslexia. I can’t function because I know – particularly with Sam – that he’s in such a pickle that I don’t function very well. Just knowing that he’s already not having a great day when he goes to school, and wondering what the day will bring; thinking I hope he’s having a good day. Also it’s exhausting as a parent. It’s exhausting trying to be positive, trying to help. (Interviewee no. 3)

Upon receiving confirmation of their child’s diagnosis, parents commonly expressed relief. Relief was often coupled with other emotions. Emotions such as remorse, regret, guilt and sadness frequently emerged in parents’ narratives. In the following example, although the parent refers to a sense of devastation at learning of her child’s diagnosis, this was coupled with a sense of relief at gaining insight into and understanding of why her intelligent child was struggling to learn:

I think even though I was probably devastated when we found out that he did have dyslexia, I was also relieved. We explained – we haven’t kept anything from him and we’ve said, “by knowing why, we can help you. You can learn, you’re not dumb”. It’s all come together since then, it’s all made sense. (Interviewee no. 11)

The diagnosis provided the parent with hope that her child would be able to learn with appropriate assistance, and hope that her child's low self-esteem would be boosted. Similarly, in the following example, the parent expresses relief that her child’s diagnosis of dyslexia will equip her with information. She hopes to find remedial assistance for her child and hopes that this will provide her with an avenue to repair her child’s diminished feelings of self-worth:

I suppose just a sense of relief, knowing that we have – it wasn’t just her not wanting to learn or us not helping her – not teaching her or spending time with her in the right way. I think it’s just relief that there are – do you know what I mean – like we have a diagnosis but we can now work
or try to work forward as much as we can to get her some help or help her and make her feel – some good self-worth. I think she was really feeling pretty deflated and self-esteem – her self-esteem is getting better because she has an understanding of it. (Mother, interview no. 21)

Also evident in this example, unlike the previous example, is an expression of relief at knowing that neither the child nor the parent is to blame for the child’s failure to master literacy skills. A similar sense of relief is expressed by a single father:

I feel guilty when she can’t read something, and when I try to get her to sound it out as best I understand – I haven’t been taught to teach. As best I understand, and I try to get her to sound the word out, and she can’t get it. Then I feel like I’ve let the side down. Then when they say well they are actually never going to get it, it’s not your teaching that’s the problem. (Interviewee no. 10)

Relief in some cases was accompanied with remorse and regret coupled with feelings of guilt and sadness at the length of time that a child remained undiagnosed:

I sat in the waiting room while she was being tested, reading through the literature, tears running down my face. It was heartbreaking for me to think that here I have a 13-year-old daughter who it had taken her all this time and imagine – what I was reading – all her angst, all her – she has eczema. I wondered how much of that – flare-ups and all that kind of thing – affected her, if it did at all. She’s very emotional. She’s a very emotional girl. … I’m divorced. I didn’t have a partner. (Interviewee no. 20)

A similar sentiment is more clearly expressed in the following example in which a mother reflects on her lack of understanding of her daughter’s difficulties pre-diagnosis. She recalls with regret how she responded in a harsh manner to her daughter’s struggles with memory and reading, presuming her difficulties to be behavioural rather than attributable to a neurological cause:

She could never ever remember instructions, and you’d try and tell her to do something, and she’d either do it back to front, upside down, around the wrong way, and I always put that down to well, she’s not listening,
In some cases, parents also described feeling self-blame for the child’s difficulties. In some instances, the initial delay in identification of dyslexia, coupled with the observation that their child was experiencing difficulties caused parents to be concerned about possible biological causes:

Oh we’re older parents’, maybe it’s something to do with that, it’s our fault. (Interviewee no. 11)

You look for things – was it because I got thyroid cancer, was that the reason why he has a challenge. You try to look for a reason for dyslexia. I actually blame myself. Was it the time that the pram rolled down the hill and he hit his head. I’m thinking that must have been it. (Interviewee no. 4)

Parents often expressed a feeling of fear for their child’s future. In some cases, parents were worried about the transition to the next year of primary school:

So yeah and she’s still – I’m actually already worried about what Grade 3 is going to be like. For me it’s like oh shit, you know Grade 2 it’s okay to be reading “the cat sat on the mat”. But geez it’s going to be hard for her when she gets to Grade 3. (Interviewee no. 6)

Frequently, parents were anxious about their child’s transition to secondary school. This common concern included how their child would cope with the increased workload, peers and self-esteem in the teenage years:

I worry, as I said earlier, at the pragmatic side of things in terms of how is she going to cope with the volume of homework. How her peers are going to view her, I think probably once they reach secondary school kids are more discerning in relation to each other’s academic process, so I worry about her self-esteem. She still occasionally has these little
landsides of self-doubt and loathing at times, which really disturbed me and I worry that that may continue to manifest and grow as she hits teenage years and adolescence. But that’s probably just a worry of most parents. (Interviewee no. 2)

A similar example of concern about a child’s approaching teenage years is expressed in this case:

I’ve been to forums where people have got up on podiums and told me that their kids have been supported by schools and then tell me that their 14-year-old daughter refuses to go to school anymore because they do not feel as though they’re supported by their school or their peers or their parents and now they’re reacting as teenagers … That’s my biggest fear. (Interviewee no. 8)

In other cases, parents feared that their children may drop out of school in their teenage years:

The scary bit? The road ahead? Quite often, for – well, I won’t say quite often because that’s a really big generalisation. Just from the students I’ve met over my years of teaching in various places, it’s a high level of school dropouts. ... I don’t know. I imagine he’ll get more frustrated. He’ll hate it more and more. He’ll get more and more behind and he won’t like it. (Interviewee no. 1)

Some parents also expressed fears about a child getting through school “intact” from a psychological perspective. Their long-term fears also centred on possible negative long-term physical and mental health outcomes as a result of stress. There was worry in relation to a potential low income and a trajectory into a life of poverty:

The main things I worry about for Matthew are how is he going to get through school intact without too much stress and anxiety and having a breakdown? How is he going to cope as an adult living independently? Is he going to be able to read forms and make sure he doesn’t get ripped off and hold down a job? What is the impact of long-term stress on his health into the long term? How is that going to impact on his health? (Interviewee no. 17)
Another parent worries:

As an adult, how will you [the child] afford to go to the dentist, because you’re going to be on a low wage, because you’re not going to – the assessment said she’ll never get past a Cert. III academically, which I found really hard. They put her on this VCAL [Victorian Certificate of Applied Learning] numeracy password already and I’m thinking, she’s going to be in a low income, possibly in a low income earning job, can she afford the health care she’s going to need? (Interviewee no. 19)

Section 4: Summary

Parents commonly expressed concerns about their child’s low self-esteem and, in some cases, manifestations of depression. In some cases, parents perceived school attendance as detrimental to the child’s welfare. Parents also relayed their distress in relation to incidents of bullying of their children by their peers. This included mocking, belittling, negative labelling and social isolation. Parents acknowledged their anxiety about their children’s welfare in the short, medium and long terms. This encompassed concern for their child’s academic achievements, feelings of self-worth and their physical and mental health. There was apprehension expressed for their children’s future ability as adults to participate in the workforce, and the possible repercussions of this on their future economic status.

Throughout the interview process it was clear that parents’ experiences of their journeys elicited a range of strong emotions. Parents commonly expressed relief when the child was diagnosed with dyslexia. This relief was multi-faceted. In some instances, it was a relief for parents to understand that their child’s resistance to learning was not a sign of oppositional or defiant behaviour. In other cases, the diagnosis relieved parents of a feeling of culpability as parents. In most cases, the feelings of relief contained the seeds of hope that insights into the cause of the child’s difficulty would enable them to seek appropriate remediation for their child. Parents also expressed optimism that a diagnosis might assist in raising their child’s self-esteem. In some instances, particularly when many years had elapsed between first noticing the symptoms of literacy difficulties and the
diagnosis, feelings of relief at the child’s diagnosis contained an overlay of guilt, self-recrimination and remorse, as well as anger at the school system.

Chapter Summary

This chapter has presented the findings from the interviews with a particular focus on the period following children’s diagnosis. It has addressed the challenges associated with the lack of teacher education in relation to dyslexia, the lack of investment in the remediation of children with dyslexia and the failure to implement accommodations for their learning in the classroom context. The chapter has focused on the difficulty and financial burden experienced by some parents, including the difficulty of obtaining resources to support children’s learning from a practical and financial perspective. These findings and the differences between the state, Catholic and independent school sectors, have been explored, highlighting issues relating to inequity and access to education. The reluctance to use the term “dyslexia” experienced by some parents from their child’s school has emerged as an issue. Parental advocacy and the difficulty and implications of this role in the current social policy environment have been presented. These themes have informed all three major overarching themes: the structural invisibility of dyslexia; the contestation over resources; and the third, overarching theme, inequity and the right to an education. The overarching themes are discussed throughout Chapters 7, 8 and 9 in relation to Fraser’s theory (1989) of need recognition, the status of dyslexia and the literature relating to dyslexia. The next two chapters contain the empirical findings from the survey.
CHAPTER 5:
QUANTITATIVE FINDINGS – NAVIGATING THE JOURNEY
PRE AND POST DIAGNOSIS

Introduction

The findings from the survey are presented over two chapters. Chapters 5 and 6 add a breadth of descriptive and quantifiable data to the existing knowledge base about the experiences of parents of children with dyslexia.

Chapter 5 is divided into three sections. Section 1 presents the data from the survey relating to respondents’ experiences before their child was diagnosed with dyslexia. It explores the route to diagnosis, examining how parents first noticed the signs of their child’s learning disability, who first noticed the signs, the prevalence of dyslexia in the respondent’s family’s and the professionals that respondents consulted to explore the observed difficulties the child was encountering. The data contain information on the average time frame that elapsed between the child’s first sign of difficulty and the diagnosis of dyslexia.

Section 2 contains findings in relation to respondents’ experiences following the diagnosis of their child. (There is also some reference to the pre-diagnosis phase.) It presents results findings relating to respondents’ feelings post
diagnosis, the level of ease or difficulty they experienced finding help for their child and their sense of being able to assist their child. Further, it outlines patterns in relation to the professionals that respondents consulted for assistance once their child was diagnosed and the challenges respondents experienced pre and post diagnosis.

Section 3 explores the topic of resources. It focuses on respondents’ expenditure pre and post diagnosis of their child. It outlines the amount respondents spent on assessment of their child’s challenges, the cost of funding support and the type of resources respondents wished to obtain for their children but were unable to due to financial constraints. It also examines the broader economic implications for respondents in relation to working arrangements and household expenditure.

Chapter 6 contains findings from the survey relating to respondents’ experiences in relation to the response of their child’s school to dyslexia, data on terminology and labels used by schools and respondents’ advocacy and recommended reforms.

Section 1: The Route to Diagnosis

Respondents (n = 403) were asked to recall the initial signs that alerted them that their child was experiencing difficulty (see Table 18). Multiple category selections were made by respondents resulting in on average seven signs that alerted respondents to their child’s difficulty. The most frequently cited sign (95.8%) was their child’s difficulty with reading, spelling or writing. Nearly three-quarters of respondents (73%) indicated that the comparison between their child’s grasp of literacy skills in relation to the child’s peers contributed to their concern for their child. Slightly fewer respondents (67.7%) indicated that in comparison to other children in the family there were signs of difficulty which caused concern. It was common for respondents (71%) to notice an unexplained gap between their perception of their child’s intelligence and their child’s achievement at school.
Table 18: Initial Signs of Dyslexia Before Diagnosis

<table>
<thead>
<tr>
<th>Dyslexia signs (multiple response)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child experienced difficulty with reading, spelling or writing</td>
<td>386</td>
<td>95.8</td>
</tr>
<tr>
<td>Child had difficulty keeping pace with school peers in relation to literacy levels</td>
<td>294</td>
<td>73.0</td>
</tr>
<tr>
<td>Unexplained gap between perception of child’s intelligence and child’s achievement at school</td>
<td>286</td>
<td>71.0</td>
</tr>
<tr>
<td>Compared to parent’s other child or children, this child had difficulty with literacy</td>
<td>273</td>
<td>67.7</td>
</tr>
<tr>
<td>Child had difficulty remembering lists or following instructions</td>
<td>235</td>
<td>58.3</td>
</tr>
<tr>
<td>Child had difficulty copying words from a board</td>
<td>206</td>
<td>51.1</td>
</tr>
<tr>
<td>Child was unhappy at school</td>
<td>186</td>
<td>46.2</td>
</tr>
<tr>
<td>Child had difficulty concentrating in class</td>
<td>185</td>
<td>45.9</td>
</tr>
<tr>
<td>Child experienced unusual levels of tiredness after a school day</td>
<td>180</td>
<td>44.7</td>
</tr>
<tr>
<td>Comments were made by teachers</td>
<td>145</td>
<td>36.0</td>
</tr>
<tr>
<td>Child showed physical symptoms of distress in relation to going to school (e.g. vomiting or other visible signs of anxiety)</td>
<td>122</td>
<td>30.3</td>
</tr>
<tr>
<td>Standard school testing (e.g. NAPLAN) revealed a problem</td>
<td>84</td>
<td>20.8</td>
</tr>
<tr>
<td>Child refused to attend school</td>
<td>82</td>
<td>19.9</td>
</tr>
<tr>
<td>Child displayed disruptive behaviour in class</td>
<td>58</td>
<td>14.4</td>
</tr>
<tr>
<td>Other signs</td>
<td>70</td>
<td>17.4</td>
</tr>
</tbody>
</table>

Difficulty remembering lists or following instructions was noted by 58.3% of respondents. In over half the cases (51.1%), respondents said that they noticed other signs of cognitive difficulty in the classroom such as their child’s difficulty copying material from the board. It was not established how respondents became aware of this sign. Possible explanations include that children informed their parents of this challenge or parents observed incomplete information or a lack of written material in children’s school books.
Close to half of the respondents (46%) indicated that their child’s unhappiness as a result of school attendance alerted them to the presence of difficulty. Respondents’ comments shed further light on this insight:

A happy, extremely bright and lively child became very depressed and withdrawn after school started. (Respondent no. 382)

In almost a third of cases (30.3%), children’s unhappiness in relation to school attendance was accompanied by physical symptoms of distress such as vomiting and other visible signs of anxiety.

Respondents’ written comments revealed that children’s distress in relation to their difficulty with grasping literacy skills was evident in response to homework tasks and not limited to school attendance. Homework, particularly reading aloud at home in the early years of school, was noted by several parents as a key indicator of the child’s difficulty:

High levels of angst doing homework and readers (Respondent no. 86)

My child would physically push away from a book when it was time to read, wouldn’t sit still, cried at the very thought of having to read and would throw tantrums. (Respondent no. 169)

Additionally, 45.9% of respondents observed that children had difficulty concentrating and 44.7% revealed that their child’s unusual level of tiredness at the end of a school day was a sign which concerned and alerted them to the child’s difficulty.

Thirty six percent of respondents reported that “comments were made by teachers” regarding signs of their child’s learning difficulties. The term “comments” is a broad term. It is clear from the data presented in Table 19 (n = 403) that 54 teachers (13.4%) made direct comments to parents about the child’s literacy difficulties. This suggests that the 22.6% of the “comments” reported by respondents in response to this question were comments of a generic nature, not pinpointing dyslexia as a possible underlying cause of the child’s difficulty.
Respondent’s responses to this question reveal that standard school tests, such as NAPLAN and the South Australian Spelling Test, did not commonly reveal children’s learning disabilities. Only 20.8% of respondents indicated that children’s test results contributed to their understanding that their child was experiencing challenges with literacy.

A child’s refusal to attend school was noted as an indicator of difficulty by 19.9% of respondents. In 14.4% of cases, respondents indicated that their child’s disruptive behaviour at school was a sign that the child was experiencing difficulties. It is not clear whether this was due to the fact that disruptive behaviour was not common, that disruptive behaviour was not reported to parents or that parents did not interpret reports of disruptive behaviour as signs of a possible learning disability.

Respondents were asked to identify who first noticed the signs that their child was experiencing difficulties in relation to literacy (see Table 19).

Table 19: Person Who First Noticed Child was Experiencing Difficulties in Relation to Literacy

<table>
<thead>
<tr>
<th>Person who first noticed child’s literacy difficulties</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>A parent or carer noticed child was struggling with literacy</td>
<td>286</td>
<td>71.0</td>
</tr>
<tr>
<td>A school teacher noticed and informed the parent</td>
<td>54</td>
<td>13.4</td>
</tr>
<tr>
<td>Child’s school report showed that the child was experiencing difficulties</td>
<td>12</td>
<td>3.0</td>
</tr>
<tr>
<td>A specialist teacher informed the parent</td>
<td>7</td>
<td>1.7</td>
</tr>
<tr>
<td>The child spoke to parent or their teacher about their difficulties</td>
<td>6</td>
<td>1.5</td>
</tr>
<tr>
<td>A psychologist informed the parent</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Testing highlighted that there was a problem</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Other</td>
<td>34</td>
<td>8.4</td>
</tr>
</tbody>
</table>

In the majority of cases (71%), parents or primary carers first identified early signs of the child’s dyslexia. Respondents indicated that in only 13.4% of
cases did teachers note the signs of the child’s difficulty and notify the parent. In 3.0% of cases teachers indirectly informed parents of the child’s difficulty via comments indicating concern in the child’s school report. This implies that in 97% of cases there was no concern expressed by teachers in the child’s report in relation to the child’s possible learning disability. In 1.7% of cases, specialist teachers noticed the child’s difficulties and notified the parent. The low number of specialist teachers’ comments to parents in the first instance may reflect the fact that the children are commonly referred to the specialist teacher by the classroom teacher. A classroom teacher who did this would in all likelihood have notified the parent of the need for remedial assistance with literacy.

It is noteworthy that a few respondents clarified that, although the child’s teacher first noticed the signs of dyslexia, this occurred in some instances in secondary school rather than primary school:

A teacher in year 10 after all her schooling suggested there may have been a problem. No one else noticed or mentioned it. (Respondent no. 272)

No teacher ever said a thing suggesting investigation including the Grade 6 home room teacher who was also the school’s “wellbeing officer”. Appears strengths masked weaknesses until Grade 8. (Respondent no. 372)

Although it was very rare for a child to self-report difficulties (1.5%) to their parents, it was slightly more prevalent than the discovery of difficulties via testing such as NAPLAN (0.5%) or via information provided by a psychologist (0.5%). The low number of psychologist notifications may be a consequence of the fact that a child is unlikely to be referred to a psychologist before a sign of difficulty or distress is noticed by a teacher, other professional or a parent.

The 8.4% of respondents who indicated “other” in response to this question referred to an occupational therapist (Respondent no. 36), speech therapist (Respondents no. 44 and 355), a parent helper in the child’s classroom (Respondent no. 32), a family friend (Respondent no. 363) and a grandparent.
It was a mix of the school teacher and we as parents had noticed. He always had very little interest in reading (Respondent no. 246)

In the following case, it was the parents combined with a range of professionals within and external to the school:

Initially my son’s teacher punished him for being slow finishing his work by collating all the unfinished work and making him complete it at the end of the week whilst his classmates played outside. I was mortified and saddened. This was in Grade 1!! He would get really upset. I pushed the school for extra help and the remedial teacher who happened to be the vice principal took him on even though she said there was no space for him. Anyway she was the first person to mention a tracking issue. We then had his eyes checked and the wonderful optometrist did this extra assessment on him and said he should see a psychologist for an educational assessment. (Respondent no. 365)

Inherent in this parent’s quote is that it is the significance of the interpretation of the signs of the child’s difficulty which is of key importance. The teacher who noted signs of the child’s difficulty responded in a punitive manner rather than with further enquiry. Parental advocacy, direction from a remedial teacher and assessment by an optometrist led to referral to an educational psychologist.

Respondents (n = 403) were asked whether they consulted with any professionals before they became aware that their child had dyslexia, for example audiologists, optometrists or speech therapists. They were given the option of answering “yes” or “no”. Data which had emerged from the interviews indicated that the route to diagnosis was often circuitous, time consuming and expensive. This survey question was asked in order to gain further insight into the pathway to diagnosis. The majority of respondents (80.6%) indicated “yes” that they had sought help from professionals. Those who answered “yes” to this question were directed to a further question asking them to indicate from whom they sought help.
and advice. The results are represented in Table 20. The 19.4% who indicated “no” were not directed to the further question.

Table 20: Professionals that Parents or Carers Sought Help or Advice from Before Diagnosis

<table>
<thead>
<tr>
<th>Professional (multiple response)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s teacher</td>
<td>259</td>
<td>80.4</td>
</tr>
<tr>
<td>Optometrist</td>
<td>211</td>
<td>65.5</td>
</tr>
<tr>
<td>Audiologist external to child’s school</td>
<td>149</td>
<td>46.3</td>
</tr>
<tr>
<td>Special education or reading recovery teacher at child’s school</td>
<td>143</td>
<td>44.4</td>
</tr>
<tr>
<td>Principal of child’s school</td>
<td>99</td>
<td>30.7</td>
</tr>
<tr>
<td>Speech therapist external to child’s school</td>
<td>98</td>
<td>30.4</td>
</tr>
<tr>
<td>Educational psychologist external to child’s school</td>
<td>90</td>
<td>28.0</td>
</tr>
<tr>
<td>General practitioner</td>
<td>88</td>
<td>27.3</td>
</tr>
<tr>
<td>Education psychologist at child’s school</td>
<td>74</td>
<td>23.0</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>57</td>
<td>17.7</td>
</tr>
<tr>
<td>Speech therapist at child’s school</td>
<td>54</td>
<td>16.8</td>
</tr>
<tr>
<td>Special education teacher outside child’s school</td>
<td>52</td>
<td>16.1</td>
</tr>
<tr>
<td>SPELD Victoria</td>
<td>43</td>
<td>13.4</td>
</tr>
<tr>
<td>Specialist medical doctor</td>
<td>40</td>
<td>12.4</td>
</tr>
<tr>
<td>Alternative health practitioner</td>
<td>34</td>
<td>10.6</td>
</tr>
<tr>
<td>Irlen clinic</td>
<td>31</td>
<td>9.6</td>
</tr>
<tr>
<td>A friend with a child with dyslexia</td>
<td>16</td>
<td>5.0</td>
</tr>
<tr>
<td>Dyslexia support group</td>
<td>10</td>
<td>3.1</td>
</tr>
<tr>
<td>Audiologist in child’s school</td>
<td>8</td>
<td>2.5</td>
</tr>
<tr>
<td>Neuropsychologist</td>
<td>7</td>
<td>2.2</td>
</tr>
<tr>
<td>Health centres</td>
<td>6</td>
<td>1.9</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>5</td>
<td>1.6</td>
</tr>
<tr>
<td>Social worker in child’s school</td>
<td>4</td>
<td>1.2</td>
</tr>
<tr>
<td>Social worker external to child’s school</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Other</td>
<td>43</td>
<td>13.4</td>
</tr>
</tbody>
</table>
Responses to this question \((n = 322)\) reveal that on average parents consulted five professionals or others with dyslexia-specific knowledge (e.g. friends, dyslexia support group) to seek help before a diagnosis of dyslexia was confirmed. In the majority of cases (80.4%), respondents consulted teachers. Special education teachers or reading recovery teachers were consulted in 44.1% of instances, and special education teachers external to the school were consulted by 16.1% of respondents. Respondents consulted their child’s school principal in 30.7% of cases. The data reflect that 553 teachers (including classroom teachers, principals and special education teachers) were consulted for advice by 322 respondents. This demonstrates that in this study, teachers were the most likely professionals to be approached by parents for help and support in understanding the challenges that their children with undiagnosed dyslexia were experiencing.

Optometrists were consulted in 65.5% of cases. (Respondents’ notes in the category “other” indicate that respondents consulted general optometrists as well as specialist behavioural optometrists and educational optometrists.) This suggests that respondents investigated their children’s eyesight to ascertain if their difficulties with reading were related to poor eyesight.

Educational psychologists were consulted in relation to children’s difficulties by 51% of respondents prior to their children receiving a diagnosis. A slightly lower number of educational psychologists (23.0%) were consulted within the child’s school context compared to the higher number of educational psychologists (28%) who were consulted externally to the school. A consultation with a neuropsychologist (2.2%) was much less common.

In seeking to understand children’s literacy difficulties, respondents reported consulting audiologists in slightly less than half the cases (48.8%). The overwhelming majority of audiologists consulted were external to the child’s school (46.3%). Audiologists within the child’s school context were much less frequently consulted (2.5%), possibly reflecting the lack of availability of services from audiologists within the school context. Similarly, close to half of the cohort of respondents (47.2%) reported that they consulted speech therapists. The
majority of speech therapists (30.4%) were consulted external to the child’s school, almost double the rate of speech therapists consulted within the school’s context (16.8%). Respondents sought assistance and advice from occupational therapists in 17.7% of cases.

Respondents reported seeking advice from general medical practitioners (27.3%). They were referred by general medical practitioners to specialist medical practitioners in 12.4% of cases. This suggests that the general medical practitioners who made the referral to specialists were unsure how to interpret the signs of the child’s learning disability.\(^9\) It is unknown whether general practitioners also suggested to respondents that they consult other professionals, such as psychologists.

The not-for-profit (fee-for-service) dyslexia specialist organisation, SPELD Victoria, was approached for support and advice by 13.4% of respondents prior to the child’s diagnosis. Additional comments revealed that one respondent sought help from another dyslexia association, ADA. Additionally, four respondents enrolled their children in commercial remedial assistance centres that offer generic programs for children with academic difficulties.

Data from this survey demonstrate that, in an effort to understand their child’s difficulties, 10.6% of respondents sought assistance from alternative health practitioners such as naturopaths and kinesiologists. This occurred at a slightly higher frequency than consultations with Irlen\(^{10}\) clinicians (9.6%) who diagnose visual processing disorders associated with dyslexia. The low consultation rate of Irlen practitioners may be a result of several factors. One contributing factor may be that if respondents were unaware of the possibility that their child has dyslexia, they would not follow up specialist assistance associated with dyslexia. Additionally, Irlen syndrome (also known as Meares–Irlen syndrome) has been

---

\(^9\) In the Australian context, specialist medical practitioners can only be consulted following a referral from a general medical practitioner.

\(^{10}\) Irlen clinics test for visual perception difficulties or visual processing difficulties. Irlen practitioners claim that Irlen syndrome affects 15% of the general population and 50% of those with reading disabilities (www.irlenclinic.com.au).
the subject of controversy and scepticism reflecting a lack of research evidence in relation to its legitimacy as a syndrome (Crabtree, 2011, p. 182).

Respondents sought the expertise of physiotherapists in 1.6% of cases and approached health centres for support in 1.9% of cases. Health centres employ multi-disciplinary health teams, consisting of for example, nurses, doctors, social workers, speech therapists, psychologists and occupational therapists. It is therefore unclear which category of professional parents consulted within the context of health centres.

Of relevance to this study is that respondents rarely consulted with social workers, either in school (1.2%) or external to the school (0.3%). Social workers emerged from this study as the least likely of all professionals to be consulted by respondents. Respondents were more likely to approach a friend with a child with dyslexia (5.0%) than consult a social worker. Evidence presented in Chapter 1 of this thesis highlighted the lack of social work engagement with dyslexia in practice, research and the policy field. Therefore, in light of this knowledge it is unsurprising that very few respondents consulted with social workers. However, reflecting on the data presented in Table 18 which demonstrated that close to half of respondents (n = 403) indicated that they noticed signs of their child’s distress as a result of school attendance, it is noteworthy that social workers were not consulted with higher frequency.

In summary, the circuitous route parents embarked on to explore their children’s learning disability involved engagement with an average of five professionals before a diagnosis of dyslexia was provided. The costs associated with this journey, and the parents’ feelings about the route to diagnosis, are presented in subsequent tables in this chapter.

Respondents (n = 403) were asked to give an approximate indication of how old their child was when the first signs of dyslexia became apparent (see Table 21). The mean age was 5.86 years (SD 1.68, LL 5.69, UL 6.02). Respondents (n = 396) indicated that the age of the child when they were formally diagnosed or assessed as having dyslexia was 8.67 years (SD 2.24, LL 8.46, UL 8.90). This demonstrates a gap of 2.81 years (approximately three school years).
between the parents’ initial concerns for the child and obtaining a diagnosis of dyslexia.

Table 21: Child’s Age at Appearance of First Signs of Dyslexia and Age at Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis stages</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>LL</th>
<th>UL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at appearance of first signs of dyslexia</td>
<td>403</td>
<td>5.86</td>
<td>1.68</td>
<td>5.69</td>
<td>6.02</td>
</tr>
<tr>
<td>Age at formal diagnosis of dyslexia</td>
<td>396</td>
<td>8.67</td>
<td>2.24</td>
<td>8.46</td>
<td>8.90</td>
</tr>
</tbody>
</table>

Note. CI = confidence interval, LL = lower limit, UL = upper limit.

The Prevalence of Dyslexia in the Family of the Respondent

Respondents were asked to indicate if anyone in their family (in addition to the child referred to in the survey) has been diagnosed with dyslexia or displays symptoms of dyslexia (undiagnosed dyslexia).
Table 22: Child’s Family Members with Suspected or Diagnosed Dyslexia

<table>
<thead>
<tr>
<th>Dyslexia in the family (multiple response)</th>
<th>n (n = 403)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s other biological parent may have dyslexia but has never been diagnosed</td>
<td>133</td>
<td>33.0</td>
</tr>
<tr>
<td>Child’s aunt or uncle has suspected or diagnosed dyslexia</td>
<td>92</td>
<td>22.8</td>
</tr>
<tr>
<td>No one in the family has suspected or diagnosed dyslexia</td>
<td>83</td>
<td>20.6</td>
</tr>
<tr>
<td>Child’s grandparent has suspected or diagnosed dyslexia</td>
<td>78</td>
<td>19.4</td>
</tr>
<tr>
<td>Child’s parent responding to questionnaire may have dyslexia but has never been diagnosed</td>
<td>56</td>
<td>13.9</td>
</tr>
<tr>
<td>Child’s first cousin has suspected or diagnosed dyslexia</td>
<td>54</td>
<td>13.6</td>
</tr>
<tr>
<td>Child’s younger sibling has suspected or diagnosed dyslexia</td>
<td>29</td>
<td>7.2</td>
</tr>
<tr>
<td>Child’s other biological parent has diagnosed dyslexia</td>
<td>24</td>
<td>6.0</td>
</tr>
<tr>
<td>Child’s older sibling has suspected or diagnosed dyslexia</td>
<td>17</td>
<td>4.5</td>
</tr>
<tr>
<td>Child’s parent responding to questionnaire has diagnosed dyslexia</td>
<td>10</td>
<td>2.5</td>
</tr>
<tr>
<td>Other</td>
<td>35</td>
<td>8.7</td>
</tr>
</tbody>
</table>

Many researchers argue strongly that there is a genetic link to dyslexia (Pennington, Gilger, Pauls, Smith, Smith & DeFries, 1991; Snowling et al., 2003). The interplay of genetics and environmental factors remains under scrutiny (Snowling et al., 2003), however there is evidence from multiple studies that approximately a third of children with dyslexia have a parent with symptoms of dyslexia (Wood & Grigorenko, 2001). A study found that approximately 31% of children with either one or two parents with dyslexia are identified as having a reading difficulty by their school (Wood & Grigorenko, 2001). This figure doubled to (62%) when formal diagnostic tests were carried on the sample group (Wood & Grigorenko, 2001).

Approximately one third (33.0%) of respondents (n = 403) indicated that they believe that the child’s other biological parent may have dyslexia but has never been formally diagnosed. Of the respondents, 13.9% believe they have
symptoms which may indicate undiagnosed dyslexia. The percentage of respondents with diagnosed dyslexia is 2.5%. A slightly higher percentage of respondents, 6.0%, indicated that the child’s other biological parent has been diagnosed with dyslexia. These figures indicate that it was more likely for the parent without suspected or diagnosed dyslexia to complete this survey than the parent with suspected or diagnosed dyslexia.

The combined percentage of parents in the study who have either diagnosed dyslexia or suspected dyslexia is 55.4%. Additionally, the figures reveal that amongst the parents in this cohort, 46.0% believe that they or their partner has suspected, undiagnosed dyslexia. This possibly reveals a hidden population of adults with undiagnosed dyslexia.

In 20.6% of cases, respondents indicated that there was no dyslexia (diagnosed or suspected) evident within the family prior to their child’s diagnosis. A marginally higher number of respondents (22.8%) indicated that the child’s aunt or uncle had suspected or diagnosed dyslexia and 19.4% indicated there was a grandparent in the family with suspected or diagnosed dyslexia. There were 13.6% of respondents who stated that their child had a cousin with diagnosed or suspected dyslexia. In 7.2% of cases, the respondent indicated that a younger child in the family has suspected or diagnosed dyslexia. In 4.5% of cases, respondents indicated that an older sibling of the child referred to in the survey has diagnosed or suspected dyslexia.

There were 8.7% of respondents who chose the category “other” (to indicate a family member not listed in the question). In the comments related to this question, respondents provided information relating to other family members who may have suspected or diagnosed dyslexia, for example second cousins, great-uncles, half-siblings and, in some cases, family members on both parents’ sides of the family. In summary, this question found that in all but 20.6% of cases, there were patterns of dyslexia in the respondent’s immediate or extended family.
Section 2: Navigating the Journey Post Diagnosis

Table 23 displays results from a question seeking information about the respondent’s feelings upon confirmation of their child’s diagnosis of dyslexia. Respondents were provided with a list of feelings from which to select their answers.

