The lived experience of adults with dyslexia:
An exploration of the perceptions of their educational experiences

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By

Kathleen Tanner

B.Ed. (UTAS), Grad. Dip. Special Ed. (UTAS), Grad. Cert. TESOL (Macq.),

M.Ed. Studies (UTAS).

School of Education

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I, Kathleen Tanner, declare that this thesis is my own account of my research and contains as its main content work that has not previously been submitted for a degree at any tertiary education institution.

Kathleen Tanner

June, 2010
Abstract

This thesis examines the life choices of a small cohort of adults with dyslexia. In particular, it focuses on the influence of their educational experiences (primary, secondary and post-secondary) on their understanding of their dyslexia and how this knowledge assisted them in understanding their role within a society that places high value on strong literacy skills.

Each of the participants in this study had previously completed a customised course for adults with dyslexia developed by TAFEWA. Most were diagnosed as having dyslexia in adulthood, a small number as part of the process that led to their enrolment in the TAFE course. The researcher was both a lecturer in that program and played a critical role in designing a number of core units, particularly the Understanding and Managing Dyslexia unit from which participants in this study were drawn.

The study shows how the participants benefited from their participation in this course as it their enhanced understanding of dyslexia. This enhanced understanding facilitated positively reframing of their attitudes towards their dyslexia and society’s attitudes to people who display limited literacy skills. Prior to the course, the participants, who ranged in age from early 20s to 60+, believed that society was setting them up to fail.

Traditionally dyslexia has been interpreted through a medical-scientific lens. This study adopts a different approach that is holistic in focus, is situated within an interpretivist paradigm and draws from a range of methodologies, including phenomenology, feminist theory and narrative inquiry to develop a series of case
studies that draw individual experiences together. A significant feature of the thesis is the adoption of an ecological framework developed from Urie Bronfenbrenner’s (1979) social ecology theories of human development and in particular his Person, Process, Context and Time (PPCT) process (1992), to present individual participants and analyse their life experiences. The time component, in particular, is important in the context of lived experience.

The analysis is based on the life narratives of 10 individuals that focus on their educational experiences and the influence this had on their life choices. Data collection involved a series of one-on-one semi-structured conversations and a face-to-face focus group.

This thesis goes beyond the work of Bronfenbrenner to reinterpret the ecological model and presents an alternate conceptual framework in which society is likened to a river flowing across a landscape. The individuals are a key part of the river alongside the micro and exo systems. The landscape represents the macrosystem and the framework within which the river flows. In a human context this equates to the relationship of the individual to society and the significance of change linked to the passing of time.

A key argument is that the lenses through which dyslexia is viewed directly influence the way people with dyslexia are perceived in a wider societal context. The language used and the emphasis in a societal context placed on literacy skills, not only limits, but also marginalises and excludes those with literacy difficulties. Thus the thesis moves beyond the medical/scientific framework within which the concept of dyslexia is traditionally viewed. Whatever dyslexia is or is not, it is clear there exists a group of people for whom day-to-day living in a literacy-based society presents unique
challenges and the present study investigates how they have experienced these challenges.
# Table of Contents (Brief)

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>iii</td>
</tr>
<tr>
<td>List of Figures</td>
<td>xv</td>
</tr>
<tr>
<td>List of Tables</td>
<td>xvi</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>xvii</td>
</tr>
<tr>
<td><strong>Chapter 1:</strong> Introduction</td>
<td>1</td>
</tr>
<tr>
<td><strong>Chapter 2:</strong> Review of Literature</td>
<td>11</td>
</tr>
<tr>
<td><strong>Chapter 3:</strong> Methodology</td>
<td>48</td>
</tr>
<tr>
<td><strong>Chapter 4:</strong> Introduction to the Participants - Capturing the Essence of their Lived Experiences</td>
<td>82</td>
</tr>
<tr>
<td><strong>Chapter 5:</strong> Educational Experiences viewed through the Lens of New Knowledge gained through the Dyslexia Course</td>
<td>105</td>
</tr>
<tr>
<td><strong>Chapter 6:</strong> Life Choices and the Emergence of Reframing</td>
<td>150</td>
</tr>
<tr>
<td><strong>Chapter 7:</strong> Reframing Dyslexia</td>
<td>171</td>
</tr>
<tr>
<td><strong>Chapter 8:</strong> Conclusion</td>
<td>231</td>
</tr>
<tr>
<td>References</td>
<td>245</td>
</tr>
<tr>
<td>Appendices</td>
<td>268</td>
</tr>
</tbody>
</table>
Table of Contents (Full)

Abstract iii
List of Figures xv
List of Tables xvi
Acknowledgements xvii

Chapter 1: INTRODUCTION 1
Situating Dyslexia 3
Rationale for the Study 6
Significance of the Study 7
Aim of the Study 8
Overview of the Study 9

Chapter 2: REVIEW OF LITERATURE 11
Literature review Section One:
The Cultural Construction of Literacy 11
  Economic and social impact 12
  Job complexity linked to literacy skills 13
  Society, education and literacy skills 14
The Societal Construction of Failure 16
  The failure factor 17
  Constructed assumptions and beliefs 21
Individual Responses to the Key Factors of Failure 22
  Behavioural and affective responses 22
  Personal attributes that enhance success or non-success 24
    Self awareness versus lack of self awareness 25
    Proactivity versus reactivity 26
    Perseverance versus lack of perseverance 26
Emotional stability/emotional coping strategies versus lack of emotional stability and coping strategies 26

Appropriate goal setting and self-directedness versus lack of appropriate goal setting 27

Presence and use of effective support systems versus lack of use of effective support systems 28

Responses to the Demands of a Literacy-based Society 29

Negative adjustments 29

Dropping out of school 30

Social impact of isolation and/or exclusion 30

Financial difficulties linked to lack of occupational success- unsuccessful 'niche picking' 31

Positive adjustments 32

Personal attributes - ability to 'think outside the square' 32

Effective compensatory strategies 32

Literature Review Section Two:

Assumptions and Beliefs about the Concept of Dyslexia 34

What defines the concept of dyslexia? 35

Dyslexia as a disability or difficulty? 37

Hidden or non-evident - how does the visibility of dyslexia impact on definition? 38

Dyslexia: myth or reality? 39

Does adult dyslexia exist as a phenomenon? 41

Research Lenses through which Assumptions and Beliefs about Dyslexia are Driven 42
Quantitative versus qualitative research - childhood versus adult

Summary of Literature Review Chapter

Chapter 3: METHODOLOGY

Research design: Where to, and Why? The Decision Trail and Life's Influences

A phenomenological perspective emerges

How is disability viewed and understood?

Situating Bronfenbrenner's PPCT in the context of this study

Summary of Methodology

The Conduct of the Study

Choosing the participants

Information about the participants

Background information about the TAFE course for people with dyslexia

Data collection

Individual interviews - narrative-based

Focus group interview session

Research diary

Limitations of study

"Volumes of Data" - How was it Organised and What was Done with it?

Stage one: Individualising data - capturing the essence of participants' lived experiences

Use of narrative technique

Development and inclusion of the conceptual
Stage two: Data reduction into sets of information - a cross case analysis of educational experiences

Summary of Chapter

Chapter 4: INTRODUCTION TO THE PARTICIPANTS - CAPTURING THE ESSENCE OF THEIR LIVED EXPERIENCES

Participant 1: David
Participant 2: Joseph
Participant 3: Juanita
Participant 4: Kim
Participant 5: Kerrie
Participant 6: Robert
Participant 7: Riley
Participant 8: Sam
Participant 9: Christine
Participant 10: Sarah

Chapter 5: EDUCATIONAL EXPERIENCES VIEWED THROUGH THE LENS OF NEW KNOWLEDGE GAINED THROUGH THE TAFE DYSLEXIA COURSE

Schooling Information about each Participant

Remedial assistance

Year completed high school

Post secondary education information (not including TAFE dyslexia course)

Perceptions of the Educational Setting as a System or Institution

Repeating year levels
Perceptions of Individuals (Teachers and Peers) within the Educational Setting

Teaching characteristics

Perceived responses to identification of strengths and difficulties during primary and secondary years

Referred the student to a support staff or remedial group or attempted support in the classroom context

Ignored or appeared oblivious to participants' needs

Perceptions of teacher responses in an adult learning context

Referred participant to Dyslexia course

Referred to other courses/forms of support

Attempted to support and adjust teaching and learning linked to identified job-related qualities

Non-supportive

Bullying

Peer Responses

Primary and secondary years

Importance of peers

Bullying

Name calling

Victimisation and public humiliation

Emotional manipulation

Positive acknowledgment of skills

Perception of the part of Significant Others

Self-Perceptions in the Context of the Education Setting

Self-perception as influence by words and labelling
Chapter 6: LIFE CHOICES AND THE EMERGENCE OF REFRAMING

Primary and Secondary Life Choices

Proactive life choices
   Personal motivation and perseverance

Reactive life choices
   Withdrawal
   Compensatory responses
   Negative self-efficacy

Out of individual participant's control

Life choices made by significant others

Life Choices - Post Secondary Education

(before Dyslexia Course)

Proactive Life Choices
   Personal motivation and perseverance
   Advocacy
   Disclosure of literacy difficulties

Reactive choices
   Withdrawal
   Compensatory responses
   Negative self-efficacy

Out of individual participant's control

Life Choices - Post Secondary (after Dyslexia Course)

What does the Literature say about Reframing?

Summary of Chapter

Chapter 7: REFRAMING DYSLEXIA
The Reframing Process

Recognition

First stage of recognition
Second stage of recognition
Third stage of recognition

Degrees of Acceptance

Changing one's perspective of dyslexia from negative to positive
Acceptance of the need to use compensatory strategies
Acceptance of the pragmatic need to access external support
Awareness of well-known and successful people with dyslexia

Understanding

Membership of a unique group
Self-understanding linked to understanding and confusion of mixed messages
Engaging in a dialogue about dyslexia

Plan of Action

Change in mindset and understanding
Personal motivation and perseverance
Pragmatic plans of action linked to employment and study
Personal plans of action linked to passion

Advocacy

Public advocate
Advocacy for others with literacy difficulties

Disclosure of Dyslexia
Appendix C  Course Details  276
Appendix D  Visual Timeline  278
Appendix E  Patton Model of Question Types  279
Appendix F  Capturing the Essence of each Participant through a
Narrative of their Life Story  281
Appendix G  Positive and Negative Teaching Techniques  322
Appendix H  Signposts of dyslexia dependent on the interplay
within contexts  325
Appendix I  Types of disclosure and signposts of dyslexia  327

LIST OF FIGURES

Figure 3.1  Bronfenbrenner’s social ecology conceptual model  56
Figure 3.2  Data Collection and Analysis  73
Figure 4.1  David  95
Figure 4.2  Joseph  96
Figure 4.3  Juanita  97
Figure 4.4  Kim  98
Figure 4.5  Kerrie  99
Figure 4.6  Robert  100
Figure 4.7  Riley  101
Figure 4.8  Sam  102
Figure 4.9  Christine  103
Figure 4.10  Sarah  104
Figure 7.1  The stages of reframing  174
Figure 7.2  Types of disclosure  203
Figure 7.3  Participants’ contextual influences across all systems  212
Figure 7.4  Timeline of David’s key life experiences    216
Figure 7.5  Full reframing within all contexts        225
Figure 7.6  Embedded assumptions and beliefs about people with insufficient literacy skills        227
Figure 7.7  Formation of tributaries by individuals  227
Figure 7.8  Process of reframing          228

LIST OF TABLES

Table 2.1  Lenses through which dyslexia is viewed within the literature        43
Table 5.1  Schooling information about each participant        106
Table 5.2  Post secondary education information about each participant  110
Table 5.3  Positive and negative traits of educators             122
Table 5.4  Words and labels used to describe participants by key stakeholders        147
Table 6.1  Key attributes of proactivity and reactivity          150
Table 6.2  Life choices across educational timeframe          151
Table 6.3  Life choices - primary and secondary  152
Table 6.4  Life choices - post secondary (before Dyslexia course)  160
Table 6.5  Life choices - post secondary (after Dyslexia course)  165
Table 6.6  Reframing stages and characteristic examples        168
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Chapter 1

INTRODUCTION

I’ve said it before and I’ll say it again – we’re vulnerable! Society makes us vulnerable! I can read – but not good enough in society’s eyes. I can write – but not good enough in society’s eyes. I try to spell – but I’m just not good enough. Why should I have to show everyone that I’m not good enough by having to respond to everything in writing. Society stinks – it doesn’t care about everyone – I’ve got lots to offer, lots of ideas but because I can’t write them down the way you’re meant to – forget it! In society’s eyes I’m a failure (David, interviewee).

A core group of adults exist in the community who are of average to above average intelligence, have had adequate schooling and yet have experienced difficulties decoding the written word (Nosek, 1997). Some have been diagnosed or identified as having dyslexia throughout their early educational experiences. Therefore, they may have an understanding of their personal characteristics. David (quoted above) on the other hand was not identified until adulthood. He was a participant in the research reported in this thesis. He, like many other adults with literacy difficulties, has encountered a society, and particularly an educational system, which claims that wisdom and knowledge are transmitted through the written media and success in this area leads to success in society (Lyster, 1999). Living with this embedded attitude “can have the effect of making people … feel they are not seen as functioning adults … and feel they cannot be open about their difficulties because such attitudes are supported in popular culture” (Herrington, Hamilton & Mace, 2001, p. 2). The quote below illustrated the influence of such attitudes on David.

I’ve lived my life thinking I had a mental illness. I went through school thinking I had a mental illness. My father treated me like I had a mental
illness. And people look at me if I can’t fill in a form as if I have a mental illness ... now I know I have dyslexia – it’s not a mental illness but the people out there still don’t know it ... I went through school and was told I had to read and write to get a good job ... look at me ... no job, no writing, no reading, no nothin (David).

Communication within western society is predominantly based on decoding the written word. The expectation is that all members should be able to read and write. This value is instilled in people from an early age when they are institutionalised within the education system. Society’s aim, which is reflected within educational paradigms and curricula, is for its members to become literate and, therefore, functioning or productive members of society. In everyday lives people are surrounded by print – menus, signs, instruction booklets, timetables, emails and endless forms to fill in. With literacy demands in society steadily increasing (Anstey & Bull, 2004; Wolff & Lundberg, 2003), due to globalisation as well as changes in information technology (Anstey & Bull, 2004; Tuijnman, 1995), more and more emphasis will be placed on written language skills if people are to cope.

Tuijnman (1995) claimed that the links between society, economic growth and development, particularly in the industrialised world, are all based around high literacy levels and that “inadequate levels of literacy among a broad section of the population potentially threaten the strength of economies and the social cohesion of nations” (p. 13). Within a current Australian context, the NITL (National Inquiry into the Teaching of Literacy) Teaching Reading - Report and recommendations (DEST, 2005b) states that literacy success is imperative as the basis of “occupational success, productive and fulfilling participation in social and economic activity as well as for the nation’s social and economic future” (p. 16). This reflects the ideological goal of capitalism embedded in the view that members need to be economically productive.
I’m seeing that there is a big need in the community to understand cause a lot of intelligent people that can do a lot for society but aren’t in actual fact, is hampered by the education system and with their self esteem goes down and they can’t – reading and writing’s everything in society, if you can’t express your intelligence in writing then it becomes very, very hard (David).