Table 23: Feelings of Respondents Post Diagnosis

<table>
<thead>
<tr>
<th>Feelings (multiple response)</th>
<th>n (n = 387)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relieved</td>
<td>248</td>
<td>62.6</td>
</tr>
<tr>
<td>Worried</td>
<td>166</td>
<td>41.9</td>
</tr>
<tr>
<td>Guilty for not realising the difficulty earlier</td>
<td>155</td>
<td>39.1</td>
</tr>
<tr>
<td>Anxious</td>
<td>131</td>
<td>33.1</td>
</tr>
<tr>
<td>Hopeful</td>
<td>116</td>
<td>29.3</td>
</tr>
<tr>
<td>Upset</td>
<td>106</td>
<td>26.8</td>
</tr>
<tr>
<td>Angry</td>
<td>69</td>
<td>17.4</td>
</tr>
<tr>
<td>Distressed</td>
<td>68</td>
<td>17.2</td>
</tr>
<tr>
<td>Disappointed</td>
<td>44</td>
<td>11.1</td>
</tr>
<tr>
<td>Confused</td>
<td>39</td>
<td>9.8</td>
</tr>
<tr>
<td>Hopeless</td>
<td>34</td>
<td>8.6</td>
</tr>
<tr>
<td>Curious</td>
<td>31</td>
<td>7.8</td>
</tr>
<tr>
<td>Guilty for passing this on to the child</td>
<td>26</td>
<td>6.6</td>
</tr>
<tr>
<td>Shocked</td>
<td>24</td>
<td>6.1</td>
</tr>
<tr>
<td>Surprised</td>
<td>15</td>
<td>3.8</td>
</tr>
<tr>
<td>Disbelieving</td>
<td>11</td>
<td>2.8</td>
</tr>
<tr>
<td>No specific feeling</td>
<td>10</td>
<td>2.5</td>
</tr>
<tr>
<td>Ashamed of my child</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Other</td>
<td>112</td>
<td>28.3</td>
</tr>
</tbody>
</table>
On average, respondents \((n = 387)\) indicated that there were three key feelings that arose for them in response to their child’s diagnosis: relief, worry (or anxiety) and guilt. Most common was a feeling of relief (64.1%) on receiving the child’s diagnosis. In the comments sections, many respondents expanded on their feelings of relief. Two subthemes emerged:

The feeling was a combination of relief and hope. We felt that now we new [sic] what was going on we could put strategies in place to support our daughter. (Respondent no. 142)

Relieved that there was a reason, something to work with ... A starting point. Since diagnosed he has coped better. (Respondent no. 269)

Relief was associated with the hope that a diagnosis would enable the child to receive appropriate support and remediation. The second subtheme to emerge was relief at receiving validation:

It is both a relief and sadness to find your child has a specific learning difficulty. It is a relief because it makes sense, makes it not anyone’s “fault”, it restores some faith in your instincts which have been telling you all along that something “more” was going on here for your child when teachers/experts keep telling you are just an overly ambitious middle-class parent who can’t accept their child for who they are. But it is hard to realise and accept this is something your kid will have to struggle with. You don’t want that for them. (Respondent no. 341)

It was commonly expressed by respondents (42.9%) that they felt worried upon receiving their child’s diagnosis. Additionally, 33.9% of respondents indicated that they felt “anxious”. When combining these two feelings, which can be classified as similar along a continuum of severity, approximately three-quarters (76.8%) of respondents felt either “worried” or “anxious”.

A high percentage of respondents (40.1%) expressed a sense of guilt for not realising earlier the root cause of their child’s difficulties. In the “other” section, respondents elaborated on this feeling, elucidating that guilt arose from respondents’ perceptions of their lack of timely advocacy and the provision of early intervention and remediation for their child. Accompanying this guilt was remorse expressed by respondents for their insensitive and occasionally punitive
treatment of their child resulting from misunderstanding the child’s struggle with literacy. Failure to grasp literacy skills was sometimes confused with lack of application or with misbehaviour:

It is also easy to blame yourself for not pushing harder sooner on your child’s behalf, and for all the shitty things you may have said to your kid about reading along the journey, when you didn’t know it wasn’t because they weren’t trying or paying attention or whatever. I used to get really angry with my son for not being able to look at the page or not being able to recognise a word like “the” that he had just read in the previous sentence. (Respondent no. 341)

Guilt for passing on the genetic predisposition for dyslexia was much less commonly expressed by respondents; it was cited by 6.7% of respondents. Results presented in Table 22 reveal that of the 403 respondents who completed the survey, 13.9% of respondents suspected that they may themselves have undiagnosed dyslexia and 2.5% had diagnosed dyslexia. Those with a clearly identified diagnosis of dyslexia thus constitute a very low percentage of respondents. Therefore, the number of respondents who expressed guilt for the involuntary act of passing on genetic material could be considered reasonably high.

Close to a third of respondents (30.0%) expressed feeling “hopeful” upon obtaining their child’s diagnosis. Conversely there were 8.8% of respondents who reported that they felt “hopeless” upon learning of their child’s diagnosis.

Respondents expressed feeling “upset” upon learning of their child’s dyslexia in 27.4% of cases. There was a subgroup of respondents (17.6%) who indicated that they felt “distressed” which can be classified as being further along the same continuum as those who felt “upset”. This indicates that close to half of the respondents (45%) felt either upset or distressed upon receiving their child’s diagnosis. It is unclear whether respondents felt upset as a result of not obtaining the diagnosis earlier, or because of the difficulties the child may encounter or because of difficulties experienced by the respondent. This reflects the difficulty of obtaining depth when measuring a qualitative phenomenon embedded in a quantitative survey instrument. It highlights the frequency of feeling but not the
underlying cause. This is somewhat mitigated by the fact that 112 respondents (out of 396 respondents) chose to elaborate on their answers to this question in the comments section.

There was a subset of respondents (17.8%) who indicated that they felt “angry”. Many of these respondents chose to expand on and clarify their feelings of anger in the comments section:

Angry that my concerns were ignored. I had brought it up with his paed [paediatrician] when he was eight and I was blown off. (Respondent no. 40)

Angry that it had taken so long to be recognised in [the] school system. (Respondent no. 71)

I was very angry that the teacher didn’t listen to me when I expressed my concerns to her “your [sic] an over reacting parent and comparing your children” was her response to my concerns!! (Respondent no. 72)

Respondents clarified that their “anger” resulted from treatment of the child, and sometimes of themselves, by the school or other professionals, the dismissal of parental concerns for their child and the delay in receiving a diagnosis.

In 11.4% of cases respondents expressed that they felt “disappointed”. In some cases, comments clarified that this sense of disappointment was related to the failure of the education system or school to identify and support their child in a timely manner. This is the same sentiment expressed by many respondents who felt “angry”:

Not disappointment in my child more in the educational system in Australia. (Respondent no. 52)

Disappointed that education professionals did not engage in appropriate dialogue. “Blaming conversation” accusing my son to be “lazy” ...

Dyslexia poorly understood by professionals. What hope for parents and child. (Respondent no. 64)
There were less commonly occurring emotions indicated by respondents such as “confusion” (10.1%), “curious” (8%), “shocked” (6.2%), “surprised” (3.9%) and “disbelief” (2.8%). A small number (2.6%) of respondents indicated that they did not have any specific feelings associated with the diagnosis of their child. There was a respondent (0.3%) who indicated that they felt “ashamed” of their child for being diagnosed with dyslexia.

A large number \((n = 112)\) of respondents chose to expand on their feelings in the comments section. The most common themes to arise in the respondents’ comments in answer to this survey question was that respondents felt “frustrated” upon receiving their child’s diagnosis:

Frustrated with the Education Department for not helping. (Respondent no. 124)

Frustrated because I had suggested at school for years that my child was struggling and everyone kept saying she was ok. It was only when she was in year 8 and she was becoming increasingly upset that despite trying really hard at school she was not achieving good school results that I persuaded her to get an assessment done by an educational psychologist. (Respondent no. 207)

I was frustrated that it had taken so long to get a diagnosis. During the time it took to get a diagnosis, my son believed that he was stupid. His self-confidence suffered and he stopped enjoying school. It then became an uphill battle to get him to once again believe in himself. (Respondent no. 255)

The frustration reflected in these and other respondents’ comments is related to the length of time to reach a diagnosis, the lack of knowledge about the signs of dyslexia within the school environment, the subsequent lack of support for the child and the damage that the invisibility of dyslexia within the school environment caused the child from the emotional and educational perspectives.

Of note amongst the 112 reflections noted in “other” section to this question were two positive comments. One respondent provided the comment “empowered” (Respondent no. 149). Similarly, another respondent reflected on her feelings and that of her child:
Henry felt empowered and had a new confidence. I was delighted with his new confidence and knew this new understanding of his learning parameters meant we could now work effectively with school and other professionals toward best outcomes. (Respondent no. 355)

As shown in Table 24, the majority of respondents \((n = 391)\) reported that finding help for their child post diagnosis was “very difficult and challenging” \((n = 153)\) or “difficult” \((n = 123)\) which is a combined total of 276 respondents representing 70.6% of respondents to this question. Fewer respondents \((18.2\%)\) found that it was “neither easy nor difficult” to find help for their child. A minority of respondents \((11.3\%)\) found it “easy” to find help to support their child.

Table 24: Level of Ease and Difficulty in Finding Help for Child Post Diagnosis

<table>
<thead>
<tr>
<th>Level of difficulty</th>
<th>(n)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy</td>
<td>44</td>
<td>11.3</td>
</tr>
<tr>
<td>Neither easy nor difficult</td>
<td>71</td>
<td>18.2</td>
</tr>
<tr>
<td>Difficult</td>
<td>123</td>
<td>31.5</td>
</tr>
<tr>
<td>Very difficult and challenging</td>
<td>153</td>
<td>39.1</td>
</tr>
</tbody>
</table>

This question elicited 183 written responses in the optional “comments” section. This was the largest response to any comments section. Underlying the main themes which emerged from this question was respondents’ strong desire to tell their story and be heard. The other key themes which emerged were a sense of isolation, a lack of support and marginalisation:

We live in a regional area there is NO HELP available for dyslexia. (Respondent no. 359)

The support provided by the school was minimal and of little value. This was used as a tactic to get us to leave. The student were [sic] made to be very visible and it was a negative experience all round for the child. We paid for a lot of private tuition and support. We did move schools and were promised what looked like best practice but was extremely damaging in hindsight and provide little by way of learning outcomes. It was hard to know what to do and I have formal qualifications in Social
Work and Disability so it also left me feeling very inadequate and alone. (Respondent no. 377)

The level of specialist understanding at school is very low. I have moved schools twice because of the ignorance and incapacity of the school to respond appropriately. … Throughout the entire school journey, I have had many people suggest or hint that my son would learn to read if I home-schooled him. To me, this is a massive cop-out. Perhaps the suggestion is not intended to send the message that my child will be completely abandoned by the education system the instant they can convince me to take the responsibility off their hands, but that’s how it comes across. (Respondent no. 383)

Further exploring the theme of ease and difficulty associated with support post-diagnosis respondents were asked about their own sense of being able to assist their child (see Table 25).

Table 25: Respondent’s Feeling of Being Able to Assist their Child

<table>
<thead>
<tr>
<th>Sense of ability to assist child</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confident and well equipped to help child</td>
<td>86</td>
<td>22.0</td>
</tr>
<tr>
<td>Uncertain about how to help child</td>
<td>185</td>
<td>47.3</td>
</tr>
<tr>
<td>Anxious and unsure about how to help child</td>
<td>120</td>
<td>30.7</td>
</tr>
</tbody>
</table>

One hundred and eighty five respondents, representing close to half of all respondents (n = 391), indicated that they felt “uncertain about how to help” their child. A further 30.7% of respondents felt “anxious and unsure about how to help” their child post diagnosis. There was a minority of respondents (22.0%) who felt “confident and well equipped” to help their child post diagnosis.

Exploring this theme further, a question was asked to ascertain whether the assessment containing the child’s diagnosis included recommendations for the parent and the school to support the child’s learning. This question was designed in order to explore a minor theme which was identified in the interviews, that is that some interview participants had not been provided with recommendations within the report they had received, exacerbating the difficulty in identifying
support for their child. The survey data indicates that this was quite rare. Respondents \((n = 391)\) reported that in 90.8% of cases, the assessment reports did contain recommendations. Therefore, 9.2% of respondents reported that their child’s report did not contain recommendations to assist the child, parents and school implement appropriate strategies for remediation.

In order to explore the pathway parents embarked upon post diagnosis to seek support for their child, respondents were asked to indicate from whom they sought help (see Table 26). Respondents were permitted to select more than one response.
<table>
<thead>
<tr>
<th>Professional (multiple response)</th>
<th>$n$ ($n = 385$)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s teacher</td>
<td>351</td>
<td>91.2</td>
</tr>
<tr>
<td>Principal at child’s school</td>
<td>220</td>
<td>57.1</td>
</tr>
<tr>
<td>Special education teacher at child’s school</td>
<td>190</td>
<td>49.4</td>
</tr>
<tr>
<td>Educational psychologist</td>
<td>124</td>
<td>32.2</td>
</tr>
<tr>
<td>Special education teacher outside child’s school</td>
<td>109</td>
<td>28.3</td>
</tr>
<tr>
<td>SPELD Victoria</td>
<td>108</td>
<td>28.1</td>
</tr>
<tr>
<td>Speech therapist</td>
<td>94</td>
<td>24.4</td>
</tr>
<tr>
<td>Educational optometrist</td>
<td>77</td>
<td>20.0</td>
</tr>
<tr>
<td>A friend or acquaintance with a child with dyslexia</td>
<td>76</td>
<td>19.7</td>
</tr>
<tr>
<td>General practitioner</td>
<td>62</td>
<td>16.1</td>
</tr>
<tr>
<td>Audiologist</td>
<td>54</td>
<td>14.0</td>
</tr>
<tr>
<td>Irlen clinic</td>
<td>51</td>
<td>13.2</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>45</td>
<td>11.7</td>
</tr>
<tr>
<td>Alternative health practitioner</td>
<td>32</td>
<td>8.3</td>
</tr>
<tr>
<td>Specialist medical doctor</td>
<td>28</td>
<td>7.3</td>
</tr>
<tr>
<td>Neuropsychologist</td>
<td>12</td>
<td>3.1</td>
</tr>
<tr>
<td>Not sought support</td>
<td>7</td>
<td>1.8</td>
</tr>
<tr>
<td>Social worker</td>
<td>6</td>
<td>1.6</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>6</td>
<td>1.6</td>
</tr>
<tr>
<td>Health centre</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Other</td>
<td>87</td>
<td>22.6</td>
</tr>
</tbody>
</table>

On average, respondents indicated that they sought help from four categories of professionals post diagnosis. The majority of respondents approached their child’s teacher (91.4%). Over half of the respondents approached the principal of the child’s school seeking help and advice (57.3%) and slightly below half of all respondents (49.5%) sought help from a special education
teacher at the child’s school. Respondents sought support from special education teachers outside the school context less frequently (28.4%) than from their in-school counterparts.

There were 32.3% of respondents who indicated that they consulted an educational psychologist. The frequency of respondents’ consultations with a neuropsychologist was much lower (3.1%).

There were 108 respondents (28.1%) in this sample who sought help from SPELD Victoria. However, it should be noted that as the survey was posted on SPELD Victoria’s website (amongst multiple other sites), this figure may be an over-representation.

Speech therapists were consulted by 24.5% of respondents, and 20.1% of respondents sought help from educational optometrists. Respondents sought advice from a friend or acquaintance with a child with dyslexia in 19.8% of cases. The data demonstrate that respondents slightly more frequently consulted friends on this matter than a general medical practitioner (16.1%). In 7.3% of cases, respondents were referred by a general medical practitioner to a specialist medical practitioner. (It is unknown which type of specialists respondents were referred to, as this was not requested). Support from alternative health practitioners such as kinesiologists and naturopaths was sought slightly more frequently (8.3%) than support from specialist medical practitioners.

Respondents sought support from audiologists (14.1%), occupational therapists (11.7%) and an Irlen clinic (13.3 %) in relatively low numbers.

Physiotherapists and social workers were consulted in equally low numbers (1.6%). Two respondents (0.5%) approached a health centre for support. Seven respondents (1.8%) indicated that they did not seek help from any professionals.

Although a substantial proportion of respondents selected “other” (22.6%), responses in this section were not recoded due to the variation in how participants had used the “other” category. Data which emerged from the comments in the “other” category highlighted that respondents frequently stated that they sought help from a tutor. In some cases, respondents referred to agencies such as ADA
and Kids Like Us; others referred to the support they sought from self-help parent support groups.

Information was sought from respondents in relation to the challenges that they faced in dealing with their child’s dyslexia (see Table 27).

Table 27: Challenges Parents or Carers Experienced in Dealing with Child’s Dyslexia

<table>
<thead>
<tr>
<th>Challenge (multiple response)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concern about child’s self esteem</td>
<td>329</td>
<td>85.5</td>
</tr>
<tr>
<td>Concern or anxiety about child’s future study and work prospects</td>
<td>313</td>
<td>81.3</td>
</tr>
<tr>
<td>Teacher’s lack of knowledge about dyslexia</td>
<td>294</td>
<td>76.4</td>
</tr>
<tr>
<td>Expenses related to helping child with their learning needs</td>
<td>264</td>
<td>68.6</td>
</tr>
<tr>
<td>Lack of guiding policy about how to recognise and deal with dyslexia</td>
<td>262</td>
<td>68.1</td>
</tr>
<tr>
<td>Difficulty choosing appropriate resources to support child</td>
<td>255</td>
<td>66.2</td>
</tr>
<tr>
<td>Advocating for child at child’s school</td>
<td>247</td>
<td>64.2</td>
</tr>
<tr>
<td>Expenses related to diagnosis</td>
<td>243</td>
<td>63.1</td>
</tr>
<tr>
<td>Lack of support from child’s school</td>
<td>240</td>
<td>62.3</td>
</tr>
<tr>
<td>Lack of consideration for child from child’s teachers</td>
<td>215</td>
<td>55.8</td>
</tr>
<tr>
<td>Difficulty gaining access to resources to support child</td>
<td>188</td>
<td>48.8</td>
</tr>
<tr>
<td>Concern about child’s welfare and well being</td>
<td>177</td>
<td>46.0</td>
</tr>
<tr>
<td>The unexplained difficulties before a diagnosis was established</td>
<td>176</td>
<td>45.7</td>
</tr>
<tr>
<td>Encountering people who deny dyslexia exists</td>
<td>173</td>
<td>44.9</td>
</tr>
<tr>
<td>Communication with child’s school</td>
<td>164</td>
<td>42.6</td>
</tr>
<tr>
<td>Difficulty accessing reliable and consistent information about dyslexia</td>
<td>160</td>
<td>41.6</td>
</tr>
<tr>
<td>Child feeling stigmatised</td>
<td>139</td>
<td>36.1</td>
</tr>
<tr>
<td>Difficulty accessing information about dyslexia</td>
<td>70</td>
<td>18.2</td>
</tr>
<tr>
<td>Parent has not experienced any challenges</td>
<td>6</td>
<td>1.6</td>
</tr>
<tr>
<td>Other</td>
<td>68</td>
<td>17.7</td>
</tr>
</tbody>
</table>
The categories listed in this question reflect minor themes and subthemes which arose from the interviews. Responses to this question \((n = 385)\) indicated that the most prevalent challenge for respondents was concern for their child’s self-esteem (85.5%) in the present, and for their future prospects in relation to their ability to engage in future study and the workforce (81.3%). Close to half (46%) of respondents expressed that they held “other concerns for their child’s welfare and wellbeing”. Fewer respondents, slightly more than a third (36.1%), indicated that they were concerned that their child experienced stigma as a result of their dyslexia. These categories reflect psychosocial issues of concern.

The results demonstrate that respondents found many challenges associated with the child’s school environment. Approximately three quarters (76.4%) of the respondents indicated that teachers’ lack of knowledge in relation to dyslexia was a challenge for them in dealing with their child’s dyslexia. Sixty eight percent of respondents thought that the lack of guiding policy within the school context caused challenges. The interrelated challenges of being required to advocate for children and the lack of support from the child’s school were cited with almost equal frequency: 64.2% and 62.3% respectively. Over half of the respondents (55.8%) also cited the lack of consideration for their child by their child’s teachers as a challenge. Additionally, 42.6% of respondents indicated that they found communication with their child’s school challenging.

Expenses associated with dyslexia and a lack of resources presented frequently as a challenge. Findings highlighted that respondents found the expenses related to assisting their child with their learning needs (68.6%) slightly more challenging than the expenses related to diagnosis (63.1%). Whilst expenses related to diagnosis were clearly challenging for 63.1% of respondents, expenses related to remediation are ongoing. Issues with resources were not limited to costs. Difficulty choosing appropriate resources to support children was found to be challenging for 66.2% of respondents. Difficulty gaining access to resources to support children was cited by close to half of the respondents (48.8%) as a challenge.
The next most common cluster of themes in relation to challenges experienced by respondents was the lack of information, knowledge and awareness in the school environment about dyslexia and its impact on respondents. Close to half of the respondents (45.7%) indicated that the period before their child’s diagnosis in which they experienced unexplained difficulties was challenging. A similar percentage of respondents (44.9%; \( n = 173 \)), stated that encountering denial of the existence of dyslexia was a challenge they had experienced. Fewer respondents, close to a third (31.4%), referred to the difficulty they had experienced gaining a diagnosis of dyslexia. A relatively small percentage of respondents (18.2%) indicated that they had found difficulty accessing information about dyslexia; however, a much greater percentage of respondents (41.6%) stated that they found it challenging to access consistent and reliable information about dyslexia. An extremely small percentage of respondents (1.6%; \( n = 6 \)) did not experience any challenges associated with dyslexia.

**Section 3: Resources**

A theme which arose from the interviews was the burden of costs associated with the route to a diagnosis of dyslexia and the remediation of dyslexia. The survey questions discussed in this section aimed to quantify the costs and the impact of these costs. Respondents were asked to indicate how much they spent on services to assess their child’s difficulties (see Table 28).
Table 28: Amount Spent on Assessment Services

<table>
<thead>
<tr>
<th>Spending range</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>$0 to $100</td>
<td>9</td>
<td>2.3</td>
</tr>
<tr>
<td>$101 to $500</td>
<td>9</td>
<td>2.3</td>
</tr>
<tr>
<td>$501 to $1000</td>
<td>48</td>
<td>12.4</td>
</tr>
<tr>
<td>$1001 to $1500</td>
<td>55</td>
<td>14.2</td>
</tr>
<tr>
<td>$1501 to $2000</td>
<td>54</td>
<td>14.0</td>
</tr>
<tr>
<td>$2001 to $2500</td>
<td>40</td>
<td>10.4</td>
</tr>
<tr>
<td>$2501 to $3000</td>
<td>36</td>
<td>9.3</td>
</tr>
<tr>
<td>$3001 to $3500</td>
<td>21</td>
<td>5.4</td>
</tr>
<tr>
<td>$3501 to $4500</td>
<td>1</td>
<td>4.4</td>
</tr>
<tr>
<td>$4501 to $5000</td>
<td>11</td>
<td>2.8</td>
</tr>
<tr>
<td>$5001 or above</td>
<td>64</td>
<td>16.6</td>
</tr>
<tr>
<td>Unsure of expenditure</td>
<td>11</td>
<td>2.8</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>2.8</td>
</tr>
</tbody>
</table>

In summary 16.6% of respondents (n = 386) spent $5001 on assessment services. This is a very substantial amount for those on low incomes and indicates that there were multiple tests conducted by a variety of professionals. Some respondents provided further information in the comments section stating that they spent “$30,000” (Respondent no. 58) and “Over $10,000 within a one-year period” (Respondent no. 194). This indicates both a high expenditure and a complex route to diagnosis. The second most frequent expenditure category was the range $1001–$1500, with 14.2% of respondents indicating they spent a sum within this range to assess their child’s learning difficulties.

A very low number of respondents (5%) spent $500 or under. Comments in the “other” category clarify that one respondent obtained funding from a faith-based charity for the child’s assessments. Another respondent explained that their
child’s assessments had been provided by the Victorian Department of Education and Training without cost to the family.

Information was sought from respondents regarding expenditure to date on the child’s learning and support needs including counselling, workshops, tuition fees and resources such as computer programs, aids, workbooks, special textbooks and technology (see Table 29).

Table 29: Cost of Support Purchased to Assist Child with Needs

<table>
<thead>
<tr>
<th>Spending range ($)</th>
<th>n (n = 349)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–100</td>
<td>7</td>
<td>2.0</td>
</tr>
<tr>
<td>101–500</td>
<td>13</td>
<td>3.7</td>
</tr>
<tr>
<td>501–1000</td>
<td>31</td>
<td>8.9</td>
</tr>
<tr>
<td>1001–1500</td>
<td>27</td>
<td>7.7</td>
</tr>
<tr>
<td>1501–2000</td>
<td>37</td>
<td>10.6</td>
</tr>
<tr>
<td>2001–2500</td>
<td>31</td>
<td>8.9</td>
</tr>
<tr>
<td>2501–3000</td>
<td>19</td>
<td>5.4</td>
</tr>
<tr>
<td>3001–3500</td>
<td>23</td>
<td>6.6</td>
</tr>
<tr>
<td>3501–4500</td>
<td>20</td>
<td>5.7</td>
</tr>
<tr>
<td>4501–5000</td>
<td>15</td>
<td>4.3</td>
</tr>
<tr>
<td>5001 or above</td>
<td>126</td>
<td>36.1</td>
</tr>
</tbody>
</table>

Responses to this question (n = 349) indicate that 98% of respondents spent funds to obtain resources to support their children’s learning and support needs. The data indicate that 63.9% of respondents spent a sum of $5000 or under and 36% of respondents spent an amount over $5001.

In order to gain insight into ongoing expenditure required to support children’s learning needs, respondents (n = 378) were asked if they incurred annual ongoing costs related to their child’s dyslexia, for example costs associated with extra tuition. The majority of respondents (82.0%) indicated that there were
extra costs. Only 18.0% of respondents reported that there were no annual ongoing costs. Respondents who indicated that there were ongoing annual costs were directed to a question which asked them to estimate the annual ongoing figure of these costs. (See information presented in Table 30).

Table 30: Annual Ongoing Costs of Respondent

<table>
<thead>
<tr>
<th>Costs</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>LL</th>
<th>UL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual ongoing costs</td>
<td>290</td>
<td>4762.76</td>
<td>6175.30</td>
<td>4051.12</td>
<td>5474.40</td>
</tr>
</tbody>
</table>

Note. CI = confidence interval, LL = lower limit, UL = upper limit.

Results from the questions regarding annual ongoing costs demonstrates that respondents \( (n = 290) \) on average indicated that they spent $4762 (\( SD $6175.30, LL $44051.12, UL $5474.40 \)) annually to support their children’s learning needs. This level of expenditure has equity and social justice implications for children with parents on low incomes.

Respondents were asked to indicate what additional resources they would like to obtain for their children but have been unable to do so due to limited resources (see Table 31). The assumption underlying this question is that their annual ongoing expenditure outlined in Table 30 will to some extent reflect the respondents’ financial capacity to provide resources for their children.

Table 31: Types of Resources that Parents Want for Child but Unable to Obtain

<table>
<thead>
<tr>
<th>Resources</th>
<th>( n = 205 )</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tutoring</td>
<td>161</td>
<td>78.5</td>
</tr>
<tr>
<td>Software for computers</td>
<td>122</td>
<td>59.5</td>
</tr>
<tr>
<td>Computer technology</td>
<td>105</td>
<td>51.2</td>
</tr>
<tr>
<td>Therapy</td>
<td>97</td>
<td>47.3</td>
</tr>
<tr>
<td>Workbooks</td>
<td>39</td>
<td>19.0</td>
</tr>
</tbody>
</table>

Of the 205 responses to this question, over three quarters (78.5%) indicated that they were unable to obtain access to tutoring for their child due to
financial constraints. This indicates respondents’ perception of the importance of tutoring, which implies that respondents believe that the child’s learning needs are not being adequately met within the school system. One respondent’s comments elucidated this point:

Recognition by the education system that dyslexia is a problem in our schools, that it is missed right from prep, and an adequate education system to deal with and teach these kids. They deserve an education.
(Respondent no. 316)

This respondent highlights the lack of responsiveness of the education system to the needs of children with dyslexia.

Responses to this question indicated that 59.5% of respondents felt that computer software programs were a resource they wished to purchase but were unable to obtain. A further 51.2% of respondents indicated that they would like to purchase computer technology to assist their child. Ninety-seven respondents representing close to half of respondents (47.3%) to this question regarding resources indicated that they would like to be able to afford therapy for their child. Additionally, 19% would like to purchase workbooks to assist their child with remediation but have experienced financial constraints that have not enabled this to occur.

A key subtheme to emerge from the written responses in the comments section of this question was that the inability to access suitable resources is not limited to parental funding constraints but is complicated by a lack of knowledge and support in assessing and locating effective interventions and resources:

We would spend whatever it takes to support him but it’s hard to know what to do and where to spend the money! (Respondent no. 203)

Lack of access to services rather than lack of funds is the problem for us
(Respondent no. 338)

Respondents (n = 379) were asked whether there were other economic impacts on the family, for example giving up work, not returning to work or housing implications. This question arose from the emergence of these themes
within the interviews. The aim was to quantify the frequency of occurrence of these themes. Over half of the respondents (56.5%) indicated that they did not experience these larger economic impacts.

There were 43.5% of respondents who indicated that they had experienced broader economic impacts as a direct result of the child’s dyslexia. Respondents were asked to elaborate on this topic. Themes were identified and coded and distributed in Table 32 reflecting frequency.

Table 32: Economic Repercussions on Respondents and their Families

<table>
<thead>
<tr>
<th>Impact</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced work to part time</td>
<td>45</td>
<td>32.1</td>
</tr>
<tr>
<td>Unable to participate in workforce</td>
<td>35</td>
<td>25.0</td>
</tr>
<tr>
<td>Family sacrifices</td>
<td>28</td>
<td>20.0</td>
</tr>
<tr>
<td>Unplanned private school fees</td>
<td>23</td>
<td>16.4</td>
</tr>
<tr>
<td>Increased absentee days from work</td>
<td>14</td>
<td>10.0</td>
</tr>
<tr>
<td>Significant increase in travel time and expenses</td>
<td>8</td>
<td>5.7</td>
</tr>
<tr>
<td>Increased working hours</td>
<td>7</td>
<td>5.0</td>
</tr>
<tr>
<td>Costs for training and education of parent regarding dyslexia</td>
<td>7</td>
<td>5.0</td>
</tr>
<tr>
<td>Working below professional capacity</td>
<td>5</td>
<td>3.6</td>
</tr>
<tr>
<td>Downsized or moved house</td>
<td>5</td>
<td>3.6</td>
</tr>
</tbody>
</table>

Respondents (n = 140) to this question cited multiple economic impacts. Approximately one third of respondents (32.1%) cited that they reduced work hours from full time to part time to assist them to support their child’s needs:

Reducing working hours from full time to part time so that I can be there to assist with homework/tutoring as my daughter is unable to do it unassisted. Also need to be available to take her to/from appointments
(Respondent no. 55)

It is clear from data tabulated in Table 13 regarding employment status that the reduction in working hours refers only to females. No males in this survey
indicated that they worked part time and all males were engaged in the paid workforce. Comments indicated that respondents reduced work hours in order to support their child’s additional learning needs and to enable them to gain access to additional service outside of school hours.

A further 25% of respondents indicated that their child’s dyslexia resulted in them being unable to participate in the workforce at all. The respondents’ comments reveal that despite their desire to work, their child’s dyslexia was a significant barrier to participation in the workforce:

- Not able to return to work. I have to ferry Eddie to and from tuition, do extra reading and homework, manage his behaviours. Meet with paediatrician. Generally been impossible to return to work. (Respondent no. 50)

- Not returning to work in order to home school to provide support for my child. (Respondent no. 224)

Respondents’ comments revealed that in order to provide support for their child’s learning and support needs, in 20.0% of cases families sacrificed other needs:

- The cost of seeking help for our children has meant no holidays, no dental work, needing to work six days a week. (Respondent no. 305)

- We can’t make any headway on our home loan, we can’t afford to maintain our car regularly, we can’t afford the type of holidays we like. I can’t afford to buy new clothes for the kids, etc., etc. (Respondent no. 175)

It emerged from the data that 16.4% of parents incurred expenses related to unplanned private school fees. Table 17 of this study demonstrates that 24.2% of respondents’ children are enrolled in the independent school sector compared with the general population figure of 14.3% (ABS, 2013). Data from the responses to this question shed light on this phenomenon.

There were 10% of respondents who indicated that they had experienced increased absenteeism from work as a direct result of their child’s dyslexia.
Comments related to this occurrence explained that absenteeism from work resulted from the need to transport and accompany children to attend diagnostic, remedial and therapeutic appointments:

- It has been extremely hard on us financially. To take our son to appointments I had to take time off work. (Respondent no. 340)

- I have taken a great deal of time out of my working days to provide therapy. (Respondent no. 112)

Respondents (5.7%) indicated that in some cases they incurred significant expenses as a result of increased travel time in order to access appropriate school or additional resources:

- Changed schools now have to drive 40 km more a day (Respondent no. 47).

- Have to travel 3hr round trip for Speech Therapy and 1.5hrs for OT [occupational therapist] (Respondent no. 94)

A small number of respondents (5%) reported that they increased their working hours to cover additional expenses that were incurred by the financial cost of their child’s dyslexia. In most cases, this was a result of the cost of independent school fees:

- Mum has had to take on more days at work to afford private school fees (Respondent no. 138).

- A further 3.8% of respondents stated that they are working below their professional capacity to have the flexibility to accommodate their child’s needs.

- Have had to choose a lesser job closer to home to ensure I can support the kids with tutoring (Respondent no. 267).

- I am a trained teacher but due to the extensive hours required to work full time, and the added stress of having two children unhappy with school, I have chosen to work as a CRT [casual replacement teacher]. This work is erratic and has not provided a full-time wage. I average 2.5 days / week over the full year (Respondent no. 109).
There were also a small number of respondents (5%) who stated that they incurred costs in training and educating themselves in relation to dyslexia. In some cases, this study path also required respondents to step out of the workforce:

In order to support her I gave up work. Additionally I completed a certificate IV in education support in the hope that I could further support her (Respondent no. 119).

A small number of respondents (3.6%) indicated that they downsized or moved house in order to fund education and support for their child or to move closer to a school that could cater for their child’s needs:

Made decision to keep her in private school for more help and sold family home to fund (Respondent no. 152).

Summary

Encapsulated in the findings in this chapter is an exploration of parents’ experiences as they navigate a pathway through public and private service providers and an array of resources, to identify their child’s dyslexia and support their learning needs. The key contribution of this chapter is the data, which shed light on the indicators of children’s literacy difficulties and the signs which respondents observed. It demonstrates that literacy skills such as reading, spelling and writing were the most prevalent indicators. Comparison with their child’s siblings, and to a lesser extent peers, also alerted respondents to their child’s difficulty.

Data contained in this chapter also demonstrate that before securing a diagnosis, respondents on average consulted five professionals for support and advice. Mostly notably, in the first instance, respondents consulted with the child’s teacher. On average there was a gap of 2.81 years identified from the time the child was first suspected of having difficulties until diagnosis. Over half of respondents indicated that they or one of their other children had diagnosed, or suspected but undiagnosed, dyslexia.
This chapter unveiled information which suggests that, most commonly, respondents indicated that they felt relieved upon receiving confirmation of their child’s diagnosis of dyslexia. Commonly, this feeling of relief was combined with worry for their child. The majority of respondents indicated that dealing with their child’s dyslexia was either difficult or very difficult and challenging. Additionally, the majority of respondents felt uncertain or anxious and unsure how to help their child with the challenges presented by dyslexia. In seeking support, the majority of respondents approached their child’s teacher or school principal. Respondents indicated that their greatest challenges were related to concern for their child’s self-esteem as well as concern for their child’s future study and work prospects. Another major concern for respondents was their perception of the lack of teacher knowledge in relation to dyslexia.

The majority of respondents indicated that they obtained resources to support their child’s learning needs. Concurrently, whilst needing to provide additional resources to support children to enable learning, in some cases respondents’ workforce participation was curtailed by the need to provide practical support and assistance to their child with dyslexia. It is clear from the data that the main responsibility for obtaining resources to support children was relegated to respondents, that is to parents.
CHAPTER 6:
QUANTITATIVE FINDINGS – PARENTS’ CHALLENGES AND RECOMMENDATIONS

Introduction

Chapter 6 follows on from the proceeding empirical chapter by presenting findings in relation to respondents’ experiences of and reflections on the response of schools to their children’s dyslexia. It reports the number of schools to date that respondents’ children have attended. It quantifies the number of moves resulting from a school’s response to dyslexia. This chapter is divided into three sections. The first section reveals the confidence levels of respondents in relation to teachers’ understanding of dyslexia and compares data between the school sectors. It also contains data on respondents’ perceptions of the helpfulness and the support provided to their children, and reports on similarities and differences between the different school sectors.

Section 2 contains findings relating to terminology and labels used within schools to describe dyslexia as well as experiences relating to the use of the term “dyslexia” and respondents’ understanding of this matter. It contains information about the labelling of children with dyslexia.
The third section of this chapter focuses on parents’ policy reform recommendations and advocacy. This section provides insight into respondents’ levels of satisfaction and dissatisfaction with government policy and support for children with dyslexia. It highlights respondents’ policy recommendations and sheds light on the role of parent advocates. It also shares findings in relation to respondents’ views on an opportunity to have their voice heard on this topic.

Section 1: Experiences and Reflections on the Response of Schools to the Child’s Dyslexia

This section presents respondents’ perceptions and experiences in relation to the recognition of their child’s learning needs within the child’s current school. The data in this section contains cross-sector comparisons between the experiences of respondents with children in the state, Catholic and independent school sectors.

The data represented in Table 33 is divided between children’s school moves in primary and secondary school. The data indicate that respondents with children in primary school or whose children had completed primary school ($n = 376$) moved their child between schools at a frequency with a mean of 2.49 ($SD$ 0.77, $LL$ 2.41, $UL$ 2.56). In the secondary school context, respondents ($n = 138$) indicated that the number of school moves was 1.22 ($SD$ 0.61, $LL$ 1.11, $UL$ 1.32). A possible explanation for the higher number of school moves in primary school is that it is more likely that respondents chose a secondary school for their child with the knowledge that their child had dyslexia and therefore it may have contributed to the choice of school.

Table 33: Number of Schools Attended by Child

<table>
<thead>
<tr>
<th>School level</th>
<th>$n$</th>
<th>$M$</th>
<th>$SD$</th>
<th>$LL$</th>
<th>$UL$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>376</td>
<td>2.49</td>
<td>0.77</td>
<td>2.41</td>
<td>2.56</td>
</tr>
<tr>
<td>Secondary</td>
<td>138</td>
<td>1.22</td>
<td>0.61</td>
<td>1.11</td>
<td>1.32</td>
</tr>
</tbody>
</table>

Note. CI = confidence interval, $LL$ = lower limit, $UL$ = upper limit.
Data from Table 34 \((n = 270)\) indicate that 57.4\% of children’s school moves were unrelated to the school’s treatment of their child’s dyslexia. The remaining 42.6\% or 115 cases in which children moved between schools reflect the respondent’s dissatisfaction with a school’s response to dyslexia. This suggests a high degree of dissatisfaction coupled with a belief by respondents that there is variability between schools in relation to their approach to dealing with dyslexia. Further questions drilled down into exploring satisfaction and dissatisfaction within and between school sectors.

Table 34: School Moves due to Previous School's Response to Dyslexia

<table>
<thead>
<tr>
<th>Response</th>
<th>(n) ((n = 270))</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>155</td>
<td>57.4</td>
</tr>
<tr>
<td>Yes</td>
<td>115</td>
<td>42.6</td>
</tr>
</tbody>
</table>

Table 35 reflects the level of confidence that respondents have overall in their child’s teacher’s understanding of dyslexia and the learning and support needs of their child. Answers were coded according to school sector. It should be noted that this data reflects respondents’ overall level of confidence in the child’s current teachers, which implies that for some respondents this is an assessment of their level of confidence after they moved their child to a new school due to dissatisfaction with their previous school.

Table 35: Overall Confidence in Teachers’ Understanding of Dyslexia

<table>
<thead>
<tr>
<th>Response</th>
<th>State school ((n = 194))</th>
<th>%</th>
<th>Catholic school ((n = 81))</th>
<th>%</th>
<th>Independent school ((n = 91))</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>35</td>
<td>18.0</td>
<td>25</td>
<td>30.9</td>
<td>35</td>
<td>38.5</td>
</tr>
<tr>
<td>No</td>
<td>159</td>
<td>82.0</td>
<td>56</td>
<td>69.1</td>
<td>56</td>
<td>61.5</td>
</tr>
</tbody>
</table>

It appears that the majority of respondents with children in all school sectors did not have overall confidence that their child’s teachers have a good understanding of dyslexia and insight into their child’s learning and support.
needs. Respondents with children in the state school system \((n = 194)\) were the least confident of all groups, with only 18% expressing confidence in their child’s teachers. Results from respondents with children in the state schools demonstrate that these respondents were close to half as likely as parents in the independent school \((n = 91)\) to feel confident that their child’s learning and support needs are being met. However, it is of note that despite this discrepancy, only 38.5% of respondents with children in the independent school sector felt confident in their child’s school teachers in relation to this matter. Respondents with children in the Catholic school system \((n = 81)\) were confident in 30.9% of cases that their children’s learning needs were being met. A lack of confidence in teachers understanding dyslexia and their child’s needs was prevalent in the majority of respondents across all three main school sectors.

Narrowing the focus to the current school year and the child’s current teachers, respondents were asked to rate their child’s teachers’ understanding of dyslexia and its impact on their child’s learning needs. These results were then categorised according to school sector (see Table 36).

<table>
<thead>
<tr>
<th>Level of understanding</th>
<th>State school</th>
<th>Catholic school</th>
<th>Independent school</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>((n = 191))</td>
<td>((n = 80))</td>
<td>((n = 89))</td>
</tr>
<tr>
<td>Excellent</td>
<td>9</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Very good</td>
<td>16</td>
<td>16</td>
<td>13</td>
</tr>
<tr>
<td>Good</td>
<td>34</td>
<td>22</td>
<td>21</td>
</tr>
<tr>
<td>Fair</td>
<td>69</td>
<td>24</td>
<td>29</td>
</tr>
<tr>
<td>Poor</td>
<td>63</td>
<td>15</td>
<td>13</td>
</tr>
</tbody>
</table>

In summary, results for this question clearly demonstrate that a majority of respondents \((n = 390)\) have a negative perception of teachers’ levels of
understanding of dyslexia in the state, Catholic and independent school sectors in Victoria. Close to a third of respondents with children in all sectors rated teachers’ knowledge as “fair”. This was the rating with the most congruity in frequency between teachers in all sectors. The results for teachers in the state school system in relation to their understanding of dyslexia and its impact on children’s learning needs were worse than the results for either the Catholic or independent sector. Results for teachers in the independent sector were only slightly better than perceptions of teachers in the Catholic sector.

Respondents who had children in the state system \( (n = 191) \) rated teachers’ understanding of dyslexia as “excellent” in only 4.7% of cases and “very good” in 8.4% of cases. Respondents in the Catholic education sector \( (n = 80) \) considered teachers’ knowledge regarding dyslexia as “excellent” in an even lower percentage of cases (3.8%) than respondents in the state education system. However, they were much more likely to rate teachers’ knowledge as “very good”, with 20% reporting this rating for teachers in the Catholic school sector.

Respondents with children in the independent school sector \( (n = 89) \) rated teachers’ knowledge as “excellent” in 14.6% of cases. Of note is that only 14.6% of respondents rated teachers’ knowledge in the independent school sector as “very good”, compared to 20% of respondents in the Catholic sector. However, overall, when combining the categories “very good” and “excellent”, teachers in the Catholic system were rated in these categories in 23.8% of cases, and results for the independent sector were marginally higher at 29.2%. Teachers in the Catholic school sector were also more commonly rated as having a “good” level of knowledge as compared to the state school teachers (17.8) and the independent school teachers (23.6%). One third (33%) of state school teachers, 18.8% of Catholic school teachers and 14.6% of independent school teachers were rated as having a “poor” understanding of dyslexia and its impact on children’s learning needs.

The comments made in addition to the respondents’ ratings highlight a few key issues. Respondents pointed out that students enrolled in secondary school have multiple teachers and that there can be great variation between teachers in
their knowledge of and response to dyslexia. These comments related to all school sectors:

I provide information to the teacher each year, no teacher in five years of primary school have [sic] any idea on how to teach a dyslexic child, depends on the teacher, this year a teacher who is prepared to learn about dyslexia (Respondent no. 75). 11

As he is currently attending secondary school (year 7), he has many teachers. Some are very good and offer support and allowances in his education and exams but others are quite ignorant and dismissive of how their teaching impacts his learning process. (Respondent no. 172) 12

Like any profession, there are good and bad teachers – some school years are better than others. (Respondent no. 34) 13

A key theme to emerge was respondents’ recognition that teachers trained in Victoria were not provided with mandatory training in relation to dyslexia. Therefore, teachers’ knowledge in relation to dyslexia was inconsistent and related to whether or not they had elected to undertake learning in this field:

Again, it varies from teacher to teacher. Learning difficulties have not been a mainstream part of teacher training for many years and only some student teachers are doing units on it. It is unfair to expect teachers to know what they don’t know. However, many other countries know about learning difficulties and legislate to support students (Respondent no. 109).

Teachers aren’t specifically training [sic] to recognise or support learning difficulties like dyslexia. This is a terrible problem. My understanding is that the strategies that help dyslexia would also help other forms of difficulties and slower learners. It doesn’t make sense not to invest in it. (Respondent no. 135)

Whilst Table 36 presented respondents’ perceptions of teachers understanding of dyslexia and its impact on their child’s learning needs, Table 37

---

11 This respondent’s child attended a state school.
12 This respondent’s child attended a Catholic school.
13 This respondent’s child attended an independent school.
reflects respondents’ perceptions of how helpful their child’s current school is in addressing their learning needs.

Table 37: Respondents’ Perceptions of School Helpfulness in Addressing Learning Needs

<table>
<thead>
<tr>
<th>Helpfulness</th>
<th>State school (n = 194)</th>
<th>%</th>
<th>Catholic school (n = 81)</th>
<th>%</th>
<th>Independent school (n = 91)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very unhelpful</td>
<td>31</td>
<td>19.1</td>
<td>14</td>
<td>17.3</td>
<td>15</td>
<td>16.5</td>
</tr>
<tr>
<td>Somewhat helpful</td>
<td>111</td>
<td>57.2</td>
<td>38</td>
<td>46.9</td>
<td>33</td>
<td>36.3</td>
</tr>
<tr>
<td>Helpful</td>
<td>27</td>
<td>13.9</td>
<td>18</td>
<td>22.2</td>
<td>24</td>
<td>26.4</td>
</tr>
<tr>
<td>Very helpful</td>
<td>19</td>
<td>9.8</td>
<td>11</td>
<td>13.6</td>
<td>19</td>
<td>20.9</td>
</tr>
</tbody>
</table>

In summary, the findings indicate that the most frequently reported perception across all school sectors is that respondents find that their child’s school is “somewhat helpful” in addressing their child’s learning needs. It is of note that “somewhat helpful” is one rank above “very unhelpful”. Table 37 also displays respondents’ low selection of the category “very helpful” across the three main sectors of the education system. It is interesting to note that close to a third (36.3%) of respondents with children in the independent school sector rated the school as “somewhat helpful”, and only 20.9% as “very helpful”.

Table 38 provides insights into parents’ perceptions of the support provided to children in the context of their school.
Table 38: Parents’ Perceptions of Support Provided by School According to Sector

<table>
<thead>
<tr>
<th>Type of support (multiple response)</th>
<th>State school</th>
<th>Catholic school</th>
<th>Independent school</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( n ) ( (n = 186) )</td>
<td>( n ) ( (n = 74) )</td>
<td>( n ) ( (n = 87) )</td>
</tr>
<tr>
<td>None</td>
<td>51</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>One-to-one or group remedial classes in literacy specifically designed to help with dyslexia</td>
<td>10</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>One-to-one or group remedial classes not specifically designed to help children with dyslexia</td>
<td>47</td>
<td>28</td>
<td>43</td>
</tr>
<tr>
<td>Visiting professional support</td>
<td>11</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Psychological support and counselling</td>
<td>9</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>Facilitated program designed to raise child’s self-esteem</td>
<td>11</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>An aide in the class specifically to support child with dyslexia</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>An aide in the class that helps a cluster of students with various learning difficulties</td>
<td>34</td>
<td>37</td>
<td>21</td>
</tr>
<tr>
<td>School has centralised records to facilitate awareness for incoming teachers regarding child’s learning needs</td>
<td>26</td>
<td>17</td>
<td>26</td>
</tr>
<tr>
<td>Professional development for child’s teachers in relation to dyslexia</td>
<td>18</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>School has written dyslexia awareness and teaching policy documents</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Technological support or equipment</td>
<td>35</td>
<td>20</td>
<td>31</td>
</tr>
<tr>
<td>Adapted curriculum</td>
<td>35</td>
<td>13</td>
<td>27</td>
</tr>
<tr>
<td>Consideration such as extra time for exams and homework requirements, print-outs of material from board, oral instead of written tests</td>
<td>56</td>
<td>25</td>
<td>44</td>
</tr>
</tbody>
</table>
The results contained in this table demonstrate distinct differences and trends in relation to respondents’ experiences and perceptions of remediation and support and approach to supporting children with dyslexia between and within school sectors.

In summary, of note is that the state funded education system had the largest percentage of respondents (27.4%) who indicated that there is no support offered to their child. Respondents with children in the Catholic sector indicated that no support was offered in 10.8% of cases, and in the independent sector the figure was very similar at 9.2%.

Most frequently cited by respondents with children in the Catholic sector \((n = 74)\) was that children were offered the support of an aide in the classroom who assists a cluster of children with learning difficulties (50%). It is of note that this approach occurs in practice but is not a documented policy approach. This is made evident by the data in Table 38 which reflects that 0 respondents with children in the Catholic education system \((n = 74)\) indicated that their child’s school has a written dyslexia awareness and teaching policy document. It is also noteworthy that the provision of an aide to a cluster of students is much less likely in the independent school sector (24.1%) and the state system (18.3%).

Respondents with children in the independent school sector \((n = 87)\) most commonly named accommodations such as extra time for exams and homework, print-outs of materials from the board and oral instead of written tests as the most frequently provided support for children with dyslexia (50.6%). This occurred much less frequently in the Catholic system (33.8%) and the state system (30.1%). It is of note that these accommodations are not associated with high expenditure for the school as they are largely related to additional time and adjustment rather than expense. The granting of these provisions has major implications relating to systemic inequity, which will be discussed in Chapter 8.

In the independent school sector, one-to-one or group remedial classes not specifically designed for children with dyslexia were reported by close to half of all respondents with children in that sector (49.4%). Figures for both the Catholic school sector (37.8%) and the state system (25.3%) were lower. In relation to the
independent sector, 20.7% of respondents reported that their children were receiving remedial tuition specifically designed for the needs of children with dyslexia. This low percentage was even lower in the Catholic and state school sectors, at 9.5% and 5.4% respectively. Respondents with children in the independent school sector also indicated a higher frequency (35.6%) for the provision of technological support or equipment compared with the Catholic school sector (27.0%) and the state school sector (18.8%).

Respondents representing all sectors reported perceptions of low rates of teachers undertaking in-service professional development training in relation to dyslexia. However, the low rates for the state sector (9.7%) and the Catholic sector (8.1%) were close to half the rate for the independent school sector (16.1%).

Respondents in the independent school system reported almost double the rate of the provision of adapted curriculum reported by respondents in the state system (18.8%) and the Catholic system (17.6%).

The implementation of facilitated programs to assist students with self-esteem enhancement were reported most frequently by respondents with children in the Catholic sector (16.2%). Rates for the independent school sector were lower at 9.2% and even lower in the state sector at 5.9% This low result combined with the low rate of provision of psychological support and counselling (4.8%) reportedly provided for children with dyslexia in the state school system, suggests that children’s wellbeing is most at risk in the state school system which is also the sector with the fewest learning support resources. Findings indicate that the Catholic and independent school sectors place a slightly stronger emphasis on psychological support for students with dyslexia, with 17.6% of respondents in the Catholic school sector and 19.5% of respondents in the independent school sector indicating that their children had access to support and counselling. Despite this comparatively stronger emphasis, the majority of students did not have access to support and counselling through their school. This implies that the majority of respondents would need to purchase this support on the private market for it to be available for their children. This is an important finding when one considers the
findings contained in Table 27 which indicated that the greatest challenge faced by respondents \((n = 383)\) was concern for their child’s self-esteem (85.5%).

Respondents with children in the Catholic school system perceived that their children had access to support services from visiting professionals (such as speech therapists) with a frequency of 12.2%. This is higher than the percentage indicated by respondents with children in the state system (5.9%) and marginally higher than the rate perceived by respondents in the independent school system (10.3%). However, all the rates are relatively low.

Centralised record keeping regarding children’s learning difficulties for use by incoming teachers was more frequently perceived by respondents to exist in the independent school sector (29.9%) than in either the state (14.0%) or Catholic education system (23.0%).

Clear patterns of responses to dyslexia within school sectors emerged, which suggests that there are some clearly defined practices in relation to the treatment of children with dyslexia within school sectors. However, data from Table 38 demonstrate that the majority of respondents with children in all school sectors perceive that there is a paucity of written dyslexia awareness and teaching policy documents in existence within their schools. The starkest indication of this deficit was demonstrated by respondents with children in the Catholic system \((n = 74)\). These respondents indicated that 0% of schools have policy documents. However, the commonalities across schools in the Catholic sector suggests otherwise. It is possible that there is an unofficial policy or one that is not communicated to parents. Notably, this could also be the case in other sectors. Only 1.1% of respondents in the state system, and 2.3% of respondents with children in the independent school sector, perceive that policy documents relating to dyslexia exist. This result points to a large policy deficit.

**Section 2: Terminology and Labels**

Research by Louden et al. (2000) revealed that, historically, multiple terms have been used to describe dyslexia. A question was posed to survey respondents
to ascertain the terminology currently used to describe dyslexia which they had encountered (see Table 39).

Table 39: Terminology Current School Uses to Describe Dyslexia

<table>
<thead>
<tr>
<th>Terminology (multiple response)</th>
<th>n (n = 361)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyslexia</td>
<td>183</td>
<td>50.7</td>
</tr>
<tr>
<td>Learning difficulty</td>
<td>159</td>
<td>44.0</td>
</tr>
<tr>
<td>Needs learning support</td>
<td>85</td>
<td>23.5</td>
</tr>
<tr>
<td>Specific learning difficulty</td>
<td>67</td>
<td>18.6</td>
</tr>
<tr>
<td>Parent is not sure</td>
<td>61</td>
<td>16.9</td>
</tr>
<tr>
<td>Learning disability</td>
<td>58</td>
<td>16.1</td>
</tr>
<tr>
<td>Special needs</td>
<td>27</td>
<td>7.5</td>
</tr>
<tr>
<td>Specific learning disability</td>
<td>20</td>
<td>5.5</td>
</tr>
<tr>
<td>School states that it does not wish to label child</td>
<td>20</td>
<td>5.5</td>
</tr>
<tr>
<td>Student at risk</td>
<td>14</td>
<td>3.9</td>
</tr>
<tr>
<td>Student at educational risk</td>
<td>14</td>
<td>3.9</td>
</tr>
<tr>
<td>Other</td>
<td>37</td>
<td>10.2</td>
</tr>
</tbody>
</table>

Multiple answers to this question around terminology were permitted. Table 39 reveals that the most commonly used term to describe dyslexia indicated by all respondents (n = 361) was the word “dyslexia” which occurred with a frequency of close to 50%.

The term “learning difficulty” was the second most commonly utilised term with a frequency of 44%. This is in contrast to the term “learning disability”, which was much less commonly used with a frequency of 16.1%.

The third most commonly used term was the generic term “needs learning support” which was used almost half as frequently as “learning difficulty”. One possible explanation for this is that it would be counterintuitive and controversial to use the term “needs learning support” but subsequently not provide the child with learning support.
The term “specific learning difficulty” was the next most commonly used term. Specific learning “difficulty” was much more commonly used than specific learning “disability”. This reinforces the finding that there is a greater propensity to use the term “difficulty” rather than “disability” in the Victorian school context.

There was low frequency of the use of the terms “special needs”, “student at risk” and “student at educational risk”. In a small percentage of cases, respondents indicated that their children’s schools informed them that they did not wish to give the child a label. Although an infrequent occurrence, the implications of not labelling a child who has dyslexia with a term that contextualises their disability may have multiple ramifications. (This theme is examined in light of the literature on this topic in Chapter 8.) There were no distinct patterns which emerged in the comments section in relation to alternative terminology used to describe dyslexia.

In a separate question, respondents ($n = 374$) were asked if they had ever experienced any objections from the child’s current or past schools to the use of the word “dyslexia”. This question was asked in light of the experience of several interview participants who had experienced such objection and was designed to ascertain the frequency of this occurrence. The majority of respondents (63.6%) reported that this had not occurred. Close to a third of respondents (36.4%) indicated that they had experienced objections by their child’s school to the use of the word “dyslexia”. Respondents who had experienced resistance to the use of the term were asked to describe their understanding of this rejection.
Table 40: Rationale for Objections to Use of the Word “Dyslexia”

<table>
<thead>
<tr>
<th>Objections</th>
<th>( n ) (( n = 80 ))</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyslexia does not exist</td>
<td>28</td>
<td>35.0</td>
</tr>
<tr>
<td>Symptoms relegated to negative factors intrinsic to child</td>
<td>19</td>
<td>23.8</td>
</tr>
<tr>
<td>Inexplicable opposition to the use of word</td>
<td>19</td>
<td>23.8</td>
</tr>
<tr>
<td>Opposition to use of labels</td>
<td>11</td>
<td>13.8</td>
</tr>
<tr>
<td>Symptoms relegated to negative factors intrinsic to parent</td>
<td>8</td>
<td>10.0</td>
</tr>
</tbody>
</table>

The respondents’ \( (n = 80) \) most frequent response was that they had experienced resistance to the use of the term “dyslexia” as a result of the belief that dyslexia does not exist (35%).

There were 23.8% of respondents who experienced an inexplicable opposition to the use of the term. Likewise, 23.8% of respondents perceived that resistance to use of the term was due to teachers’ attribution of blame for the child’s difficulties to factors intrinsic to the child rather than to the syndrome of dyslexia.

They are uneducated so believe the child to be lazy, attention seeking, stupid. (Respondent no. 19)

the teacher’s view was that he was simply lazy when it came to writing. He knows the answers so therefore the issue was one of work avoidance due to stubbornness or being lazy and nothing else. … It’s only an excuse. No he is just lazy. It’s his behaviour not his ability to learn as he is a smart kid. (Respondent no. 58)

The belief by teachers that a child is lazy, attention seeking or stupid rather than has dyslexia may also suggest that they do not “believe” dyslexia exists or may have no knowledge of the syndrome. Eleven respondents (13.8%) reflected that teachers had expressed opposition to the use of a label to describe the child’s learning disability:

It does not help the student being labelled. (Respondent no. 238)
The previous state school thought it would stigmatise Emily using that word. (Respondent no. 65)

They don’t like to put labels on people. (Respondent no. 301)

Eight respondents (10%) reported that they experienced being blamed by teachers for their child’s difficulties:

My child’s learning difference was because “I was an over anxious parent”

they blame the parent usually me (Respondent no. 220).

Respondents were asked if their child had ever been labelled by a teacher, psychologist or other professional. The question did not specify whether this labelling occurred before diagnosis or after diagnosis as it sought to understand the experience of parents and children with dyslexia rather than the pathway to diagnosis on this occasion. It was asked in order to gain insight into what dyslexia is mistaken for in the school environment. The majority of options provided were pejorative terms, however options to select “this had not occurred” or “other” were provided. Following data collection, the results were analysed according to gender to determine if there were any patterns and differences for male and female children and their parents (see Table 41).
Table 41: Labels Used by a Teacher, Psychologist or other Professional According to Gender of Child

<table>
<thead>
<tr>
<th>Terminology</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( n = 160 )</td>
<td>( n = 216 )</td>
</tr>
<tr>
<td>Being lazy</td>
<td>40 (25.0%)</td>
<td>79 (36.6%)</td>
</tr>
<tr>
<td>Being a daydreamer</td>
<td>47 (29.4%)</td>
<td>73 (33.8%)</td>
</tr>
<tr>
<td>Has a hearing or processing disorder</td>
<td>40 (25.0%)</td>
<td>64 (29.6%)</td>
</tr>
<tr>
<td>Has a reading disorder</td>
<td>30 (18.8%)</td>
<td>56 (25.9%)</td>
</tr>
<tr>
<td>This has not occurred</td>
<td>51 (31.9%)</td>
<td>46 (21.3%)</td>
</tr>
<tr>
<td>Attention deficit disorder</td>
<td>14 (8.8%)</td>
<td>39 (18.1%)</td>
</tr>
<tr>
<td>Other</td>
<td>29 (18.1%)</td>
<td>36 (16.7%)</td>
</tr>
<tr>
<td>Having low intelligence</td>
<td>22 (13.8%)</td>
<td>28 (13.0%)</td>
</tr>
<tr>
<td>Has Asperger’s</td>
<td>7 (4.4%)</td>
<td>23 (10.6%)</td>
</tr>
<tr>
<td>Having a conduct disorder</td>
<td>5 (3.1%)</td>
<td>21 (9.7%)</td>
</tr>
<tr>
<td>Comes from a dysfunctional family</td>
<td>8 (5.0%)</td>
<td>8 (3.7%)</td>
</tr>
<tr>
<td>An intellectual disability</td>
<td>3 (1.9%)</td>
<td>8 (3.7%)</td>
</tr>
<tr>
<td>Autistic</td>
<td>3 (1.9%)</td>
<td>6 (2.8%)</td>
</tr>
</tbody>
</table>

*Note.* Multiple responses were permitted in this question; therefore, frequencies do not add up to 100%.

Data presented in Table 41 indicate that in this sample the gender of children with dyslexia impacted on the frequency of labelling and the type of labels the children received from teachers and other professionals. Overall, males in this cohort were more frequently labelled and given pejorative labels than females. For example, males \( (n = 216) \) were most frequently considered “lazy” (36.6%). Respondents indicated that females were most frequently not labelled (31.9%). Females \( (n = 160) \) were less frequently considered or labelled “lazy” than males (25.0%). Respondents indicated that 21.2% of males were not given any other label.

Males in this sample were more likely to be labelled a “daydreamer” (33.8%) than females (29.4%). However, the most common label females were
assigned was “daydreamer”. Whilst this label reflects a misinterpretation of the symptoms of dyslexia and is therefore inaccurate, it is not as pejorative a term as “lazy”.

Both males and females were labelled by professionals as “having a hearing or processing disorder”. This occurred for males at the frequency of 29.6% and for females in 25% of cases. (In some cases, children with dyslexia may have hearing or processing disorders, however this requires diagnosis by a qualified audiologist or psychologist.) The next most frequently used label was “reading disorder”. This term (which is often used interchangeably in the United States to describe dyslexia) was more commonly attributed to males (25.9%) than to females (18.8%). Once again this demonstrates a pattern of more frequent labelling of males in this sample.

The perception that children have “low intelligence” occurred in 13.8% of cases for females and 13.0% of cases for males. In contrast, in this cohort males (3.7%) were marginally more likely to be labelled than females (1.9%) as having an “intellectual disability”. The only other category of labels (other than “low intelligence”) applied more frequently to females than to males was “comes from a dysfunctional family” which occurred with a frequency of 5.0% for females and 3.7% for males. Whilst the difference is slight, it reflects a general trend in the data throughout this table of a greater propensity towards more frequently blaming males for their academic failure than females. This is a matter that requires further exploration and research.

Amongst this cohort, respondents reported more frequently that males were more likely than females not only to be given pejorative labels but also to be considered as being affected by syndromes other than dyslexia. Professionals labelled 18.8% of males as having ADD and 8.8% of females. Whilst it is possible that some children referred to by respondents have a dual diagnosis of dyslexia and ADD, this study attempted to screen out respondents with children with a dual diagnosis. Males (10.6%) were also labelled as having “Asperger’s syndrome” with a higher frequency than females (4.4%). Consistent with this pattern of a tendency to more frequently pathologise boys, males were three times
more likely to be labelled as having a “conduct disorder” than females. Respondents’ comments provided further insights. Themes that arose included children being given the labels “naughty”, “rude”, “immature”, “disruptive”, “slow”, “not an academic student”, “it’s a boy thing”, “anxious”, “anxiety disorder”, “low self-esteem”, “separation anxiety” and “not trying”. Children were often given more than one label:

Easily distracted doesn’t pay attention in class lacking resilience fails to “have a go” doesn’t follow instructions sensitive to criticism has trouble socially with “friends” and aggressive children / easily offended / sulks / over sensitive (Respondent no. 330).

Tuned out, turns off, isn’t trying (Respondent no. 71).

Naughty, disruptive, rude, unwilling to learn. (Respondent no. 187)

There was also a smattering of positive comments amongst the negative comments:

Nearly every teacher in secondary school has made remarks such as a “pleasant addition to the class, but needs to pay more attention, try harder, be more of an independent learner” (Respondent no. 381).

No matter how often you try to enlighten teachers about dyslexia they seem to come back to the same point that your child just needs to pay closer attention and try harder. It’s the same every single year. (Respondent no. 394)

The attribution of labels to children with dyslexia suggests that gender plays a role in labelling. Data from this table also suggests that a lack of insight into the symptoms and impact of dyslexia on children’s learning and behaviour creates a risk that children may be negatively mislabelled.

Section 3: Parental Advocacy and Policy Reform

This section contains respondents’ understandings of policy, views on current policy and recommendations for policy change. It also contains insights into respondents’ advocacy roles in relation to gender.
In the first instance, respondents were asked questions concerning levels of satisfaction with current government policy in relation to dyslexia (see Table 42).

Table 42: Level of Satisfaction with Support provided by State and Federal Government

<table>
<thead>
<tr>
<th>Level of satisfaction</th>
<th>State government</th>
<th>Federal government</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( n = 371 )</td>
<td>( n = 371 )</td>
</tr>
<tr>
<td></td>
<td>( n )</td>
<td>( n )</td>
</tr>
<tr>
<td>Not sure what is provided</td>
<td>135</td>
<td>36.3</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>255</td>
<td>68.6</td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td>9</td>
<td>2.4</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>2</td>
<td>0.5</td>
</tr>
<tr>
<td>Satisfied</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Very satisfied</td>
<td>5</td>
<td>1.4</td>
</tr>
</tbody>
</table>

*Note.* Multiple responses were permitted in this question; therefore, frequencies do not add up to 100%.

Data represented in Table 42 indicate two distinct themes. Firstly, respondents \( (n = 371) \) are overwhelmingly dissatisfied with the current level of support for children with dyslexia from the state government (68.6%) and the federal government (61.7%). No respondents expressed satisfaction with the current Victorian state government support for children with dyslexia, however 1.4% of respondents \( (n = 5) \) indicated that they were “very satisfied” with the state government’s response and one respondent was satisfied with the current support from the federal government. The second strong theme which emerged from this data demonstrates the respondents’ lack of clarity regarding policy at both the state and federal levels. There were 36.3% of respondents who indicated they were “not sure what is provided” by the state government and 44% who indicated they were “not sure what is provided” by the federal government.

The category “other” \( (n = 57) \) contained comments expressing anger and sadness relating to the lack of government support:
It is a disgrace at both the state and federal level (Respondent no. 67).

There is NO support, it’s like we are the dirty secret that no one wants to acknowledge (Respondent no. 205).

There were also comments which acknowledged the impact of the lack of government support and the resulting inherent systemic inequity for children from lower socio-economic backgrounds:

Nothing is supplied. All children with Dyslexia need to qualify for funding in schools so that an aide is allocated to the classroom, otherwise it is very difficult for the child to access the curriculum and keep up with their peers. I have great concern for families that do not have the funds for private tuition and other costs of paediatricians and private psych help (Respondent no. 50).