**Situating Dyslexia**

Dyslexia is most often described as a specific literacy-based learning impairment. Among other things, dyslexia can impact on an individual’s self-esteem, self-perception and self-concept and influence life choices. This does not imply that all adults with low literacy levels ‘have’ dyslexia, but it is likely that a proportion of these adults may have dyslexia, which can significantly affect their lives. This raises the question, what is dyslexia? Literature suggests there is global disagreement about dyslexia (Humphrey & Mullins, 2002; Jacob et al, 1998; Poole, 2003; Miles, Wheeler and Haslum, 2003; Ramus et al, 2003). Although there may be an agreed upon medical/scientific definition of dyslexia, this is not accepted by all stakeholders and will be discussed further within the Literature Review chapter. Seigal (1999) claims there is a degree of consensus as a range of characteristics that constitute dyslexia exists: in particular the core deficit of phonological processing that affects single word decoding involving identifying and “knowing the relationship between letters and sounds” (p. 306). This definitional debate has influenced recognition, and even existence, of dyslexia as a learning difficulty/disability in Australia. A simple medical definition describes dyslexia as a neurological malfunction (Ramus, Dakin, Day, Castellote, White, & Frith, 2003; Shaywitz, 2003), affecting the individual’s ability to process the written word. This is not to say that individuals can’t read or write, but the process is not fully automated. Theories suggest that many
characteristics of dyslexia go beyond text decoding with definitions drawing on scientific, medical, educational, political and cultural perspectives.

The language surrounding discussions about dyslexia is clearly situated within a medical/scientific framework and this has directly influenced how dyslexia is viewed, particularly in an educational context. The language directs us to define an individual’s identifiable characteristics and behaviours and suggests that people with dyslexia form a homogeneous group. This is despite the fact that there has been a concerted push for the adoption of “people–first, disabilities second language” both within an educational and social setting (Foreman, 2008, p. 17). This approach requires the person to be identified before the dyslexia. This is not restricted to dyslexia: it is an issue that covers the entire disability field. In the broader context this approach “convey[s] the impression that the person’s disability is just one of their many characteristics, just a part of their humanity” (ibid, p.17). This thesis seeks to present dyslexia within the context of individual life experiences. In many ways this thesis interrogates the past discourse surrounding dyslexia and for this reason personal pronouns will be used to refer to the uniqueness of each participant with terms such as ‘their’ or ‘my’ dyslexia. Accordingly, it is hoped that this thesis will contribute to a gradual reframing of the way dyslexia is perceived.

International research suggests approximately 5 to 10% of adults and children exhibit dyslexia (diagnosed and undiagnosed) (Smythe, Everatt & Salter, 2004). This statistic is likely to differ across cultures due to the “complexity in orthography of different languages” (Slaughter, 2001, p. 1). The exact number of adults with dyslexia in Australia is unknown, perhaps due in part to this definitional disagreement and a lack of acknowledgement of dyslexia within educational paradigms. In the UK,
However, up to 10% of the population are diagnosed with dyslexia (Buscombe, 2005), and in the USA “over thirty-five million men, women and children” (Nosek, 1997, p. 1).

While no quantitative data exist regarding the prevalence of adult dyslexia in Australia, anecdotal evidence suggests that overall literacy levels are a cause for concern. Results from the 1997 Australian Bureau of Statistics (ABS) census revealed that:

… approximately 20 per cent of Australians aged 15-74 years have been identified as having ‘very poor’ literacy skills, with an additional 28 per cent who could be expected to experience some difficulties in using many of the printed materials that may be encountered in daily life (DEST, 2005a, p. 13).

A further Adult Literacy and Life Skills Survey (ALLS) conducted in 2006 found that results were “slightly higher than those in 1996” (ABS, 2008a) with:

just over half (54%) Australians aged 15 to 74 years ... assessed as having [the] prose literacy skills needed to meet the complex demands of everyday life and work. Results were similar for document literacy with 53% (ABS, 2008b).

Federal politicians and educationalists have long claimed that literacy levels in Australia are ‘low’ and that curriculum changes are needed. During 2004, Dr Brendan Nelson, then Federal Minister for Education, Science and Training, commissioned the National Inquiry into the Teaching of Literacy (NITL). NITL focussed on exploring and reporting on current practices of literacy acquisition in Australian schools. Nelson claimed “literacy is the fundamental key to a child’s future success, happiness and ability to participate as a contributing adult member of society” (Media Release, 2005, p. 4). These concerns about low literacy levels point to the institutional, pedagogical and structural problems that exist, but more
importantly, awareness and acknowledgement that childhood difficulties may translate into major issues for adults.

**Rationale for the Study**

The impetus for research in this area has been influenced by two key factors: (1) the limited availability of scholarly, qualitative literature on dyslexia across the lifespan; and (2) the author’s experience as a lecturer of adults with dyslexia at a Technical and Further Education college (TAFEWA) in Perth, Western Australia. TAFEWA currently offers the only certified course specifically for adults with dyslexia – **Certificate 1: Foundation Skills for People with Dyslexia**. The course is designed to provide participants with knowledge and understanding of dyslexia as well as enable them to develop skills to further their vocational prospects and desires. From its inception in 2003 it has had over 200 enrolments with the majority undiagnosed throughout their primary and secondary educational experiences.

The content presented in the first unit of the certificate enabled students to acquire knowledge about dyslexia from a scientific and social perspective. During sessions many of the students disclosed personal experiences that revealed their perceptions of societal attitudes, including the daily barriers of living in a literacy-focussed society in which “non-literate” are viewed as uneconomically productive. They spoke about the exclusion they felt because of society’s reliance on the written word as a form of communication. Many spoke of the erosion of their self-esteem due to the discrimination they had experienced within an educational setting. Some shared the strategies they used to give the appearance of strong and competent literacy skills.

Expressions of emotional turmoil and feelings of inadequacy were revealed. So too were statements of resilience, motivation and a desire to succeed at all costs. **In-class**
discussions frequently returned to the frustration they felt about how the educational system had failed them, in particular its inability to identify their dyslexia earlier in life. Had this occurred, they believed that they would have understood their dyslexia earlier.

Working with these adults highlighted the whole continuum of dyslexic characteristics that have been reported in the literature from a medical/scientific perspective. More importantly it revealed the social and emotional influence of their experiences across their life span. Finally it emphasised the value that these adults placed on such a customised course and the influence that it appeared to have on their personal well-being, that is in helping them to understand and accommodate their dyslexia.

**Significance of the Study**

The significance of this study is evident at a number of levels. Firstly, it provides a framework to consider the perceptions across the life span of people with dyslexia within a literacy-focussed society. Secondly, it seeks to situate the definitional debate regarding the existence of dyslexia within a framework that provides a focus on an ecological approach – one that considers, in particular, the educational and social implications of dyslexia as opposed to the medical-scientific approach that has dominated and perhaps even held back understanding to date and influenced the development of a concept of ‘failure’.

Whilst there is a developing body of international research about adults with dyslexia (Farmer, Riddick & Sterling, 2002; Kurnoff, 2000; Pelkey, 2001; Pollack, 2005, Riddick, Sterling, Farmer & Morgan,1999), in Australia the field is relatively underdeveloped. In particular the following questions have attracted limited attention
from Australian academics: (1) What it really means and feels like for an adult to live with dyslexia and how this influences daily life; (2) the educational experiences of people with dyslexia across the lifespan; (3) identification and analysis of specific customised courses for adults with dyslexia; and (4) the identification and analysis of exclusion barriers, which society has created for people with ‘hidden disabilities’ (Tanner, 2009b), and how these influence life choices.

Much of the research tends to be located within a medical/scientific perspective, one that reflects a deficit perspective as opposed to an holistic ecological perspective. It presents as tunnel-visioned. The attitude that “dyslexia is a myth” is both perpetuated and exacerbated by a lack of definitional agreement as to its exact characteristics. On one hand this can be attributed to the nature of language used within a medical/scientific perspective and the quantitative evidenced-based nature of this paradigm. More importantly, this perspective puts the emphasis on the person as the ‘problem’ not the way in which society is constructed.

**Aim of the Study**

The main aim of this study is to present the lived experiences of adults with dyslexia who have participated in a customised course for adults with dyslexia. In doing so, it reveals their perceptions of educational experiences across their life span and highlights the multitude of influences shaping these perceptions.

The study also highlights how attitudes to diversity are constructed within society. In particular, it seeks to highlight societal attitudes toward low literacy levels. Its aim is to explore the perceptions of these attitudes by adults with dyslexia, including how they believe members of society actually perpetuate these attitudes.
“Historically, the dominant conceptual frameworks to study dyslexia stem from psychological or educational practice .... [which are] summarized within a medical or educational model approach” (Macdonald, 2009, para. 1). This study, on the other hand, is situated in an ecological perspective. It uses the life narratives of adults with dyslexia who have knowledge of dyslexia due to their participation in a customised TAFE dyslexia course. It then uses an ecological approach to identify and analyse all influences within their life, not just their dyslexia. This is unique to this area of research.

**Overview of the Study**

Chapter two presents an overview of the literature that has directly influenced and guided the discussion throughout the thesis. The first section discusses the cultural construction of literacy with particular reference to the societal construction of failure for people with literacy difficulties. The second section highlights core assumptions and beliefs about the concept of dyslexia.

Chapter three discusses the methodology guiding and underpinning this study. It also presents the ‘thinking trail’ of the researcher and the personal influences that were evident in the methodological approaches adopted. It clearly acknowledges prior understanding and experience, and helps to dispel the notion of pure objective interpretation (Crotty, 1998). Finally, this chapter includes the study design and procedures of data collection and a discussion of grounded analysis techniques used throughout the thesis.

Chapter four presents a comprehensive case study. This is based on the life experiences of David, one participant in the course. Some of David’s comments have already been used to introduce this chapter. Chapter four also includes an introduction
to, and an overview of, the experiences of the other nine participants in this study. Their full narratives are included in the appendices. Each narrative provides a chronological perspective of the educational experiences of participants and includes wider life influences and experiences as told to the researcher. Conceptual diagrams for each individual, based on Bronfenbrenner’s social ecology model (1992), present their life experiences in detail.

Chapters five and six present the results and a discussion of data. Chapter 5 reveals the participants’ perceptions of their primary, secondary and tertiary educational experiences, whilst chapter 6 discusses the emergence of life choices across the lifespan.

Chapter seven draws together these perceptions and resulting life choices as influenced by participants’ involvement in the dyslexia course. It also proposes a reinterpretation of Bronfenbrenner’s model, one that repositions the way individuals with dyslexia, and even the concept of dyslexia, are presented within a societal context.

The final chapter pulls the threads of this study together by questioning the relevance of a purely medical/scientific model in an educational setting and beyond. It also highlights the need for an ecological approach. In this context it discusses the implications and recommendations arising from this study.
Chapter 2

REVIEW OF LITERATURE

This chapter is presented in two sections. Section one specifically addresses: (a) the cultural construction of literacy in western societies; (b) the societal construction of failure for people who experience literacy difficulties; and (c) the responses of people with dyslexia to the constructed factors of failure and to the every day demands of a literacy-based society.

Section two discusses the assumptions and beliefs surrounding the concept of dyslexia that exists within the both research and wider communities including: (a) what defines this concept; (b) whether it is acknowledged as a disability or a difficulty; (c) the impact of it being considered a hidden or somewhat hidden disability; and (d) the existence of adult dyslexia. It then identifies the range of research lenses through which dyslexia is viewed.

Literature Review Section One: The Cultural Construction of Literacy

The importance placed on literacy is reflected in the way society is structured and its emphasis on the written word. Effective communication in western society requires that individuals be able to decode the written word. Text literacy is fundamental to life and there is an implied expectation that all people should be able to read and write. This value is instilled in people from an early age when they are institutionalised within the education system through to late adolescence and beyond. In fact society continually rewards its members who can read and write. For adults who are challenged by the literacy demands of society, this embedded attitude
permeates their daily living alongside the barriers that are hidden or not obvious to members of society who have good literacy skills. The literature highlights a number of social barriers that exist for adults who experience literacy difficulties.

**Economic and social impact**

Tuijnman (1995), in a report for the Organisation for Economic Co-operation and Development (OECD), "concluded that low literacy levels were a serious threat to economic performance and social cohesion" (p. 13). Links between society, economic growth and development, particularly in the industrialised world, are literacy based. He stated that:

... adult literacy has come to be seen as crucial to the economic performance of industrialized nations. ... Today, adults need a higher level of literacy to function well: society has become more complex and low skill jobs are disappearing. Therefore, inadequate levels of literacy among a broad section of the population potentially threaten the strength of economies and the social cohesion of nations. (Tuijnman, 1995, p.13)

Tuijnman’s report also links high literacy levels with greater social cohesion (p. 23). In an Australian context, as revealed in the introduction, a recent report into the teaching of literacy (NITL, 2005b) highlights the importance of literary success for all Australians in determining “the nation’s social and economic future” (p. 16). The former Australian Federal Minister for Education, Science and Training, Dr Brendan Nelson, who commissioned the report, claimed that: “literacy is the fundamental key to a child’s future success, happiness and ability to participate as a contributing adult member of society” (Media Release, 2005, p. 4). Herrington, Hamilton and Mace (2001) argue, however, that there is no “evidence that literacy skills are actually holding back … economic development and that to change individual literacy skills will change the structure of the employment market” (para. 3).
Literacy or rather illiteracy, appears to have become politically infused. McDermott and Varenne (1995) claim four main cultural assumptions exist that support this politicisation:

- Literacy is inherently good for the individual;
- Literacy is good for a culture;
- Literacy is difficult to acquire; and
- Literacy should be transmitted to illiterates in classrooms (p. 341).

In Australia, the media is an active conduit of this politicisation process, particularly in the publicity linked to national benchmarking and the reporting of nationwide literacy testing. The *Sydney Morning Herald* (2008, January 19) cited Ilana Snyder, an Associate Professor in Education at Monash University, who claimed “literacy has become a vicious political battleground” (p. 3). Headlines such as “Backlash at schools ranking” (Tomazin, 2009, September 26), “Schools to go back to basics to lift flagging literacy” (Tomazin, 2008, October 17) and “Casualties of the literacy wars” (smh.com.au, 2008, January, 19) fuel and exacerbate this perspective.

**Job complexity linked to literacy skills**

Literacy demands in today’s society are steadily increasing (Anstey & Bull, 2004; Wolff & Lundberg, 2003) due to globalisation, as well as changes in information technology (Anstey & Bull, 2004; Tuijnman, 1995). It has become the:

- era of the ‘fast word (computers, E-Mail, fax machines, the Internet).

Written language (e.g. reading, writing and spelling) is essential to survival in school, the workplace, and just plain day-to-day living. Even the simplest job requires a basic reading ability … adult reading skills vary from superior to nonexistent, with the numbers increasing in the low performing or functionally illiterate groups. For the individual with superior written language skills, the fast word is a breeze. For the adult who has poor reading, writing, and spelling skills, the fast word is a nightmare (Nosek, 1997, p. 3).
Preen (1991) identifies being literate as an enabler to greater independence through occupational and higher income opportunities. Further, this occupational status also allows for greater social mobility and social connections.

**Society, education and literacy skills**

From a Western perspective, attending school and demonstrating adequate school achievement, along with acceptable social behaviour, are viewed as important factors within the context of society’s norms. Within the educational context:

[I]t is important to master the written media. If not, you will be shut out from the knowledge, perhaps wisdom, and information important for your personal development … into a citizen who is able to take part in life acknowledging the rules and laws developed through years in democratic societies. The society develops on the basis of communication (Lyster, 1999, p. 1).

This view is supported by Reid-Lyon (1997) who states, "Our society is one in which print is ubiquitous and the ability to decipher words on the page [is] a substantial prerequisite to learning in school, feeling good about yourself, going to college, and obtaining meaningful employment"(p. vii). Herrington, Hamilton and Mace (2001) claim that: “without certain levels of literacy, adults do not function in society … [this] can have the effect of making people … feel they are not seen as functioning adults … and feel they cannot be open about their difficulties because such attitudes are supported in popular culture” (para. 6).