Another respondent shared their perception of the impact of the lack of government support of children with dyslexia on the integrity of a psychological diagnostic assessment in the case of a psychologist employed by the Education Department:

Our daughter was in a state primary school and we were advised (by the teachers) that there was no point having her assessed by the department psychologists as their job was to find that the child did NOT need any funding support. (Respondent no. 226)

Respondents’ views regarding changes to government policy to assist children with dyslexia were explored and are presented in Table 43.
Table 43: Policy Changes Parents or Carers would Like to See at the State or Federal Government Levels

<table>
<thead>
<tr>
<th>Government policy changes (multiple response)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist training for qualified teachers regarding dyslexia</td>
<td>350</td>
<td>94.3</td>
</tr>
<tr>
<td>Special consideration granted for children with dyslexia at VCE (Victorian Certificate of Education) level</td>
<td>347</td>
<td>93.5</td>
</tr>
<tr>
<td>Policy for dyslexia awareness and training to be mandatorily included in general teacher training</td>
<td>339</td>
<td>91.4</td>
</tr>
<tr>
<td>Dyslexia awareness and support to be part of school policy documents including welfare, induction and discipline policy</td>
<td>308</td>
<td>83.0</td>
</tr>
<tr>
<td>Funding for computer technology and software to assist students in class and with homework</td>
<td>285</td>
<td>76.8</td>
</tr>
<tr>
<td>Funding for teachers’ aides</td>
<td>277</td>
<td>74.7</td>
</tr>
<tr>
<td>Universal screening for dyslexia for all primary school students</td>
<td>267</td>
<td>72.0</td>
</tr>
<tr>
<td>Funding for evidence based self-esteem raising programs for all children</td>
<td>261</td>
<td>70.4</td>
</tr>
<tr>
<td>Funding to enable purchase of specialist equipment</td>
<td>256</td>
<td>69.0</td>
</tr>
<tr>
<td>Funding for remedial teachers</td>
<td>255</td>
<td>68.7</td>
</tr>
<tr>
<td>Schools required to report to an independent body regarding compliance with reasonable accommodation for students who have dyslexia and other disabilities</td>
<td>228</td>
<td>61.5</td>
</tr>
<tr>
<td>Schools required to collect data on students who have dyslexia regarding educational outcomes, suspension, attendance, parent complaints and request for allied health support</td>
<td>201</td>
<td>54.2</td>
</tr>
<tr>
<td>Random review by independent body of compliance with education standards for disability support</td>
<td>182</td>
<td>49.1</td>
</tr>
<tr>
<td>No changes, satisfied with current policy</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Other changes</td>
<td>63</td>
<td>17.0</td>
</tr>
</tbody>
</table>

Respondents \( (n = 371) \) were able to select multiple answers to this question and on average respondents indicated that they supported nine proposed policy changes. The overwhelming majority of respondents \( (94.3\%; n = 350) \) indicated that in-service specialist training for teachers in relation to dyslexia was a priority for change. Correspondingly, \( 91.4\% \) of respondents \( (n = 339) \) indicated...
that they would like the inclusion of dyslexia awareness and training to be mandatory in all teacher training courses.

A majority of respondents (93.5%) was in favour of special consideration to be granted to students with dyslexia undertaking the VCE.

There was also a high percentage of respondents (83.0%) who indicated their desire for schools to incorporate dyslexia awareness and support in policy documents including welfare, induction and discipline policies. Table 38 revealed that respondents believed that written policies within schools incorporating dyslexia awareness and teaching policy was non-existent in the Catholic education sector and extremely rare in the state and independent school sectors.

Approximately three quarters of respondents (76.8%) would like changes to the provision of funding for computer technology and software to assist students in class with homework. A further 69% of respondents expressed a desire for funding for specialist equipment to assist children with dyslexia. Both these findings reflect a sense that appropriate resourcing in schools to assist children with dyslexia is absent. Close to three quarters of respondents (74.7%) expressed a wish for funding for aides in classrooms to assist students with dyslexia. At a marginally lower rate (68.7%), respondents indicated that they wanted the provision of remedial teachers as a resource in schools.

Close to three quarters of respondents (70.4%) advocated for evidence based self-esteem raising programs in schools for children with dyslexia. Respondents demonstrated support for schools to report to an independent body regarding compliance with reasonable accommodations for children who have dyslexia and other disabilities (61.5%). Additionally, close to half of the respondents (49.1%) supported a policy of random reviews by an independent body of schools’ compliance with education standards for disability support. Over half of the respondents (54.2%) also showed support for a policy requiring schools to collect data on students with dyslexia in relation to educational outcomes, suspension, attendance, parent complaints and requests for allied health support.
There was one respondent (0.3%), an outlier, who indicated no desire for policy change. A subset of respondents (17%) contributed comments to add depth to their selected response. Many of these responses reiterated strong support for initiatives which they had selected from the question options. There were multiple comments which expressed a sense of urgency and desperation for change which emphasised the need to support children and their parents and the need for equity of treatment:

YES and now not tomorrow. (Respondent no. 301)

Any change – I feel very unsupported by the school system (Respondent no. 394)

Support for parents either in terms of information packs or other support. Knowledge of resources available, consistent treatment of students with dyslexia. (Respondent no. 3)

There were three respondents who advocated for funding for “brain training programs” for children. Anti-bullying programs and education programs for students were recommended by a few respondents:

Funding for bullying programs so that students are encouraged to have an inclusive rather than exclusive outlook. (Respondent no. 5)

Also awareness [that] children who have LD [learning difficulties] are more prone to be bullied by other students. Programs to educate teachers, school staff so they are more aware of what’s going on in classroom and schoolyard. (Respondent no. 31)

Respondents were asked which level of government they believe should create and fund the proposed changes to policy.
Table 44: Respondent’s Preference for Government Level Policy Changes

<table>
<thead>
<tr>
<th>Level of government</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Either</td>
<td>211</td>
<td>56.9</td>
</tr>
<tr>
<td>Federal government</td>
<td>128</td>
<td>34.5</td>
</tr>
<tr>
<td>State government</td>
<td>32</td>
<td>8.6</td>
</tr>
</tbody>
</table>

In summary, over half (56.9%) of all respondents (n = 371) indicated that they would be satisfied with either State or federal government lead policy changes. Around one third of respondents (34.5%) favoured federal government responsibility for policy initiatives. Federal government leadership and, by implication, nationally consistent policies, were much more favoured by respondents than policy change at a State government level (8.6%). This is an interesting finding in light of the fact that responsibility for education in Australia rests within the jurisdiction of the state government.

A key finding from the data contained in Table 45 is that the majority of respondents who completed this survey perceived themselves as advocates. Secondly, data in Table 45 reveal that the overwhelming majority of respondents to this survey who act in the advocacy role for their child are female. Females responding to this question (n = 357) indicated that in 73.9% of cases they act as the child’s advocate. In a quarter of cases in which the mother (or female carer) was the respondent to the survey, the father (or male carer) also participated in the advocacy work on behalf of the child. In 0.8% of cases in which the mother completed the survey, the child’s father assumed the advocacy role. Amongst male respondents (n = 15) to the survey, 20% (n = 3) took on the advocacy role. In contrast to the female respondents, male respondents indicated that in 60% of cases this advocacy role was shared. Males who responded to the survey (n = 15) indicated that in 80% of cases they took on the advocacy role and the child’s mother took on the advocacy role alone in 20% of cases. The low number of male respondents to the survey on the one hand makes it very difficult to draw conclusions from this data; on the other hand, the low number of males completing the survey suggests the phenomenon requires further exploration. The
exploration of this theme of advocacy and gender is discussed in light of the literature on this topic in Chapter 8.

Table 45: Parental Advocacy

<table>
<thead>
<tr>
<th>Advocate</th>
<th>Female</th>
<th></th>
<th>Male</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Respondent to questionnaire</td>
<td>264</td>
<td>73.9</td>
<td>3</td>
<td>20.0</td>
</tr>
<tr>
<td>Both parents</td>
<td>90</td>
<td>25.2</td>
<td>9</td>
<td>60.0</td>
</tr>
<tr>
<td>Other parent</td>
<td>3</td>
<td>0.8</td>
<td>3</td>
<td>20.0</td>
</tr>
</tbody>
</table>

In addition, 16 respondents chose to add comments which revealed that in two cases children were now able to advocate for themselves, and that other family members such as the child’s step-parent, grandparent, or aunt assisted with advocacy. Additionally, in some cases organisations such as ADA assist with advocacy, and in one case a friend supported the respondent by accompanying them to meetings at the child’s school. There was also a comment from a mother related to the impact of the child’s father’s own experience of dyslexia on his capacity to advocate for his child:

My husband has dyslexia as well and feels unable to assist with our child’s learning he also finds it difficult to offer emotional support as it makes him very upset remembering his own school days and how unhappy he was. (Respondent no. 124)

There were several comments explaining that mothers are advocates, not because of a lack of interest on the part of fathers, but due to fathers’ long work hours and women’s lesser paid work commitments or more flexibility from employers. Literature suggests that women are more likely to be carers and advocates for children in the education sphere (Golden & Erdreich, 2014; Ryan & Runswick-Cole, 2008). Another possible cause for the high percentage of females as advocates was the division of labour roles within the family. Data presented in Table 32 indicate that, in this cohort, it is women who have reduced their
participation in the paid workforce in order to care for their children’s additional learning and support needs. This matter is discussed in more detail in Chapter 8.

The final question of the survey asked respondents if there was any other information they would like to add. Respondents’ responses \( n = 135 \) contained two key themes. One theme was a sense of gratitude to the researcher for initiating this research, which they hoped would be a harbinger of change, coupled with gratitude and relief for being given an opportunity to be heard. Respondents also used this open-ended question to relay experiences which they felt were important to be heard:

I really hope your survey provides data that will help the government realise something needs to be done to support children and adults with dyslexia. Funding is paramount, teachers are unable to provide that support needed in the current classroom setting. Children in schools are suffering and falling through the cracks if they don’t have a strong advocate that is willing to fight for them. Individual laptops with programs designed to assist learning need to be provided (we were willing to buy our own but the school said no their curriculum doesn’t support it) (Respondent no. 124).

Also evident in the response cited above is a sense of the social injustice manifest in the lack of government recognition and resources and the inequity caused by a system which requires children to have “strong advocates” and parents with resources if they are to succeed educationally. The themes of discrimination and a lack of social justice were also evident in other responses:

Very grateful for your research. I feel my child is discriminated against for all of her 10 years at school and it distressed me that no one values her enough. She has so much to contribute but is constantly looked on as stupid (despite the fact her IQ lies over top 1% in many areas) (Respondent no. 152).

The current situation [in] Australia results in Australia not meeting Human Rights obligations. The impact on these young people and families is unacceptable and must change. There is much to do. (Respondent no. 377)
While I can afford testing and interventions, I was astounded to find that this is not readily funded by the govt. (even if means tested) and there are long waits for any govt-funded assistance. Surely, it would ultimately save society money by diagnosing and treating early to make people with dyslexia reach their potential and become as full a member of society as possible. (Respondent no. 367)

There were also testimonies of the impact of the lack of policy recognition of dyslexia on relationships and family functioning, highlighting the negative impacts on children but also on parents:

Having a child with Dyslexia, in a country that barely recognises it, has put an incredible [sic] strain on our family and our marriage. Both together and individually, we have been taxed financially and emotionally. The distress we have been through watching our son go from a happy, articulate and happy little boy to an increasingly anxious, distressed and suicidal child over the course of his primary school experience has been horrendous (Respondent no. 5).

**Summary**

This key contribution of this chapter is the quantitative and qualitative findings which shed light on the experiences encountered by parents of children with dyslexia in the three major school sectors in Victoria. In exploring respondents’ perceptions of confidence in the ability of their child’s teacher to cater for, support and help accommodate their child’s learning needs, all sectors ranked poorly, with the greatest dissatisfaction for all indicators of satisfaction and confidence in the state school sector. Additionally, findings indicate that, while slightly more common in the independent school sector, it was rare in all school sectors for children to receive either one-to-one or group classes specifically designed for children with dyslexia.

Findings demonstrate that the term “dyslexia” is the most frequently used terminology to describe dyslexia in the school context. However, some respondents indicated that they had experienced opposition to the use of the term “dyslexia” by their child’s school. The term “learning difficulty” is a more frequently preferred term than “learning disability” to describe dyslexia.
Pejorative labels such as “lazy” and “daydreamer” were used by teachers to describe children in a minority of instances. Data demonstrate that labels were more frequently assigned to males than females. Gender was also prominent in relation to advocacy. Responses demonstrated that in the majority of this survey’s cohort, it is the mother who acts as advocate for the child.

Findings demonstrate that respondents are dissatisfied with the current level of support provided to their children by the state and federal government. Many respondents are also unsure of what support is provided. Parents recommended a raft of policy changes and reforms. These policy recommendations regarding dyslexia are discussed in Chapter 9 of the thesis.
PART C:
DISCUSSION
CHAPTER 7:
DISCUSSION – AN EXAMINATION AND
CONTEXTUALISATION OF THE EXPERIENCES OF
PARENTS OF CHILDREN WITH DYSLEXIA

Introduction

This study contributes to the discourse on dyslexia by shedding light on the experiences of parents of children with dyslexia and highlighting the status of dyslexia in Victoria. Chapters 7, 8 and 9 contain a synthesis and an interpretation of the quantitative and qualitative findings from this study, contributing to this previously unexplored subject. The discussion draws on international literature in relation to dyslexia and utilises Nancy Fraser’s (1989) theoretical model of needs recognition as a framework to contextualise the experiences of parents and the status of dyslexia. Fraser’s model of needs recognition contains an overarching framework with which to understand the transformation of the unrecognised needs of marginalised citizens into social, political and economic recognition within the landscape of a Western liberal democracy (Fraser, 1989). A contribution to Fraser’s theoretical model of need recognition is proposed in light of the findings from this study. Implications of the findings of this study for the field of social
work research and practice are discussed. Key policy recommendations arising from the findings and literature examined in this study are presented.

The discussion chapters are structured around the three major themes which emerged from the qualitative findings. These overarching themes consist of:

- the structural invisibility of dyslexia;
- contestation over resources; and
- inequity and the right to an education

Each of these themes contain multiple subthemes which were presented in the qualitative findings in Chapters 3 and 4 and are reflected upon in relation to the status of recognition of dyslexia in the discussion chapters. The discussion chapters—Chapter 7, Chapter 8 and Chapter 9—are divided according to the aforementioned three major themes.

Chapter 7 begins with an exploration of the structural invisibility of dyslexia and parents’ struggle for recognition of their children with dyslexia within the education system. Chapter 8 focuses on the contestation over recognition and the allocation of resources. It examines the interplay of responsibility between the state, educational institutions and the family, taking into consideration socio-economic factors. It addresses the issues associated with parental advocacy including the role that gender plays in parental advocacy. Chapters 7 and 8 address the first two research questions of this study. The first research question relates to parents’ experiences of the pathway to diagnosis of their child’s dyslexia and how they experience gaining recognition and support for their child’s learning needs:

RQ1. What are the experiences of parents who live in Victoria, Australia who have a child with dyslexia with regard to:
(a) the pathway to the diagnosis of their child with dyslexia; and
(b) gaining recognition and support for their child’s learning needs arising from dyslexia.
The second research question which underlies this study is the status of dyslexia. This question was referred to continuously throughout each chapter of the findings:

RQ2. What is the status of the recognition of dyslexia in Victoria and how does it impact on parents?

Chapter 9 contains a discussion of the third major theme arising from this study which is inequity and the right to an education. This chapter continues addressing the second research question relating to the status of the recognition of dyslexia and includes a response to the third research question which concerns policy recommendations arising from this study:

RQ3. What policy recommendations regarding dyslexia arise from this study?

These three discussion chapters benefit from the use of Fraser’s model of needs recognition which is embedded, analysed and expanded upon throughout each chapter.

**Structural Invisibility of Children with Dyslexia**

Fraser describes “needs-talk” as an “idiom for political conflict” and has observed that it has become “institutionalised as a major vocabulary of political discourse” (Fraser, 1989, p. 291). The discourse relating to dyslexia in this thesis identifies dyslexia as a “need” and as a site of political contestation in relation to its recognition in Victoria. The term “recognition” used in relation to dyslexia is ambiguous and multifaceted. In the context of this discussion, the term “recognition” is used in four distinct but interrelated contexts. First, dyslexia is genetic in origin, manifesting in brain neurology which leads to specific processing deficits (Frith, 1999; Shaywitz, 2003). There are no external physical markers and therefore its manifestation is invisible to the eye (Fuchs, Fuchs & Speece, 2002). Dyslexia becomes visible in the individual at a behavioural level by observance of a range of symptoms which include poor reading and writing occurring on a continuum of severity (Frith, 1999). To those without knowledge
of and insight into symptoms of dyslexia, it is a wholly invisible syndrome which is sometimes confused with low intelligence (Washburn et al., 2013). The second form of “recognition” connotes recognising or identifying the manifestation of dyslexia on an individual level. This type of recognition is intermeshed with the third form of recognition—namely, recognition that dyslexia is a distinct and bona fide syndrome—and with the fourth form of recognition—namely, political recognition. Fraser (2003) acknowledges that the Hegelian, philosophical roots of her definition of recognition are recognition as “rooted in social patterns of representation, interpretation, and communication” (p. 13). She asserts that “non-recognition” includes “being rendered invisible” and being subjected to “disrespect” (Fraser, 1989, p. 13). This is the fourth type of recognition referred to in this discussion. All four forms of “recognition” are of significance to this study and are referred to in this discussion.

Fraser (1989) provides a theoretical model with which to shift the discourse from a focus on a particular need to a discourse about the recognition of needs, “the politics of need interpretation” within a socio-political context (p. 292). Fraser (1989) divides the politically contested struggle of needs recognition into three phases. The first stage is the struggle between those interest groups who wish to establish that the need contains a valid political claim for recognition and those who contest this claim. The second stage is the struggle by competing interests over the interpretation and definition of the need, as this will determine how the need is met and by whom. The third stage of Fraser’s model is the struggle over the provision of resources. The question which arises at this stage is from whom and to whom will provisions be distributed to meet this need (Fraser, 1989, p. 294).

Fraser observes that the state begins to assess the needs of its citizens by first posing the question: “Shall the state undertake to satisfy the social needs of a given constituency, and if so, to what degree?” (1989, p. 145). The “constituents” in this study encompass both children with dyslexia and their parents. When Fraser’s contention is applied to the context of this study, it could be argued that in the absence of satisfaction of the needs of children with dyslexia by the state, the weight of parents’ importance as constituents is increased. Conversely, in the
context of a political economy and educational environment in which the learning needs of children with dyslexia are met by the state (and their psychosocial needs given due consideration), the role of parents as constituents is decreased.

**Identifying the Site of Struggle for Need Recognition**

The findings of this study indicate that the first stage of the struggle “to establish or deny the political status” (Fraser, 1989, p. 294) of dyslexia in Victoria is largely located at the interface between parents and school personnel such as teachers, principals and other professionals. The trajectory of parents’ journey uncovered by this study indicates that parents begin to grapple with the lack of recognition of dyslexia when they begin to engage with their child’s school in an attempt to understand their child’s problems with literacy. The findings suggest that parents commonly experience the dismissal of or a resistance to their concerns by the school and a misattribution of the underlying cause of the difficulties. Erroneous labelling and disputes over terminology with teachers characterise the beginning of parents’ struggle to have their child’s needs recognised within the school context. This is explored more fully later in the discussion. The salient issue is that the struggle for political recognition commences at the coalface on an individual level between parent and school. Whilst the forces that underlie the lack of recognition emanate from the macro political level at the early stage of parents’ struggle, parents experience these forces on a personal level and grapple with contextualising the underlying cause of the adversity.

**Insights into the Journey to Identification and Diagnosis of Dyslexia**

Respondents to the survey \((n = 403)\) indicated that in 71% of cases it was parents who identified the signs of their child’s struggle with literacy. Parents \((n = 403)\) reported that teachers noticed signs and informed parents of their concerns in 13.4% of cases. This discrepancy between the high rate of parental identification of signs of children’s learning disability and the low incidence of teachers’ observations of the signs, is the first indicator of the invisibility of
dyslexia across the state, Catholic and independent school sectors. This finding from the survey is congruent with the narratives which emerged from the interviews with parents. Amongst the 21 interviewees, there were no instances in which a teacher approached a parent to raise concerns about a child’s progress with literacy. There was only one exceptional case in which a teacher and a parent conjointly concurred in the first instance that a child was demonstrating signs of struggle with literacy that required further investigation.

On first analysis, the findings from this study are inconsistent with earlier Australian research findings. Rohl, Milton and Brady (2000) report findings from a survey questionnaire completed by 377 school officials from a national sample derived from the Catholic, independent and state sectors. Results from that questionnaire found that school officials indicated that classroom teachers were involved in the identification of 81% of children’s “learning difficulties”. Whilst the terminology “learning difficulties” is used by Rohl et al. (2000), their study captures children with dyslexia as one of the four subsets of student included in the study. The study by Rohl et al. (2000) had a national focus, rather than a Victorian focus, and surveyed school officials rather than parents. However, on deeper analysis it is clear that the vast discrepancy in findings between this present study and the study by Rohl et al. relates to the fact that in the majority of cases, school officials report that children’s difficulties are identified by the observation that a child has fallen two or more years behind expected benchmarks academically (Rohl et al., p. 13). The 2000 survey did not ask participants if, during those two or more years of the child’s progressive failure in literacy, the parents had approached teachers with their concerns. Findings emerging from the study in this thesis are congruent with overseas study findings. In the United Kingdom, Riddick’s (1995) qualitative study found that amongst 22 interviewees it was the child’s mother who first identified that there was something wrong (p. 461). Additionally, in 15 of the 22 cases (69%), it was the mother who first identified that the problem may be dyslexia. In only five instances in Riddick’s

14 The other three subsets of students included in the study are: children from low socio-economic conditions which places them at educational risk; children with low levels of cognitive ability; and children from homes in which English is not the first language: (Rohl et al., 2000, p. 5).
study (1995) did teachers identify and raise concerns with the parent in relation to the child’s literacy skills. While Riddick’s study is qualitative and does not contain quantitative data, its findings points to a similar trend evident in the data from this study.

In the present study, parents who participated in the survey and the interviews overwhelming reported that the three most prevalent signs of children’s dyslexia pre-diagnosis were difficulties with reading, spelling or writing. Parents’ observations of their child’s difficulty keeping pace with school peers academically, and an unexplained gap between parental perception of their child’s intelligence and the child’s achievement at school, were common signposts leading to the investigation of children’s struggle with literacy. The commonality between these indicators is that they relate to children’s academic progress. Interviewees and survey respondents indicated that these signs of academic struggle were often accompanied by negative psychosocial indicators such as a drop in self-esteem, anxiety, depression and resistance to school attendance.

Findings from the survey quantified consultation patterns indicating that parents in their search for answers to their child’s difficulties pre-diagnosis sought help from on average five professionals before securing a diagnosis of dyslexia. Most frequently, parents sought advice and help from the child’s teacher. This finding demonstrates that teachers are commonly perceived by parents as the experts most qualified to assist with identifying causes of unexpected difficulties with literacy. This is unsurprising as teachers are charged with the responsibility for teaching children to read and write. The failure of teachers to recognise the signs of dyslexia and to refer parents directly to appropriate services and supports is indicative of systemic failure to invest in teachers’ development of knowledge in relation to dyslexia. This theme of teacher training in relation to dyslexia and teachers’ response to dyslexia is discussed throughout this chapter. However, a thorough analysis examining the structural constraints which lie at the core of the issue and recommendations for future policy developments in the area are presented in Chapter 8, which examines inequity and the right to an education.
The Pluralistic Discourse Relating to Children’s Needs

Fraser’s needs recognition framework proposes that each political struggle over needs contains a pluralistic discourse (1989). Fraser describes these pluralistic discourses as the socio-cultural “means of interpretation and communication” and refers to them using the initialism “MIC” (1989, p. 294). MIC discourses contain tensions in relation to language and classification of the need (Fraser, 1989).

One thread of the pluralistic discourse lies in the themes emerging from the findings of this study which identify the occurrence of clashes between schools and parents over the identification of signs of dyslexia and the differing perceptions and interpretations of the initial signs of children’s literacy struggles. Emerging from the interview findings is a clear pattern of teachers refuting, misattributing, dismissing and minimising parents’ concerns in relation to their children’s slow academic progress and mastery of literacy skills. There are very few exceptions to this pattern. Commonly, teachers attributed the child’s literacy failure to negative behaviour and innate factors such as lack of intelligence, lack of effort, laziness, lack of risk taking and immaturity. In some instances, they attributed blame to the parents or the home environment. This pattern of misattribution and blame is consistent with themes arising from findings in Riddick’s study of parents of children with dyslexia in the United Kingdom (1995). A theme which emerged from Riddick’s qualitative study was the sense of blame felt by parents as a result of the school’s interaction with them in relation to their child’s literacy struggles (1995, p. 465). Insights from the present study illustrate the conflicting discourse over children’s needs and struggles and teachers’ rejection of parental concerns, indicating the potential neglect of dyslexia in the educational context as a whole. The delegitimisation of parents’ feelings or concerns creates a sense of cognitive and emotional dissonance for parents and is a by-product of the lack of instruction in relation to dyslexia in pre-service teacher education. Respondents to the survey (n = 385) were asked to identify any challenges they experienced in dealing with their child’s dyslexia. Three quarters of respondents highlighted the challenge caused by teachers’ lack
of knowledge about dyslexia (76.4%). The invisibility of dyslexia—that is, the “being rendered invisible” as a result of “non-recognition” (Fraser, 1989)—combined with the lack of physical, visible markers which identify the manifestation of dyslexia, coalesces with the lack of teacher training and awareness of dyslexia as a distinct and bona fide syndrome. This mix of factors leads to tension between parents and schools in relation to the discourse around the needs of children with dyslexia.

**Gender, Labels and the Invisibility of Dyslexia**

This study identifies that the pluralistic discourse in relation to dyslexia in Victoria also contains tension, post diagnosis, in relation to the use of language, labels and terminology to describe dyslexia. Data from the survey quantify the use of labels and language to describe dyslexia according to gender. Findings suggest that the gender of the child may influence teachers’ (and other professionals’) perceptions of the underlying cause of the child’s difficulty and their assignment of labels.

Results from the survey indicate that children’s academic failure is often attributed to negative intrinsic factors such as supposed laziness, daydreaming, having a conduct disorder or possessing low intelligence. Correspondingly, in Riddick’s study of parents in the United Kingdom, it was found that parents perceived that their child had been informally labelled as “thick or slow” and labelled “lazy” by teachers (Riddick, 2010 citing Riddick, 1995, p. 86). An Australian study on the attribution of the characteristic of “laziness” by parents and teachers concluded that the learning needs of an unknown number of children may be ignored due to the erroneous presumption of laziness (Gilmore & Boulton-Lewis, 2009).

In this study, the data in relation to labels assigned to children were further analysed by gender. The largest difference in labelling of males and females occurred in relation the pejorative label of “lazy”. This finding on the application of the erroneous label of “laziness” supports earlier Australian research by Elkins (2000). Elkins lamented that the practice of blaming a child with a learning
disability for being “lazy” was “still pervasive” when he was writing in 2000. Other research highlights that the stigma associated with negative labels such as “lazy” and the relegation of challenges which are neurological in origin to attitude and effort has ramifications for children’s self-esteem (Gilmore & Boulton-Lewis, 2009). Children’s low self-esteem emerges as a significant concern for parents in this study and is discussed later in this chapter. Mislabelling a child with dyslexia as “lazy” also contributes to the invisibility of the underlying condition. There are a range of possible negative outcomes from the misattribution of a child’s learning disability to laziness and other labels such as “daydreamer” or “lacking in intelligence”. These include the risk that a child will remain undiagnosed for a lengthy period of time, poor academic outcomes as a result of a lack of remediation, possible punitive treatment by teachers for perceived “daydreaming” or “laziness” as well as negative impacts in relation to conflict within the family (Gilmore & Boulton-Lewis, 2009; Levine, 2003; Weiner, 1984). Data from this study support these findings. In addition, there is the alarming danger of students believing that the negative label given to them is accurate and, therefore, sliding into a self-fulfilling negative spiral. Interviews revealed that in some cases parents mistook their child’s learning disability for signs that the child was not making an effort to learn or was demonstrating laziness. This sometimes resulted in harsh and punitive treatment of children. In one particular case of a child who was diagnosed at 16 years of age (Interviewee no 5), the remorse of the parent for her punitive treatment was very apparent in the interview.

Punitive treatment of children resulting from the mistaken belief that the child is not making an effort to learn is not limited to parental behaviour towards children. Evidence from interviews and surveys suggests that teachers occasionally engage in harsh treatment of children, such as restricting the play time of a child in the early years of school for slow work progress.

While the data from this study demonstrates that both males and females with dyslexia (diagnosed and undiagnosed) are at risk of negative labelling, the risk is slightly higher for males. This is the case for all categories excluding the labels of “comes from a dysfunctional family” and “having low intelligence”. The frequency rates for these categories are only slightly higher for females than males.
and it is therefore important to consider the implications for both genders. Both family of origin and intelligence are characteristics that are static and unchanging. Therefore, perceptions that the underlying cause of a child’s problem is that the child has low intelligence or belongs to a dysfunctional family may contribute to low expectations of the child or a belief the remediation will not be effective. A study into the consequence of teachers’ low expectations of students found that such expectations of a student’s ability to perform academically may result in a self-fulfilling prophecy of poor performance (Saracho, 1991; Westwood, 1995). Other studies confirm this finding, highlighting that teacher confusion surrounding dyslexia may result in a degree of “learned helplessness” amongst teachers which translates into simplification of student learning tasks and lowered teacher expectations (Kerr, 2001). There is a suggestion arising from the interview findings that negative perceptions and stereotypes of single mothers may place children at increased risk of their teacher having low academic expectations. Further research in this area could examine this issue to ascertain whether children from single parent families face additional barriers to the identification of dyslexia resulting from stigma and negative stereotypes associated with single parenthood.

A study conducted in 2000 suggests that there is considerable confusion amongst Australian teachers in relation to the difference between learning disabilities which are intrinsic to the neurology of the child and factors which contribute to educational risk (Nichols, 2000, p. 29). Nichols (2000) highlights that it appears that teachers erroneously associate the Commonwealth-defined risk factors for educational disadvantage (such as poverty, low family expectations and challenges to the family unit such as sickness and disability) as the root cause of learning disabilities (p. 29). Findings from the present study suggest that little has occurred to effect change during the intervening years since 2000. Research from other countries shows different findings. Of note is an international cross-cultural comparison study of pre-service teachers’ knowledge of dyslexia in the United Kingdom and the United States which found that teachers did not attribute casual blame for dyslexia to the home environment (Washburn et al., 2013, p. 13). Moats (2014), a distinguished literacy expert, acknowledges the inadequacy of teacher training in relation to literacy acquisition and notes that educational institutions
that provide teacher training are faced with an important task of challenging the “established schemas of educators who believe that learning to read should be easy or natural, and who are ready to blame parents, cultures, poverty, or laziness for students’ failure to read” (p. 85). This is critically important to addressing the hardship that children with dyslexia face in Victoria.

According to parents’ views, males referred to in this survey were thought by teachers, psychologists and other professionals to have a “conduct disorder” at approximately three times the rate of females. There is a great deal of debate in the literature regarding the prevalence of dyslexia in males and females (Chan et al., 2007; Limbrick, Wheldall & Madelaine, 2008; Quinn & Wagner, 2015; Shaywitz et al., 1990). This study contributes to this debate on prevalence by providing evidence that in this survey sample, according to parents, females less frequently attracted labels from teachers and were less likely to demonstrate challenging behaviour in the classroom than males. There is previous Australian research evidence demonstrating that males are more likely to display disruptive behaviour in the classroom, and females are more likely to display more passive behaviour (Prior et al., 1995). Irrespective of the underlying cause of this phenomenon—whether it relates to internalised female and male social norms and conditioning or to teacher’s perceptions of behaviour and gender—or, indeed, whether it reflects reality, the differences in labelling of males and females has implications for the identification and treatment of the child’s dyslexia. Males who act out behaviour to distract attention from their difficulties or to unconsciously externalise their distress are at risk of having their dyslexia misidentified and treated as a conduct disorder. Alternatively, they may have their behaviour and needs investigated more quickly than females who internalise feelings and do not demonstrate problematic or disruptive behaviour in the classroom.

Males referred to by parents in this study were more likely than females to be assigned labels pathologising their behaviour, for example ADD and Asperger’s syndrome. While there is research evidence that 15–25% of people diagnosed with dyslexia will also have a diagnosis of ADHD (Shaywitz et al., 1990), this study attempted to include only parents of children with a single
diagnosis of dyslexia. It is therefore likely that these additional labels (of ADD and Asperger’s syndrome) were incorrectly applied to many children referred to by parents in this study. The increased and, presumably, erroneous labelling (in most cases) of boys has implications for how they and their parents may be treated by teachers and whether their literacy concerns are taken seriously. Both of these possibilities would serve to exacerbate the structural invisibility of dyslexia and delay remediation. These findings also suggest that parents of sons with dyslexia and parents of daughters with dyslexia contend with a different set of barriers in their interactions with teachers resulting from a slightly different set of perceptions regarding the issues their children face. This has implications for the issues they face in their parental advocacy role when interacting with the child’s school and in other contexts. Findings from this study suggest that barriers faced by parents of males in obtaining support are more likely to be related to the pathologising of male behaviour or misattribution of their behaviour arising from their learning disability. By contrast, barriers faced by parents of females in obtaining support for their daughters are more likely to be related to a heightened invisibility of their dyslexia.

**Obstacles on the Route to Diagnosis**

Findings from the interviews and the survey reveal that parents grapple with navigating their own unique pathway through a myriad of fee-for-service providers in a multitude of professional disciplines to uncover the cause of their child’s difficulty. These findings concur with the report from the National Working Party on Dyslexia which highlighted in 2010 that there is no specified diagnostic pathway for children or adults with dyslexia in Australia. Very few parents who participated in the interview process for this study were aware of or granted access to state-funded psychological assessments through the Department of Education. Interviews indicated that the lack of guidance through the maze of services created a financial burden for parents and also caused parents to feel isolated and unsupported. Research comparing the policy treatment of dyslexia in the Netherlands with that in Australia highlighted that, unlike the Netherlands where health insurance covers diagnosis and treatment of dyslexia, in Australia
parents need to secure the services of an educational psychologist (Steeg & Firth, 2012). Firth et al. (2010) point out that, consequently, only people with a secure and adequate income are able to access a diagnosis of dyslexia and support services.

Findings from the survey (n = 364) concur with the contention of Firth et al. (2010). Half of the respondents (50.8%) spent between $1001 and $3000 to obtain a diagnosis. Whilst there were 13.5% of respondents who spent between $3000 and $5000 on assessments, 17.6% indicated that they spent over $5000 on exploring the child’s difficulties with literacy. This amount of expenditure is a substantial outlay in financial terms. It also has social justice and equity ramifications. Table 27 in Chapter 5 displays data which demonstrate that respondents (n = 385) indicated with a frequency of 63.1% that they found it challenging to meet the expenses they incurred whilst seeking a diagnosis for their child. This is particularly striking as the demographic data relating to survey participants’ income demonstrates that, on average, these parents have an income higher than the general population. Furthermore, these findings attest to the fact that children were frequently subjected to an extensive array of unwarranted and time-consuming tests. This raises the question of the impact of frequent and extensive testing not just on family budgets and time but on the child’s self-perception.

The quantification of expenditure sheds light on the indirect route parents embark on in the pathway to diagnosis. However, it also illustrates inherent systemic problems with the relegation of responsibility for identification of children’s learning difficulties to parents. Reflecting on their expenditure, some parents were acutely aware that the expenses involved with ultimately obtaining a diagnosis would be prohibitive for families from low socio-economic backgrounds and expressed their distress at this injustice. The cohort included in this study consisted solely of parents who had successfully navigated the system to obtain a diagnosis. The voices unheard by this study are those who remain in limbo with children who are undiagnosed. Data from this study suggest that the undiagnosed in this social policy regime are most likely to be children from families with low socio-economic backgrounds who do not have the resources
required to fund testing. They are most likely to be children whose parents are not empowered to advocate for resources within the school environment due to disability, disadvantage, low self-esteem or lack of English language skills. They may lack familiarity with the workings of the education system in Victoria due to migrant status. This raises an important and concerning social justice issue relating to educational equity and access to resources. This relates not only to resources for testing for dyslexia, but also resources for remediation and accommodation with the school system. The focus on resources is expanded upon and discussed in relation to recognition and Fraser’s needs recognition model in Chapter 8 along with inequity and the right to education.

**The Serendipitous Nature of Diagnosis**

Findings from this study demonstrate that the length of time that children remain in limbo, with undiagnosed dyslexia and experiencing academic failure, varies substantially. The quantitative data demonstrate that on average children remain undiagnosed from the appearance of initial problems until diagnosis for an average of 2.81 years; this equates to three academic years. While 16 children out of a total of 396 were diagnosed in less than six months from the first observation of symptoms of difficulty, at the other end of the spectrum, six children remained undiagnosed for 12 years. Findings from the interviews show that the time a child remains undiagnosed varies amongst this cohort from 18 months at one end of the spectrum to 11 years at the other. Averages have the effect of concealing individual experience within statistical data. However, parents’ narratives evident from the interviews reveal the extent of the pain and suffering of children who remain undiagnosed for lengthy periods.

A necessary constraint of this study is that it only includes the experiences of parents whose children have secured a diagnosis of dyslexia from a qualified psychologist. Dyslexia, even in policy regimes where there is a long history of recognition (such as the United States), often remains “undiagnosed, undocumented or not revealed” (Taymans, 2012, p. 13). The fact that this study captures the experiences of parents who have obtained a diagnosis for their child
skews the statistics on the gap in time between the first sign of difficulty and the age at diagnosis. Not included in the data from this study are those children whose symptoms remain undiagnosed or misinterpreted. Also missing from this data are the voices of those parents for whom the cost of diagnosis remains prohibitive. Consequently, the figure of 2.81 years from first sign to identification at best provides us with a skewed glimpse of the gap in time from parental concern for a child to point of diagnosis.

Findings from this study suggest that, in the absence of mandated state educational policy stipulating that all children experiencing literacy difficulties require screening for dyslexia, the timing of a child’s diagnosis will remain dependent on a range of serendipitous factors. These factors include encountering a teacher (or another professional) with knowledge of dyslexia and pursuing further investigation despite deterrence by teachers. Other factors which influence the timing of diagnosis include having direct access to an educational psychologist through the state education system or sufficient resources to access private consultations that lead directly or circuitously to an assessment for dyslexia. Evidence also suggests that a parent’s ability to advocate for their child to gain access to the services of an educational psychologist within the Department of Education and Training may also impact on the timing of diagnosis. Therefore, in some cases, parents’ advocacy skills are an important factor for children in securing a diagnosis of dyslexia in Victoria. This has far-reaching ramifications for those children whose parents are ill equipped to act as advocates due to poor English language skills, lack of confidence in interacting with the education system due to lack of education, their own dyslexia or lack of familiarity with the Australian education system or with advocacy. Additionally, parents with mental health issues or other forms of disability or those whose workforce participation does not allow the flexibility required to engage in advocacy during school hours, are likely to experience greater hardship with the role of advocate.
The Impact of Dyslexia in the Family on Recognition and Identification of Dyslexia

Many leading researchers contend that dyslexia is a genetically heritable condition (Galaburda, LoTurca, Ramus, Fitch & Rosen, 2006; Ramus, 2006; Snowling et al., 2003). Findings from the quantitative data demonstrate that respondents \((n = 403)\) collectively identified 611 people amongst their nuclear or extended family with diagnosed, or suspected but undiagnosed, dyslexia. Findings from the interviews also shed light on the fact that in the majority of cases there is diagnosed, or suspected but undiagnosed, dyslexia in the child’s nuclear (i.e. the child’s parents) or extended family. However, this knowledge in most instances did not translate into a quicker route to diagnosis for the child referred to in the interviews. In some cases, a parent revealed to their partner that they also had dyslexia only after their child was diagnosed. In other cases, it was revealed to parents that they had indicators of undiagnosed dyslexia once their child was diagnosed. Sometimes psychological denial processes prevented parents from wanting to acknowledge the possible existence of dyslexia in their child. Where there was more than one child with dyslexia in the family, in some instances this fact was helpful in speeding up the progress to diagnosis for the second child; and other cases, the differences in manifestation of symptoms between children did not help in the identification of dyslexia, but was of assistance in accessing support services.

Impact of Delay in Identification of Dyslexia

A delay in identification of dyslexia impacts on the timely application of effective educational intervention (Washburn et al., 2013). Australian researchers Coltheart and Prior (2007) observed the seriousness of “thousands of children in Australian schools who are struggling with literacy requirements every day, and whose future will be seriously compromised if they do not receive expert help” (p. 7). The Australian Senate committee report, “Education of Students with Disabilities” (2002), found that there is a skills shortage amongst teachers, reflecting a training deficiency, in relation to teaching children with disabilities,
including learning disabilities such as dyslexia (2002, p. xxi). The committee partially attributed the blame for the skills shortage to the fact that university courses are driven by the demand of market forces (2002, p. xxii). It recommended that the federal government accept fiscal responsibility and fund an investment in teachers’ knowledge and skills in relation to teaching children with disabilities (2002, p. xxiii). Evidence from the experiences of parents in this study suggests that the federal government has not implemented this recommendation. This lack of political will and action renders dyslexia virtually invisible in the classroom.

The failure to address teacher education in relation to dyslexia is related to a lack of investment in this goal and therefore the ongoing systemic invisibility of dyslexia. The lack of systemic recognition contributes to the individualisation of the problem. In other words, the submerged status of dyslexia in Victoria impedes the struggle “to establish or deny the political status” of dyslexia (Fraser, 1989, p. 294) and, at the same time, is the root cause of the problem that parents encounter in meeting the needs of their children. This implies that under some conditions, Fraser’s model of the politics of needs interpretation requires a “prequel” to the first phase of recognition. In the case of dyslexia, the symptoms are manifested in the individual and their experiences are shaped by the response of the environment before the syndrome can be identified. The unidentified cause of the child’s distress and the submerged status of dyslexia make it very difficult for parents to understand their child’s needs and initiate effective advocacy for appropriate support. Until the needs of children with dyslexia and their parents are understood, acknowledged and treated universally with an effective overarching and effective policy response, each family begins a solitary and challenging journey to identification of dyslexia in a state of confusion and an environment of obfuscation. This is confirmed by data which demonstrate that on average parents consult five professionals before obtaining a diagnosis. Additionally, parents who participated in interviews reflected on their perceptions of the pathway to diagnosis and support, describing it in terms such as “a journey full of frustration and lack of clear information”, “a maze” and “a patchwork of discovery”. Their descriptions and testimonies of struggle to understand their child’s difficulty and
forge a pathway to support illustrate the importance of raising the profile of
dyslexia in the community generally, and within the context of schools
specifically. Therefore, evidence from this study suggests that the prequel to stage
one of Fraser’s model—“establishing or denying the political status of a need”
(1989, p. 294)—is raising awareness of the existence of the “need” in public
discourse. In relation to invisible or hidden needs, such as dyslexia, it is only once
awareness is raised that the battle to establish the political status of the need can
begin.

Summary

This chapter sheds light on the multifarious factors contributing to the
structural invisibility of dyslexia in Victoria. As such it provides a discussion and
analysis of the findings and literature in relation to the challenges parents face on
the route to the diagnosis of dyslexia and on the pathway to gaining support and
recognition for their children’s learning needs. Using Fraser’s (1989) model of
needs recognition, the discussion illustrates that there is systemic failure at a
structural level to support children with dyslexia. The struggle for needs
recognition of children with dyslexia is largely being waged by parents at their
interface with schools. The obstacles that parents face as the result of the lack of
recognition of dyslexia due to a lack of teacher knowledge and awareness of
dyslexia, and other constraints which hamper the provision of support to children,
are explored and discussed. The mislabelling of children’s difficulties and the
rejection of parents’ concerns are identified as being caused by the lack of
recognition of dyslexia as well as contributing to the lack of recognition of
dyslexia.
CHAPTER 8:
DISCUSSION – RESOURCES AND INEQUITY

Introduction

This chapter addresses the first two research questions of this study. It discusses the findings relating to parents’ experiences of the pathway to diagnosis of their child’s dyslexia and their experiences of gaining recognition and support for their child’s learning needs. This sheds light on the status of dyslexia. In particular, this chapter focuses on the second major theme to emerge from the findings, that is the struggle over recognition and the allocation of resources. The chapter is divided into three sections. The first section contains an analysis of the findings in relation to the terminology schools used to refer to dyslexia and the implications of the use of terminology for the recognition of dyslexia. The second section discusses the findings in relation to advocacy, gender and the power struggle between parents and schools. The third section contains a discussion of the status of dyslexia in the political and legislative environment and the impact of recognition on the interpretation of the needs of children and the provision of resources. All sections draw on the findings and relevant literature including Fraser’s (1989) model of need recognition. The synthesis of this material responds
to the third research question, “What is the status of dyslexia in Victoria and how does it impact on parents’ experiences of seeking support for their child?”

Contestation over the Recognition of Dyslexia and the Allocation of Resources

According to Fraser’s model of need recognition, the second phase of the struggle involves contestation over how the need is defined and interpreted. The outcome of this struggle influences what measures are taken to satisfy the need (1989, p. 294). Fraser’s model refers to the macro picture of the struggle over the definition and interpretation of the need in the political arena. In the case of the struggle for recognition of dyslexia in Victoria, evidence from this study suggests that the political battle is being fought by parents in isolation and occasionally in coalition with each other. The main site of contestation for need recognition of children with dyslexia is the interface between parents and schools. It is in the school context that contestation over language, interpretation, need definition and resources are fought. Whilst on occasion a skirmish breaks out of the boundaries of the private domain and enters the public arena in the form of a newspaper article, a public inquiry, a court case or a government initiated working party, the site of the main contestation is largely confined to the individual level. Forces that confine the struggle for the recognition of dyslexia to the private and economic domain may be partially attributable to the neoliberal agenda, with its focus on relegating responsibility from the polity to the private domain. As long as the bulk of the battle for recognition of dyslexia is confined to individual struggles between parents and schools, it will be excluded from the discourse of social justice (Riddell, 2009). Evidence from this study demonstrates that this relegation of the struggle for recognition to the private domain is highly problematic for parents in relation to the identification of dyslexia, labelling of dyslexia, the negotiation with schools in relation to resources, remediation and treatment of children. Additionally, this study shed lights on the problematic nature of the individualisation of the battle over use of language and over resources. Findings reveal the extent of the burden on parents from an economic perspective.
Section 1: Exploring Power and Labels – The Ramifications of the Failure to Recognise Dyslexia

F indings from the interviews and surveys demonstrate a level of disputation around the terminology used to describe dyslexia. The debate over terminology contains within it deeper layers of contention relating to a more fundamental battle over the existence of dyslexia. The outcome of this struggle, as described by Fraser, influences the outcome of the provision of resources, funding and remediation on an individual level. On the macro policy level, the struggle over terminology and the definition of need and recognition remain an ongoing political battle in Victoria. Fraser’s model highlights that institutions “support relations of dominance and subordination” (Fraser, 1989, p. 299). Fraser suggests that institutional interpretations advantage the dominant group and disadvantage the subordinate group. In this power equation, parents and their children are the subordinate players. As members of the subordinate group, parents are pressured by the dominant group (schools and, more broadly, the associated government authorities) to comply and to “scale back their aspirations and adapt their beliefs” to the “sanctioned institutional practices” (Fraser, 1989, p. 299).

Serry and Hammond (2015) state that in Australia, “the term dyslexia is being increasingly used by governments, policy makers, schools and parents to describe individuals with severe reading problems” (p. 144). Survey findings from this study \((n = 361)\) contained in Table 39 (in Chapter 6) demonstrate that in approximately half of all cases (51.1%), the child’s school used the term “dyslexia” to describe their child’s learning disability. Findings also reveal that approximately a third of parents experienced resistance to the use of the word “dyslexia”. The survey findings are useful in demonstrating the frequency of use of the term “dyslexia” as well as the extent of its rejection from the lexicon. However, the interviews provide deeper and more nuanced insight into how the conflict over terminology was experienced by parents. One parent relayed that the school would “contradict” her use of the word and suggest it was better to describe it as a “problem” with spelling and a “problem” with reading (Interviewee no. 3). Other parents’ comments illustrating the conflict over
terminology included: “it seemed like an aversion to using the word by any professional” (Interviewee no. 17) and “they don’t recognise dyslexia. It’s almost a dirty word” (Interviewee no. 15). Some parents were unsure how to interpret this rejection of the term “dyslexia”. A subset of parents felt that it represented a resistance to labelling by the school. Some parents experienced it as a more strategic rejection of the term by the school: “they don’t know what to do with it and they didn’t really want to support it. No funding, no resources” (Interviewee no. 3). This theory was also purported by other parents who suggested that schools are disinclined to recognise dyslexia because “if they did they’d have to therefore put funding towards it” (Interviewee no. 15).

Parents’ views expressed on this topic in this study are supported by evidence from an Australian study which suggests that some States’ resistance to supporting children with special educational needs despite the existence of the Disability Standards for Education 2005 stems from budgetary concerns that the percentage of children in Australian schools with special educational needs might be as high as 18% of students (Galletly, Knight & Dekkers, 2010, p. 136). Interestingly, these parental insights which are supported by Galletly et al. (2010) can be used to extend Fraser’s theory of need recognition (1989). Fraser’s model of need recognition contends that the definition and interpretation of a need will play a key role in determining what measures are ultimately taken to satisfy the need. Fraser’s theory refers to the macro political environment, suggesting that the state will address the need with measures which reflect the agreed definition and interpretation of the need. However, parents’ experiences and theories relating to school officials’ refusal to use the term “dyslexia” suggest that the inverse of Fraser’s theory is also valid. That is, the lack of political recognition and therefore lack of resource provision by the state to educational institutions influences what language is used to describe the need at the coalface. Therefore, it is possible that schools do not choose to use the word “dyslexia” as a consequence of the lack of political recognition and resources afforded to students with dyslexia. This results in a negation of dyslexia at the interface between schools and parents. It can potentially create a self-perpetuating cycle in which the lack of state measures to address the needs reinforces the lack of identification and definition of the need.
on the ground; and the lack of agreed definition leads to a lack of measures at the state level.

It is interesting to observe that the negation of dyslexia by school officials on occasion occurred more broadly and deeply than at the level of terminology. In some cases, the negation of dyslexia as a legitimate syndrome occurred in addition to the rejection of the word “dyslexia”. Survey respondents who indicated that they had experienced objections to the use of the term “dyslexia” at their child’s school ($n = 80$) were asked about their understanding of this rejection. The most frequent response was that parents thought it was a result of teachers’ “belief” that dyslexia does not exist (35%). This is a phenomenon which is not unique to Australia. The UK Government-commissioned Rose Report acknowledged the historical debates about the existence of dyslexia and quashed the debate with a call for professionals to build expertise in identifying and effectively remediating dyslexia (Rose, 2009, p. 9). Gwernan-Jones and Burden (2010) suggested that teachers’ conceptions about dyslexia necessarily impact on their attitude and approach to teaching children with dyslexia. In the Australian context, the House of Representatives Select Committee on Specific Learning Difficulties in 1976 concluded that the term “‘dyslexia’ serves no useful purpose” (Cadman, 1976, p. 2). The long-term impact of this conclusion is hard to measure. However, it appears safe to conclude that it set dyslexia on a slow track to political recognition and contributed to its trajectory toward semi-obscurity in teaching institutions. It is possible to surmise that this lack of attention to dyslexia within teacher education may lead some teachers to believe that dyslexia does not in fact exist.

The Debate over Labels

Findings from the survey question relating to objections to the use of the word “dyslexia” ($n = 80$) also demonstrate that 23.8% of parents found the rejection of the term by their child’s school inexplicable. This reflects both a gap in communication and the relative powerlessness of parents. A subset of parents were informed by teachers that they did not want to use the word “dyslexia” due to their opposition to the use of labels. Research by Riddick (2010) in the United
Kingdom contends that children with dyslexia and their parents found that having the label “dyslexia” to describe their struggles with literacy was helpful to children. Riddick’s study demonstrated that the dyslexia label helped children understand that they were not “stupid” and placed in context the source of their difficulties, and that children found it reassuring to know that others experienced the same phenomenon (Riddick, 2010, p. 84). Another UK study, by Taylor, Hume and Welsh (2010), compared the use of different labels given to children with dyslexia. Findings demonstrated that children who were given the generic label “special educational needs” scored lower on self-esteem scales than those who were given the label “dyslexia”. Taylor, Hume and Welsh (2010), drawing on Riddick’s research, hypothesised that different labels have differing effects. They suggest that the more precise labels, such as “dyslexia” provide a framework and context for children to understand their own difficulties and an appreciation of strengths associated with dyslexia (Taylor, Hume & Welsh, 2010, p. 198). This research suggests that while teachers’ resistance to use of labels has some validity, each label needs to be considered on its own merit. In the case of dyslexia, there is evidence to suggest that it can be helpful for the child in relation to self-esteem and assist with counteracting negative teacher stereotypes of children’s so-called “laziness”, “lack of effort” or “low intelligence” (Nalavany, Carawan & Rennick, 2011; Rodis, Garrod & Boscardin, 2001). These negative stereotypes will be countered more effectively in the Victorian context if conditions in the environment are transformed and awareness is raised about the validity and existence of dyslexia and the manifestation of its symptoms.

Fraser’s model of need recognition places importance on the contestation over interpretation and definition of the need in relation to the provision of resources (1989). While findings from this study affirm this as valid, the model does not take into account the importance of interpretation of the need in relation to the impact on the personal wellbeing of an individual. The psychological impact on constituents in the subordinate group as a result of the struggle over need recognition could be a useful addition to Fraser’s theoretical model, particularly when utilised in the social work context.
Parental Concern for Children’s Self-esteem

Parents’ concern for their children’s self-esteem was highlighted in both the interviews and the survey. While this issue featured as a theme throughout the interviews, it is apparent from the survey findings that parent’s greatest sense of difficulty related to their child’s low level of self-esteem. Findings contained in Table 27 of the survey data demonstrate that 85.5% of respondents (n = 383) cited their child’s self-esteem as their greatest challenge. Interview participants highlighted their concern about children’s negative self-concept, anxiety and in some cases depression and suicidal ideation. This was noted in relation to young children and teenagers. Findings demonstrated that experiences of ongoing day-to-day academic failure negatively impacted on children’s self-esteem, contributing to sadness and in some cases depression, anxiety and suicidal ideation.

It is not possible to attribute children’s low self-esteem referred to by parents in this study to a single cause. International research in relation to self-esteem and learning disabilities suggests that low self-esteem is a result of factors relating to a sense of academic failure, to feeling different and factors inherent to the nature of the learning disability (Raviv & Addison Stone, 1991). While these factors may be present in the Victorian context it is clear from this study that the lack of support for children’s learning needs, the negation of their needs and lack of accommodations designed to assist them also contributes to the degree to which children fail academically as well as contributing to negative social and emotional consequences for children. The social model of disability distinguishes between the individual’s impairment and the disability caused by the failure of the society to accommodate people of all abilities (Oliver & Barnes, 2012). It provides a theoretical framework which enables the contextualisation and reframing of “disablment”. Findings from this study suggest that factors relating to the lack of recognition in the environment adversely impinge on children with dyslexia and contribute to their feelings of low self-esteem and anxiety in some cases. The application of the theory of the social model of disability suggests that a child will have more opportunity to thrive academically, psychologically and socially if their learning needs are recognised and the environment adjusted to accommodate and
support them. In light of the evidence from this study derived from parental observations and concerns about their children’s low self-esteem, depression and levels of anxiety a need for policy change to better recognise and accommodate children’s learning needs may be required.

Studies of predictors of success for students with dyslexia suggests that it is good coping patterns rather than the level of severity of a child’s learning disability that will have the greatest impact on positive outcomes (Goldberg, Higgins, Raskind & Herman, 2003; Margalit, 2003). Navigating life with a learning disability will contain challenges inside and outside of the educational environment. This suggests in addition to a school environment that caters to the needs of children with dyslexia, programs designed to teach successful coping skills to reframe their adversity arising from their lifelong disability would be beneficial (Firth, Greaves & Frydenberg, 2010). This implementation of programs to support children’s positive development of self-esteem is supported by parents who participated in the survey.

**Implications of a Diagnosis of Dyslexia**

This study contributes to our understanding of parental responses to the diagnosis of dyslexia. Most frequently, survey participants ($n = 387$) expressed relief following the diagnosis of their child (64.1%). It is clear from the interviews and the survey findings that this sense of relief contained a combination of validation and hope: validation that their instincts were correct (there was something “wrong”) and hope that now action could be taken to support their child’s learning.15

Congruent with these findings are the results of the 1995 study by Riddick in the United Kingdom. Riddick’s study was interview based and the results were also quantified numerically. Of the 22 mothers who participated in Riddick’s research, 90% felt relief upon receiving the confirmation of a diagnosis. Findings

15 It was not within the scope of this study to explore children’s feelings in relation to their diagnosis and the attribution of a label, however this subject is recommended for a future research direction, as current Australian research could not be located.
from the present study and Riddick’s study are consistent with research findings in relation to the diagnosis of disabilities more broadly, which have found similar relief expressed by research participants (Seligman & Darling, 1997). Writing in the context of the United Kingdom, Rogers (2007) contends that receiving a “diagnosis” assists parents accept the problem faced by their child and that a “label” is a “tool in aiding the most appropriate provision for the child’s educational and emotional support” (Rogers, 2007, p. 57). Rogers also claims that without this label, the “child, parents, school and teachers are left without appropriate funding and support for each child’s needs” (p. 57). In contrast to the United Kingdom, findings from this study illustrate that receiving the diagnosis and label of “dyslexia” in the context of Victoria does not ensure that appropriate resources or support is provided. The recognition of needs of children with dyslexia are further along the recognition continuum in the United Kingdom than in Australia generally and in Victoria specifically. Evidence contained within the findings from the survey and the interviews demonstrate that parents’ sense of relief and hope that the diagnosis will provide children with a pathway to remediation is thwarted when, overwhelmingly, schools fail to implement diagnostic report recommendations. The lack of support and resources attributed to the remediation of dyslexia post diagnosis are discussed later in this chapter.

Survey findings demonstrate that following “dyslexia” the most frequently used term by teachers and other school personnel was “learning difficulty” (43.6%). A nationwide Australian study in 2000 found that school personnel (n = 350) across all sectors in all states and territories most frequently used the term “learning difficulty” as a catch-all phrase within which children with dyslexia were also categorised (Louden et al., 2000). However, in Louden et al.’s (2000) study, this category was an umbrella term that did not differentiate between students with low intelligence, children from backgrounds in which English is not the mother tongue and students whose environment places them at educational risk. The present study suggests that, when compared to the year 2000, there is a slightly more nuanced understanding of dyslexia in the current environment. However, this is tempered by the evidence from this study which demonstrates that respondents (n = 361) reported that the term “learning disability” is not
commonly used by schools, with a frequency of 9.6% across schools. This frequency of usage of “learning disability” is similar to the frequency found by Louden et al. in 2000 when it was used in 10% of cases. It can be hypothesised that the relatively high frequency of use of the term “difficulty” rather than a “disability” has ramifications for recognition and remediation of dyslexia. If dyslexia is called “dyslexia” but viewed as a “difficulty” not a “disability”, it may be perceived as an impermanent “difficulty”—something encountered that may be overcome or may abate with time, whereas the nature of dyslexia is that it is a lifelong condition (Shaywitz, 2003; Washburn et al., 2013, p. 2). Additionally, referring to dyslexia as a “difficulty” rather than a “disability” may obscure the fact that children (and adults) with dyslexia are protected from discrimination by the DDA 1992.

The evidence from this study in relation to the contestation over definition and categorisation of the “need” corresponds with Fraser’s theory on the second stage of need recognition (1989). There is evidence from this study that the definition and categorisation of dyslexia has ramifications for parent’s advocacy for their children, as well as for the allocation of resources, remediation and policy implications.

Section 2: Parental Agency: Power, Gender and Advocacy

Section 1 of this chapter discussed the phenomenon of the rejection, misattribution, blame and minimisation of parents’ concerns by teachers and other school personnel. Section 2 of the discussion connects to this theme. It presents the argument that the cognitive and the emotional dissonance experienced by parents in response to this phenomenon acts as the catalyst for a parent’s transformation into an educational advocate. An analysis and discussion of parents’ advocacy role, and its relationship to gender and power, is also provided in this section.

In each interview conducted for this study, parents’ narratives highlighted their agency as advocates for their children. Evidence from this study demonstrates that the catalyst that initially transformed parents into advocates for
their children was their persistent “gut feeling” in spite of teachers’ rejections and misattributions of children’s problems, that something was “wrong”. This gut feeling and sense of dissonance arising in response to teachers’ views spurred parents to investigate their child’s difficulties further and to take a leadership role in investigating the problem and seeking assessment and treatment. Similar results were found by Riddick in the context of her UK study of parents (1995 cited by Riddick, 2010). Riddick’s results confirm an earlier study by Booth (1978, cited by Riddick, 2010) in relation to parents of children with severe development delay. Both studies demonstrate that parents who suspected that something was wrong with their child’s development consulted with professionals who variously reassured them that there was nothing wrong with the child, dismissed their concerns or suggested to the parents that they had unrealistic expectations of their child’s intelligence (Riddick, 2010, p. 78).

Riddick highlights that parents defer to the professionals’ opinion, but at the point that their convictions override their belief in the experts they seek out their own pathway to resolving the child’s issues (2010). The findings from this study mirror those of Riddick (2010). The interviews with parents highlighted that as the sense of cognitive dissonance heightened parents were less inclined to rely on teachers’ expertise and began to initiate their own research and investigation into the child’s difficulties. It is at this point in parents’ trajectories on the dyslexia journey that they cease to perceive teacher as “experts”. These findings are also supported by similar findings from a North American study of parents of children with severe disabilities (Nespor & Hicks, 2010). Nespor and Hicks found that parents of children with disabilities begin to treat professionals’ knowledge with scepticism when they feel that professionals’ knowledge contradicts their own perceptions of their child (2010). Evidence from Nespor and Hicks’s study suggests that parents’ responses to teachers at this point is anger rather than submission (2010, p. 317). Similarly, this study found that as the sense of dissonance increased, contestation and friction emerged between parents and teachers and/or other school professionals such as psychologists, and this was transformative for parents. This was the point in parents’ trajectory along the dyslexia journey that emerged as a pivotal phase of transformation from parent to
advocate. In the one outlying case amongst interviewees in which contestation over the child’s difficulties did not occur, the transformation into the advocacy role commenced when the parent discovered the school’s lack of resources to support their child. The advocacy role was assumed by the parent but simply at a later stage than for other interviewees. By extension, it is the environment of “misrecognition” which propels parents to assume the role of parent advocate or educational advocate. Systemic changes to the recognition of dyslexia, in particular the knowledge level of teachers and the provision of resources for children with dyslexia, would significantly ease the pressure on parents of children with dyslexia.

**Structural Challenges for Parents in the Advocacy Role**

Survey responses ($n = 385$) reveal that 64.2% of parents found it challenging to advocate for their child at school. Findings highlight that parents are required to develop a depth of knowledge about literacy, interventions and resources for which they feel ill equipped. Parents’ reflections on their journey to secure resources demonstrate that they feel unqualified and ill equipped to know what support services or remediation their children require.

Parents describe their advocacy efforts using terms such as “pushing”, “driving” and “fighting”. These terms are used in reference to their struggle for support for their child within the school environment. They advocate for extra tuition, assistance, accommodations, use of resources and, occasionally, their child’s right to participate in mainstream activities from which they have been excluded. Evidence from the interviews and surveys demonstrates that, despite the majority of parents obtaining psychologists’ reports which contain recommendation to assist with remediation and accommodation of children’s learning needs and sharing these reports with schools, schools struggle to implement the recommendations of the reports. Findings suggest that whilst parents advocated for the implementation of the report findings, some parents had insight into the constraints of the systems that were working against their efforts. Piecing together parents’ insights, a picture emerges of the lack of implementation of reports being attributable to a lack of school resources including funding,
technology, training and skills as well as support from the hierarchy of the school, pressures on teachers managing a diverse range of student needs and overarching lack of recognition by the government. Some parents also expressed an understanding that psychologists’ reports were not written in the lingua franca of the educational system. Galletly, Knight and Dekkers (2010) writing in the Australian context highlight an interrelated issue: they point out the irony of the fact that children who fail to perform academically are referred to a medical framework for testing and upon their return to the classroom with a diagnosis and a methodology outlined for support, the educational environment that referred them for assessment is unable to offer them services they require to meet their learning needs (p. 139). The lack of streamlined services intersecting to benefit the child with dyslexia is evident at this juncture. The failure of the environment to meet children’s needs becomes a further difficulty for children as it is the catalyst that propels parents to seek fee-for-service assistance for their child. This has financial consequences for households, which will be discussed shortly.

The difficulty for parents in seeking services is compounded by isolation and a sense that they lack authoritative advice in the face of an array of possible services in the market. This was summed up by many parents but particularly encapsulated by a father who stated: “oh hell where do you go, what do you do?” (Interviewee no. 7). The sense of isolation and lack of support is a theme that arose throughout the interviews. This extended to parents with professional qualifications in teaching and in social work.

Blum (2015) observed that mothers are relatively less empowered than professionals in schools, even when those mothers are trained teachers professionally, an issue highlighted in this study’s interviews.

Even despite having a professional teaching background, parents in this study found themselves to be powerless without a collective voice and political recognition. It suggests further evidence that the battle for recognition is being fought by necessity on an individual basis, parent by parent, against institutions. This is symptomatic of the lack of political recognition to provide an “umbrella protection”. Whilst dyslexia remains an enclave in what Fraser refers to as the
“economic” and “domestic” zones, it remains depoliticised (1989, p. 298). One of the unfortunate outcomes of individual advocacy in a climate of “misrecognition” is that any gains that are made on an individual level are not transposed to the whole system. Nespor and Hicks (2010), reflecting on the role of parent advocates, pessimistically suggest that the evolution of policy is complex and gains made by parents often evaporate when their child leaves the context of the school (p. 330). Perhaps this was recognised by some parents in this study who chose to advocate on a wider, more systemic, level in addition to advocating for their children. It can be argued, however, that some parents viewed the very act of participating in this research as an act of advocacy.

**Gender and Advocacy**

Demographic material collected in the survey data demonstrates that of the 403 respondents, 95.5% \( (n = 385) \) were female and 4.5% \( (n = 18) \) were male. Likewise, females were vastly over-represented in the interviews. Of the 21 interviewees, only 4 were male. Three of those males attended interviews with their female partners. Only 1 male, a single parent with sole caring responsibility for his daughter, presented for an interview alone.

In relation to advocacy by parents for their children, survey participants \( (n = 357) \) indicated that 0.8% (3 males/fathers) assumed the advocacy role singlehandedly. The data indicate that in 25.2% of families who participated in the survey, the advocacy role was shared by both parents and that 73.9% of advocates were women/mothers acting alone. This skewed gender balance is not unique to this study. Others writing in the Australian context highlight the existence of the gender division of educational labour in the home (Nichols, 2000). Additionally, Blum (2015), writing in the context of the United States, notes that in the disability arena mothers are most commonly advocates for children with disabilities. Blum referred to research evidence (Home, 2002; Gray, 2003; Scott, 2010) which demonstrates that “having a disabled child, whether with visible or invisible impairments only exacerbates the division of labour and responsibility” in the home (Blum, 2015, p. 8). Fraser’s need recognition model (1989) contains the contention that in male-dominated capitalist societies, the political is defined
separately from the economic and the domestic or personal spheres (p. 168).
Extending this thesis to the context of dyslexia and parental advocacy, it implies that under the current paradigm, if the needs of children with dyslexia are to successfully break out of the domestic arena and into the political and economic realm, it will be beneficial for males/fathers to become more involved in advocacy.\textsuperscript{16} It would be reductionist (and dangerously close to “mother-blaming”) to suggest that the relegation of the educational (and other) needs of children to the sphere of women’s work is the sole cause of the failure of dyslexia to “break away” from the domestic sphere in Australia and become politicised. Neither is gender inequity the only by-product of the slow emergence of dyslexia from the domestic or private arena. The relegation or the failure thus far of dyslexia to successfully fully emerge into the public domain is more complex than gender roles and gender division can explain. The relegation to the private sphere is symptomatic of the current status of dyslexia; it also serves as a contributing factor to dyslexia’s lack of recognition, in turn contributing to ongoing inequity in the treatment of children with dyslexia.\textsuperscript{17} Interestingly an interrelated finding in relation to gender and the relegation of dyslexia to the private sphere is the impact of advocacy and the support needs of children on women’s/mothers’ ability to participate in the workforce. This is discussed in the next section of this chapter.