One assumption that exists in western cultures is that one’s literacy level is directly linked to one’s level of intelligence. Lyster (1999) suggests: “In different cultures, the word intelligence is applied to different forms of competence and different forms of competence are therefore focused as important in different cultures” (p. 6).
In an ideal world, education provision should reflect understanding and knowledge of learning disabilities, and governmental recognition of diversity demonstrated by the commitment to provide funding and appropriate educational provision for all students. Reddy and Sujathamalini (2003) cite a case whereby the Indian government was concerned by the low-literacy levels throughout the country and therefore provided funding for literacy programs to operate. However, the authors claim, these were ineffectual because they did not reflect an understanding of how people with specific learning disabilities/difficulties learn. Brock (1995), on the other hand, claims that due to the non-recognition of specific learning disabilities by educational authorities in some countries there is little, if any, commitment to providing appropriate services for these students.

According to Poole (2003) a scientific paradigm has dominated educational policy and decision-making since the Descartes era. This paradigm underpins Australia’s perspective regarding dyslexia. Recognition of learning disabilities within an Australian educational context is based on ‘failure’ that is determined by ‘diagnosis’. This then provides ‘evidence’ to support funding to ‘fix or treat’ the problem. Poole (2003) believes a shift is required in what drives the formulation of educational policy. Poole’s view that: “a child must first fail in school before s/he is identified” (p. 171) is widely but not exclusively held.

Educators need to view all influences on a student’s development, not just from their cognitive level and a deficit perspective. This leads to the acknowledgement that people acquire literacy in different ways – not all brains are wired to automatically decode the written word through visual and auditory means (Shaywitz, 2003). There needs to be a refocus on pedagogy and a re-evaluation of the educational
practice/delivery in relation to teaching of literacy skills, particularly for those with learning difficulties/disabilities (Gorman, 2003; Herrington et al, 2001; Humphrey, 2002; Humphrey & Mullins, 2002; Raskind, Goldberg, Higgins & Herman, 2002). This, however, is too late for the many adults who have struggled through the education system but, for those returning to study or up-skilling through on-the-job training, this needs to be considered. Reid and Kirk (2001) claim that if learning styles are recognised and accommodated in the workplace then employers can “gain maximum benefit from the dyslexic employee and [this] can prove to be cost effective” (p. 19).

The Societal Construction of Failure

The cultural construction of literacy previously discussed reveals the value-laden-ness of cultural assumptions and beliefs. It highlights the clear divisions that have developed in society in response to those who respectively have or do not have adequate literacy skills. Perry (1970) refers to these as the ‘in-group’ and the ‘out-group’. “The division is between the familiar world of authority-right-we [and] the alien world of illegitimate-wrong-others” (Perry, 1970, p. 59). Those members who do not conform to the norm and have limited literacy skills to cater for the societal pressure of written communication are part of the out-group as societal responses to their literacy level and efforts are dictated by the subtle prejudice of the assumptions and beliefs determined by the in-group.

The in-group may justify the negative attitude and treatment by blaming the out-group for choosing to be deficient. If the in-group is a majority, in society, and in command of most of the resources (jobs, positions of authority, leadership, ownership), it might unconsciously favor its own members, and portray its own members more favorably in many contexts [by adjusting and regulating society demands, beliefs and assumptions to suits the needs of this group] (Sevo & Chubin, 2008, p. 9).
This is clearly reflected in the manner in which literacy types are used and structured. This is further illustrated in the following quote:

In any society there are many literacies and many settings in which they might be used, but some are more powerful than others, they can assist in the acquisition of money, power and status because they give the user access to the dominant and/or powerful groups in that society. Conversely not having particular literacies can result in deprivation and alienation (Anstey & Bull, 2004, p. 11).

Two key factors emerge from the literature to explain how society has developed in response to ‘insufficient’ literacy skills. The first will be referred to as the failure factor, which comprises five subtypes. The second factor encompasses assumptions and beliefs held by members of society toward people with literacy difficulties. The following discussion is based on research that has emerged from the dyslexia literature and refers predominantly to the experiences of individuals with dyslexia.

The failure factor

Failure is identified by researchers as a key factor influencing the lives, emotional well-being and life choices of adults with dyslexia (Brock, 1995; Farmer, Riddick & Sterling, 2002; Herrington, Hamilton & Mace, 2001; Humphrey, 2002; Lyster, 2001; McNulty, 2003; Palombo, 2001; Pollack, 2005; Poole, 2003; Reid Lyon, 1997; Riddick, Sterling, Farmer & Morgan, 1999; Scott, 2003; Williams & McGee, 1994; Wolff & Lundberg, 2003). The literature highlights the impact of the failure factor on the self-perception and self-efficacy of adults with dyslexia and their resultant attitudes and perceptions regarding how society has ‘failed them’. The literature identifies a typology of failure, which is developed around the following five subtypes:

- **System Failure** (Brock, 1995; Herrington & Mace, 2001; Humphrey, 2002; McNulty, 2003; Nosek, 1997; Pollack, 2005; Reddy &
Sujathamalini, 2003; Williams & McGee, 1994; Wolff & Lundberg, 2003);

- **Constructed Failure** (Poole, 2003);
- **Public Failure** (Brock, 1995; Fink, 1998; Scott, 2003);
- **Family Failure** (Scott, 2003);
- **Personal Failure** (Brock, 1995; Palombo, 2001; Pollack, 2005; Raskind, Goldberg, Higgins & Herman, 2002; Riddick, 1996).

*System failure* (as identified by Herrington, Hamilton & Mace, 2001) is evident when inappropriate educational opportunities and provision is provided for specific learning styles. This may result in “academic or school failure” (Brock, 1995; Humphrey, 2002; McNulty, 2003; Reddy & Sujathamalini, 2003; Williams & McGee, 1994; Wolff & Lundberg, 2003). Educators’ knowledge and understanding about specific learning disabilities such as dyslexia, as well as their own individual belief systems and attitudes, influence their “behaviours, philosophies and even their effectiveness” (Kerr, 2001, p. 82). Ignorance, failure or inaccurate acknowledgement or identification of needs by educators (Ash, Bellew, Davies, Newman, & Richardson, 1997; Brock, 1995; Humphrey, 2002; Palfreman-Kay, 1998; Pollack, 2005) were cited as the causes of bad schooling experiences by adults within the literature. These resulted in “low expectation, insensitive teaching and a weak curriculum” (MacKay, 2002, p. 160).

Kerr (2001) identified educationalists as indicating a sense of “disempowerment, or learned helplessness, when faced with a student diagnosed with ‘dyslexia’” (p. 83). This included a dramatically reduced expectation of literacy learning and/or a *dumbing down* of tuition. Fink (1998), however, noted that where educationalists were informed and understood the learning and life needs, they “played pivotal roles in assisting most of the individuals with dyslexia” (p. 9).
**Constructed failure** (as coined by Poole, 2003) is linked to the scientific/medical perspective in which dyslexia is interpreted and ‘treated’ in an educational context. Failure in school is the key to identification and diagnosis (Poole, 2003). A prescriptive ‘diagnosis’ determines this failure and provides evidence to support funding to ‘fix or treat’ the problem. According to Poole (2003), treatment is more often medically based than educational. She states that a scientific paradigm “currently drives educational policy” (p. 171).

Within an Australian context, this is exacerbated by the view that schools will receive additional government funding to support students with additional needs only when a scientific or medically suggested label or evidence is attached to a condition (Tanner, 2009b, p. 787).

People with dyslexia are immediately ruled out because of this policy. Westwood (2008) claims that schools are provided with funding to support students with ‘learning difficulties’. However, he argues that students with dyslexia require “more frequent and intense tuition” than schools provide (p. 10). Recognition of, and provision for, students with dyslexia is also hindered by the definitional gymnastics evident throughout the literature as to what dyslexia actually is or whether it even exists. Poole (2003) suggests that an ecological perspective, rather than a purely educational and scientific perspective, needs to be used to view the concept of dyslexia.

**Public failure** (Scott, 2003) of people with dyslexia. The school context provides many opportunities for ‘public failure’ because demands are constantly placed on students to demonstrate their literacy skills within a public forum. For an adult, public failure in life can be constant, particularly with society’s emphasis on communicating via the written word. This may be evident, for example, when having to fill in forms, reply to an email, read a letter and then reply, read signs, provide
personal information or read a menu. Public failure quite often results in “public humiliation” (Fink, 1998) in which responses by others include physical bullying or verbal and non-verbal negative cues that are intended as exclusionary devices.

**Family failure** is embedded in the attitudes of caregivers and siblings, as well as linked to the individual’s personal belief that they are “failing their parents” (Scott, 2003, p. 84). Scott highlights the attitude of many parents who believe that success in literacy is important for academic success. This, in turn, may result in the child feeling a sense of guilt, due to their inability to please their parents, and a belief that “continued academic failure will lead them to lose their parents’ love” (p. 84).

**Personal Failure** is a culmination of the previous four sub types. It begins from the time an individual enters an educational institution and is accompanied by the early realisation that they are not learning or keeping up with their peers. This, according to Palombo (2001), develops into a lifelong ‘fear’ of learning and of new or unknown situations. This may also develop into a sense of feeling worthless, ashamed and of lesser value. Riddick (1996), in a study of children with dyslexia, suggested the existence of a self-fulfilling prophecy regarding attribution of failure. Personal failure reflects the “psycho-emotional dimensions of disability” (Reeve, 2006, p. 95) that in turn reflects the personal as opposed to public experiences of social oppression. This oppression “operates on the ‘inside’ as well as on the ‘outside’” (Thomas, 2003) and is fuelled by attitudes to dyslexia in a societal context. This internalisation can exacerbate a sense of powerlessness and promote negative self-esteem.

In a 20-year study of students with learning disabilities, including people with dyslexia, Raskind, Goldberg, Higgins and Herman (2002) identified “success attributes”, that is personal characteristics, behaviours, attitudes and conditions (p.
that enabled students to succeed in adulthood despite the difficulties and failures they encountered throughout their school life. They claimed that those students who did not have these “success attributes” experienced a “continued failure” throughout their life. Reiff, Gerber and Ginsberg (1993) believe “failure is a natural part of growing, learning and achieving. Perhaps the problem lies in an institutionalized attitude that failure is bad, a sign of weakness and incompetence” (para. 37).

**Constructed assumptions and beliefs**

The second key factor identified throughout the literature that influenced the social and emotional well-being of individuals, were the positive and negative assumptions they encountered on a daily basis. Assumptions linked to difference are constructed within a societal context and have been internalised by members of society who perpetuate these attitudes. Duffy (2002) refers to them as “cultural carriers” (cited in Mackay, 2002). These assumptions and responses play a key role in determining perceptions of self and behavioural responses of adults with dyslexia. The majority of these assumptions and attitudes may stem from embedded beliefs, ignorance and/or a lack of understanding. They reflect a discriminatory stigmatisation of individuals with dyslexia, many of whom in the literature indicated experiencing varying degrees of bullying, ridicule, humiliation, and discrimination linked to these assumptions and beliefs. Being labelled by peers, educators, and work colleagues as lazy, stupid, thick, dumb, crazy, mentally retarded (Brock, 1995; Hagtvet et al.; Humphrey, 2002; Humphrey & Mullins, 2002; Lyster, 2001; McNulty, 2003; Nosek, 1997; Taylor, 2000) made many believe they were of lower intelligence than their peers throughout their school life. For some this has continued into adulthood. This is illustrated by the following quote from Scott (2003), which was provided within a counselling context:
The many dyslexic people who reach the conclusion that they are worthless, 'rubbish', 'a pile of shit' (common descriptions) do so because they read this in the faces, voices, body language and direct statements of their parents, siblings, friends, peer group at school, teachers, other relatives, work colleagues and employers. These people have also ridiculed and bullied dyslexic people on the basis of their poor reading, writing and spelling and all the times the dyslexic person is late, lost, disorganised, loses or forgets things, and misreads or misunderstands instructions. A dyslexic person has internalised this gale of critical information and often uses it to define both who they are and how they relate to other people (p. 90).

These constructions of failure can not only be perceived in the context of people with dyslexia but can be applied and generalised across a spectrum of people experiencing difficulties in a literacy-based society including, but not restricted to, people of non-English speaking background, those from literacy sparse backgrounds, individuals who have had a chronic illness and limited educational provision as well as those who are illiterate due to insufficient educational opportunities. Whatever the reason, these failure and assumption factors still exist.

**Individual Responses to the Key Factors of Failure**

The literature has identified the following range of ways in which individuals with dyslexia respond to the challenge of these elements within a literacy-based society.

**Behavioural and affective responses**

As a direct result of the experience of failure and assumptions encountered by individuals with dyslexia throughout their lives, it is possible to identify a range of negative behavioural responses and affective consequences. The reactive nature of the responses appeared to be linked to the perception of individuals that they are failing in society because they are failing in their literacy skills, with this resulting in the belief they are failing as a person. This inability to compartmentalize their learning difficulties and understand how they influence their life, according to Raskind and
colleagues (1999), leads to maladaptive reactionary responses to life’s experiences as opposed to proactive responses indicating a sense of control over their circumstances. Such maladaptive responses include low self-esteem/ self-concept/ self image and negative self-confidence (Brock, 1995; Humphrey & Mullins, 2002; McNulty, 2003; Nosek, 1997; Palombo, 2001; Preen, 1991; Riddick, Sterling, Farmer & Morgan, 1999; Scott, 2003; Williams & McGee, 1994; Wolff & Lundberg, 2003); relationship difficulties and social encounters and increased emotional insecurity (Brock, 1995; Humphrey, 2002; McNulty, 2003; Nosek, 1997; Preen, 1991; Scott, 2003; Wolff & Lundberg, 2003); stress, heightened anxiety levels, and depression (Everatt, 1997; Humphrey, 2002; McNulty, 2003; Reid & Kirk, 2001; Riddick et al, 1999; Scott, 2003; Wolff & Lundberg, 2003); trauma associated with learning difficulties (McNulty, 2003; Orenstein, 2000 & Khan 1974 as cited in McNulty; Scott, 2003); to the development of defence mechanisms to cope with the above feelings including learned helplessness (Humphrey & Mullins, 2002; Riddick et al, 1999), victim personality (Scott, 2003) and outer and inner defences (Scott, 2003).

There was an overwhelming consensus of opinion and evidence within the literature that low self-esteem, accompanied by an eroded self-confidence, was a direct reaction to, or consequence of, attitudes and failures experienced throughout life.

In contrast to maladaptive responses, those individuals with dyslexia who have achieved success or have a sense of purpose, react to their dyslexic characteristics in a creative and flexible manner, particularly in the face of adversity (Nosek, 1997). An understanding of their dyslexia and the societal framework in which one lives is proposed as the reason why. This creative flexibility enables functional compensation
strategies to be used and modified to achieve success (Horne, 2002; McNulty, 2003; Nosek, 1997).

**Personal attributes that enhance success or non-success**

Success and non-success attributes were identified in a small range of studies with adults with learning disabilities (LD). In a quantitative 20-year study of adults with LD (which included adults with dyslexia), Raskind, Goldberg, Higgins and Herman (1999) identified six types of success attributes that were indicated amongst ‘successful participants’ in their study. These attributes, they claimed, “were more powerful predictors of success than numerous other variables, including IQ, academic achievement, life stressors, age, gender, socioeconomic status, and ethnicity” (Raskind et al, 2002, p. 202). The six attributes are:

- Self-awareness;
- Proactivity;
- Perseverance;
- Emotional Stability;
- Appropriate goal setting and self-directedness; and
- Presence and use of effective support systems (Raskind et al, 2002).

In conjunction with these success attributes Raskind and colleagues also identified the following six non-success attributes, (which do not necessarily mirror the opposing success attribute) that adults with LD who have not been successful in life, demonstrated:

- Lack of self-awareness;
- Reactivity;
- Lack of perseverance;
- Emotional instability;
• Lack of goal setting or self-directedness; and
• Lack of use of social system.

The success and non-success attributes identified by Raskind and colleagues (1999) are highly prominent in the literature pertaining to individuals with learning disabilities (including the literature covering dyslexia). The attributes are now discussed in relation to the dyslexia literature.