The findings in relation to parental advocacy suggest that the individualisation of the child’s problem and the lack of systemic recognition of dyslexia in the education system in Victoria will result in the continued marginalisation of children who lack an advocate (parent or other). Evidence from this study suggests that, until intervention by parent advocates occurred, in almost all cases children’s learning needs remained largely invisible at best, and blamed on children and their families at worst. Extrapolating from this finding, it is not far-fetched to suggest that children without an advocate are at a disadvantage in the current policy regime. This personal disadvantage serves to amplify the social

\textsuperscript{16} Alternatively, further structural societal change is required in relation to the position of women, in which women are no longer expected to shoulder an unequal share of responsibility for children. However, this is clearly a longer-term project.

\textsuperscript{17} Inequity is a key theme which will be discussed in Chapter 9.
injustice of the effects of the lack of recognition of dyslexia within the education system. Without a serendipitous encounter with a teacher or a particular school environment that recognises dyslexia (in spite of the status quo of invisibility in the policy environment), children who lack an advocate will be at risk of suffering negative long-term educational, economic and social outcomes.

Survey findings demonstrate that parents (n = 391) in the majority of cases found that navigating their way to find help for their child post diagnosis was “difficult” or “very difficult and challenging” (70.6%). A question contained in the survey which asked respondents to rate the ease and difficulty level of their journey dealing with their child’s dyslexia to date opened the floodgates for parents to tell their stories. Parents used the comments section to write their story. Story after story relayed the obstacles on the pathway to diagnosis, attempts to gain recognition and support from the child’s school, and the struggle to forge a direction that will assist their child educationally and emotionally.

Parents expressed frustration at the difficulty involved with advocating for their children’s rights effectively whilst feeling unclear about what their rights entail. Critical realism posits that:

The world is composed not only of events, states of affairs, experiences, impressions and discourses, but also of underlying structures, powers, and tendencies that exist, whether or not detected or known through experience and/or discourse (Patumäki & Wight, 2000, p. 44).

Evidence from this study suggests that in advocating for their children, parents grappled not only with the effects of the lack of political recognition of dyslexia, but also with the ripple effects of the consequences of the lack of recognition, such as ignorance in the environment about dyslexia, the attribution of blame, power struggles, a lack of resources and layers of resistance in the environment to providing assistance to children. Also adding to parents’ sense of burden is their mystification as to why the policy environment is construed in a manner that negates the recognition of dyslexia and their child’s legitimate need for support. Advocacy is a subset of the difficulty faced by parents. A survey question which asked parents which challenges they had experienced found that
of the 385 respondents, 1.6% \((n = 6)\) had not experienced any challenges as a result of their child’s dyslexia. These findings do not simply reflect on the difficulties inherent in the advocacy role, but point to a whole set of issues including the struggle for resources and navigating the path forward post diagnosis.

**Section 3: Hidden Economic Consequences of Dyslexia**

A discussion outlining parents’ experiences of expenditure and resources required on the route to diagnosis was presented earlier in this chapter. In addition, this study contributes to the discourse on dyslexia in Victoria by providing evidence that there are multiple ongoing costs associated with the support and remediation of their child’s dyslexia which may cause hardship to parents. Costs include tuition, counselling, resources (e.g. technology, computer programs, and aids), workbooks and textbooks. Exacerbating the hardship caused by the outlay of finances, a subset of parents indicated that their participation in the workforce was also affected and shaped by the support needs associated with their child’s dyslexia. These findings demonstrate that at the same time as they are incurring increased costs as a result of the needs of their children, some parents are also losing income. Evidence from this study suggests that some parents are experiencing overlooked economic consequences as a result of the state and federal governments’ absence of funding of resources for children with dyslexia.

Table 32 of the findings contains data in response to a question about the economic impact of caring for a child with dyslexia. It demonstrates that 25% of 140 respondents indicated that, as a result of their child’s need for support with homework, absenteeism from school and the need for children to attend tutoring and other appointments, they were unable to participate in the workforce. It is clear from demographic data reflected in Table 13, which contains information relating to employment status, that all males are employed in full-time work or in their own business. Therefore, it is possible to deduce that those parents who are represented in Table 32 who are not currently engaged in the workforce or who
are working part-time are female. This sheds light on the gendered nature of caring for children with dyslexia amongst this cohort of parents.

The data illustrate that 32.1% of mothers reduced full-time work commitments to part-time work to meet their children’s support needs. Factors such as the need to transport children to speech therapy services, counselling and hobby or sporting activities impacted on their ability to participate in the workforce. Whilst it could be argued that parents with children without dyslexia also struggle to accommodate after-hours sporting and hobby activities for their children, these activities take on an extra dimension of importance for children with dyslexia. Findings from the interviews indicate that parents observed that it was important for children to participate in hobbies unrelated to academic activities. This provided them with a domain in which they could excel and thereby help to boost their self-esteem and wellbeing through successful endeavours.

Literature suggests that mothers of children with disabilities face marginalisation and hidden oppression as their unpaid work is devalued and invisible (Home, 2002). Evidence from this study demonstrates that some mothers of children with dyslexia who participated in this study are excluded from the workforce. In these cases, mothers directly attribute their lack of participation, or reduced capacity to participate, in the workforce to the failure of the education system to cater properly for their children’s learning and support needs. This implies that mothers of children with dyslexia are bearing the brunt of the career sacrifices and the subsequent short- and long-term ramifications of these sacrifices.

This study did not investigate Home’s (2002) claim relating to the devaluing of mother’s unpaid and invisible work in relation to their child’s disability within the home. However, there is evidence, highlighted earlier, of the diminution and undervaluing of parents’ opinions and experiences by professionals who challenged parental perceptions of their child’s struggle and dismissed them. In some cases, this occurred with the use of direct language such as “you’re just a mummy, you don’t know what you’re talking about. I am the
In other cases, it was implicit and oblique rather than directly dismissive of parents. Regardless of the form of delivery this message took, it added to parents’ burden and sense of isolation and marginalisation (female and male) associated with the lack of recognition of dyslexia and lack of support, assistance and direction for parents.

Parents who responded to this survey question \( n = 140 \) also indicated that they made other family sacrifices (20%) to finance their children’s learning needs. These sacrifices included forgoing holidays, medical treatment such as dental work, maintenance of the family car, buying clothes and purchasing items they felt were required by the family. In a few cases, parents indicated that they downsized or moved houses to be closer to a particular school. Others sold the family home to be able to afford independent school fees. Some parents indicated that they worked below their professional capacity, were absent from work more often and increased their travel time to take children to particular schools or appointments. Additionally, of the 140 parents who responded to this question, a few families (5%) indicated that they increased their work hours in order to afford school fees at an independent school. There were 16.4% of families who indicated that they incurred unplanned independent school fees. This contributes to the explanation of the data presented in Table 17 (Chapter 2) which demonstrates the higher rates of enrolment in the independent school sector by children with dyslexia compared to the general population.

In summary, the data from this study suggest that having a child with dyslexia under the current policy regime poses the risk to families of multifarious negative economic consequences relating to parents’ workforce participation, increased expenditure, decreased standard of living and increased economic pressure. The data reveal that while the economic impact of dyslexia affects the whole family unit, women’s workforce participation is more likely to be negatively impacted under the current policy regime. This is an issue of social justice concern reflecting a confluence of factors such as the lack of available support in schools to meet the needs of children with dyslexia and its intersectionality with the gendered nature of caring in society.
Constraints and Barriers in Relation to Remediation

Constraints and barriers to obtaining resources for the remediation of children emerged as a theme from this research. Data from the survey \((n = 205)\) indicate that three quarters of parents \((78.5\%)\) felt unable to provide the tutoring they felt their child required to improve their literacy skills. Parents also deemed other resources desirable but unobtainable, for example computer technology, software, workbooks and therapy. In interpreting these data, it is important to consider that the demographic data relating to this study’s parent cohort indicated that their average incomes and education level were above the norm when compared to the general Australian population. It can be ascertained from this that, in lieu of the state’s provision of resources to children with dyslexia, the majority of children with dyslexia are disadvantaged educationally. In addition, those children whose families are in middle-income and low-income brackets experience an even higher level of disadvantage. This should be of concern to government and the community generally. Evidence from the survey and the interviews suggests that parents were concerned that the education system is failing to cater for children with dyslexia, with particular concern for children whose families are economically disadvantaged and unable to purchase support and resources.

The survey posed a question to parents in relation to the challenges they have experienced as a result of their child’s dyslexia. Respondents to this question \((n = 385)\) indicated in 68.6% of cases that they view meeting the expenses related to helping their child with their learning needs as challenging. It is clear from these findings that the passive relegation of the provision of services and resources by the state to families, which can be viewed as a feature of neoliberalism, disadvantages the most economically marginalised. The consequence of this has negative economic ramifications for parents (and by extension, their children) but there are also social justice, equity and access implications. The failure of the state to provide funding for remediation and resources for children with dyslexia dictates that children whose families do not have the resources required to support their learning needs by purchasing services on the private market will not have access to the required level of support. The
data from this study demonstrate that in addition to buying in services, parents with sufficient resources moved their children from state and Catholic education sector to the more costly independent sector.

**Summary**

One of the key contributions of this chapter is the exploration of power and the ramifications of the failure of recognition of dyslexia on children and parents. Utilising Fraser’s model of need recognition, this chapter highlights the importance of terminology used by school officials to describe dyslexia. The discussion in this chapter contributes a new perspective to Fraser’s theory. It suggests that the importance of interpretation has implications for need recognition, but may also have a psychological impact on constituents in the subordinate group struggling for recognition. This is particularly important from a social work context. Language and labelling were shown to have ramifications for children’s wellbeing as well as implications for parental advocacy, recognition and the provision of resources.

This chapter contributes to an understanding of parents’ advocacy activities and the status of dyslexia. It also provides insights into the economic and workforce participation implications of having a child with dyslexia and contextualises this within a social justice framework.
CHAPTER 9: INEQUITY AND THE RIGHT TO AN EDUCATION

Introduction

This chapter contains a discussion of the third major theme arising from this study: inequity and the right of children with dyslexia to an education. This is contextualised in relation to parents’ experiences of their children’s treatment in the different school sectors and factors such as family income as well as the broader context of teacher education in relation to dyslexia. Utilising Fraser’s (1989) model of need recognition, this chapter adds further insights in relation to the second research question relating to the status of dyslexia. It also includes a response to the third research question which concerns policy recommendations arising from this study. The response synthesises parents’ policy recommendations with the general findings from the study with reference to the literature on dyslexia.

Findings throughout the study illustrate that children from families with greater economic resources have greater access to clinical testing, remediation and resources. This has access and equity implications for obtaining special consideration when undertaking the Victorian Certificate of Education, a gateway
to higher education in Victoria. Additionally, findings suggest that whilst there are 
some advantages for children with dyslexia who attend a fee-for-service 
independent school, enrolment in an independent school does not in all cases 
grant children access to appropriate educational support and teaching. The 
findings therefore suggest that inequity and the right to an education for children 
with dyslexia is more complex than purely having sufficient economic resources. 
These themes are explored in this section of the discussion.

**Inequity and Systemic Failure to Recognise Dyslexia**

It was clear from the interview findings that in some cases parents 
withdrew their child from attending a school as a result of perceptions of the 
school’s inadequate response to their child’s learning needs. Findings demonstrate 
that some children were moved to new schools in the same school sector as their 
former school and some to schools in different sectors. The most common trend 
observed amongst interviewees involved parents moving their child from the state 
and Catholic sectors to the independent school sector. This occurred in 7 out of 21 
cases. Parents indicated that they perceived the more highly resourced 
independent school sector as being better equipped to cater for their child’s 
educational and psycho-social needs than the state or Catholic school sectors. 
Some parents also indicated that they believed that the independent school sector 
has the capacity to provide an environment which facilitates better communication 
with parents and increased access to extra-curricular activities to support their 
child’s healthy development of self-esteem.

Findings revealed that in some cases an independent school met parental 
expectations; in other cases, whilst it was deemed an improvement in comparison 
to the state or Catholic sector, it was still considered inadequate and unsatisfactory 
in meeting their child’s learning needs. The survey was a helpful tool with which 
to quantify parental perceptions and levels of satisfaction in relation to all school 
sectors.

The quantification of the variability between and within school sectors and 
the degree of dissatisfaction with all sectors’ response to dyslexia is one of the key
contributions of this research. Survey responses demonstrated that 270 out of 403 respondents moved their child from one school to another. Findings demonstrated that of the 270 children who were moved to a new school, 42.6% were moved as a direct result of parental dissatisfaction with the school’s response to dyslexia.

The state education system administered by the Victorian Department of Education and Training has the strategic intent of giving “every Victorian the best learning and development experience” (Retrieved October 25, 2017 from http://www.education.vic.gov.au/about/department/Pages/default.aspx). The perception of parents with children in the state school sector ($n = 194$) was that their school was “very helpful” in meeting the learning needs of children in only 9.8% of cases. Additionally, parents rated this sector as being “helpful” in only 13.9% of cases (see Table 37). This is a combined total of a frequency of 23.7%. This is an alarmingly low frequency, particularly when considering that according to ABS data, 62.5% of children in the general population are enrolled in the state school system (ABS, 2013). Whilst there can be no debate that this figure points to unacceptably low levels of “helpfulness” within the state school sector in relation to students with dyslexia, it also suggests that despite a low level of resources, there are small pockets of the state school system from which lessons can be learnt. This is supported by the findings from the interviews in which parents referred to a particular state school which successfully transformed its approach to supporting children with dyslexia. In this particular case, change was a result of parent advocacy influencing the school leadership. A principal transformed a state school, in this example, by implementing dyslexia awareness training throughout the school and creating an open and aware culture. This school could be singled out as an exemplar of best practice. Furthermore, it suggests that a helpful approach to meeting needs of children with dyslexia is not restricted to the domain of the independent school sector, which is out of financial reach or not ideologically compatible for many parents.

Whilst a “very helpful” or “helpful” attitude was more commonly perceived by respondents in the independent school sector, it was not ubiquitous. Combining the results regarding respondents ($n = 91$) in the independent school sector who found their child’s school to be “helpful” (26.4%) with those who
considered the child’s school to be “very helpful” (20.9%), the total frequency for this positive rating was 47.3%. This demonstrates that fewer than half of parents with children in the independent school sector in this sample felt that their child’s school is “helpful” or “very helpful” in addressing their child’s learning needs. The Catholic school system fared less well in parents’ opinion than the independent school sector. There were 22.2% of respondents (n = 81) with children in the Catholic school system who rated their schools as “helpful”. Combining this figure with the figure for the category of “very helpful”, the Catholic school system met these children’s learning needs in just over a third (35.8%) of cases.

There were similar patterns revealed by the data in relation to teachers’ understanding of dyslexia in the three school sectors. Table 36 reveals that the highest-ranking sector for “excellence” in relation to teachers’ understanding of dyslexia and its impact was the independent sector. However, this is qualified by the fact that it received a rating of excellence with a frequency of just 14.6% out of 89 cases which is a very low rate of excellence. Nevertheless, it is higher than the rates for the Catholic sector (3.8% out of 80 cases) and the state school sector (4.7% out of 191 cases). So, whilst the independent school sector rated more highly than the other two sectors, it does not demonstrate a high degree of excellence. Additionally, in relation to the quantification of negative perceptions of helpfulness (unhelpfulness), there was minimal difference in perception between sectors. In summary, finding a school in Victoria that will be “very helpful” with a high degree of “excellence” in understanding children’s dyslexia learning needs is challenging.

A question of relevance is whether parents have unrealistic expectations of schools because the parents lack in-depth knowledge of dyslexia. Dyslexia is a lifelong condition (Shaywitz, 2003; Washburn et al., 2013; p. 2). However, it is possible that some parents are not aware of this and expect that children can overcome it with appropriate remediation. There are many questions that could further refine the findings in relation to parents’ perceptions of excellence in teaching and in relation to their understanding of dyslexia; however, they are outside the scope of this exploratory study. However, these findings do suggest
that families with fewer economic resources will have less chance of accessing a school that they feel addresses their child’s learning needs than families with ample resources. Parents rating their experiences of the independent school sector demonstrated that, whilst the independent school sector received higher ratings for parental satisfaction and confidence than the state and Catholic school sectors, the majority of parents of children in the independent school sector were not confident that their child’s learning needs were understood and being met by teachers. The marginal difference between parental perceptions of teachers across the sectors is possibly a reflection of the fact that teachers working across the education system emerge from the same higher education institutions. It may also demonstrate a relatively similar level of investment in in-service teacher training across the sectors in relation to dyslexia.

Studies of the general population of children demonstrate that frequent school moves are associated with negative outcomes for students (Haveman, Wolfe & Spaulding, 1990; Singh, Winsper, Wolke & Bryson 2014). Studies demonstrate that student dislocation resulting from school moves has an association with lack of high school completion (Haveman, Wolfe & Spaulding, 1990). This would suggest that in the current educational policy context, the risk of school non-completion faced by children with dyslexia is exacerbated by the lack of consistent recognition and funding for dyslexia between sectors and within school sectors. Additionally there is evidence that frequent school moves may contribute to difficulty with peer relationships, being subjected to bullying, anti-social behaviour and an increased risk of poor mental health outcomes (Singh et al., 2014). These increased educational and social risks as well as potential mental health ramifications raise heightened concerns for children with dyslexia. This study demonstrates that a lack of systemic consistent policy across the state contributes to an increased incidence of school moves thereby unjustly increasing risks of long-term harm to the vulnerable population of children with dyslexia.

It can be concluded from these findings that increased access to educational resources is one important component of remediation, however it is not sufficient to create conditions of equity. This study suggests that children with dyslexia in all sectors are disadvantaged by the lack of comprehensive recognition
of dyslexia and funding allocation to assist children with dyslexia. The movement of a child from school to school and sector to sector reflects an attempt by parents to find the exception to the norm, a pocket of recognition in which their child can find respite from the climate of non-recognition. In addition, in light of parental dissatisfaction shown in the study it appears that teacher training is of key importance in implementing such policy changes.

**A Two-Tier Educational System of Discrimination**

The findings from this study highlight the multiple implications of the failure of dyslexia to receive clear political recognition. The identification and remediation of the educational and the psycho-social support needs of children with dyslexia are, according to these findings, relegated to the private sphere. From a social justice perspective, this reflects a policy failure. The failure of the state to provide resources to identify and to remediate dyslexia results in the creation of a neoliberal two-tier system. Findings from this study suggest that one tier contains children whose socio-economic background creates the possibility (but not the guarantee) that they can access resources and remediation and a chance to fulfil their academic potential despite their dyslexia and the systemic policy failure to cater for their needs. The other tier contains children whose dyslexia, combined with a lack of parental resources arising from socio-economic disadvantage or struggle, sets them on a potential trajectory of academic failure and its subsequent negative lifelong consequences. While this study suggests that this two-tier system exists, it is not the sum total of the story but rather an over-simplification. In situ under the current policy regime, a two-tier system is a best-case scenario. This is because even children from families with financial resources experience obstacles to recognition of their condition and barriers to effective remediation, such as lack of teacher knowledge, a subsequent lack of accommodations in the classroom and the limited application or complete lack of provisions (e.g. appropriate software) to support their learning. The finding demonstrate that access to resources and the private education market fails to fully mitigate the impact of the lack of sufficient political recognition of dyslexia. The lack of a clear and comprehensive policy framework to recognise and support
students with dyslexia exacerbates class and economic disadvantage. This study has highlighted a systemic failure within all school sectors to ensure the rights of children with dyslexia to an education which enables them to reach their full potential and ensures their future wellbeing despite their dyslexia.

Applying Fraser’s Theory to the De-politicisation of Inequity

Fraser’s theory of need recognition provides a useful tool with which to understand this phenomenon of the failure of the education system to justly meet the needs of children with dyslexia. Fraser highlights that “official—economic capitalist system institutions … depoliticize certain matters by economizing them” (Fraser, 1989, p. 299). Fraser (1989) explains that needs relegated to either the domestic or economic spheres are prevented from reaching the political arena. Evidence from this study suggests that in the state, Catholic school systems, children’s needs are relegated to the domestic domain; however, in the independent school sector, needs are placed along a continuum of tension posed between the private and the economic domains. This implies that while the lack of political recognition affects all families with a child with dyslexia (regardless of school sector enrolment), those children from families with lower socio-economic status are likely to be more profoundly affected. The lack of specific policy to address dyslexia and the failure to allocate resources therefore exacerbates disadvantage, creating conditions of inequity and social injustice.

Based on evidence from this study, Fraser’s contention that the relegation of needs to the family or economic sphere serves to depoliticise a need can be extended. This study suggests that families who are dissatisfied with the state or Catholic school system are inclined, when resources permit, to move their child to the independent school sector. In effect, in an attempt to have their child’s need recognised, they move the child from a sector in which the needs of the child are relegated to the domestic sphere (due to the sector’s failure to accommodate the child’s needs) to the economic sphere (the independent school sector). It could be argued that in taking this action parents unwittingly contribute to the depoliticisation of the need. This movement of the need from the domestic to the
economic sphere (or in reality, a combination of economic and domestic, as data indicate that the independent schools also fail to adequately cater for children with dyslexia) does not challenge the status quo and the social injustice of the unmet need. In place of political action, parents purchase private education to resolve their child’s need for greater educational support. This highlights that in a neoliberal economy in which the purchasing of services is regarded as good citizenship, “needs” may be moved back and forth between the domestic and the economic spheres without breaking out of either of these enclaves successfully into the social sphere. The social arena, according to Fraser, is the site where the need breaks out of the family and the economic space before it transforms into the political space. This deepens our insight into the process of the politicisation of need, demonstrating how the neoliberal regime in which needs are relegated to the private or economic spheres subverts the trajectory of the politicisation of a need by virtue of the need moving from the family or domestic to the economic space rather than the social space (1989, p. 301). Fraser contends that it is in the social space that the politicisation and the forces against politicisation come into contest with each other. The social sphere is the precursor to the need being translated into “claims for government provision” (Fraser, 1989, p. 301). It is clear from the findings of this study that, while there is some discursive debate humming in the background in the social sphere in which rival professional perspectives on remediation, treatment, diagnosis and labelling compete, the main site of contestation is between the domestic sphere (parents) and public and private institutions (schools). The findings demonstrate that parents with resources are able to slightly side-step the private sphere and enter the economic domain by moving their children to the private sector of education—although, again, without a guaranteed benefit to the child. While in some cases parents advocate in the social sphere (as well as privately for their own child), to date in Victoria, dyslexia has not successfully reached the domain of the political to any significant extent.

Fraser’s model of need recognition outlines that the third phase of the recognition of need is the struggle over the allocation of measures and resources required to satisfy the need. At this juncture provisions are allocated or withheld. If they are allocated, the struggle relates to what is allocated to whom and by what
mechanisms (Fraser, 1989, p. 294). Whist the struggle for resources remains between individual parents and schools, victories can only be achieved on an individual level. This is not equity and this is not social justice. Riddell (2009) contends that “children with additional support needs require more rather than less, redistribution and recognition, but policies need to be couched within a discourse of rights rather than individual needs” (p. 283). To date, despite the inclusion of dyslexia in the DDA 1992 and the occasional breakout into the social domain, the discourse predominantly remains submerged at the level of individual needs. The lack of momentum, when dyslexia breaks out into the social domain for short periods of time (for example, with the convening of the National Dyslexia Working Party in 2010) but then returns to its submerged position, is informative. The recognition of dyslexia is not following a linear pathway. This observation contributes to Fraser’s model of need recognition by demonstrating that, as in the case of dyslexia in Victoria, the trajectory to need recognition may be circuitous rather than linear, proceeding, flailing and re-emerging, buffeted by changing political leadership and forces of neoliberalism.

**Marginalisation of the Most Vulnerable**

The relegation of dyslexia to the personal realm or the family domain has significant consequences for children. Evidence from this study suggests children encounter a lack of dyslexia awareness and knowledge amongst teachers and a lack of policy and practice to identify and support their learning style on a daily basis throughout their school career. The availability of resources to support them is largely dependent upon the socio-economic status of their parents. This results in further disadvantage for those who are already experiencing disadvantage, for example children from low socio-economic groups, refugees or recently settled migrants or those from indigenous backgrounds (Riddell & Brown, 1994, p. 329). Oliver (1986) theorises that it is not an individual’s impairment which is the root cause of disablement in society, but rather society’s socially oppressive treatment of the disability which disables. Applying this lens to dyslexia in the current social policy context in Victoria, the degrees of disablement are not only determined by the severity of dyslexia, but also by the context of the child—for example, the
socio-economic status of their family (which determines resources for testing and remediation), the degree of parental support and understanding, and the treatment of dyslexia by a teacher and within the child’s school environment. The degree of disablement experienced by children with dyslexia, therefore, depends not only the severity of their dyslexia and their coping skills in dealing with adversity, but also on their socio-economic context and the political forces impacting on the environment.

This study did not specifically focus on issues associated with dyslexia and the Victorian Certificate of Education (VCE). However, survey data demonstrates that respondents \((n = 371)\) to the survey question asking for their priorities regarding key policy changes highlighted that special consideration for children at VCE level was a major concern, occurring with a frequency of 93.5%. This second only in frequency to respondents’ recommendation of specialist training for teachers (94.3%). This demonstrates how concerning this issue is to parents. Moreover, when the general findings of this study are combined with existing Australian research literature, they serve to illustrate a structural inequality resulting in potential discrimination in relation to the VCE. Steeg & Firth (2012) highlighted that in Victoria, to be considered eligible for special consideration and accommodations for exams by the overseeing state government body, the Victorian Curriculum and Assessment Authority (VCAA), evidence of a documented professional diagnosis must be provided and accompanied by a history of compensatory strategies and accommodations implemented by the student’s secondary school. This remains the case currently. The VCAA guidelines for special provision for exams stipulate that provisions for examinations are granted on a case-by-case basis and that the VCAA takes into consideration “the history of the school-based special provisions and arrangements for each student” (Retrieved November 14, 2017 from http://www.vcaa.vic.edu.au). Findings from this study demonstrate that there are significant barriers to the identification of dyslexia in the first instance without significant parental investment. Furthermore, findings demonstrate the children attending the state school system are less likely than their counterparts in the independent system in particular (and to a lesser extent the Catholic system) to
receive provisions, adjustments, support and help from their school. Therefore, there is likely to be less documented history of adjustments for children in the state school sector and, to a slightly lesser extent, the Catholic system. This suggests that students disadvantaged by a history of a lack of accommodations, resources and support face a spiralling combination of disadvantages which culminate in the reduced likelihood of provisions to assist them in their attempt to undertake the VCE examinations. As successful completion of the VCE leads to access to higher education, this potentially sets them up for ongoing barriers to equal opportunities in life.

The finding and conclusions of this study in relation to marginalisation of the most vulnerable correspond with the findings of a national Senate inquiry into the education of students with disabilities (Australian Senate, 2002). This inquiry highlighted the concern that children with all forms of disabilities (including learning disabilities) and their parents are not provided with the level of support they require. In particular, children with disabilities from socially disadvantaged backgrounds (and those with multiple disabilities) face increased barriers and risks to accessing education. The inquiry flagged this inequality as a major human rights issue.

A Key to Systemic Reform: Teacher Education and Training

Utilising the framework of Fraser’s model of need recognition, the lack of teacher knowledge in relation to dyslexia can be perceived as evidence of the failure of dyslexia to reach the status of what Fraser would deem “a runaway need”—that is, a need that has “broken out of domestic or official economic enclaves to enter that hybrid discursive space [referred to as] the social” (1989, p. 171). The “social” is defined by Fraser as the space where heterogeneous stakeholders contest the politicisation and de-politicisation of the “need” and discourse is waged in relation to if, how and by whom the emerging “need” should be met. Alliances are forged in this space and if the need is successfully politicised, it is translated into recognition and intervention by the state (Fraser, 1989, p. 171). As highlighted in Chapter 1 of this thesis, there are some early
indications in Victoria that dyslexia is beginning to enter the “social” realm. Examples are the reference to dyslexia on the Victorian State Education Department website and the consultation process with key literacy experts and other stakeholders initiated by a previous federal government which resulted in the formation of the National Dyslexia Working Party. Key recommendations for reform were produced by this working party reform and remain on the public record. However, the failure to date of dyslexia to successfully emerge into the policy realm is particularly evident in the lack of mandatory and in-depth integration of dyslexia awareness and support into the curriculum for teachers in training. This is both a symptom of the failure of dyslexia to reach the social realm and a contributing factor to the failure.

Findings from this study demonstrate that the systemic failure to provide teachers with awareness, education and teaching strategies for children with dyslexia impacts negatively on parents, children and teachers. Correspondingly, those parents who encountered teachers who possessed knowledge relating to dyslexia expressed very positive feelings about these experiences and the consequences for their children. Parents’ narratives contained an occasional vignette of a teacher who was able to identify and accommodate their child’s dyslexia learning needs. In one case, a parent’s advocacy efforts successfully influenced a primary school principal to transform the culture of a school to be “dyslexia friendly”. The latter was achieved through education and training for all staff. Evidence from this study demonstrates that the lack of structural recognition of dyslexia results in instances of recognition being the exception. Individual stories of recognition occurred in outlying cases only and were sporadic and infrequent. Louden et al. (2000) evocatively referred to children with learning difficulties and disabilities in the Australian school system as a “moving target” (p. 23). This description emanates from an educationalist perspective. A parental perspective given in this study was: “it is like we fell through the cracks in the system” (Interviewee no. 5). This observation succinctly encapsulates a core theme at the heart of the findings of this study—that is, that children with dyslexia and their parents are greatly impacted by the systemic failure of the education system to recognise dyslexia. Individual voices, narratives and descriptive data
combine as testimony to the fact that, one by one, many children with dyslexia and their parents fall through the same proverbial cracks in the system and they do so in isolation. This conclusion is supported by a report compiled by a consortium of youth disability advocacy services (Youth Disability Advocacy Service, 2008). The report refers to “the lack of support for students with learning difficulties or other ‘hidden’ or recently recognised disabilities” (p. 8). It also highlights the lack of specialist training for teachers, resulting in students with learning disabilities being left to flounder (Youth Disability Advocacy Service, 2008).

Australia’s failure to equip teachers with the appropriate training is not unique. A US study conducted in Texas examining teachers’ knowledge of dyslexia demonstrates that there is considerable confusion amongst teachers on the characteristics of dyslexia and, consequently, a lack of clear knowledge about helpful remediation strategies to support students with dyslexia (Worthy et al., 2016). In the United Kingdom, the seminal Rose Report, an independent report entitled “Identifying and Teaching Children and Young People with Dyslexia and Literacy Difficulties” (2009) demonstrates that the United Kingdom previously lacked attention to teacher training. The report recommended that:

All teachers of beginner readers should have at least a working knowledge of what to look for that suggests a child may be at risk of dyslexia and know where to seek advice and what steps are needed to help them (Rose, 2009, p. 16)

The Rose Report marked a major shift in the investment of resources in teacher training in relation to dyslexia in the United Kingdom. It proposed a three-tier model of addressing the deficit of knowledge and the treatment of children with dyslexia. The first tier comprises the provision of current information to all classroom teachers about the identification of literacy problems; tier two consists of the availability of specialist training to develop expertise in some teachers in all schools; and tier three equips some specialist teachers with advanced specialist skills. These teachers are available to be accessed in each local area (Rose, 2009, p. 16). In Canada, the Learning Disabilities Association of Canada (LDAC) recommends that children with dyslexia should be provided with specific instruction tailored to their needs but also the accommodations in class and the
development of compensatory strategies and self-advocacy skills (Stegemann, 2016).

The data from this study supports the recommendations of the Rose Report (2009) and the position of the LDAC. The findings suggest that teachers (including classroom teachers, principals and special education teachers) are the most frequently consulted professionals in relation to dyslexia. Therefore, equipping teachers with knowledge of the signs of dyslexia, information about the most appropriate avenues for further investigation, and how to provide remediation and strategies for support for children would appear to be essential.

In the Australian context, there has been a raft of significant reports highlighting the need for urgent action. Examples are the “National Disability Strategy Youth Roundtable Report” (Youth Disability Advocacy Service, 2008); the Senate committee inquiry and report, “Education of Students with Disabilities” (Australian Senate, 2002); “Mapping the Territory: Primary Students with Learning Difficulties – Literacy and Numeracy” commissioned by DETYA (Louden et al., 2000); the report by the Victorian Equal Opportunity and Human Rights Commission “Held Back” (VEOHRC, 2012); and the recommendations produced by the National Dyslexia Working Party (2010). Symbolically, these reports represent attempts to move dyslexia out of the social realm and into the political realm. Yet despite this suite of reports produced over the recent decades, there has been no systemic change to rectify the identified problems of the treatment of children with dyslexia in schools. The questions which arise in response to this inaction are: What is the cost of this failure to children? And what is the cost of this failure to the Australian community as a whole? The findings from the interviews contain a very poignant quote from a parent who relayed that her young child in primary school feels as if his school is “burying” him alive and he “can’t breathe”. This helps to demonstrate that while long-term ramifications of the failure to support children with dyslexia are important, the day-to-day experiences of children are of equally great significance. Suffering of children is omnipresent. While this study provides insight into parents’ experience of having a child with dyslexia, the suffering that was revealed suggests that there is an urgent need for further research, something that will be highlighted in the
concluding chapter of this thesis. Australian researchers contend that approximately 20% of children emerge from schools with literacy levels that can be deemed very poor. A further 10% of students leave the school system with serious, unresolved reading difficulties which limit their capacity for full involvement in society (Coltheart & Prior, 2007, p. 7). There is no information on what percentage of these children suffer from dyslexia (Coltheart & Prior, 2007). From an economic perspective, the World Literacy Foundation estimates that the worldwide cost of illiteracy is US $1.2 trillion dollars and in the Australian context is US $25.05 billion (World Literacy Foundation, 2015, p. 8). These estimates must be considered in light of the fact that not all who suffer from illiteracy have dyslexia, and not all who have dyslexia are illiterate. However, it is not far-fetched to suggest that a significant percentage of those who suffer from illiteracy in Australia are those who have undiagnosed dyslexia and have fallen through the “cracks in the system”. Furthermore, economics is only one measure of cost; the cost to the individual, taking a holistic perspective along their life trajectory, is of great importance (Alexander-Passe, 2006; Daniel et al., 2006; Long et al., 2007; Mugnaini et al., 2009; Willcutt & Pennington, 2000).

**The Status of Dyslexia and Recognition of Needs**

This study set out to learn about parents’ experience of gaining a diagnosis, recognition and support for their child and insight into the status of dyslexia in Victoria. The nature of parents’ experiences translates into findings which chronicle parents’ struggle for the recognition of their children’s needs, providing crucial insights into the lack of formal state and institutional recognition of dyslexia.

One of the difficulties encountered by parents and reported in this study is the obscure status of dyslexia. Parents question how much they can “rock the boat” (Interviewee no. 1) without sufficient information to inform their advocacy efforts. The lack of clarity around the rights and entitlements of children with dyslexia within the education system adds a layer of complexity and difficulty to parents’ struggle for recognition of their child’s dyslexia. This was identified
directly by some parents; in other cases, it was gleaned indirectly from within the narratives. The lack of clarity serves to impede the emergence of the need into the social realm, highlighted by Fraser (1989) as a precursor to the recognition of needs. This difficulty in the identification of the status of dyslexia contributes to the continuation of systemic inequity and a lack of recognition. There was a sense conveyed by some research participants that the obscurity surrounding the rights of children with dyslexia is an intentional obfuscation to avoid fiscal responsibility for remediation. Whilst arguably the conditions of a neoliberal environment add to the level of difficulty in securing an allocation of fiscal resources from the state, there are other elements in the legislative and administrative environment that contribute to the current lack of full recognition of dyslexia.

As highlighted in Chapter 1 of this thesis, although on first inspection it would appear that children are protected by the DDA 1992 and the Disability Standards for Education, the absence of dyslexia as a neurological disability from the application for individual disability funding from the Commonwealth Government shifts more fiscal responsibility to the State Department of Education. The state, in turn, devolves funding allocation and responsibility to the school level. Evidence from this study suggests that the lack of awareness of dyslexia within the school environment results from a failure to specifically direct fiscal resources from the State and Commonwealth levels and from a failure of policy generally. This failure results in the relegation of responsibility for dyslexia from the school to the child’s family.

Exacerbating the obscurity of the status of dyslexia in Victoria is the ambiguity around terminology. Dyslexia in Victoria hovers in quasi-limbo between the State government’s description of dyslexia as a “difficulty” and the federal government’s categorisation of dyslexia as a “disability”. The use of language to describe dyslexia is not a trivial matter; it impacts on the recognition of dyslexia at the micro and macro levels. There are layers of deep political significance in defining and describing dyslexia. The lack of clarity leaves parents of children with dyslexia unsure of their rights. This is compounded by the lack of direct reference to dyslexia in the DDA 1992 and the Disability Standards for
Education 2005. Although the lack of reference to particular disabilities is, by
design, a positive and expansive gesture, the effect of its absence from the
wording of policy and legislation, combined with the lack of a nationally
consistent definition, is to leave parents with children with dyslexia without a
clear frame of reference.

The failure to provide a nationally consistent definition, and the ultimate
relegation of responsibility for the identification and remediation of dyslexia to
the family, are major systemic failures which fail to take account of the child’s
right to an education. The 2002 Senate Report (which predated the Disability
Standards for Education 2005) acknowledged that the Commonwealth must
accept a level of financial responsibility to assist the States to comply with the
Disability Standards for Education (which were in draft form in 2002). However,
this has not been the case to date. Whilst the intention to protect children from
discrimination in the educational context is clearly stipulated in the Standards, the
mechanisms with which to actively promote equal opportunity and freedom from
discrimination for children with dyslexia has failed.

**Parental Perceptions of the Status of Dyslexia**

The influence of political and economic regimes and their resounding
impact on institutional structures and philosophies permeate the narrative of
parents throughout the interviews. At times, interviewees directly engage with the
political discourse in their descriptions of the structural challenges they have
encountered in dealing with their child’s dyslexia. In these instances, interviewees
make reference to their child’s right to an education, the inadequacy of resources
in the state funded education system, discrimination, lack of recognition of the
existence of dyslexia, the financial burden of remediation borne by parents, the
lack of teacher training in relation to dyslexia and the burden of cost of the
diagnosis of dyslexia on parents.

The recognition by parents in this study of the political and structural
forces at play is made clearly evident by parents who have transformed into
advocates for their children and/or lobbyists and activists for dyslexic children
more broadly. In other cases, while the neoliberal forces which shift financial responsibility from the public domain to the private sphere impact on parents, the underlying cause of this burden is not apparent to some parents. In these cases, interviewees identify the end-game of these factors in the form of their impact on their child and on themselves, but struggle to make sense of the underlying cause. While they experience the flow-on effects of the lack of recognition by the policy regime, the root cause of this experience seems to them inexplicable, persecutory and an invisible menace. In some instances where the hand of the political economy remains invisible, interviewees attribute the root cause of the challenges they are facing to be, at worst, malevolence and at best, a deficiency in an individual teacher or group of professionals within the school. While this suggests that some parents view the causes of the challenges relating to dyslexia as attributable to agency and not structure, this would be an over-simplification as insights into agency versus structure vary between interviewees but also within each interview.

Some parents consider the lack of funding to support students with dyslexia as political, stemming from the lack of recognition of dyslexia. At other times, it is viewed as a result of a tight-fisted government with policy driven by a desire to stem public spending. Regardless of the interpretation, parents in this study experience dyslexia as politically unrecognised, invisible and relegated to the personal sphere.

The Agenda for Change: The Social Work Role

Curran (2010), writing from a social work perspective and drawing on a Foucauldian framework, contends that it is not enough for children with disabilities to be “free from excluding and abusive practices” (p. 821). The findings from this study concur with this contention. The legislative frameworks which are designed to prevent discrimination fail to adequately protect the rights of children with dyslexia and facilitate their equal access to education. Active recognition in the form of dyslexia-specific funding, policies and practices specifically designed to grant these children access to education and the
opportunity for the development of healthy self-esteem are required. Curran (2010) hypothesises that societal transformation is possible if academics and disability activists inspire a new way of thinking about disability and children. Whilst Curran may well have been referring to social workers in the catch-all terms “disability activists and researchers”, this study specifically names social work as having a key role to play in the transformation of conditions for children with dyslexia. Social work as a profession in Australia and internationally has failed to date to contribute in any significant manner to the discourse on dyslexia. Despite the fact that disability, broadly speaking, has been categorised as having a low profile in the social work field (Bigby, 2013), it is within the realm of social work to make a significant contribution to the disability field broadly, and the dyslexia field specifically, as researchers, activists and practitioners. Social work values and its promotion of social justice and human rights (Bigby, Tilbury & Hughes, 2017) align with the need for work in rectifying the systemic injustices. Social work has a mandate to advocate for individual and societal wellbeing (AASW, 2016), social change on critical issues relating to inequity, marginalisation, discrimination and social injustice (Weiss, Gal & Katan, 2006). A recommendation arising from this study is that social workers engage in supporting dyslexia advocacy and activism on a macro and individual level as well as engage in direct support to children and their families. Social workers can play a role in relieving the isolation, powerlessness and lack of support currently experienced by parents as expressed by this study’s participants. In relation to service delivery, there is a role for social work not just in casework, but in the creation and delivery of group programs to promote self-advocacy and self-esteem-raising programs for children. This is crucial when taking into account the findings from this study which correlate with international studies. These studies indicate that some children with dyslexia suffer from anxiety, depression, academic failure, truancy and suicidal ideation (Alexander-Passe, 2007; Daniel et al., 2006; Long et al., 2007; Mugnaini et al., 2009; Willcutt & Pennington, 2000).
An Investment in Recognition and Change

Parents who participated in this study are very clear in their recommendations for future policy changes. Of key importance is the investment in teacher training and education to support children’s learning needs. As previously highlighted, the findings of this study support parents’ recommendations for teacher awareness and training in order to transform conditions in the classroom for children with dyslexia. This change requires an agenda of major transformation in the status of dyslexia and an investment of resources by the Commonwealth and State governments. Teacher training and education is a key tenet of dyslexia recognition in other English-speaking countries such as the United Kingdom (Rose, 2009). It is crucial that awareness and knowledge of dyslexia is integrated into pre-service teacher training as well as in-service training for currently serving teachers. Buswell et al. (2004), drawing on the work of the British Dyslexia Society, recommend that teachers need appropriate training in order to identify signs of dyslexia, become aware of the cognitive impact of dyslexia on individual students, adapt assessments, enable children to develop their strengths and thereby contribute to the development of healthy self-esteem, and, if required, seek help and advice when encountering problems in dealing with child’s dyslexia. Buswell et al. also note that it is incumbent upon teachers to respond sensitively to parents’ anxieties and concerns about their children (2004, p. 417). Norwich, Griffith and Burden (2005) promote a concept of extended professionalism in which teachers demonstrate sensitivity to parents’ views, foster positive and respectful working relationships and develop an understanding of the time parents have committed to investigating their child’s learning problems and the work they invest in assisting them in the home (p. 163). The findings from this study concur with the aforementioned recommendation. It is clear that parents possess valuable insights into children’s learning difficulties, which could hasten the route to diagnosis and remediation. It is also clear from the findings that parents invest a great deal of time and resources in supporting their children’s learning challenges and that a parent–teacher partnership is in the best interests of the child. Evidence from this study also suggests that siloed medical and social science knowledge on the existence and features of dyslexia will not
cross professional boundaries into the educational arena without adequate resources and intention. This suggests that a greater level of multidisciplinary sharing of knowledge (in addition to parent and teacher cooperation) is required in order to facilitate a deeper knowledge base for all professionals involved in the support of children with dyslexia and their families.

Fraser’s (1989) model of need recognition recognises that in the modern state, power, status and access to resources are influenced by factors such as socio-economics and “gender, race, ethnicity and age” (p. 296). Findings from this study demonstrate that socio-economics plays a significant role in the barriers experienced by parents struggling for recognition of their child’s learning needs in the current political context. Gender also plays a role in the dynamics of the struggle experienced by mothers at the interface with the school. There are economic and workforce flow-on effects for women as a result of children’s dyslexia. The lack of participation of diverse ethnic groups in this research points to a lack of available data on this group of parents in relation to dyslexia. The hidden state of parents of children from diverse ethnicities and those with Australian indigeneity does not bode and suggests extreme marginalisation. When dyslexia successfully breaks out into the “social” at the “switch point” (Fraser, 1989, p. 301), future reform and implementation of programs for children with dyslexia must contain consideration of ethnicity, gender and socio-economics.

Fraser (1989) contends that when needs are recognised, they become “objects of state intervention” (p. 302). Under the current status quo, a change in the status of dyslexia is contingent upon change at the federal government level. It requires the inclusion of funding for dyslexia, alongside sensory, physical and intellectual disabilities—all of which currently receive funding from a Commonwealth Government funding program (Australian Senate, 2002). This requires a nationally agreed-upon definition of dyslexia as recommended by the National Dyslexia Working Party (2010).

Parents expressed strong support for a recommendation for special consideration and provisions for examinations at VCE level. This is under the jurisdiction of the Victorian Government. The inequity and discrimination
currently inherit in the limited allocation of provisions for exams and assessments at VCE level are largely hidden from public scrutiny. This is a result of the fact that the struggle for recognition of learning disabilities is being waged by parents, one by one, against the bureaucracy. The advantages provided to children from higher socio-economic groups is also hidden within the processes of the VCAA. Whilst the history of school provisions remains a key consideration for the granting of examination provisions, there remains the potential that children from families with resources and those who attend independent schools will have an advantage over their counterparts in the state sector and, to a lesser extent, the Catholic sector. However, under the current system, even those in the independent school sector are at risk of disadvantage due to the lack of recognition of dyslexia and adjustment of examination methods to take into account the impact of dyslexia on an individual on a case-by-case basis. This inequity is in critical need of exposure, review and overhaul. To prevent inequity, the foundations for equity for children with dyslexia need to be built into the education system across all sectors from the outset of children’s entry into the school system.

An investment in resources for universal screening of children for dyslexia, subsidised diagnostic services and funding for remediation of dyslexia, resources (such as aides, equipment, technology), targeted remediation programs and tutoring and counselling were articulated by parents as key priorities by parents who participated in the survey. In addition, these recommendations emerged as priorities naturally from the narratives of parents who participated in interviews. Investment in self-esteem-raising programs for children with dyslexia, an overarching policy to direct schools to address the learning needs of children with dyslexia, and the implementation of strategies outlined in psychologists’ reports in the classroom to support children’s reasonable accommodations in class, all arose as central tenets of a platform for change.

It is clear from this study that change at the State Education Department level to monitor the application of the funding by schools to students with dyslexia is required. The discretionary use of funding by schools for struggling students, and the lack of auditing and oversight from a central authority to monitor
support for students with dyslexia, was flagged by parents as a priority for policy change.

A transparent, easily accessible policy which refers to dyslexia as a disability would serve to highlights its status under the Disability Standards for Education 2005. The combination of all the recommendations outlined in this section would combine to decrease the inequality currently experienced by children with dyslexia between school sectors. Policy change and full recognition with the inclusion of a federal definition of dyslexia would potentially have a cascading effect on general awareness in the broader community. The increased visibility of the ubiquity of dyslexia may serve to decrease the stigma associated with secrecy and the false belief that dyslexia is a guise for laziness or stupidity. Galletly, Knight and Dekkers (2010), acknowledging the possible far-reaching and dire social, health and economic consequences of a lack of support for children with special educational needs, call on the Australian Government to rebalance the “prevailing mismatch between what could be, and what is” (p. 136).

Consistent institutional policy in relation to the treatment of children with dyslexia would help redress the inequity currently experienced between institutions. It would also mitigate against differing treatment of dyslexia by teachers at the same school. Fraser’s (1989) model states that when a need is successfully politicised it is translated by the state into an “administrable need” (p. 306) and becomes redefined as a “social service” (p. 306). The need is reconceptualised at this point, administered by experts, and the voices of those who are the recipients of the social services are depoliticised. Ironically, this suggests that the expected outcome of successful politicisation of needs is the delivery of service and an accompanying de-politicisation of the need.

The final stage of the recognition of dyslexia is yet to occur in Victoria. If Fraser’s model is used as a predictive tool, it serves as a cautionary warning to dyslexia stakeholders. De-politicisation creates a risk of re-isolating parents as individual social service users and individualising their issue, which is a semi-powerless position. As such, it would seem that maintaining an active political presence following the translation of the need into a social service would be
strategic. Such a move would serve as a safeguard against any possible future erosion of rights or recognition and the redistribution of responsibility for dyslexia to the realm of family.
CHAPTER 10: CONCLUSION

The final chapter of this thesis describes the overall contribution of this study. It revisits the aims of the study and describes how the core research aims and objectives have been addressed. A discussion of the limitations of the study is included as well as directions for future research. The thesis concludes with final reflections about the importance of this study.

This study contributes to the discourse on dyslexia by providing new insight into the experiences of parents with school aged children with dyslexia in Victoria, Australia. It addresses the research aim of shedding light on parents’ experiences of the pathway to the identification and diagnosis of their child’s learning disability and their experience of seeking recognition and support for their child’s learning needs arising from dyslexia. The utility (and the beauty) of Fraser’s (1989) model is that it is a tool which is used in this study to inform us of the status of recognition of dyslexia. Just as importantly, it is a lens with which to understand and make sense of parents’ journey arising from the status of dyslexia in Victoria. Policy recommendations arising from this research were derived from the use of Fraser’s model, insights from research literature, the findings inherent in this study and, directly, from the voices of parents who contributed to this study. The findings from this study give voice to a largely invisible group of
parents in Victoria. Parents who participated in this study shared a strong desire to share their stories, to be heard and to contribute to change. The short span of time it took to recruit the parents who participated in the interviews and the large influx of survey respondents following publicity was evidence of their sense of disenfranchisement and their desire to inform researchers and policy makers.

Limitations of this Study

The criteria for participation in this study included the requirement that parents must have obtained a formal sole diagnosis of dyslexia from a qualified practitioner for their child. The reason for stipulating this criterion was to ensure that the study included a distinct and discrete focus on parents with a child with dyslexia. However, in achieving this, those parents for whom the cost of diagnosis is prohibitive were excluded. This implies that while the study remained focused on the target group, it may have excluded representation from low socio-economic groups. It also excluded those who had a child with the signs and symptoms of suspected dyslexia but who had yet to receive a diagnosis. By necessity this study also excluded those potential research participants whose children were currently grappling with the impact of undiagnosed dyslexia.

An additional limitation of this study related to diagnosis is that whilst interview participants were required to show the researcher a written diagnosis of dyslexia from a qualified practitioner, it is also possible that some participants’ children had undiagnosed, or diagnosed but unrevealed, comorbidity. In the case of survey participants, the same issues apply, however participants were not required to provide evidence of their child’s diagnosis and participation relied on participants’ integrity when answering the screening question regarding their child’s sole diagnosis of dyslexia. The Plain Language Statement for the survey (see Appendix A) (which all participants were required to confirm they had read before proceeding) contained a statement specifying that eligibility was conditional on their child’s “single diagnosis of dyslexia” and pointed out that this meant that the child “does not have other conditions such as Attention Deficit Disorder or acquired brain injury”. Whilst all participants confirmed this was the
case, there is no way to verify this information. It would be reasonable to assume that some participants who filled out the survey may have had children with a dual diagnosis of dyslexia and another condition or another undiagnosed syndrome.

One could conjecture that another limitation of this study is that there is a probability that parents’ participation in this study was motivated by negative experiences and a desire for change. Those parents who are completely satisfied with their experiences of the treatment of their child’s dyslexia may not have felt as motivated to participate as those that wish to advocate for change.

A limitation relating to the survey tool is that it was posted on the internet in written form, requiring approximately 40 mins to complete and necessitating the participant to possess a reasonable level of literacy skills. There is considerable evidence that dyslexia is a heritable condition (Snowling et al., 2003). This and evidence from the study itself (highlighting the presence of dyslexia in the family) implies that some potential participants may have found participation in the survey too onerous. While some participants may have overcome this barrier with the use of text-to-voice assistive technology, some potential participants may not have had access to this technology and self-selected out of the survey.

An issue that may be considered a limitation arising from the survey is a lack of knowledge about how a child’s attendance within a particular school sector impacts on parental expectations of school support and the remediation of dyslexia. Parental ratings of school support are by nature subjective. However, a question arises about whether parents of children in the fee-paying independent school sector have higher expectations of levels of help and support for their child’s dyslexia than their counterparts in the less expensive Catholic sector and subsidised government school sector. This is a matter that would require further research to investigate.

Further Research Directions

The findings from this study begin to shed light on the experiences of parents of children with dyslexia in the Victorian context. In light of the paucity of
research in relation to dyslexia in the Australian context and the lack of social work’s contribution to the discourse on this issue, there are a wealth of suggested key themes for future research. This study highlighted the need for research in relation to the following topics:

(a) an examination of the experiences and outcomes for children with dyslexia from families from low socio-economic groups, CALD groups and Indigenous families;

(b) a study to further investigate issues relating to equity and discrimination between school sectors with a specific focus on the comparison between school sectors of the provisions granted by the VCAA to students with dyslexia at VCE level;

(c) an exploration of the impact of negative labelling and misidentification of students with dyslexia;

(d) a study entailing a comparison of self-esteem and wellbeing of students with dyslexia between a school in which teachers are trained in understanding and teaching students with dyslexia and a school in which teachers have not received specialist dyslexia training in the Australian context;

(e) an exploration of factors which serve to reduce barriers to achieving a diagnosis of dyslexia;

(f) a study of parental expectations of schools in relation to the remediation of dyslexia and teachers’ perceptions and experiences of parental advocacy to inform teacher training in relation to dyslexia specifically in relation to effective communication with parents;

(g) a study to examine the views and experiences of children with dyslexia of different ages in a variety of educational settings;

(h) a study using a social justice lens to examine the impact of having a child with dyslexia on the workforce participation patterns of mothers;

(i) an exploration of the impact of single parenthood status on teachers’ perceptions of children with dyslexia and their parents;
(j) an examination of how parents perceive dyslexia and their perspectives on the use of the term “dyslexia”. 18

Further, a particular focus on what support the children themselves find helpful from an educational and psycho-social context is warranted. Referring to the importance of the principles of empowerment, inclusion and consultation, the slogan “nothing about me without me” underpins the philosophy of disability rights movements’ worldwide (Nelson, Lord & Ochocka, 2001, p. 37). Congruent with this philosophy, studies which give voice to children and adults with dyslexia in Australia would be of great benefit to future dyslexia research and policy development.

**Concluding Reflections**

As a researcher, I understand that “there is no such thing as a view from nowhere” (Baglieri et al., 2011, p. 274). At the outset of this study, my son who has dyslexia, was aged 12 and in his last year of primary school. At the completion of this study, he is a young adult engaged in a tertiary technical education course. The navigation of the journey through to the completion of secondary school was long and arduous. It included advocacy, emotional care and the provision of academic support and scaffolding. It also included undertaking two successive years of legal action against VCAA in order for him to receive the extra time required to enable him to complete his VCE exams. The provisions which were achieved through legal action in Year 11 (for the one VCAA subject he undertook that year) had to be recontested for his final subjects in Year 12. This legal action was provided pro bono but it speaks to the heart of the systemic inequity. Without the access to legal resources, provisions for Year 12 would not have been granted. Serendipity worked in my son’s favour in this instance. His case study adds to the evidence base provided in this study of the urgent need for systemic reform. Social justice demands that entry to higher education for children with learning disabilities should not depend on the social capital, school

---

18 While all the above-mentioned topic lend themselves to research in the social work field, the first four topics are particularly salient to a social work study due to their focus on social and economic disadvantage, disadvantage, discrimination and self-esteem issues.
sector, socio-economic status and the luck of encountering a dyslexia-friendly environment.

My experience as a mother of a child with dyslexia provided me with an insider perspective and was the initial seed from which this study originated. However, the day-to-day, year-by-year motivating force was the quest to frame this issue within a social justice framework in order for it to contribute to an evidence base for social change. Throughout this study I challenged, examined and reflected on my subjective interpretation of the empirical findings. The mixed methodology and supervision process were extremely helpful tools to ensure the validity of data and interpretation. The social work lens with its social justice orientation remained as a valid fixture throughout the study. A key contribution of this study is the framing of the status of dyslexia as a social justice issue in the Australian context. This study’s findings provide the data and analysis that reveal that all sectors of the education system in Victoria fail to provide children with dyslexia adequate access to education and academic support, thus jeopardising their academic outcomes and ignoring known risks of harming their psycho-social wellbeing.

Underlying the recommended policy reform and measures outlined in Chapter 9 of this thesis is a demand for clearer political recognition of dyslexia and a consequent development of an agreed dyslexia definition and funded policy that specifically supports initiatives such as early diagnosis, mandatory dyslexia teacher training, and school-based resources to support children who have dyslexia. This study demonstrates that at the heart of parents’ experience of struggle in contending with their child’s dyslexia is the invisibility of dyslexia and the lack of an explicit policy principle which addresses the state’s recognition of dyslexia. Without clear and explicit policy which addresses the recognition of dyslexia and the allocation of funding, children with dyslexia are marginalised and their needs are negated. Experiencing a lack of acknowledgement, support and guidance in relation to their child’s condition, the findings indicated that parents mostly hover in limbo until they take charge of advocacy for their child’s needs. In the meantime, they are buffeted and swirled around in a policy vacuum experiencing contemporaneous effects of the lack of recognition at each juncture.
of their journey. This study’s findings show that the absence of this formal recognition impacts negatively and directly on the lives of children and parents.

This study benefited from Fraser’s (1989) need recognition theory. It provided the theoretical tool with which to identify the submerged status of dyslexia in Victoria. In utilising Fraser’s theory, a critique was provided that contributed new insights to its richness.

It is the hope of the researcher that by giving parents a voice and analysing and grounding the interpretation of that voice in Fraser’s theory that this study will contribute to positive change. It is hoped that it will serve as a launching point for future research and contribute to the building of an evidence base from which to develop future effective policy and practice in relation to dyslexia in Victoria.


308


*Disability Discrimination Act 1992* (Cwlth)  

Disability Standards for Education 2005 (Cwlth)


Gray, M., & Gibbons J. (2007). There are no answers, only choices: Teaching ethical decision making in social work. *Australian Social Work, 60*(2), 222–238.


definition, prevalence, identification and support of learning disabilities in
Australian schools. *Australian Journal of Learning Difficulties, 16*(2),
159–180.

phenomenological analysis and its contribution to qualitative research in
psychology. *Qualitative Research in Psychology, 1*(1), 39–54.


linkage analysis of university faculty online survey response behavior*

Snowling, M.J., Gallaher, A. & Frith, V. (2003). Family risk of dyslexia is
continuous: Individual differences in the precursors of reading skills. *Child
Development, 74*(2), 358–373.


Contemporary Journal, 14*(1), 53–62.

178–182.


research: From data triangulation to mixed method models designs. In A.
Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social


APPENDICES
APPENDIX A: Survey – Plain Language Statement

Plain Language Statement
Human Research Ethics Approval No. 1238564

Invitation to take part in an online survey as part of a research project:

The experiences and views of parents of a child with dyslexia in Victoria

Purpose of this Project
This project aims to explore the experiences of Victorian parents of children with dyslexia. There is very little known about the experiences of parents of children with dyslexia in Victoria. The researcher would like to hear the voices of parents to help shed light on this important subject and share this information with other researchers, support agencies, parents, and policy makers.

Invitation to participate in the project
Parents or carers of a child aged between 7 and 18 with a child who has been diagnosed as having dyslexia are invited to participate. The research will be conducted via an online survey which will explore parent’s experience of:

- the process of discovering that their child is effected by dyslexia
- gaining a formal diagnosis of dyslexia
- finding information, support and resources to assist their child and themselves
- responses to their child’s dyslexia
- key challenges they face in supporting their child

In addition, the research will seek parents’ ideas regarding current policy and ideal policy in this field.

Before reading the detailed information below, please ensure you are eligible to participate:

- You must be a parent or carer of a child currently aged between 7 and 18 who has a formal single diagnosis of dyslexia from a practitioner qualified to confirm this diagnosis. Please note that a “single diagnosis” of dyslexia means that the child does not have other conditions which could potentially impact on their ability to read, spell and write, such as attention deficit disorder or acquired brain injury.
- You must be currently living in Victoria and also have lived here at the time of the child’s diagnosis.
Who is conducting the research?
Katherine Levi is a PhD student at the School of Social Work, in the Faculty of Health Sciences at The University of Melbourne. She is also the parent of a child with dyslexia. Katherine is conducting this research as part of her doctoral thesis. The research is being supervised by Professor Cathy Humphries (Department of Social Work), Dr Nola Firth (Honorary Research Fellow, Melbourne Graduate School of Education and the Murdoch Childrens Research Institute) and Dr David Rose (Department of Social Work).

Why participate in this research?
To date little research has been conducted focussing on the experience of Victorian parents whose children have dyslexia. There is growing interest from the government in relation to support for dyslexia. We would like to gain a broad snapshot of the experiences and insights of parents’ of children with dyslexia and contribute to this discussion.

What are the benefits of participating in this research?
Being a parent with a child who has dyslexia can be challenging. Some participants may find a benefit in having an opportunity to discuss their experiences and feelings. Some participants may also feel positive about the possibility of having their voices heard by policy makers and by other researchers in the field. However, the researcher acknowledges that there may be no direct benefits to participants. The completed thesis will be available for review and an electronic copy of it can be sent to participants if desired.

What will I be asked to do if I become a participant in this research?
If you voluntarily agree to take part in this research you will be asked to read the terms of consent and indicate your consent electronically. The survey should take you approximately 30 to 40 minutes to complete.

The survey will ask questions such as:
- Basic information about you such as age in years, educational level, occupation, marital status, number of children, household income, country of birth and the language you speak at home.
- Background information about your child with dyslexia such as age, gender, age of diagnosis, the type of school they attend.
- Questions about your experience as a parent of a child with dyslexia such as how you have gathered information about dyslexia, from whom you have sought help and advice, resources you have accessed, the response of your child’s school to dyslexia, positive experiences, challenges and hopes and fears for your child’s future.
- Questions about costs associated with having a child with dyslexia.
- Reflections on what sort of policy in relation to dyslexia you would like to see in the future.
You will also be given an opportunity to raise any issues you feel are important.

**What will the survey information be used for?**
The information you provide in the survey will be analysed for themes and statistical data along with all the other survey responses. Individual quotes may be used from your surveys to highlight points in the final report. Please be assured that the research team has no way of identifying you personally and quotes will not be attributed and information you provide cannot be linked to you personally.
The completed research will be submitted for a PhD degree. There may also be articles published and talks given at conferences about the findings from this research.

**Will the information I provide remain confidential?**
Yes. Your personal information will remain entirely confidential at all times and your answers will remain anonymous. You will not be asked to provide any information that will identify you. Your complete (or incomplete) survey will not be traced to you. The completed survey will be stored securely in a locked filing cabinet and in a secure, password protected computer.
As required by The University of Melbourne regulations this information will be retained for a period of 5 years from when the reports on the research are published.

**Do I have to take part in this research?**
Your participation in this research is completely voluntary. You can withdraw your consent at any time up until you submit the completed survey online. Once submitted as it cannot be traced to you, it cannot be withdrawn.

**Are there any risks to me for taking part in this research?**
It is highly unlikely that there is any risk to you in taking part in this research. It is possible that thinking about this topic may cause you some discomfort or mixed feelings by revisiting past negative experiences or fears about your child’s well-being.
If you feel at all uncomfortable or concerned following the survey you are welcome to contact the researcher and set up a time for a meeting or have a discussion by phone or Skype. Additionally or alternatively you could contact SPELD VIC who are supportive of this research and employ people skilled at providing information and support regarding dyslexia. If this survey raises difficult material, you may wish to contact Professor Cathy Humphreys for advice and support. (Contact details for these supports are provided at the end of the online survey).

**Where can I find the results of the research?**
The results of this research will be available in late 2014. A summary of the project will be linked to The Melbourne University Department of Social Work website as well as SPELD VIC’s website.
Who can I contact if I have concerns about the research or require further information?
If you have any concerns about the research or would like more information you can contact the researcher or members of the supervisory team at The University of Melbourne as follows:

Katherine Levi: Katherinelevi@optusnet.com.au
Tel: 0409 334020

Professor Cathy Humphreys
Department of Social Work
cathy.humphreys@unimelb.edu.au
Tel: (03) 8344 9427

Dr David Rose
Department of Social Work
Tel: (03) 8344 9423
drose@unimelb.edu.au

Dr Nola Firth
Murdoch Childrens Institute
Nola.firth@mcri.edu.au
Tel: (03) 9035511

If you have any concerns about the conduct of the research you can also contact:
The Executive Officer
Human Research Ethics
The University of Melbourne
Phone: 83442071
Fax: 93476739
APPENDIX B: Interview Guide

The experience and views of parents of a child with dyslexia in Victoria

Semi-Structured Interview Schedule

Date of interview

Method:  
Interview (SPELD / Melbourne University or external public location)
Skype
Telephone

Interview start time:

Interview end time:

Diagnosis by whom

When

Sighted

Can you tell me why you decided to be involved in this research project?

SECTION 1: Background demographic information about interviewee and child

Interviewee's gender and formal relationship to child
Educational level,
occupation,
marital status,
age
number of children,
country of birth and the language they speak at home
What motivated you to take part in this research

Biggest challenges?
Background information about child with dyslexia such as age, gender, age of diagnosis, the type of school they attend – State, Catholic, Independent, home schooled.

SECTION 2: The process of discovering that your child has dyslexia
Probes: How did you become aware of the learning difficulty/signs?

From whom did you seek help/advice/information?

What sort of supports and challenges did you find in uncovering your child has dyslexia?

What were the range of needs you had as a parent?

What needs did you have for your child in this early stage of the process?
I am particularly interested in the response of the school and what you experiences have been in relation to your initial concerns about your child’s learning difficulties.

How have you found the response from other people who are significant in your child’s life?

SECTION 3: Finding information, support and resources to assist your child
Can you share with me the path you took to find out information about dyslexia and support and resources for your child?

Can you reflect on how difficult or easy was it to determine which path you should take in locating supports, information and resources to assist your child.

Can you describe the usefulness of the supports and resources that you located and used?

What were the challenges and positives actions and outcomes that arose along the way?

Can you talk about your feelings and reflections about this process of seeking to assist your child with their learning needs?
SECTION 4: Reflections on the experience of supporting your child

Can you share your reflections on any difficulties or challenges as well as positives and benefits of your child’s dyslexia?

What are your hopes and fears for your child’s future?

SECTION 5: Reflections on current policy and ideal policy

Do you have a sense of the policy in place in Victoria in relation to dyslexia?

Can you share with me your ideas about the strengths and challenges and weaknesses of the current Victorian policy in relation to dyslexia?

Can you also share with me your ideas and reflections on the challenges and weaknesses of current Federal policy in relation to dyslexia?