**Self-awareness versus lack of self awareness**

‘Successful’ individuals demonstrated an awareness of their strengths and weaknesses. They could distinguish between their difficulties, linked specifically to their learning disability, and other individual characteristics in a process called “compartmentalization” (Raskind et al. 2002). Their difficulties did not define who they are. This increased self-awareness, acceptance and openness of one’s difficulties was also identified by Gerber & Reiff (1991), Hellendoorn & Ruijsenaars (2000), Scott (2003), Kurnoff (2000), Morrison and Cosden (2000) and Taylor (2000). Adults who lacked this self-awareness were non-accepting of their difficulties, even denying their existence or need for support. Adults who were self-aware were able to ‘niche pick’ employment that was “compatible and appropriate”. However unsuccessful individuals “appeared unable to find a niche due to the global nature of their disabilities which influenced their success across multiple contexts” (Goldberg, Higgins, Raskind & Herman, 2003, p. 226).

**Proactivity versus reactivity**

Individuals with this attribute participated fully within their environment and “believed they had the power to control their own destinies and affect the outcome of their lives” (Raskind et al, 2002, p. 203). A key factor was the preparedness to make
informed decisions that impacted on, and enabled them to control their life and make successful life choices. Unsuccessful individuals were passive or ‘reactive’ in their responses with little if any acknowledgement that they could change events. Their reactions led to avoidance, particularly of potentially negative events (Scott, 2003).

**Perseverance versus lack of perseverance**

Successful individuals kept pursuing their goals despite adversity. They maintained the attitude that difficult situations were necessary learning experiences, and that in the end, their struggles would help them improve their character and, ultimately, reach their goals. (Raskind et al, 2002, p. 203).

Perseverance was also identified by Gorman (2003), Hellendoorn and Ruijssenaars (2000), and Kurnoff (2000). Some individuals “elevated it to the status of a ‘special talent’ about which they felt great pride” (Goldberg et al., 2003, p. 227). Those individuals who lacked this attribute gave up if faced with any barriers that they attributed to others and not their efforts.

**Emotional stability/emotional coping strategies versus lack of emotional stability and coping strategies**

Successful individuals with this attribute have a high sense of motivation and emotional stability which is reflected in their ability to deal with and reduce stress, anxiety and frustration (Hellendoorn & Ruijssenaars, 2000: Nosek, 1997; Raskind et al., 2002). They are able to recognise triggers and have developed coping mechanisms (Goldberg et al, 2003). Hellendoorn & Ruijssenaars, (2000), McNulty (2003), Gerber and Reiff (1991), and Morrison and Cosden (1997) believe this attribute to be directly linked to temperament and genetic personality traits.

Resilience and flexibility were imperative within this success attribute (Hellendoorn & Ruijssenaars, 2000; Nosek, 1997; Raskind et al, 2002; Scott, 2003). Lack of these successful attributes led to affective consequences such as stress (Everatt, 1997;
Humphrey, 2002; Scott, 2003; Wolff & Lundberg, 2003), evidence of depression (McNulty, 2003), increased sensitivity to criticism and heightened self-consciousness (Brooks, 1997).

**Appropriate goal setting and self-directedness versus lack of appropriate goal setting**

Goal-setting was another ‘success attribute’ of adults with dyslexia (Hellendoorn & Ruijssenaars, 2000; Nosek, 1997). Raskind and colleagues (2002) claim goal setting is a direct result of perseverance and motivation to succeed despite all the negative experiences and barriers to learning and life. Goals that successful adults set were realistic and based not only on past experiences and understanding of their ‘disability’ but also future attainable desires. Temperament and personal characteristics were identified as positive characteristics that enable individuals to “make realistic educational and vocational plans” (Gerber and Reiff, 1991; Hellendoorn & Ruijssenaars, 2000; Morrison and Cosden, 1997). Adults that lacked this success attribute did not express future plans in regard to employment or education or “expressed plans that were grandiose or unrealistic, given his or her capabilities and status” (Raskind et al., 1999, p. 49).

**Presence and use of effective support systems versus lack of use of effective support systems**

Individuals with this success attribute were aware of and accessed “support, guidance and encouragement ... from ‘significant others’” (Raskind et al., 2002, p. 204). The impact of family/caregivers as effective support systems were also identified by Brock (1995), Fink (1998), Gerber and Reiff (1991), Hellendoorn and Ruijssenaars (2000), Kurnoff (2000), Lyster (1999), Morrison and Cosden (1997), McNulty (2003) and Scott (2003). Goldberg and colleagues (2003) further identified changes in “the
nature of support systems as study participants moved from early adulthood ... to middle adulthood” (p. 228). Where individuals did not appear to have family or close support, or expectations from these ‘significant others’ were unrealistic or ambiguous, they did not actively seek assistance unless in a ‘crisis situation’ (Raskind et al, 1999). Hellendoorn and Ruijssenaars (2000) state that “parental support appeared to be a powerful predictor of adult adjustment and well being” (p. 3).

Hellendoorn and Ruijssenaars (2000) cite studies by Gerber and Reiff (1991), Morrison and Cosden, (1997), and Rogan and Hartman (1976, 1990) who identify a further three success and non-success factors that they refer to as ‘protective factors’. These three factors, which link specifically to educational experiences, are:

A family background that values education ... recognition of the learning disability at a relatively early age [and] intensive, effective intervention during the elementary school years (p. 229).

Raskind and colleagues (2002) state that further research is needed regarding these success and non-success attributes of people with learning disabilities, particularly the extent to which “these attributes can be taught or learned”, or whether they are genetic attributes. They believe that attention within an educational context should not only be on academic achievement but also on the acquisition or development of these attributes (p. 207). Hellendoorn and Ruijssenaars (2000) claim “the socioemotional impact of learning disabilities such as dyslexia has been a neglected field” (p. 229).

Goldberg and colleagues (2003) indicate that while studies have documented “the consequences of having an LD” (p. 222), they do not address the “relationship between specific choices and their antecedent variables [and] how these variables shape an individual’s life course” (p. 223). This is significant in that these researchers are indicating dyslexia needs to be studied within a wider context, one that considers
all influences on an individual rather than simply the uniqueness of the individual’s
dyslexic characteristics.

Responses to the Demands of a Literacy-based Society
The degree to which an individual develops success or non-success attributes
influences the choices they make, and the manner in which they adjust to the demands
of living in a literacy-based society. The following discussion indicates the range of
negative and positive adjustments identified in the literature.

Negative adjustments
In response to the sustained experience of failure many people with dyslexia have
endured throughout their early and current life, the literature highlights three negative
adjustments that adults with dyslexia may have chosen. These three adjustments are:
(1) dropping out of school and its linkages to anti-social behaviour; (2) personal
isolation or exclusion; and (3) employment adjustments linked to financial
circumstances. When considering each of these adjustments, attention needs to be
directed to the previous discussion of success and non-success attributes that have
been indicated as influencing these adjustments.

Dropping out of school
Morrison and Cosden (1997) indicated that “dropping out of high school” had the
capacity to have a significant impact on adjustment in adulthood. Dropping out of
school was considered a ‘risk factor’ in negative adjustment (cited in Hellendoorn &
Ruijssenaars, 2000, p 2). They found that dropping out was linked with disruptive or
anti-social behaviour. Similarly, Lyster (1999) cites studies that have defined a
relationship that exists between reading and delinquency as well “as reading failure
and antisocial behaviour” (p. 3). When failure to read or write occurs within the school situation, Lyster (1999) claims that an inability to ‘keep or build self-confidence’ develops, therefore these students try to protect their self-esteem by developing behavioural strategies to cope with school. Quite often these are disruptive behaviours. After dropping out of the school system these disruptive behaviours can, in some cases, develop into criminal behaviours. Gorman (2003) cites Professor Frank Woods who claims “dyslexics are also overrepresented in the prison population” (p. 57). “The latest studies using psychometric testing suggest that the incidence of dyslexia amongst offenders is three to four times that found in the general population” (British Dyslexia Association (BDA), 2004-5: p. 5). This statistic highlights the need for not only appropriate educational responses but also psycho-social responses to the diverse needs of these individuals.

**Social impact of isolation and/or exclusion**

For some individuals with dyslexia the social disadvantage of loneliness owing to isolation and/or exclusion was viewed as negative. This isolation or exclusion can be understood in three ways. Scott (2003) proposed it may be a *personal construct* to protect self esteem, Ash and colleagues (1997) suggested this isolation could be a *social construct* developed as a result of exposure to negative attitudes, particularly through peer interactions, and the social stigma associated with difference. Finally, Lyster (1999) suggested isolation, through *system exclusion* linked to inappropriate educational provision, may occur. An example of systemic exclusion may include the withdrawal from class for ‘special assistance’, being allocated to a special education unit, or the lack of educational support resulting in a lack of acknowledgement that, according to Lyster (1999), ‘gives a feeling of isolation’. According to Wood (as cited in Gorman, 2003) “new research shows that children with dyslexia are more
likely than non-dyslexics to drop out of school, withdraw from friends and family or attempt suicide” (p. 57).

**Financial difficulties linked to lack of occupational success – unsuccessful ‘niche picking’**

Financial difficulties are, for many adults, linked directly with poor occupational success and, as such, become a source of frustration and stress (Nosek, 1997). For adults in employment with dyslexia there tended to be a reluctance to make the adjustments necessary to change jobs or seek promotion, even if it meant higher pay. Seeking new employment is linked with the risk associated with disclosure of one’s literacy levels reflected in the following claim by Lyster (1999) that:

[I]literate presents an intrinsic barrier to occupational success. A reluctance to change jobs is common among dyslexics and persons with learning disabilities … This might stem from anxiety precipitated by having to develop new strategies and fear of being ‘found out’ (p. 4).

The trend within workplaces to up-skill or up-grade qualifications and job knowledge is a source of anxiety, particularly if the expectation is that the individual attend an educational institution as opposed to on-the-job training. “For many adults in this situation, their memories of being taught evoke fear and loathing and they would not consider returning to formal education for what they imagine could be more of the same” (Herrington et al. 2001, para 4). This fear can lead to them resigning from their current employment dependent upon the workplace attitude and knowledge of their strengths and weaknesses.
Positive adjustments

The literature indicated two positive adjustments that enabled individuals to respond positively to the literacy demands they encounter. The first adjustment is related to personal attributes, the second to compensatory strategies.

Personal attributes – ability to ‘think outside the square’

Researchers have found that adults with dyslexia who had been successful in their lives, predominantly from an occupational perspective, tended to be visionaries, lateral thinkers and highly creative. Everatt (1997, p. 14) claims some adults with dyslexia have the ability to view things multi-dimensionally. They have lateral thinking skills and “… enhanced creativity and visual skills …” (see Aaron & Guillemord, 1993; Davis, 1995; Edwards, 1994; Vail, 1990: West, 1991). For example “3D thought processing” is claimed by Ehardt (2008) to be an evolutionary adaptive strength that Davis (1997) refers to as a ‘gift’. Gorman (2003) states that:

… dyslexics are over-represented in the top ranks of artists, scientists and business executives. Perhaps because their brains are wired differently, dyslexics are often skilled problem-solvers, coming at solutions from novel or surprising angles and making conceptual leaps that leave tunnel-visioned, step-by-step sequential thinkers in the dust. They talk about being able to see things in 3-D Technicolour or as a multi-dimensional chess game (p 57).

Effective compensatory strategies

Another key factor identified that enabled adjustment to the demands of living in a literacy-focused society was the development of compensatory strategies (Fink, 1998; Jacob, Wadlington & Bailey, 1998; Palombo, 2001; Reid & Kirk, 2001; Wolff & Lundberg, 2003). Goffman (1963) refers to them as ‘passing techniques’. These strategies or compensation skills operated on two levels – a functional level and a compensation level. On a functional level an individual uses strategies that
“bypass[ed] the effects of the deficit or ... enhance[d] functioning by using areas of strength to make up for cognitive limitations” (Palombo, cited in McNulty, 2001, p. 2). For example, this could involve presenting information orally to a group using diagrams, pictures and/or 3d visuals as memory and sequence prompts as opposed to reading from written text or presenting a written document. On the other hand, strategies on a compensation level are those devised by the individual to ‘cover-up’ and help “manage the stigma and feelings related to experiencing difficulty and failure with learning that negatively affect self-esteem” (McNulty, 2001, p. 2). An example of a compensation strategy adopted when required to read in public is to claim to have forgotten one’s reading glasses and ask someone for reading assistance. In developing these strategies individuals are able to hide their dyslexic characteristics (Jacob et al, 1998).

Reiff, Gerber and Ginsberg (1993) refer to these compensatory or passing strategies as ‘learned creativity’ and indicate that they involve complex and divergent problem-solving strategies. This positive perspective “assumes that persons with learning disabilities can learn specialized and individual methods for coping and succeeding with the very circumstances previously deemed overtaxing” (para. 21).


**Literature Review Section Two:**  
*Assumptions and Beliefs about the Concept of Dyslexia*

The following discussion addresses the complexity of the concept of dyslexia and the assumptions and beliefs within which it is constructed. Like any terminology, the assumptions and beliefs reflect a range of perspectives and interpretations. The concept of dyslexia needs to be understood not only historically, but also within a cultural context.

As indicated in the introduction, research suggests there are five to ten percent of adults (Smythe, Everatt & Slater, 2004), who are of average to above average intelligence and have adequate schooling and yet struggle to decode the written word despite educational intervention. According to Smythe and colleagues (2004), these people have dyslexia. From a scientific perspective dyslexia is viewed as a neurological difference (Habib, 2000; Shaywitz, 2003) that affects the individual’s ability to process the written word. That is not to say they are completely illiterate, but rather that the process is not fully automated, and at times glitches are encountered when they attempt to interpret written text.

The British Dyslexia Association (BDA) presents the following definition that it ‘feel[s] best describes dyslexia’:

Dyslexia is a specific learning difficulty which mainly affects the development of literacy and language related skills ... It is characterised by difficulties with phonological processing, rapid naming, working memory, processing speed, and the automatic development of skills that may not match up to an individual’s other cognitive abilities. It tends to be resistant to conventional teaching methods, but its effects can be mitigated by appropriately specific intervention (British Dyslexia Association, 2007).

The BDA refines an earlier definition by Padget, Knight, and Sawyer (1996)
Dyslexia is a language-based learning disorder that is biological in origin and primarily interferes with the acquisition of print literacy (reading, writing, and spelling). Dyslexia is characterized by poor decoding and spelling abilities as well as deficit in phonological awareness and/or phonological manipulation. These primary characteristics may co-occur with spoken language difficulties and deficits in short-term memory. Secondary characteristics may include poor reading comprehension (due to the decoding and memory difficulties) and poor written expression, as well as difficulty organizing information for study and retrieval. (p. 55)

Whilst Padget and colleagues (1996) refer specifically to a range of secondary characteristics, the core deficit in both definitions is that of poor phonological awareness linked to word decoding skills.

**What defines the concept of dyslexia?**

Finding a clear and concise definition – one that will be agreed upon by all researchers - is akin to finding a needle in a haystack. The majority of researchers, however, do recognise that there is no single definition of dyslexia and that disagreement exists between interested parties (Jacob et al, 1998; Humphrey and Mullins, 2002; Miles, Wheeler and Haslum, 2003; Pollack 2005; Poole, 2003; Ramus, et al, 2003). Jacob, Wadlington and Bailey (1998) claim “dyslexia is a controversial term with multiple definitions” (p. 364). Thus, it is impossible “to provide a definition of dyslexia that is accurate, reliable and agreed upon by everyone” (Humphrey and Mullins, 2002, p. 197). Poole (2003) states that even though there is a lack of an agreed single definition of dyslexia there are “a variety of accepted definitions”. She cites medical, scientific and educational definitions. Riddick, Sterling, Farmer and Morgan (1999) found that without a ‘global definition’ the comparison of studies on dyslexia, particularly between the UK and USA, is difficult. They claim there are distinct differences between definitions and acknowledged
characteristics. This equally precludes Australian research in the area where there appears to be no clear-cut or widely accepted definition. Seigel (1999) claims that “[o]ver the years, a consensus has emerged that one core deficit in dyslexia is a severe difficulty with phonological processing (e.g., Rack, Snowling, & Olson, 1992; Siegel, 1993; Snowling, 1980; Stanovich, 1988a, 1988b)” (p 306). Farmer, Riddick & Sterling (2002) agree and place this advance within a 20 year time frame. Whereas Ramus, Rosen, Dakin, Day, Castellote, White, and Frith (2003) state that “… despite decades of intensive research, the underlying biological and cognitive causes of reading retardation are still hotly debated. Indeed, there are no less than three major theories of dyslexia” (p. 841). In fact they identify five scientific-based theories: Phonological theory, Rapid Auditory Processing theory, Visual theory, Cerebellar theory and Magnocellular theory. Miles, Wheeler and Haslum (2003) believe that “the presence of severe literacy difficulties can no longer be thought of as a necessary condition for the presence of dyslexia” (p. 5) and that there are other difficulties or characteristics that need to be considered, particularly within the context of ‘degrees of dyslexia’. Therefore, they believe it is necessary to yet again “rethink our definition of dyslexia” (p. 5).

Kavale and Forness (2000), Beaton, McDougall and Singleton (1997) and Riddick (1996) claim that definitions are created and used in accordance with an individual, group or organisation’s interpretation of the definition. They call this the ‘Humpty Dumpty’ approach to definition that they relate to Lewis Carroll’s character in Through the Looking Glass who said “When I used a word ... it means just what I choose it to mean” (Kavales & Forness, 2000, p. 246).
From an educational perspective dyslexia is assessed through clinical diagnosis and it is defined within a medical framework of dysfunction and failure as opposed to a social framework. Medical diagnosis of dyslexia in many instances determines educational funding and allowances (Brock, 1995). Further to this, Ash and colleagues (1997) state that:

… the degree of disability (often quantified by the use of terms such as 'mild', 'moderate' or 'severe') depends on the extent to which physiological or intellectual performance deviates from standardised norms. The greater the deviance, the greater the degree of disability and hence the greater the intensity of any remedial treatments. Thus … [they] are 'objects' to be 'treated' and changed in accord with standards commonly accepted by society (p. 606).

**Dyslexia as a disability or difficulty?**

Not only is there global disagreement on what constitutes dyslexia, this is also exacerbated by whether it is defined as a learning difficulty or learning disability. This definitional argument falls within a political sphere and is influenced by government-based, policy driven, infrastructure that links educational funding, resources and accessibility to distinct labels. In the USA dyslexia comes under the umbrella of a “specific learning disability” and is officially defined within the *Individuals with Disabilities Education Act* [IDEA] 1990, 1997. In 2004 this act was changed to the *Individuals with Disabilities Education Improvement Act of 2004*. It identifies dyslexia as a “specific learning disability” (IDEA, 2004). In the UK the term ‘dyslexia’ is used as a key term and is identified in legislation as a learning disability (Cunningham and Firth, 2005). However, Westwood (2008) claims that in the UK they have “clouded the issue of definition even more by adopting the terms *learning difficulty* and *learning disability* to refer to individuals with an intellectual disability”(p. 12), thereby removing the defining factor of average intelligence.
Within an Australian context the debate over whether dyslexia constitutes a learning difficulty or learning disability, has yet to be resolved. Acknowledgement of dyslexia as a discrete learning disability or learning style, dependent upon one’s research perspective, is not clearly identified in educational policy. While the Australian Commonwealth Disability Discrimination Act, 1992 identifies disability as “a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction”, responsibility for public education is state or territory based (Elkins 2000) and dyslexia as a specific learning disability is not clearly defined. A diversity of definitions or labels exists that have been determined on a state-by-state or territory basis. These definitions are embedded in the non-disabled ideology that these students are able to overcome [my emphasis] their difficulties through intervention and are linked to a decision on terminology use in an historical federal report conducted in 1976 by the Select Committee of the House of Representatives (Cadman 1976). The Queensland State Education Department is the only state that clearly differentiates between ‘learning disabilities’ (including dyslexia) and ‘learning difficulties’ (Elkins 2000; Louden, Chan et al 2000; Rivalland 2000). The basis of this categorisation is linked to the power of language that directly influences economic, social and educational outcomes.

**Hidden or non evident – how does the visibility of dyslexia impact on definition?**

Reid Lyon (1997) referred to dyslexia as a ‘hidden disability’, one that is not evident until individuals are called upon to use their literacy skills in a literacy-based society. Goffman (1963) identified ‘evident’ and ‘non-evident’ disabilities, and within this context, dyslexia can be viewed as ‘non-evident’ or ‘hidden’. It may therefore be inadvertently perceived as being a result of environmental influences that can be
‘overcome’, as indicated in the Cadman report (1976), and not a life-long phenomenon. The decision to label non-obvious impairments, according to Riddick (2001b), is particularly important. She claims labels “can mediate between the individual and their cultural context and explain certain difficulties they have and thus help to prevent inaccurate or negative attributions” (p. 231). Within an Australian context Cunningham and Firth (2005) claim there is a resistance to the clarification of a clear definition that recognises specific learning difficulties such as dyslexia because of the negative concept of labelling. They cite the NSW Education Department’s director of disabilities programs, Brian Smyth-King, who stated that his department “preferred to take a ‘non-labelling approach’ to learning difficulties” (p. 7). They further suggest that the negative labelling in a classroom context from both peers and teachers alike “is far more damaging than an identification that is accurate and opens the door to an effective discourse and response” (p. 7).

**Dyslexia: myth or reality?**

Definitional gymnastics aside, there also exists some disagreement and scepticism surrounding the existence of dyslexia. This is associated with the predominant scientific/medical focus and ongoing disagreement regarding definitive characteristics of dyslexia among researchers. Whilst researchers agree to disagree about the aetiology and characteristics of dyslexia, another debate that is predominant in the literature is whether dyslexia exists or is simply a myth. There is general consensus in the literature that dyslexia does exist as a specific learning difficulty/disability (these terms are used interchangeably throughout papers cited dependent on country of origin), and it “exists in spite of adequate intelligence, educational exposure and cultural opportunities (Orton, 1996)” (as cited in Jacob, Wadlington and Bailey, 1998, p. 364). It is referred to as a ‘hidden disability’ (Reid-Lyon, 1997: cited in Nosek).
However, even though there is scientific evidence to support a neurological malfunction in the brain (Shaywitz 2003), some people still “do not believe it exists and insist there is no such thing” (Brock, 1995, p. 22). Nosek (1997) claims:

Their explanation for the puzzling behaviours of the reading disabled, or dyslexic, range from calling the disorder a hoax (perpetuated by educators to make life easier for students who are not academically astute) to calling it a clever joke played on unsuspecting bleeding hearts. Other experts say that the syndrome is caused by emotional problems or mental disorders. Yet another group of experts say the dyslexic is faking and that if he weren't so lazy, he wouldn't have so much trouble (p. 7).

A public debate aired through the UK media in 2005 between Professor Julian Elliott, a psychologist, and Professor Margaret Snowling, vice president of the British Dyslexia Association, had Elliott claiming “there is no consensus as to what it is and how to diagnose it [dyslexia]” and that it must be purely an “emotional delusion” (BBC News). Snowling (2005) acknowledges that there are ‘myths’ about dyslexia, however she definitively states: ‘there is strong scientific evidence concerning the nature, causes and consequences of dyslexia” (BDA Website, 2005).

This debate, according to Dr. G. Reid Lyon (1997) from US National Institute of Child Health and Human Development, is fuelled by misunderstanding, ignorance and reported inaccuracies leading to arguments about its existence and negative societal attitudes about dyslexia. She claims that:

Dyslexia is simply not very well understood by those who have it, and it is even less well understood by teachers, employers, and the public at large. In many ways, the disorder is an invisible one ... to most people reading is simple, and it is paradoxical to think that someone who is adept in many intellectual pursuits would have a tough time deciphering words on a page …For many years, those with dyslexia as well as the general public have received information about the disorder that is piecemeal and frequently inaccurate. At best the information is incomplete, and at worst much of the information that masquerades as science is more akin to voodoo (cited in Nosek, 1997, p vii - viii).
Does adult dyslexia exist as a phenomenon?

Beaton, McDougall and Singleton (1997) indicate that while definitions and characteristics of childhood dyslexia are clear and definitive, they “soon become muddied when the researcher or clinician is confronted with a variety of adult cases exhibiting highly heterogeneous profiles” (p. 2). It has been suggested that adult dyslexia may be ‘cured’ or even disappear once the transition from childhood to adulthood has occurred (Gerber, 2003). Dyslexia, however, “has lifelong persistence” (Ramus, Rosen, Dakin, Day, Castellote, White and Frith, 2003, p. 841) and difficulties encountered due to specific learning disabilities such as dyslexia do continue into adulthood (Fink, 1998; Gerber, 2003; Gorman, 2003; Hellendoorn and Ruijssenaars, 2000; Miles, 1993 cited in Everatt, 1997; Nosek, 1997; Raskind et al, 2002; Reddy and Sujathamalini, 2003; Riddick et al, 1999). The degree to which individuals experienced dyslexia in their childhood is of utmost significance as it may influence their adult life experiences in a world where literacy is at the forefront of daily living.

The degree to which adults are affected by their dyslexia is dependent upon specific personal attributes as well as environmental influences. Individuals may develop strategies to overcome these weaknesses and succeed or fail dependent upon their personal attributes and life experiences. Raskind, Goldberg, Higgins and Herman (2002) cite research by Johnson and Blalock (1987), Kavale (1988), Raskind, Goldberg, Higgins and Herman (1999), Reiff, Gerber and Ginsberg (1997), which supports this view. Everatt (1997) claims the identifying characteristics of adult dyslexia are not necessarily the same as those of childhood dyslexia and this makes a finite definition difficult. The severity of dyslexia determines the overall impact of its so-called disabling characteristics in adults (Bruck, 1985, 1992; Fowler and
Scarborough, 1993 cited in Fink, 1998; Miles, 1986; Miles, Wheeler and Haslum, 2003; Rack, Snowling and Olson, 1992; Van Ijzendoorn and Bus, 1994 cited in Riddick et al, 1999). It could also be argued that the experiences of children with dyslexia may have long lasting effects on how it is manifested in adulthood.

**Research Lenses through which Assumptions and Beliefs about Dyslexia are Driven**

Throughout their lives adults with dyslexia struggle to acquire the specific literacy skills required for fluent reading and spelling. This is not to say that they can’t read or write but that they experience difficulties because of the demands placed on them by a literacy-based society. There are also a host of other individual characteristics that may hinder the acquisition of literacy skills, including: short term-memory difficulties, motor-control, visual perception, and right-left brain dominance. It would, however, be naïve to claim that dyslexia can be quantified within a single medical/scientific perspective. The literature reflects a number of research perspectives that focus beyond pure identification of an individual’s personal characteristics of dyslexia.

The degree to which an individual participates and is successful or otherwise, in school and in life, can be dependent upon a host of reasons and perspectives identified within the literature. The following conceptual table (Table 2.1) identifies examples of researchers and their perspectives or lenses. It does not include all researchers in the field. Some are located in more than one perspective.

**Table 2.1. Lenses through which dyslexia is viewed within the literature**

<table>
<thead>
<tr>
<th>Lenses</th>
<th>Description</th>
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<tbody>
<tr>
<td>Medical/Scientific lens</td>
<td></td>
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42

Within this perspective, attributes of dyslexia are determined within clearly defined types or subtypes which focus on identifiable characteristics and the degree or severity of dyslexia that can be easily measured.

<table>
<thead>
<tr>
<th>Educational Lens</th>
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<tr>
<td>This perspective focuses on an individual’s ability to acquire literacy skills in an educational context. It is concerned with all facets of educational provision – in particular the appropriateness of intervention, the knowledge &amp; attitudes of educators and the positive/negative experiences of the learner.</td>
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<tr>
<th>Social/Ecological Lens</th>
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<tr>
<td>Hellendoorn et al, 2000; Kurnoff, 2000; Lyster, 1999; Macdonald (2009); McNulty, 2003; Nosek, 1997; Poole, 2003; Riddick, 2001(b); 1996; Scott, 2003.</td>
</tr>
<tr>
<td>This perspective focuses on the impact of the wider social context of an individual with dyslexia and how the influence of peers, friends, workmates, educationalists, and family alongside societal attitudes, gender, and classroom/workplace/family dynamics can influence the success or otherwise of children and adults with dyslexia throughout their life.</td>
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<tr>
<th>Personal Lens</th>
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<tr>
<td>This goes beyond the individual’s “dyslexia-type” characteristics and highlights the temperament, understanding and awareness of one’s own dyslexia and personal perceptions of self. It deals with the psycho-emotional impact of dyslexia.</td>
</tr>
</tbody>
</table>
**Quantitative versus qualitative research – childhood versus adult**

While there appears to be considerable research into childhood dyslexia, there is a dearth of published research on adult dyslexia. The majority of studies on dyslexia, both childhood and adult, employ a quantitative approach that tends to focus on individual cognitive characteristics, particularly relating to phonological difficulties and the sub-types of dyslexia (cf: Eden, Jones, Cappell, Gareau, Wood, Zeffiro, Dietz, Agnew and Flowers, 2004; Ramus et al, 2003; Wolff and Lundberg, 2003).

Riddick and colleagues (1999) used quantitative methods to measure anxiety and levels of self-esteem of students with and without dyslexia. In addition, it should be noted that Riddick and colleagues also conducted in-depth interviews with the participants with dyslexia. A range of studies of people with learning disabilities (LD) that also included people with dyslexia, have been conducted from both a quantitative and qualitative perspective. These researchers have identified a broader spectrum of adult participants with their focus on individuals with learning disabilities who have a co-morbidity of impairments focusing predominantly on specific literacy difficulties but not limited to dyslexia.

There is growing research that focuses specifically on adult dyslexia as a discrete entity and further ethnographic research about the impact of dyslexia on adults’ lived experiences is warranted. More recent research in the field includes but is not limited to the following qualitative studies - Macdonald (2009), McNulty (2003) and Hellendoorn and Ruijsseenaars (2000). Macdonald (2009) analysed life narratives of people with dyslexia within a social class focus, to identify disabling barriers linked to education and employment. He argued that “social class positioning and institutional discrimination ... shape the experiences of people” (np) with dyslexia.
McNulty (2003) used a narrative approach “to capture the common aspects of the emotional story over the life course of persons [diagnosed with dyslexia as a child]” (p. 363). He claimed: “few studies are available in the professional literature that describe the specific emotional issues related to this experience from the perspective of individuals with this learning disability” (p. 363). Hellendoorn and Ruijssenaars (2000) replicated an ethnographic study of people with learning disabilities conducted by Gerber and Reiff in 1991, and identified people with dyslexia as their key participants. Gerber and Reiff (1991) originally studied young adults growing up with learning disabilities. Hellendoorn and Ruijssenaars’ study was based on five main questions that focused on the individual’s responses/perceptions regarding the socio-emotional impact of their dyslexia and how this impacted on their ‘adjustment to adulthood’. They found that personal characteristics and temperament played an important role in the participant’s ability to succeed in life as well as other protective factors “that reduce negative consequences or increase the chance of a favourable outcome of dyslexia” (p. 229).