Do you have any ideas and suggestions for future ideal policy to support children with dyslexia?
What would you have found ideal in relation to policy for the situation you faced in relation to your child’s learning difficulties?

SECTION 6: Other issues
What advice would you give to other parents of children with dyslexia in Victoria?

How do you think my status as both a parent of a child with dyslexia and a researcher has impacted on this interview?

Are there any issues that you think are important to share which have not been covered by questions in this interview.

Thank you.
To the Human Research Ethics Panel, 12.10.12

I am writing in my capacity as CEO of SPELD Victoria to confirm to the Human Research Ethics panel that I authorize Katherine Levi-Sylvan, a PhD student with the Social Work Department of Melbourne University to negotiate with me to utilize our premises in North Fitzroy to conduct interviews with research participants.

I endorse the research which I understand is designed to explore the experiences and views of approximately 20 parents with a child with dyslexia in Victoria. I understand that the research is utilizing mixed methods and participants may participate in interviews and/or online surveys.

SPELD Victoria is able and willing to publicize information (and eventually a summary of results of the study) on our website, provide links to the survey and include information about the research in our communication to SPELD Victoria members in order to assist in attracting research participants.

I understand that participation in the research is entirely voluntary and supervised by Professor Cathy Humphreys, Dr Nola Firth and Dr David Rose and will be conducted in an entirely professional and ethical manner.

SPELD Victoria will offer access to information about support and resources available to parents who are research participants and may require further assistance for their child following the interviews or surveys, should the research raise new questions for the participants. SPELD Victoria has a renewed ‘parent/caregiver’ focus and as CEO I will ensure that research participants are given a range of available assistance.

I believe this research will be of benefit to SPELD Victoria shedding light on an important subject in which there is currently a paucity of Australian data. Please do not hesitate to contact me if you require any further information in relation to SPELD Victoria’s endorsement and willingness to practically support this research.

Regards,
Michele Semmens,
Chief Executive Officer, SPELD Victoria
Are you the parent or carer of a child with dyslexia?

Invitation to take part in an interview for research into the experiences and views of parents with a child with dyslexia in Victoria

This project is intended to help shed light on the experience of being a parent of a child with dyslexia in Victoria. It is the hope of the researcher that this project will provide an opportunity for parents to discuss their experiences and feelings and for their voices to be heard by policy makers.

Invitation to participate in the project
Parents or carers of a child (between the ages of 7 and 18 years of age) who have a child with dyslexia are invited to participate. The researcher will conduct interviews which will explore parents’ experiences and impressions of:

- How they discovered that their child is effected by dyslexia and their response to this discovery
- The pathway to gaining information about dyslexia and a formal diagnosis
- The experience of finding information and support for a child with dyslexia
- Current policy and ideal policy relating to dyslexia.

Before reading through the detailed information below, please ensure that you are eligible to participate:

- You must be currently living in Victoria
- You must be a parent of a child (currently aged between 7 and 18) with a single formal diagnosis of dyslexia from a practitioner qualified to confirm this diagnosis. (Documented diagnosis will need to be sighted by the researcher).

Who is conducting the research?
Katherine Levi is a PhD student at the School of Social Work at the University of Melbourne. She is also the parent of a child with dyslexia. She is conducting this research as part of her doctoral thesis. The research is being supervised by Professor Cathy Humphries, Dr Nola Firth and Dr David Rose.

Why do the research?
To date little research has been conducted focusing on the experience of Victoria parents whose children have dyslexia. The researcher would like to give a voice to Victorian parents’ of children with dyslexia. It is hoped that this project will give parents...
an opportunity to share the stories of their experiences of being a parent of a child with dyslexia and document their reflections. The purpose of the interview is to give the researcher an opportunity to discuss in-depth your experiences and reflections on this subject.

What will I be asked to do if I become a participant in this research?
If you agree to take part in the research you will be asked to demonstrate proof of your child’s diagnosis of dyslexia, sign a consent form and talk to the researcher about your experiences in relation to dyslexia for approximately 60 to 90 minutes. The interview can be held at SPELD’s office in North Fitzroy at Melbourne University, or via telephone or Skype depending on what suits you best.

The interviews will begin in February 2013. If you have read through all the information on the research project and are happy to participate you will need to email the researcher at katherinelevi@optusnet.com.au or telephone the researcher on 0409 334020. She will then arrange a mutually convenient time to meet with you.
Online survey about dyslexia

This online survey aims to explore the experiences and views of parents or carers of a child (aged between 7 and 18) with dyslexia. This survey is being conducted by Katherine Levi, a mother of a child with dyslexia and a PhD student in the Department of Social Work at The University of Melbourne.

The survey explores parents' experiences of:

- the process of discovering that their child is affected by dyslexia
- gaining a formal diagnosis of dyslexia
- finding information, support and resources to assist their child
- responses to their child’s dyslexia
- key challenges they face in supporting their child

It also seeks parents’ ideas regarding ideal policy in this field.

It takes around 30 to 40 minutes to complete and is entirely anonymous. (This research is approved by the Human Research Ethics Committee Approval No. 1238564.1)

Please go to:

https://www.surveymonkey.com/s/parentsviewsofdyslexia

If you have any questions about this research, please do not hesitate to contact me at katherinelevi@optusnet.com.au or 0409 334020

Thank you for your interest in this research. Your views will be greatly appreciated.
APPENDIX F: Survey Questions

ONLINE SURVEY

The experiences and views of parents of a child with dyslexia in Victoria

Thank you for agreeing to participate in this research. Please follow the instructions for each question. There are 5 sections and the survey takes approximately 30 to 40 minutes to complete. You may choose to complete the whole survey in one sitting or at any stage you can click on “save” and return at a later date to complete and submit your answers.

SECTION 1: General background information

To date there has been very little research focussing on the experiences of Victorian parents whose children have dyslexia. It is important that such information is sought and thoroughly understood. To begin with it would be very helpful for us to understand how different factors may impact upon the experience of having a child with dyslexia. This section seeks general (non-identifying) information about you and your child.

1. Please select the box that describes your relationship to the child?
   - Parent
   - Step-parent
   - Foster parent
   - Grandparent with caring responsibility for child
   - Legal guardian
   - None of the above (please clarify your relationship to the child)
     (Space provided)

2. Please indicate your gender
   - Male
   - Female

3. Please indicate the gender of your child
   - Male
   - Female

4. Please indicate your child’s year of birth. (Drop down box of 1990 to 2007)
5. Does anyone else in the family have dyslexia (suspected or diagnosed)? (Tick as many boxes as apply)
   - No-one else in the family has suspected or diagnosed dyslexia.
   - Child’s mother
   - Child’s father
   - Child’s younger/older sister/brother
   - Child’s uncle/aunt
   - Child’s grandparent
   - Child’s first cousin
   - Other (space for other answer)

SECTION 2: Identifying and diagnosing dyslexia

Dyslexia can be described as a significant and ongoing difficulty with reading, spelling and writing that is unexplained by other conditions. In Victorian schools children are not currently routinely screened for dyslexia. There is also a relatively low degree of awareness of dyslexia. This means that discovering a child has dyslexia may occur in many different ways and take varying lengths of time. In this section, we interested to learn how you discovered your child has dyslexia and the circumstances that led to this realisation.

6. How much did you know about dyslexia before your child was formally diagnosed with dyslexia?
   - No knowledge of dyslexia
   - Basic knowledge of dyslexia
   - Extensive knowledge of dyslexia

7. Sometimes parents, teachers and other professionals are alert to the fact that a child may be experiencing learning difficulties and sometimes only one person realises that this is the case. Please indicate who first noticed that your child was experiencing learning difficulties (before the formal diagnosis). Tick as many boxes as apply:
   - You or your partner
   - School teacher
   - Psychologist
   - Your child informed a parent or teacher of difficulties
   - Other – please specify (space for answer)
8. Approximately how old was your child when you (or others) first suspected he/she was experiencing difficulty with reading, writing or spelling?
(Drop down boxes of ages 3 to 18)

9. What were the signs which suggested to you (or another) that your child may need testing for dyslexia?
(Tick as many boxes as apply).
- Child experienced difficulty when learning to read
- Child experienced difficulty when spelling
- Child experienced difficulty when writing
- Child was unhappy at school
- Child refused to attend school
- Negative comments were made by teachers (e.g. child is lazy, disorganized, not bright, doesn’t listen).
- Standard school testing revealed a problem (e.g. Naplan or South Australian spelling test results).
- Child had difficulty keeping pace with school peers
- Child displayed disruptive behavior in class
- Child had unexplained difficulties with eyesight
- Child had difficulty copying from a board
- Child experienced unusual levels of tiredness after a school day
- Child had difficulty concentrating in class
- Your child had difficulty remember lists (for example instructions)
- You noticed an unexplained gap between your perception of the child’s intelligence and their achievements at school.
- Other... (Space for answer provided)

10. Before your child was formally diagnosed with dyslexia did you seek help from any professionals for apparent learning difficulties?
- Yes
- No

(If the answer is “no” survey automatically skips to question 12)

11. Please indicate from which professionals you sought help before your child received a formal diagnosis of dyslexia. (Please mark all the boxes that apply). Using the adjacent scale please indicate how useful you consider their help to have been.
(4-point Likert scale – provided across the page next to each box: Not useful, Somewhat useful, Useful, Very useful.

- The child’s school teacher
- Special education teachers at child’s school
- External special education teacher
- Educational psychologist
- Neuropsychologist
- Speech therapist
- Occupational therapist
- Social worker
- Audiologist,
- Educational optometrist,
- Physiotherapist
- GP or Specialist medical doctor
- Remedial teacher
- Irlen Clinic
- Special education teacher
- Alternative health practitioner (e.g. naturopath, kinesiologist)
- SPELD VIC
- Other please specify? (space provided)

12. In addition to the list above did you seek further information about dyslexia from other sources
   - Yes
   - No
   (If they answer No, questionnaire skips to question 14)

13. From which sources did you seek further information about dyslexia? Tick as many as of the following answers that apply and indicate how useful these sources were:
   (Scale provided next to each option - consisting of: Not useful, somewhat useful, Useful, very useful.)
   - Friends or contacts with a child who has dyslexia
   - Community health centre or maternal and child health nurse
   - Dyslexia specialist community organisations such as SPELD
   - The world wide web
   - Books
   - Department of education or another government department
   - Newspaper articles
   - Research journal articles and bulletins
   - Doctor (GP or pediatrician)
14. What was your child's age at the time of formal diagnosis? (Drop down box of numbers)

15. Please indicate how you felt when your child was formally diagnosed with dyslexia?
   - No feelings
   - Interested
   - Curious
   - Surprised
   - Shocked
   - Angry
   - Disbelieving
   - Relieved
   - Worried
   - Highly anxious
   - Unsurprised
   - Other – please describe your feelings (Space provided)

16. On reflection how would you describe the process of reaching a formal diagnosis of dyslexia?
   - Easy
   - Somewhat easy
   - Neither easy nor difficult
   - Difficult
   - Extremely difficult.

   Please add your reflections on this process if you wish (space provided)

SECTION 3: Support for your child

Dyslexia can affect children in different ways and to varying degrees. Currently in Victoria support for children with dyslexia is largely dependent upon the resources of parents and the goodwill and capacity of a child’s school. This section explores how easy or difficult it has been for you to find support for your child.

17. Once your child was diagnosed with dyslexia how easy or difficult was it to find strategies to help your child deal with his or her learning difficulties?
Very easy
Somewhat easy
Neither easy nor difficult,
Difficult
Very difficult.

18. Please indicate from which of the following professionals you sought support for your child and your assessment of how helpful they were. (Tick as many boxes as applicable)
Scale across the page provided with “Not useful, somewhat useful, Useful, Very useful”.
The child’s school teachers
Special education teachers at child’s school
External special education teacher
Doctor (GP)
Pediatrician
Educational Psychologist
Neuropsychologist
Speech therapist
Occupational therapist
Audiologists
Educational optometrist
Irlin Clinic
Physiotherapists
Social worker,
Educational specialists
Alternative therapists (e.g. naturopath, kinesiologist)
None of the above
Other – please indicate.

It is known that obtaining a diagnosis of dyslexia and supporting the learning needs of children with dyslexia can require considerable financial resources. It may be helpful for policy makers to get a snapshot of these expenses. That is why we are asking the following two questions.

19. Please indicate the approximate expenses to date involved in obtaining a diagnosis of dyslexia. (drop down boxes below)
0 to $100
$101 to $500
$501 to $1,000
$1001 to $1500
$1501 to $2000
$2001 to $2500
20. Please indicate the approximate expenses of support you have purchased to assist your child with their learning needs. (Please remember to include professional support, tuition and resources such as computer programs and aids, workbooks or special text books and technology).
  - $0 to $100
  - $101 to $500
  - $501 to $1,000
  - $1001 to $1500
  - $1501 to $2000
  - $2001 to $2500
  - $2501 to $3000
  - $3001 to $35000
  - $3501 to $4000
  - $4001 to $4500
  - $4501 to $5000.
  - $5001 or above
  - (Please indicate in space provided the approximate sum to date)

21. Can you provide an estimated figure of ongoing annual costs related to your child’s dyslexia? (For example, costs associated with extra tuition). (Space provided)
SECTION 4: Recognition of child’s needs and support within the school environment

Currently in Victoria there is very little policy to guide schools in relation to supporting children with dyslexia. This means that how children with dyslexia are treated and supported can vary a great deal. In this section we are trying to gain a snapshot of the commonalities and differences in how schools respond to dyslexia. If your child has attended more than one school please answer the following questions in relation to your child’s current school.

22. Please indicate the type of school your child currently attends
   - State school
   - Catholic school
   - Independent school
   - Special school
   - Child is home-schooled (Please state reason for this decision in space provided and skip to Section 5)

23. Is the school informed of their diagnosis?
   - Yes
   - No (Please provide a reason for this decision in space provided)

24. Please indicate the school’s response to your child’s diagnosis of dyslexia?
   (5-point Likert scale of the following: Very supportive, Supportive, Somewhat supportive, Unsupportive, Very unsupportive)

25. What terminology does your child’s current school use to describe your child’s dyslexia?
   - Dyslexia
   - Learning difficulty
   - Learning disability
   - Specific Learning Difficulty
   - Specific Learning Disability
   - None
   - The terminology varies
   - Other (please indicate in space provided).
26. Has there been any objection to using the word “dyslexia” in relation to your child’s learning difficulties?
   ○ Yes
   ○ No

   (If yes, please list the role (not the name) of the person who voiced the objection – space provided)

27. How would you rate your child’s teachers’ knowledge of dyslexia and its impact?
   ○ No knowledge
   ○ Minimal knowledge
   ○ Extensive knowledge
   ○ It varies between teachers

28. How would you rate the school in addressing your child’s learning needs?
   ○ Very unhelpful
   ○ Somewhat helpful
   ○ Neither helpful nor unhelpful
   ○ Helpful
   ○ Very helpful

29. Currently how satisfied are you with the level of support your child receives from the school?
   ○ Dissatisfied
   ○ Neither satisfied or dissatisfied
   ○ Satisfied
   ○ Very satisfied

30. Please indicate what type of support the school provides your child (Please tick as many boxes as apply)
   ○ None
   ○ Remedial classes in literacy
   ○ Psychological support and counseling
   ○ Facilitated program to raise self-esteem program
   ○ An aide in the classroom
   ○ Centralised recording to facilitate awareness for incoming teachers regarding my child’s learning needs
   ○ Professional development for my child’s teachers
31. Have you at any stage moved your child to a different school as a result of dissatisfaction with a previous school related to their treatment of your child’s dyslexia?
   o Yes (please indicate how many times – space provided)
   o No

32. Please indicate what type of support (not currently in place) do you think would be most beneficial for your child? (Space provided)

33. Have you felt challenged in dealing with your child’s dyslexia?
   o Yes
   o No (If no survey skips to question 35)

34. Please indicate which challenges you have experienced. Please mark as many boxes as apply.
   o Difficulty accessing information about dyslexia
   o Difficulty accessing reliable and consistent information about dyslexia
   o Difficult accessing resources to support your child
   o Difficulty gaining a diagnosis
   o Period before diagnosis – not knowing what was wrong
   o Anxiety about your child’s future
   o Lack of support from the school
   o People who deny dyslexia exists
   o Expenses related to diagnosis
   o Expenses related to helping your child
   o Concern about your child’s self esteem
   o Other concerns about your child’s welfare and wellbeing
   o Lack of special consideration for your child from his/her teachers
   o Teacher’s lack of knowledge about dyslexia
   o Lack of guiding policy about how to recognize and deal with dyslexia
35. Are there any positive things that have resulted from your child’s dyslexia? (Space provided)

SECTION 5: Your views about government policy on dyslexia

In this section we are interested in exploring your views on current government policy (state and federal) in relation to dyslexia. We are also interested hearing your views on ideal policy for the future.

36. Are you satisfied with the current level of support provided by the state government in relation to assisting families with a child with dyslexia?
   - Very unsatisfied
   - Somewhat satisfied
   - Neither satisfied nor dissatisfied
   - Satisfied
   - Very satisfied

37. Are you satisfied with the current level of support provided by the federal government in relation to assisting families with a child with dyslexia?
   - Very unsatisfied
   - Somewhat satisfied
   - Neither satisfied nor dissatisfied
   - Satisfied
   - Very satisfied

38. What changes if any would you like to see made to Victorian Government policy in relation to dyslexia? (Tick as many boxes as apply. If they are not changes you wish to see then please do not mark the box.)
   - None – I am satisfied with current policy
   - Universal screening for dyslexia in all primary school students
   - Funding for computer technology and software to assist students in class and with homework
   - Specialist training for qualified teachers regarding dyslexia
   - Policy for dyslexia awareness and training to be mandatorily included in general teacher training
   - Special consideration for children with dyslexia granted at VCE level (for example use of a computer or extra time)
• Dyslexia awareness and support to be part of school policy documents including welfare, induction and discipline policy
• Schools to be required to report to an independent body regarding compliance with reasonable accommodation for students who have dyslexia and other disabilities
• Random review by independent body of compliance with education standards for disability support
• Schools to be required to collect data for students who have dyslexia regarding educational outcomes, suspensions, attendance, parent complaints, requests for allied health support.
• Funding for teachers’ aides
• Funding for remedial teachers
• Funding to enable purchase of special equipment
• Funding for evidence based self-esteem raising programs for all children
• Other – (space provided)

39. Do you have any other suggestions or ideas regarding policy for the future? (space provided)

SECTION 6: Background Demographics

Thank you for your patience. This survey is almost complete. This following section is important as it will provide us with valuable insights into how the experience of having a child with dyslexia may be influenced by gender, age, locality, income and occupation.

40. Please indicate your year of birth (Drop down box of years)

41. What is your present marital status?
   • Single
   • De facto relationship
   • Married
   • Divorced
   • Separated
   • Widowed

42. Please indicate which bracket reflects your household income bracket. (drop down boxes)
   • $12,000 to $25,999
   • $26,000 to $35,999
$36,000 to $45,999
$46,000 to $65,999,
$66,000 to $85,999
$86,000 to $105,999
$106,000 to $125,999
$126,000 to $145,999
$146,000 to $166,999
$167,000 to $185,999
$186,000 to $205,999
$206,000 to $249,999
$250,000 or more

43. Were you born in Australia?
   o Yes
   o No (if no skip to question 44)

44. Are you of Aboriginal or Torres Straits background?
   o Yes
   o No

45. Is English your first language?
   o Yes
   o No

   If no, please indicate your first language. (Space provided)

46. Providing your postcode will help us understand how this experience may differ depending on where you live. Please provide your postcode (Space provided).

47. What is your highest level of education?
   o Secondary – some
   o Secondary – completed
   o Technical or further education institution
   o Completed undergraduate studies at university
   o Completed post-graduate studies at university
48. Which categories best describes your current employment status?

You

- Employed
- Unemployed
- Home duties
- Student
- Disability pension
- Single parent pension
- Pension (age related)
- Veteran’s pension

Partner

- Employed
- Unemployed
- Home duties
- Student
- Disability pension
- Pension (age related)
- Veteran’s pension

Is there anything you would like to tell us that has not been covered in this survey? (Space provided).

Thank you for taking the time to participate in this survey.

A research report with the findings from this research will be made available at www.websitelinktobeinserted

Please click the submit button. A page of support services will appear after you submit the survey. To exit click the x box in the top right hand corner of the web browser.
APPENDIX G: Interview – Plain Language Statement

Plain Language Statement

Human Research Ethics Approval No. 1238564

Invitation to take part in an interview for the research project:

The experiences and views of parents of a child with dyslexia in Victoria

Purpose of this Project
This project aims to explore the experiences of Victorian parents of children with dyslexia. There is very little known about the experiences of parents of children with dyslexia in Victoria and indeed in Australia generally. The researcher would like to hear the voices of parents to help shed light on this important subject and share this information with other researchers, support agencies, parents, and policy makers.

Invitation to participate in the project
Victorian parents or carers of a child aged between 7 and 18 with a child who has been diagnosed as having dyslexia are invited to participate. The researcher will conduct interviews which will explore parents’ experiences of:

- the process of discovering that their child is affected by dyslexia
- gaining a formal diagnosis of dyslexia
- finding information, support and resources to assist their child and themselves
- responses to their child’s dyslexia
- key challenges they face in supporting their child

In addition, the researcher will seek parents’ ideas regarding ideal policy in this field.

Before reading the detailed information below, please ensure you are eligible to participate:

- You must be a parent or carer of a child currently aged between 7 and 18 who has a formal single diagnosis of dyslexia from a practitioner qualified to confirm this diagnosis. (Documented diagnosis will need to be seen by the researcher). Please note that a “single diagnosis” of dyslexia means that the child does not have other conditions which could potentially impact on their ability to read, spell and write, such as attention deficit disorder or acquired brain injury.
- You must be currently living in Victoria and also have lived there at the time of the child’s diagnosis.
Why is proof of my child’s dyslexia needed in order to participate in the project?
The need for a diagnosis from a registered professional is to strengthen the credibility of the research and is in no way intended to undermine parental judgement.

Who is conducting the research?
Katherine Levi is a PhD student at the School of Social Work, in the Faculty of Health Sciences at The University of Melbourne. She is also the parent of a child with dyslexia. Katherine is conducting this research as part of her doctoral thesis. The research is being supervised by Professor Cathy Humphreys, Dr Nola Firth and Dr David Rose.

Why participate in this research?
To date little research has been conducted focussing on the experience of Victorian parents whose children have dyslexia. There is growing interest from the government in relation to support for dyslexia. We would like to document the experiences and insights of Victorian parents’ of children with dyslexia and contribute to this discussion.

What are the benefits of participating in this research?
Being a parent with a child who has dyslexia can be challenging. Some participants may find a benefit in having an opportunity to discuss their experiences and feelings. Some participants may also feel positive about the possibility of having their voices heard by policy makers and by other researchers in the field. However, the researcher acknowledges that there may be no direct benefits to participants. The completed thesis will be available for review and an electronic copy of it can be sent to participants if desired.

What will I be asked to do if I become a participant in this research?
If you agree to take part in this research you will be asked to demonstrate proof of your child’s diagnosis of dyslexia, sign a consent form and talk with the researcher about your experiences regarding your child’s dyslexia for approximately 60 to 90 minutes. Depending on your preference, the interview can be held at SPELD’s office in North Fitzroy, at The University of Melbourne, at a convenient suitable location near your home or via telephone or using Skype.
If you agree then the interview will be recorded using a digital voice recorder. The purpose of recording the interview is to ensure that we have an accurate record of what you say. If you do not wish the interview to be recorded the researcher will take notes instead.
The interviewer will ask you:
- Basic information about you such as age in years, educational level, occupation, marital status, number of children, country of birth and the language you speak at home.
- Background information about your child with dyslexia such as age, gender, age of diagnosis, the type of school they attend.
• Questions about your experience as a parent of a child with dyslexia such as how you have gathered information about dyslexia, from whom you have sought help and advice, resources you have accessed, the response of your child’s school to dyslexia, positive experiences, challenges and hopes and fears for your child’s future.
• Questions about costs associated with having a child with dyslexia.
• Reflections on what sort of policy in relation to dyslexia you would like to see in the future.
You will also be given an opportunity to raise any issues you feel are important.

What will the interviews be used for?
The information you provide in the interviews will be written up in notes along with all the other interviewees’ responses. Individual quotes may be used from your interview to highlight points in the final report. Please be assured that quotes will not be attributed to you personally.
The completed research will be submitted for a PhD degree. There may also be articles published and talks given at conferences about the findings from this research.

Will the information I provide remain confidential?
Yes. Your personal information will remain entirely confidential at all times. The information you provide will be stored securely in a locked filing cabinet and in a secure, password protected computer.
As required by The University of Melbourne regulations this information will be retained for a period of 5 years from when the reports on the research are published.

Do I have to take part in this research?
Your participation in this research is completely voluntary. You can withdraw your consent at any time.

Are there any risks to me for taking part in this research?
It is highly unlikely that there is any risk to you in taking part in this research. It is possible that thinking about this topic may cause you some discomfort or mixed feelings by revisiting past negative experiences or fears about your child’s well-being.
If you feel at all uncomfortable or concerned following the interview you are welcome to contact the researcher and set up a time for a meeting or have a discussion by phone or Skype. Additionally or alternatively you could contact SPELD VIC who are supportive of this research and employ people skilled at providing information and support regarding dyslexia. If the interview raises difficult material you may wish to contact Professor Cathy Humphreys from the Social Work department at The University of Melbourne for advice or support. (Contact details for these supports are provided in the attached document).
Where can I find the results of the research?
The results of this research will be available in late 2014. A summary of the project will be linked to The University of Melbourne, Department of Social Work website as well as SPELD VIC’s website. Alternatively you can also register your email address on the consent form and a summary will be sent to you.

How do I agree to participate?
If you have read through all the information on the research project and are happy to participate please email your consent form to the researcher at katherinelevi@optusnet.com.au or telephone the researcher on 0409 334020. She will then arrange a mutually convenient time to meet with you.

Who can I contact if I have concerns about the research or require further information?
If you have any concerns about the research or would like more information you can contact the researcher or members of the supervising team at the University of Melbourne as follows:

Katherine Levi  
Katherinelevi@optusnet.com.au  
Tel: 0409 334020

Professor Cathy Humphreys  
Department of Social work  
cathy.humphreys@unimelb.edu.au  
Tel: (03) 8344 9427

Dr David Rose  
Department of Social Work  
drose@unimelb.edu.au  
Tel: (03) 8344 9423

Dr Nola Firth  
Graduate School of Education  
nola.firth@mcri.edu.au

If you have any concerns about the conduct of the research you can also contact: The Executive Officer  
Human Research Ethics  
The University of Melbourne  
Phone: 83442071  
Fax: 93476739
APPENDIX H: Interview – Consent Form

RESEARCH PARTICIPANT CONSENT FORM

You are invited to participate in this study which explores the experiences and views of parents of a child with dyslexia in Victoria

The researchers include:

Katherine Levi (Primary PhD researcher)
Department of Social Work, School of Health Sciences
The University of Melbourne

Professor Cathy Humphreys (Supervisory researcher)
Department of Social Work, School of Health Sciences
The University of Melbourne

Dr David Rose (Supervisory researcher)
Department of Social Work, School of Health Sciences
The University of Melbourne

Dr Nola Firth (Supervisory researcher)
Honorary Research Fellow, Melbourne Graduate School of Education
The University of Melbourne and the Murdoch Childrens Research Institute

If you would like to participate in the interviews for this study you must read and sign and return this form:

Name of participant  .........................................................

I consent to participate in the research projected named above by completing an interview.

I acknowledge that I have read and understood the information about the project contained in the Plain Language Statement (Version 1: 1/8/2012) and that I have been given a copy to keep.
I understand the following:

- Participation is voluntary and that I have the right to withdraw at any time.
- If I choose to withdraw, I can request any information I have supplied be destroyed (up until it has been included in publication).
- That the project is for the purposes of research only and not for advice or treatment.
- Any identifiable information I provide will be de-identified and treated confidentially.
- I have been informed that should I be selected for an interview and I will be referred to by pseudonym in any publications arising from the research.
- If I agree, my interview will be tape recorded or digitally recorded and then transcribed. I understand that before the data is transcribed it will be stored securely in a locked cabinet. And that following the transcription the recording will be destroyed.
- Information, I supply may be included in reports and publications, as long as it does not identify me.
- Once signed, this consent form will be retained by the researchers and stored securely and separate to any data or information I provide.

Name (print) ..........................................................
Signature ..........................................................
Date ..........................................................

Please tick the box and provide an email address below if you would like to receive a copy of the summary of the research results when it becomes available.

Email ..........................................................
Online consent form for survey participants

The experiences and views of parents of a child with dyslexia in Victoria

Thank you for your interest in participating in this research by taking part in an online survey.

Below is information about the people responsible for the research:

Researchers: Katherine Levi (Primary PhD researcher)
Department of Social Work, School of Health Sciences
The University of Melbourne

Professor Cathy Humphreys (Supervisory researcher)
Department of Social Work, School of Health Sciences
The University of Melbourne

Dr David Rose (Supervisory researcher)
Department of Social Work, School of Health Sciences
The University of Melbourne

Dr Nola Firth (Supervisory researcher)
Honorary Research Fellow, Melbourne Graduate School of Education
The University of Melbourne and the Murdoch Childrens Research Inst.

Please complete as much of the survey as you can but if you feel uncomfortable answering any question you may leave it blank and move onto the next question or section. The whole survey takes approximately 30 to 40 minutes to complete. You can save and exit and return to the survey at any time but once you click submit you cannot add to your answers.
The survey contains questions about the following topics:

Section 1: General background information about you and your child  
Section 2: Identifying and diagnosing dyslexia  
Section 3: Finding appropriate support for your child  
Section 4: Recognition of your child’s needs and support within the school environment  
Section 5: Your views about government policy on dyslexia  
Section 6: Background demographics

At the end of the survey there is a section that provides links to further information and supports that may be useful to you.

Please tick each of the boxes below by clicking “yes” with your mouse if you agree or “no” if you do not agree. A “no” response means you do not agree and do not wish to proceed to participate in the survey.  

Before proceeding with the survey please note:  

- that for the purposes of this survey the word “parent” means a person who may be a biological or non-biological parent of a child or children with dyslexia. It also includes an adult who may be the legal guardian or main carer (e.g. grandparent or other relative or adult with responsibility) for a child with dyslexia.
- if you are the parent of more than one child with dyslexia, please answer the survey with the first child who received a formal diagnosis in mind.

I confirm that:

1. I am a “parent” of a child aged between 7 and 18 years of age, who has been formally diagnosed by a qualified psychologist as having dyslexia.
   - Yes
   - No

2. I and my child currently reside in Victoria, Australia and did so at the time of my child’s diagnosis of dyslexia.
   - Yes
   - No

3. I confirm that my child has a sole diagnosis of dyslexia and has NOT been diagnosed with any other disorder (for example ADD, ADHD an intellectual disability, an acquired brain injury).
   - Yes
   - No
I acknowledge that I have accessed, read and understood the information about the project contained in the Plain Language Statement (Version 1: 1/8/2012). I understand I can download and print or save a copy of the Plain Language Statement should I wish to do so.

- Yes
- No

I understand that:

1. I consent to participate in the research project named above by completing a survey.
2. Participation is voluntary and that I have the right to withdraw at any time.
3. That I will not be asked to provide any information that may identify me personally and that my answers will remain anonymous and not be traceable to me electronically or via any other method.
4. Information I supply and statements I may make in this survey may be included in reports and publications.
5. Any identifiable information I provide intentionally or accidentally will be de-identified and treated confidentially.
6. Completing the survey will be treated as my voluntary consent to participate in this research.
7. That the project is for the purposes of research only and not for advice or treatment.
8. If I agree, my survey will be analysed and the data I provide will be transcribed and analysed by the researchers. A hardcopy of my survey answers will be stored securely in a locked cabinet and/or password protected computer. Following the transcription and analysis of data the survey will be will be destroyed.
9. Information, I supply may be included in reports and publications, as long as it does not identify me.

If you give your consent to all 9 points listed above click “Yes”. This will take you to the first page of the survey.

Thank you for your interest.
APPENDIX J: List of Support Services

The experiences and views of parents of a child with dyslexia in Victoria

Support

If participation in this research project causes you any distress or you simply wish to find out more about the type of support and information services that are available you are welcome to contact the researchers. Alternatively you may wish to contact support services available in the community. You will find them listed following the researchers contact details.

Katherine Levi: katherinelevi@optusnet.com.au
Tel: 0409 334020

Professor Cathy Humphreys: cathy.humphreys@unimelb.edu.au
Tel: (03) 8344 9427

Dr David Rose: drose@unimelb.edu.au
Tel: (03) 8344 9421

Dr Nola Firth: nola.firth@mcri.edu.au
Tel: 0419200971
Support Services

Listed below are the general and dyslexia specific support and information services.

SPELD VIC (Dyslexia and other learning disabilities support)
Tel (03) 9489 4344
Email: CEO@speldvic.org.au
www.speldvic.org.au

Learning Difficulties Australia
Tel (03) 98906138
enquiries@ldaustralia.org
www.ldaustralia.org

Department of Families, Housing and Community Services and Indigenous Affairs
http://raisingchildren.net.au/articles/learning_disabilities.html
(Federal Government website)

Australian Psychological Association
www.psychology.org.au
Tel: (03) 8662 3300 or Toll free: 1800 333 497
Email: contactus@psychology.org.au
(For recommendations about specialists in dyslexia counselling support.)

British Dyslexia Association
www.bdadyslexia.org.uk
(Source of information about dyslexia)
Author/s:
Levi, Katherine Sarah

Title:
The experiences of parents of children who have dyslexia in Victoria, Australia: a social justice perspective

Date:
2017

Persistent Link:
http://hdl.handle.net/11343/212091

File Description:
Complete thesis

Terms and Conditions:
Terms and Conditions: Copyright in works deposited in Minerva Access is retained by the copyright owner. The work may not be altered without permission from the copyright owner. Readers may only download, print and save electronic copies of whole works for their own personal non-commercial use. Any use that exceeds these limits requires permission from the copyright owner. Attribution is essential when quoting or paraphrasing from these works.