Studies involving the educational experiences of tertiary students with dyslexia (Pollack, 2005; Riddick et al. 1999, 2002) revealed a strong influence of past and present educational environments as affecting an individual’s overall well-being. Similar to Hellendoorn and Ruijssenaars (2000) they found that student’s success was linked to individual temperament and level of self-esteem, including academic self-esteem. Pollack (2005) identified where students were willing to self-disclose their dyslexia in a tertiary context they found there were tangible benefits regarding teaching and learning accommodations and accessible resources.
Nosek (1997) and Kurnoff (2000) focussed on adults with dyslexia, but provide
generalised and anecdotal discussions as opposed to empirical-based research about
living with dyslexia. The remaining literature is written from a broader educational or
informative perspective, as well as ‘feel good’ media stories that provide an avenue
for educating the general public and highlighting an increasing public awareness of
dyslexia, alongside websites that profile adults with dyslexia. These include

It appears that the research has used particular lenses that tend to compartmentalise
aspects of dyslexia. The use of such lenses also influences the type of data generated
and the type of analysis. The small but growing number of qualitative studies linked
to the lived experience of dyslexia also indicates that current research lenses used to
investigate dyslexia may not allow for a holistic perspective of the multiplicity of
influences on an individual. A conceptual framework that addresses this conundrum,
and allows dyslexia to be considered across a multiplicity of lenses, including the
medical, educational, social ecological and personal lenses, is identified by Urie
Bronfenbrenner (1992). His framework allows individuals to be viewed and analysed
within all external aspects of the society and culture in which they live alongside the
impact of internal aspects and their individual makeup. It provides a bio-social-
psycho perspective – an approach that could be considered dyslexia-friendly. The
framework links to a social ecological framework in which the key aspects of
“process, person, context and time (PPCT)” are considered in the overall development
of an individual. Bronfenbrenner’s work is discussed in greater detail in the following
chapter.
Summary of Literature Review Chapter

This review aimed to situate the importance of literacy within a societal context and in so doing demonstrate the difficulties experienced by those whose acquisition of literacy skills does not match societal expectations. In particular, for people who have dyslexia, it addressed societal factors that have led to the construction of a sense of failure. The literature reveals that poor literacy skills impact directly on the success or otherwise of individuals with dyslexia and those with other literacy related difficulties. It also highlights the ‘tunnelled view’ through which society views people with inadequate literacy skills, identifies the themes linked to the psycho-social and emotional impact of dyslexia, and how they are exacerbated by the attitudes and beliefs embedded within society that impact on how society provides for, and how members react to, people with dyslexia. As a result of these key factors, individual responses and adjustments to literacy demands are identified.

The concept of dyslexia is surrounded by a range of perspectives and definitions. Its complexity raises core issues surrounding any discussion of adult dyslexia. More importantly it brings to the fore the range of research lenses through which dyslexia is studied and reveals a need for a more multi-faceted lens to be used in further research in this area. Whatever dyslexia is or is not, it is clear there exists a group of people for whom day-to-day living in a literacy-based society presents unique challenges and the focus of the present study is to investigate how they have experienced these challenges. How one group of people identified as having dyslexia perceive these challenges and how the research methodology was developed to examine these challenges are discussed in more detail in the following chapters.
Chapter 3

METHODOLOGY

The purpose of this inquiry was to gain insight into the lived educational experiences of adults with dyslexia. As the literature review revealed there are a range of perspectives and perceptions about dyslexia and literacy skills, many of which highlight the construction of a sense of failure that exists as a result of the importance placed on literacy skills within society. This construction of failure is perpetuated within educational systems. Therefore, by gaining insight into the educational experiences of adults with dyslexia one also gains insight into how society is structured and the beliefs and assumptions that exist.

The purpose of this chapter is to describe the methodology that underpins the research design. It also articulates the development of methodology and process of data collection and analysis. Sections of this chapter have been written in the first-person indicating an active voice in my role as researcher and the awareness of my role throughout the research process (Patton, 2002).

Research Design: Where to, and Why?

- The Decision Trail and Life’s Influences.

In order to situate this study within a methodological framework, I find myself considering what has influenced my perspective and participation within the study and why? What presents in this section is a discussion of the decision trail followed and importantly the reasons why particular paradigms influenced my thinking from two perspectives - as a researcher and personally. It identifies the changes that
emerged as I became immersed in the study based on participation, data analysis and an ongoing reading of the literature.

In considering the evolution of the study I was influenced by role as an observer in the stories of, and ongoing discussions with, the participants, as well as the factors discussed above. “Hammersley and Atkinson (1983) use the analogy of a ‘funnel’ where there is a progressive focusing of observations [and experiences] in which ... it is frequently only over the course of the research that one discovers what the research is all ‘about’” (cited in Pole and Morrison, 2003, pp. 17-46) and within the context of this study, knowing in which theoretical perspective one situates oneself. However, Patton (2002) refers to ‘border-crossing’ (p. 552) which has become more prevalent in research, where “qualitative researchers move back and forth among genres” and are influenced by a range of theoretical perspectives. Burdell and Swadener (1999) claim that ‘border crossing’ is particularly useful in the context of narrative inquiry as it allows the researcher: “to enter the world of others in ways that have us more present in their experience, while better understanding our own” (p. 21). Denzin and Lincoln (1998) believe “qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject at hand” (p. 3).

This study represents a degree of border crossing and a range of methods, within an interpretivist paradigm, that moves from a phenomenological perspective drawing from social theories and narrative inquiry but analysed and predominantly situated within an ecological framework (discussed below). It reflects my willingness as a researcher to adapt the inquiry within an interpretivist paradigm, as changes in understanding occurred or deepened accordingly, hence reflecting emergent design flexibility (Patton, 2002)
My perspective and participation within this project is influenced by 20+ years working in the field of special education in a range of roles. On a personal level, having shared my life with family members who are pro-active in the disability field and others who have disabilities, I have first-hand knowledge and understanding of the barriers that exist within daily life on a physical, social and psychological basis. I have been immersed in dealing with the ‘politics of the situation’ and how this impacts on the personal. As such, my background has been characterised by an advocacy role, both professional and personal. However I don’t believe that this has influenced my approach to this project in any negative sense. Researchers choose topics about which they are passionate and in qualitative research I acknowledge that researchers are in the research. However, I also understand that in the context of this study my role is researcher, not advocate, and I believe that I have been able to separate the two roles.

The second potential influence was my knowledge of, and relationship with, the participants of the study, who were all involved in an educational program designed specifically for people with dyslexia. This program was offered within a Technical and Further Education (TAFE) college as part of a Foundation Studies Program. During this course I became privy to the ‘stories of their lives’ in which their perceptions appeared to be linked directly to their dyslexia. The following question arose: why and to what extent did this phenomenon influence their life? At this point my thinking began moving away from a ‘political perspective’, which linked disabilities to barriers inherent in society, to more the personal impact, linked to ‘medicalised’ impairments and characteristics of dyslexia and how they constitute themselves within daily life. As my involvement within the course, and with the students, developed so too did my personal perspective, which shifted from what
Barnes (2001) referred to as ‘the personal tragedy theory of disability’. This was owing to my focus on the individual and their individual characteristics, to becoming more aware of the external influences that impacted upon their lives – in some, but not all instances, these being disabling barriers. It was at this point that I determined to investigate how these students experience their dyslexia, how they perceive their experiences and what is the essence of their experiences. I realised that the group provided the opportunity to gain insight into the experiences of living with dyslexia. I had seen first-hand these individuals reflecting on lived experience in the context of new knowledge gained by participating in the customised course.

A phenomenological perspective emerges

The study began as a phenomenological interpretative inquiry with its purpose being “to understand an identified experience/s from the perspective of the participants” (Kervin et al., 2006, p. 83). Langridge (2007, p. 9) identified the following four key aspects of the phenomenological approach:

- A focus on human experience as a topic in its own right;
- A concern with meaning and the way in which meaning arises in experience;
- A focus on description and relationships rather than interpretation and causality; and
- Recognition of the role of the researcher in the co-construction of the topic under investigation and built on an understanding of the way in which all experience must be understood in context (historical, cultural and personal).

Phenomenology was a starting point for the research approach. Langridge’s (2007) claims informed the study and its development, and are therefore detailed below:

Phenomenologists argue that it does not make sense to think of objects in the world separately from subjectivity and our perception of them ... Furthermore our perception varies according to the context, the position of the context, the position of the perceiver in relation to the object and the mood of the perceiver, among other things. There is, therefore, no- once-
and –for all knowledge to be found about a real knowable world. Instead, we have a focus on our perception of the world and how this is experienced, recognising that this will be differently meaningful to different people and even the same person in a different context. Consequently, the aim of phenomenological psychology is to study experience and how the world appears to people (pp. 4-5).

The phenomenological approach did not completely satisfy the overall purpose of this study that endeavours to go beyond pure descriptions of essence and experience to interpret the experiences and to represent their gained insight and unique challenges. This perspective is more reflected in a hermeneutic approach that seeks to “understand the meaning of experience (by searching for themes) with greater interpretive engagement with the data and a move away from the search for essences” (Langridge, 2007, p. 109).

Interviewing the participants allowed me to realise that an individual’s life was influenced by a range of internal, personal and external contexts that were both within and outside their locus of control. Further, it was difficult to separate the personal from the political by focusing purely on the essence of the lived experience that entailed documentation of reflections that could be understood within the context of human experience. This study goes beyond interpretation of the ‘situational perceptiveness’ (Van Manen, 1990, p. 156) of individuals and seeks to identify and develop an interpretation of the external and internal influences that participants recollect and reflect upon, across a time span.

**How is disability viewed and understood?**

The desire to move beyond description and develop interpretation meant that it was important for me to consider ways in which research concerning ‘difference’ had been conducted. The literature indicated that particular research lenses exist in the study of dyslexia. In view of this, I recognised the need to examine the assumptions
underpinning these research lenses. This led to an examination of the disability literature and ways in which it is constructed. The study of disability is situated within two main perspectives – a social constructivist perspective and a medical sociological perspective. There exists a distinct ‘divide’ between the two (Barnes & Mercer, 1996 cited in Thomas, 2004). Oliver (1996) claims that epistemological arguments that define these two perspectives are based around determining ‘causality’. The medical perspective directly links impairments to “the disabled people experience” (p. 34), whereas the social model does not recognise disability due to impairment, but being ‘wholly and exclusively social ... It is a consequence of social oppression” (p. 35). Even proponents of the social model of disability indicate mixed viewpoints. Finklestein (2001) claims disability is socially and culturally constructed and constitutes a form of social oppression that is politically motivated whereas Shakespeare and Watson (2001) do not view impairment and disability as separate entities. They claim “disability is a complex dialectic of biological, psychological, cultural and socio-political factors” (Shakespeare and Watson, 2001, p. 22). Thomas (2004) identifies Finklestein and Shakespeare and Watsons’ perspective of disability as being “the product of multiple bio-psycho-social forces” (p. 574).

From a medical sociological perspective it is the ‘body’ or impairment that causes restrictions, and the setting in which it occurs, determines the degree of disability. Bury (1988) indicates that disability is primarily a result of biological causes but also linked to social causes. He does not see it as a result of social oppression (Thomas, 2004).

Riddick (2001b) and Macdonald (2009) have used the social model of disability approach in relation to dyslexia. Riddick used this model in an educational context to
highlight the barriers within society that restrict educational development for people with dyslexia. Similarly, Macdonald’s (2009) research highlighted the variable of dyslexia and social class and its impact on educational and employment barriers. Focus was on the ideologies that exist within society that directly influence and create discriminatory barriers. With these perspectives in mind I needed to consider where I my thinking was situated realising this may influence development of the study.

Clearly dyslexia or any other disability label is complex in its construction and meaning. The literature review revealed the complexity of the meaning of dyslexia and the associated research lenses in which research has been presented. The social and medical constructs are somewhat limiting, as they do not consider the whole. As it is the aim of this study to move beyond compartmentalising dyslexia, it will be referred to as a concept as opposed to a disability or difference. Therefore, this allows the focus to move away from a purely personal (in a biological medical context) or political perspective and the opportunity to embrace a more holistic perspective in terms of individual lived experiences. Thomas (2001) purports that the feminist perspective on disability rejects the social model of disability as being inadequate because “important personal experiences of living with disability are left out of account, but so too are the personal experiences of living with the impairment” (p. 56).

The feminist perspective on disability sits well with Bronfenbrenner’s social ecology perspective (1979) that takes into account the wider social structure and the individual within it. It focuses equally on the development of the person and their individual characteristics and the social, cultural and political contexts in which they exist. It enables a broader perspective of the interrelationships between each entity. Its
purpose is not solely emancipatory, consistent with the feminist perspective, but increases awareness, from both an individual and systemic perspective, of the multiplicity of influences, interrelationships and perspectives within which they are perceived and develop throughout a period of time. Bronfenbrenner’s (1979) social ecology perspective, and in particular his more recent PPCT – Process, Person Context, Time model (1992), forms the basis of this research and it is within this model that participants and their lived experiences are presented and analysed.

**Situating Bronfenbrenner’s PPCT in the context of this study**

Bronfenbrenner’s theory (1992) revolves around the development of the individual within the context of their range of environments and is referred to as PPCT (process, person, context, time). More recently he has coined the phrase “the bioecological theory of human development” (2001) which he defines as:

...the phenomenon of continuity and change in the biopsychological characteristics of human beings both as individuals and as groups. The phenomenon extends over the life course across successive generations and through historical time, both past and present (Bronfenbrenner, 2001 cited in Bronfenbrenner, 2005, p. 3).

This model of human development evolved from Bronfenbrenner’s original (1979) social ecology framework and was influenced by his ‘mentor’, sociologist Kurt Lewin (Bronfenbrenner, 1977 cited in Bronfenbrenner, 2005). Lewin’s ideas were embedded in a “phenomenological conception of the environment” (Bronfenbrenner, 1979, p. 23) that stemmed from the idea that human behaviour is not purely a product but rather a function of a total situation and that the perceptions of this interaction are significant. He claimed “the individual and the world interact with and influence each other” (Myer and Moore, 2006, p. 140).
Bronfenbrenner (1979) identifies environmental factors as being of the utmost importance in overall human development, as opposed to purely genetic influences. These are pivotal to development within a social context. Using a conceptual diagram, Bronfenbrenner presents “a theory of environmental interconnectedness and their impact on the forces directly affecting psychological growth” (p. 8). His conceptual diagram is a series of concentric circles embedded within each other and is likened to a ‘set of Russian dolls’ that fit within each other.

![A diagram of Bronfenbrenner’s social ecology model as presented in the context of children, families and communities](image)

**Figure 3.1 Bronfenbrenner’s social ecology conceptual model**

The centre circle represents the individual and their genetic and personal make-up who is surrounded by layers of environmental life contexts that operate within a society. Four layers - the microsystem, mesosystem, exosystem and macrosystem - surround the individual who is directly and indirectly affected by the dynamics and interactions with each of these layers. The layers interrelate with each other in a two-way relationship, including even those layers or settings that the individual “may
never enter but in which events occur that affect what happens in the person’s immediate environment” (p. 7).

Within each of the four layers (the microsystem, mesosystem, exosystem and macrosystem) are situated unique characteristics and contexts that operate within each society.

The microsystem includes the immediate environment in which the individual interacts on a daily basis and is defined by Bronfenbrenner (1979) as “a pattern of activities, roles and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics” (p. 22). In 1992, Bronfenbrenner expanded the model to include “other persons with distinctive characteristics of temperament, personality, and systems of beliefs” (Bronfenbrenner, 2005, p. 148).

“The mesosystem comprises the linkages and processes taking place between two or more settings containing the developing person” (Bronfenbrenner, 2005, p. 148). It also refers to the degree of congruence between two settings in that the closer the match between the settings to a person’s expectations and experiences, the more positive and accommodating the interrelationships will be.

The italics in the quotes below refer to a later development of the definition in 1992. It is the values or cultural beliefs that are inherent in this system that are passed on down through the other systems and form a ‘trickle-down’ effect (Bowes, Grace & Hayes, 2009, p. 9), which reflect change over time of societal attitudes and practices.

The exosystem, encompasses the linkage and processes taking place between two or more settings, at least one of which does not ordinarily contain the developing person, but in which events occur that influences
processes within the immediate setting that does contain that person (p. 148).

The macrosystem consists of the overarching pattern of micro-, meso-, and exosystems characteristic of a given culture, subculture, or other broader social context, with particular reference to the developmentally instigative belief systems, resources, hazards, lifestyles, opportunity structures, life course options, and patterns of social interchange that are embedded in each of the systems. The macrosystem may be thought of as a societal blueprint for a particular culture, subculture, or other broader social context (p. 150).

In his later work on this model Bronfenbrenner identified the importance of human development “throughout the life course” (1992, p. 187) indicating the chronological impact from an aging perspective and an historical perspective. Hence, this augurs well for the life span perspective in which this study is situated.

The PPCT theory acknowledges to a greater degree the biological make-up of an individual and how this can influence their immediate environment – therefore acknowledging that an individual can be an active agent of change within the environment in which they operate, dependent upon the context. It also allows for an analysis of the progression of an individual’s development from “proximal to more distal contextual influences” (Bowes et al., 2009, p. 10). This is important within this study and the significance and depth of reflection participants experienced as influenced by their involvement in the dyslexia course.

A key component of the PPCT model that supports the underpinning component of this study is Bronfenbrenner’s recognition of individual experience. This includes, and takes into account, the subjective feelings that an individual may experience linked to the context/s in which they exist. This theory acknowledges that the subjective component is a very powerful force in human development and the understanding of a holistic perspective of lived experiences. It also provides the framework by which it is possible to identify and represent all the other influences on
individual participants. Bronfenbrenner’s model enables a holistic visual representation of the lived experiences of each participant to be presented and analysed that equally acknowledges the scientific/medical characteristics and social constructs, which participants perceived.

The literature shows that Bronfenbrenner’s model has been used across a range of social research areas including health (McLaren & Hawe, 2005; Myer & Moore, 2006; Stokols, 2001; Reifsnider, Gallagher & Forgione, 2005), education (Benner, Graham & Mistry, 2008; Tissington, 2008) and family-related research (Berry, 1995; Fannin, 1987, Wayne, Grzywacz, Carlson & Kacmar, 2007; Graves, Frabutt, Cabiniss, Gathings, Kendrick & Arbuckle, 2008). Research specifically related to disability that has used Bronfenbrenner’s model is limited, two examples being a study by Berry (1995), which focused on the transition of a family member with a developmental disability from an institution into the community and Gore’s (2005) examination of the marginalisation of sexual minority students with disabilities.

**Summary of Methodology**

The methodology for this study has been drawn from a range of interpretive perspectives that have influenced the researcher throughout the journey of data collection, analysis and presentation of results. The essence of the study is situated predominantly in a phenomenological perspective as underpinned by Bronfenbrenner’s PPCT theory (1992) that provides the framework for analysis and presentation of data and its intent is to gain an insight into the lived educational experiences of adults with dyslexia.
The Conduct of the Study

Choosing the participants

As previously addressed, the participants chosen for this study presented a unique opportunity to gain insight into the challenges of dyslexia. Their attendance at a customised course for people with dyslexia enabled them to reflect (both individually and as a group) on their life experiences in the context of a “new knowledge and understanding” of dyslexia and their experiences of it. Criterion sampling (Patton, 2002) was used to determine the participants of the study. “The sampling technique employed [was not] non-probability based, or purposive, because subjects [were] ... chosen for a purpose” (Alston & Bowles, 2003, p. 75). The criteria for selection required all participants to have completed the Understanding and Managing Dyslexia unit of Certificate 1: Foundation Studies for People with Dyslexia. Although not explicitly intended, an age balance occurred, as did a mix of employment status. The gender balance was uneven, however the original letters to invite participation were randomly sent.

Approval to contact students was gained through TAFEWA. Letters inviting participation, provided by the researcher, (Appendix A), along with a covering introductory letter from TAFE in which suggested text was provided by the researcher, were sent to 21 students at random. The researcher did not have access to private information and letters were sent on her behalf. As the potential participants had literacy difficulties alternate methods were used to assist participants in accessing the key information from the letters. One alternate method involved a follow-up phone call from a representative of the Foundations Studies program at TAFE who asked potential respondents if they had received and understood the letter, whether they were willing to participate, and if they had any additional questions that needed
addressing. It was intended that if sufficient numbers were not gained in the first round of letters, a second round would be sent. Of the first round, five letters were returned unopened, four respondents did not want to be involved and twelve agreed to participate. Despite initial agreement two potential participants withdrew. One contacted the researcher prior to the interview and said they would find it too difficult to revisit their past and the other gave no reason. Although it was the intention that 10 – 15 participants be involved in the study, this changed based on the availability of subjects, time constraints and individual’s desire or otherwise to be involved. The result was that ten participants participated in this study.

The aim of the study was for depth rather than breadth, an approach that encourages ‘information rich’ cases. Patton (2002) claims there are “no rules for sample size” (p. 244) and that “the validity, meaningfulness and insights generated from qualitative inquiry have more to do with [the] information richness of the cases selected and the observational/analytical capabilities of the researcher than with the sample size” (p. 245).

One particular risk factor that needed to be acknowledged was that some of the discussions may have involved talking about life experiences that may be unpleasant or of a sensitive nature. Therefore, the availability of counselling services through Murdoch University was offered to all participants. They were also advised that as voluntary participants they were free to withdraw at any time. An ‘official’ Participation Involvement Sheet (PIS) (Appendix B) was presented in written and verbal format along with a colour-coded adjusted format with key points from the PIS.
Information about the participants

Seven females and three males ranging in ages from early 20s to late 60s were involved. Two ran their own business, two were students, two had full-time employment, three had part-time employment and one was unemployed. Further information about the participants will be provided in a following chapter.

Background information about the TAFE course for people with dyslexia

The Certificate 1: Foundation Skills for People with Dyslexia is a nationally accredited TAFE course. It was initiated by Dyslexia educational specialist Dawn Matthews, in conjunction with the Dyslexia- Speld Association in Western Australia. After its first semester of delivery I was employed to develop the course content and as the principal lecturer in three of the modules. From its inception in 2003 until 2009, it has had over 300 enrolments. The majority of participants had gone undiagnosed throughout their post-secondary school experiences although some had been identified as experiencing difficulties with their learning. The course was designed to empower participants by providing them with knowledge and understanding of dyslexia as well as enabling them to develop skills to further their vocational prospects and desires. In order to enrol in the course participants required an assessment by an educational psychologist or dyslexia specialist.

During the period 2003-2005, the certificate comprised six modules. The participation and completion of the first module – Understanding and Managing Dyslexia - was one of the key criteria for participation in this study (See Appendix C for further information about the modules and learning outcomes for Understanding and Managing).
The key components of the *Understanding and Managing Dyslexia* module were to provide students with the following knowledge and skills:

- **Self-knowledge** – an understanding of their own dyslexia, individual learning style, strengths and limitations, and compensatory strategies.

- **Societal values surrounding literacy** – an awareness of societal infrastructure and attitudes and alongside vocational expectations, including the culture of the workplace and government agencies.

- **Self-efficacy enhancement** – through the identification of successful, positive role models and their attributes of success, networking with others, identifying emotional coping strategies and risk and resilience factors.

- **Self-advocacy skills** – in a vocational and life context, identifying past and current barriers – identifying and articulating adjustments or accommodations based on knowledge of strengths and limitations, social competence skills (Module 5: *Working Effectively with Others* also focussed on this). Understanding of legislative rights.

- **Awareness and accessibility of support systems** – (Module 2: *Support Mechanisms* provided additional specific knowledge for this component).

The dyslexia course both reflects and goes beyond the three areas of assistance Kerka (1998) argues should be provided “once a learning disability is identified”. These include the categories: (1). psycho-social; (2). technological; and (3). educational.

In the psycho-social area, an individual’s self-esteem can suffer from years of internalizing labels of stupidity and incompetence and experiencing dependence, fear, anxiety, or helplessness. Four ways to strengthen self-esteem (NALLD, 1994) are awareness (knowing about and documenting the disability), assessment (understanding the disability and one’s strengths and weaknesses), accommodation (knowing what compensatory strategies and techniques help, and advocacy (knowing their legal rights and services for which they qualify) (p. 3).

The course was publicised throughout a variety of sources, including the TAFE website and course advisory service; newspapers – both local and community based; flyers in libraries; local job agencies and vocational services; services linked to learning difficulties and disabilities such as Dyslexia SpeldWA, Irlen Lens Clinic, and
Independent Living Centre (ILC), as well as through the local radio, to name a few. As the course progressed students were referred from educational institutions, government agencies, as well as by word of mouth.

Of the 10 participants in this study, three found out about the course through local newspaper advertisements, three through links with the TAFE college, two through the local Dyslexia SpeldWA association (Specific Learning Difficulties) after they had been assessed, and two had been referred by government agencies – Centrelink and CRS (Commonwealth Rehabilitation Services). At the time, Sarah and Christine were tertiary students, Robert, Joseph and Juanita were employed full-time with Joseph and Juanita being self-employed. Sam was working as a volunteer. Riley (who was searching for another job) and Kerrie worked part-time, David was unemployed and Kim was on a disability pension and a perennial part-time student at TAFE.

Only three participants completed all six modules of the certificate with the remaining seven completing three to four. All completed the following three modules:

- Understanding and managing dyslexia;
- Identify, select, use and evaluate different support mechanisms to assist adults with dyslexia; and
- Strategies for developing basic literacy for adults with dyslexia.

**Data collection**

Three forms of data collection were used that generated different data sets. The three approaches to data collection comprised individual one-on-one interviews, a focus group interview session and a research diary kept by the researcher. This generated unique but inter-related data for analysis, which bolsters the credibility and trustworthiness of the study (Koch, 1994).
Individual interviews - narrative-based

Over a period of 18 months, each participant was involved in face-to-face, one-on-one, semi-structured conversations ranging from 2 – 4 hours in total. Initial interviews began with the researcher introducing a visual timeline (Appendix D) used as a visual prompt to talk about their dyslexia across the life span.

An “interview guide approach” (Patton, 2002), consisting of open-ended pre-specified questions, was used to stimulate interviews and guide initial discussion about their life story. In most instances this resulted in the development of a ‘natural’ conversation. An interview framework was developed prior to the interviews based on the “Patton Model” (Madison, 2005) (See Appendix E). It was not intended as a traditional interview guide but consisted of ‘possible pathways’ to be used if prompting or redirection was required based on the researcher’s raised awareness through previously encountered processing characteristics of the participants. They were not ‘must ask’ questions. Rather, they were open-ended questions that could be viewed as probes that were available to be used to elicit deeper discussion. Questions were built around a traditional 5 Ws and H (who, what, when, where, why, and how?) approach. The why questions were of particular importance because they provided opportunities for the participants to present their perceptions from a variety of perspectives.

Due to the previous relationship between the participants and the researcher in a supportive educational environment, the tone of each interview/conversation was relaxed and of a reciprocal nature. This sense of intimacy encouraged a sharing of personal information that during the editing process some participants asked to ‘remain off the record’. The feminist perspective on interviewing sees participants as individuals as opposed to purely objects of information and Oakley (1981) claims that
there is “no intimacy without reciprocity” (p. 49). The approach to interviewing within the context of this study is reflective of the feminist interviewing ethic. It highlights the importance of developing a mutual conversation that acknowledges an even balance of power through a known relationship. This approach reflects individual characteristics of both the interviewer and respondent, as opposed to the directive objective questioning and clear role differentiation of positivist thinking, enabling the perceptions of the lived experience of dyslexia to be presented and discussed within a mutual dialogue with the interviewer and interviewee being “conversational partners” (Rubin & Rubin, 1995).

This ethic transforms interviewers and respondents into coequals who are carrying on a conversation about mutually relevant, often biographical critical issues. This personalisation of the interview method makes it a potential agent of social change, where new identities and new definitions of problematic situations are created, discussed and experimented with (Denzin and Lincoln, 1998, p. 36).

Although this study was not intended as an emancipatory study, the interviews provided the opportunities for participants to gain new perspectives on their life experiences. Their new reflections and perhaps changed perspectives on the societal view of dyslexia and how dyslexia played out in their lives served to “interrupt” or “interrogate” previously held assumptions.

Initial interviews moved from a conversational format, in which it was hoped that discussion would sufficiently cover all aspects, to further interviews where key questions were asked of participants to allow clarification of the earlier discussion and themes that arose from initial interviews. These were still open questions that encouraged conversational flow, however they were linked to the influence of the dyslexia as it had revealed itself throughout the initial conversations as influencing
their perceptions of their past and present life and educational experiences. The key questions being:

- What are the characteristics of your dyslexia?
- How does your dyslexia affect your daily life?
- How have your educational experiences influenced your life choices?
- If you didn’t have dyslexia do you think you would have made different life choices?
- Tell me how the TAFE course has influenced your life.
- If you were Minister for Education what two changes would you make to education/schools?

Denzin and Lincoln (1998) state “it is very difficult to study direct, lived experience because language, speech and thought mediate and define the very experience one attempts to describe” (p. 39). Language processing difficulties by a number of participants challenged the construction of their experiences and my skills as a participant-observer. These difficulties arose as a variable during the interview process and had not been considered prior to this time. Throughout discussions with four of the participants I had to adjust the time required to wait for them to process questions and comments, as well as adjust the complexity of my questions and responses to their comments. Frequently their flow of discussion didn’t link to my question or comment but may have related to a comment made earlier in the interview. Often I had to keep returning to the same content/query. However as Denzin and Lincoln point out: “Interviewers must be aware of respondents’ differences and must be flexible enough to make proper adjustments for unanticipated developments” (1998, p. 53).

These interviews reflect one of the negatives identified by Pole and Morrison (2003) regarding interviews, namely that they may be: “daunting, tiring or onerous for
participants” (p. 35), as well as for first time researchers (Tanner, 2009a). However, it is imperative that in order to maintain the integrity of the conversations and the phenomena which is being perceived and expressed by the participants, that their everyday language, including construction and processing, is of utmost importance to truly maintain a phenomenological approach (Douglas & Johnson, 1977; Kotarba & Fontana, 1984; cited in Denzin & Lincoln, 1998: p. 66).

All interview conversations were based on a chronological approach focusing on life’s transition points (McLoughlin, 2001) or stages (Scott, 2003), and were supported with the use of a colour-coded visual timeline (Appendix D). The colour coding linked to educational stages. Pink represented birth to the end of primary school, blue from high school to the end of year 12 and yellow from the end of year 12 to the present. Transition points were noted on this timeline throughout each interview, however there were times when this disturbed the clarity and constancy of the conversation. This visual timeline acted as a support mechanism to (a) stimulate initial discussion within each time frame; (b) prompt memory and; (c) focus thinking and the processing of information. “Participants [were] empowered to provide more concrete and specific details about the topics discussed to use their own vocab and conceptual framework to describe life experiences” (Elliott, 2005, p. 23) and in doing so, providing evidence of an internal validity.

Pole and Morrison (2003) refer to life stories as life histories and claim that from an educational research perspective they are effective as they “allow researchers to consider what informants think is happening in education, what they expect/have expected to happen, what they make happen and what has happened to them and others as a consequence of schooling and/or educational experiences” (p. 36).
Educational experiences provided the focus for the majority of the conversations and therefore much of the information related to this. Using a life history approach is particularly useful for interpretation within an ecological perspective as life history may highlight “biological, cultural and social dimensions and patterns” (Pole & Morrison, 2003, p. 36).

Interviews were recorded and transcribed in full by the researcher. Transcripts were returned to the participants with an accompanying CD of the interview to support their reading needs. The CD also allowed them relatively stress-free processing of text and their oral conversations. Each CD also contained verbal instructions as to the requirements regarding the editing of the text. Participants were openly encouraged to contact the researcher and follow-up discussions were conducted by phone or email. This self-initiated contact provided participants with time to consider their original responses and formulate further points that may have been missed or not valid. It also allowed for memory difficulties and dysnomic characteristics, all of which may impact upon the participant’s responses in an interview situation. Phone contact also allowed the researcher to reword a question, or point presented from the interview as a “method of ensuring reliability” (Alston & Bowles, 2003, p. 50), or a question or clarification of a theme that had arisen from ongoing data analysis. Self-addressed and stamped envelopes were included for the return of manuscripts and therefore participants did not have to rely on their literacy skills to return information.

**Focus group interview session**

After interviews had been completed and data analysis revealed a range of themes, all participants were invited to participate in a focus group. The theme of ‘stages or signposts of dyslexia’ emerged in the context of all participants’ conversations about
their life experiences and in particular their process of reflection. The topic was discussed in a guided manner and did not require participants to contribute comments of a highly personal nature. According to Kaplowitz (2000), unlike individual interviews, the dynamics of focus groups tend to “inhibit participants from raising socially sensitive information ... or discussion topics” (p. 429). The focus group allowed further discussion and development of the stages of dyslexia theme and also revealed “how knowledge and more importantly, ideas both develop, and operate within a given cultural context” (Kitzinger, 1994, p. 116). It revealed similar perceptions of experience within the group that resulted in dialogue between each of the participants that expanded and teased out what they perceived as the stages of dyslexia. It also allowed for triangulation (Denzin, 1989b cited in Denzin & Lincoln, 1998, p. 73) of data alongside that from individual interviews as it allowed the researcher to consult with participants about the data that emerged to broaden and complement results. According to Koch (1994) this process of consultation enhances credibility.

**Research diary**

Throughout the period of the study I kept a range of diaries that documented the research process, decisions made throughout the research period, additional comments and conversations with participants, alongside personal reflections about my perceptions of the process and role in the study. These diaries constituted a decision or audit trail (Koch, 1994). These entries were invaluable, not only for analysis but in allowing me to revisit my evolution of thinking throughout the research process.
Limitations of study

As indicated above, it is important to note the study’s limitations: namely that the participants and researcher were known to each other prior to the study in an educator – student role. It should be noted that this may have impacted positively upon responses, in that disclosure of intimate and private experiences occurred more freely because of the mutual trust and respect that had already developed. The shift to researcher-participant changed the power dynamics, meaning that the researcher was able to capitalise on the trust built up by the participants without being in the role of teacher, which was previously the case. The established relationship allowed access into personal and private aspects particularly as the researcher had previously provided a basis for a change in their personal understanding of themselves and their dyslexia. This could enhance credibility in that disclosure of a range of experiences were more forthcoming. While ethically this may have encouraged participants to reveal more than they intended or felt comfortable with, the editing process allowed for this to be revisited and adjusted. It is also acknowledged that the relationship between the researcher and the participants may have impacted on their willingness to criticise aspects of the TAFE course in which they were enrolled, and its delivery.

It is further acknowledged that another researcher who was more removed from the group may have interpreted the data differently however one of the strengths of the project was the relationship between researcher and participant. Without this close relationship it is unlikely that such rich data would have been obtained.

It has been acknowledged that the study does not include the voices of teachers and/or the schools that participants attended. However, the focus of the thesis is the lived experience of the student. Furthermore, logistically it would have been impossible
given the age of the participants, their memories and demographics. Many of the teachers would no longer be alive or locatable. Equally some of the participants were educated across a number of states and countries.

“Volumes of Data”

How was it Organised, and What was Done with it?

Qualitative open-ended interviews in which participants reveal life histories produce a great quantity of data. This requires systematic and purposeful transcription and the organisation of data into an analytical framework. The analytical framework in this study encompassed two stages. Stage one provided depth and rich information to underpin and build on in the second stage. The stages of data analysis occurring throughout the study are as listed:

- **Stage One:** INDIVIDUALISING DATA: Capturing the essence of participants’ lived experiences.
- **Stage Two:** DATA REDUCTION INTO SETS OF INFORMATION: A cross case analysis of the educational experiences

The following diagram illustrates the analytical process undertaken and following descriptions will outline the processes within each stage.
Figure 3.2. Data collection and analysis

Stage One: Individualising data - capturing the essence of participants’ lived experiences.

This stage involved an exploration of the interview that resulted in individual narratives and a conceptual diagram of each participant’s lived experiences. This stage represents the uniqueness of each of the individual participants.

Individual recordings and transcripts were listened to and read repeatedly, and treated initially as a separate entity. Bronfenbrenner’s perspective, as represented within a series of concentric circles, was then used to present a conceptual diagram of the key information, experiences and contexts within each of the systems, relating to each individual’s perception of their life history.
The data that made up each conceptual diagram were then constructed into a narrative of each participant’s lived experiences. It is important to note that these narratives are intended to reflect the individuality and uniqueness of each of the participants and are not intended as literary gems.

Use of narrative technique

In choosing to write a narrative for each of the participants I wanted to reflect their life experiences within a defined time frame as well as capture the essence of each person. Similar to McNulty (2003), I believed that “as the participants’ final transcripts were reviewed, … preserving the elements and the unity of the story was essential to be able to provide a cohesive depiction of the events and emotional experiences over the course of life and their meanings and interrelationships” (p. 367). Although the majority of the study focuses on a thematic analysis of participant’s life experiences in the context of their educational experiences, it is important from an ecological perspective to have an inkling of the individuality and personality of each person. From a phenomenological perspective this allows the reader to view how the lived experience develops and how it is perceived through each individual and the researcher as the writer of the ‘story’. This highlights the intertextuality of each individual’s life by revealing external events and experiences, genetic characteristics, as well as the strength of character of each individual. I wanted to reflect their individuality and complexity of their ‘real life’ in a descriptive prose as opposed to solely compartmentalising their lives into thematic boxes that have been critically analysed and divorced from the individual. Using a range of strategies to present and analyse research, provides analytical diversity, which according to Coffey and Atkinson (1996), is particularly effective because it allows the researcher to “explore different facets of our data, explore different kinds of order
in them, and construct different versions of the social world” (p. 14). Smith and Sparkes (2008) believe that “this alternating movement does not privilege one form of analysis over another” (p. 26), rather it reveals greater depth and insight. Coffey and Atkinson (1996) argue that, “the more we examine our data from different viewpoints, the more we may reveal – or indeed construct – their complexity” (p. 14), thereby increasing the reader’s understanding.

The participants, in the process of telling their story, experienced a personal redefining of the perceptions of their lives that allowed them “to reconstruct a self that is coherent rather than fragmented” (Neimeyer, 2000; White & Epston, 1990 cited in Lysaght, 2007, p. 5).

Throughout the semi-structured conversations I found myself becoming immersed in their life stories and found that “listening to a story means acting not just as a scholar but also as a human being, with a heart as well as a head” (Leith, 2005, p. 129). As a result of my previous relationship with the participants, as well as during the study, the narratives allow, in part, my reflection of their character. The process of creating each narrative involved input from not only the individual but also the researcher. McCormack (2004) states:

> The initial reconstruction is by the participant as she/he recalls an experience and then describes that experience for the researcher. The researcher then reconstructs this experience as she/he transcribes, analyses and interprets the experience. A further level of reconstruction occurs as the reader reads and reacts to the experience. Knowledge constructed through this process is recognized as being situated, transient, partial and provisional; characterised by multiple voices, perspectives, truths and meanings. It values transformation at a personal level, individual subjectivity and the researcher’s voice (p. 220).

In these stories my role is in a ‘supportive voice’ as opposed to an ‘authoritative’ or ‘interactive’ voice’. That is achieved: “by profiling the narrator’s voice so that it is
heard and acknowledged in the public domain” (Chase, 2005 as cited in Connolly & Reilly, 2007, p. 522).

**Development and inclusion of the conceptual diagram**

The literature cited highlights the variety of ‘lenses’ through which dyslexia is researched and viewed. Each view is valid and indicates key factors that may influence life experiences. It is proven that neurological features do exist that constitute dyslexia, however the way in which a person experiences life, and how their dyslexia manifests itself, is dependent upon a range of ecological factors within which the person lives. In order to view the phenomena of dyslexia and how it is perceived by the participants, it is necessary to view the person within an holistic perspective that takes into account all the factors, which influence a person’s development and life, not just the individual or genetic characteristics. Cultural values, society’s infrastructure, including political views, economic decisions, educational paradigms, social norms and expectations, media images, social background, family characteristics and beliefs, educational and life experiences are all interrelated and interact with and influence individual characteristics and life choices. Results from the study by Goldberg and colleagues (2003) found that “compelling evidence [exists] that the LD [learning disability] permeated virtually every functional context of our informants’ lives, including family and social relationships, employment and community involvement” (p. 234). This I refer to as viewing an individual within an ecological perspective and can be conceptualised within Bronfenbrenner’s PPCT model (1992). I have chosen to use Bronfenbrenner’s model as an organisational tool presenting a visual snapshot of each individual’s life depicting the key components and experiences of their life. I have, however, included an addition to this framework that is a layer between the individual and their
microsystem. This layer emerged during the reading and segmenting and summarising of the initial interviews. It represents the synergism between the individual and the process of interactions within differing contexts over time. It presents the behavioural responses, individual attributes and life choices each individual has indicated when interacting with their physical, social and attitudinal environments. It needs to be emphasised that this layer is not a direct cause of dyslexia but the result of the interactions with outer layers and therefore influences decisions made within their life. This layer is similar to the function of the mesosystem, in that these attributes and choices are dependent upon the positive or negative attitudes that may or may not conflict or be incongruent with the individual’s strengths and weaknesses and linked to relationships between systems and contexts.

The focus points within each of the boxes in each layer can be either positive or negative. This highlights the view that understanding, knowledge of and acceptance, or otherwise, of dyslexia from an individual or societal perspective can be positive or negative, thereby highlighting a multi-dimensional layering of a multitude of existing attitudes that may be emanating from contexts or forces that may be within close proximity or completely remote from each individual.

The chronosystem, or time component, in Bronfenbrenner’s PPCT model, reflects time changes particularly from an historical perspective and are indicated throughout the diagram. Transition points (McLoughlin, 2001), life stages (Scott, 2003) or critical incidents (Reiff, 2004) are also incorporated within each diagram.

**Stage two: Data reduction into sets of information - a cross case analysis of educational experiences**

Stage two involved identifying all information provided during interviews linked to the participants’ three possible educational stages – primary, secondary and post-
secondary prior to the dyslexia course. It then involved developing a cross-case analysis that presented the ways in which participants perceived their educational experiences throughout this period based on their new knowledge gained from the dyslexia course.

Coding of concrete comments were extracted from the interviews, separated and dealt with separately. Step one included all comments and information being manually tabled according to the following criteria/descriptive codes:

- School attendance;
- Educational experiences; and
- Comments or further questions by interviewer.

Coding was used throughout this process at different levels from concrete through to more advanced coding involving higher level of abstraction. This “enable[d] the summarising of data by pulling together themes and by identifying patterns” (Punch, 2005, p. 199).

Step two continued this data reduction process. Within each of the above categories data was coded according to the following concrete criteria/descriptive codes and manually cut, pasted and placed under the following headings in a table format:

- School attendance: - including type of schooling public/independent/home schooling; years/grades/length of course; amount completed; location;

- Education experiences: positive and negative;

- This column was added as a result of the researcher’s ongoing comments and thoughts occurring throughout this coding. They can be viewed as a form of memoing – “a memo is the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding ... it can be a sentence, a paragraph or a few pages ... it exhausts the analyst’s momentary ideation based on data with perhaps a little conceptual elaboration” (Miles and Huberman, 1994, p. 72; Glaser, 1978, p. 83-4
cited in Punch, 2005, p. 201). Memos can “be substantive, theoretical, methodological or even personal” (Punch, 2005, p. 201).

An additional column, during the step two process, was included to indicate words or derogatory comments that participants used in reference to themselves or were used by other stakeholders about them during their educational experiences. This emerged as a commonality among all participants.

Each statement within these categories was then reduced further using the following colour code that included both descriptive and inferential coding:

- Attitudes – opinions/values (by participants) (purple)
- Teaching techniques and strategies (yellow)
- Feelings and responses (pink)
- Teacher Responses (green)
- Peer responses (blue)
- Family Responses (red)

These themes emerged and developed along the way during step two.

In some cases double coding of responses was necessary. It was at this point “themes that move across stories, across people and across contexts” (McCormack, 2004, p. 219) became evident and interpretation of this data began.

The step of interpretation became an ongoing process that “involve[d] identifying patterns, trends and explanations” (McCormack, 2004, p. 219) that provided stimulus to seek out further information and “until the categories or themes that are being researched [were] ‘saturated’” (McCormack, 2004, p. 219). It also involved a return to the literature, which was linked, but not specific to dyslexia. This was required when themes and patterns beyond initial reading emerged.
Throughout this stage, visual displays of data including charts, mind maps and conceptual diagrams were created and manipulated to provide a visual representation of the data.

Displays were used at all stages, since they enable[d] data to be organised and summarised, they show[ed] what stage the analysis ha[d] reached, and they were the basis for further analysis ... [Punch claims that] good qualitative analysis involves repeated and iterative displays of data. The same point is made in the grounded theory literature (Punch, 2005, p. 198).

These displays enabled the researcher to see visual links that were not evident in the written data and allowed for more purposeful and clearer pathways to be followed and presented within the analysis and discussion chapters.

**Summary of Chapter**

This chapter has outlined the qualitative methodological choices made by the researcher and the influences surrounding their selection. As the chapter reveals, this project uses a complex multi-methodological approach that is situated within an interpretive paradigm. It uses a narrative approach analysed from an ecological perspective. It also acknowledges the influence of feminist theory in the context of narrative and disability.

It clearly situates the influence of the researcher within the research process, as well as identifying the previous relationship between the researcher and participants.

However it is argued that this earlier relationship helped to inform the research and opened the doors that enabled the project to proceed. Without this prior relationship it is unlikely that the participants would have agreed to join the project or, if they had, their responses may not have been so open. Finally, it documents the techniques used in the process of data collection and analysis alongside the decision trail underpinning
the development of the study. The following chapters present the data and discuss the emerging themes.
Chapter 4

INTRODUCTION TO THE PARTICIPANTS

CAPTURING THE ESSENCE OF THEIR LIVED EXPERIENCES

This chapter briefly introduces each of the ten participants. Nine of the participants are identified by pseudonyms however one participant, Juanita, insisted her real name be used. She said: “I am proud to have my real name on it as I am very proud of what I have achieved, and do not mind anyone knowing I am dyslexic [sic]. I am also very proud to be part of your thesis.” As indicated in the methodology chapter, individual narratives have been created for each participant documenting a chronological story of their life. Individual conceptual diagrams of their life experiences are also included. These diagrams represent Bronfenbrenner’s (1992) PPCT model and use the diagrammatic format as indicated by Bowes, Grace, and Hayes (2009, p. 9).

In this chapter brief descriptions for nine of the participants are included whilst the full story of David appears at the beginning as a detailed case study. (All other narratives can be found in Appendix F.). In each narrative spoken text is indicated by italics. There has been no attempt to sanitise the language used as it highlights the emotional depth of responses. As indicated in the previous chapter these are not intended as literary gems but a presentation of each participant’s oral history as perceived by participants and documented by the researcher. All diagrams are presented after the brief descriptions.
**Participant 1: David**

<table>
<thead>
<tr>
<th>Age: 47</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of diagnosis: 43: Dyslexia 47: ADHD</td>
</tr>
<tr>
<td>Marital status: Divorced</td>
</tr>
<tr>
<td>Two children: Teenage daughter and son (living with mother)</td>
</tr>
<tr>
<td>Employment status: Currently unemployed</td>
</tr>
</tbody>
</table>

Our first meeting was just to ‘catch up’ and not talk dyslexia on David’s request. He had been up since 4am to make sure he arrived on time. We met outside the local library and he insisted on showing me an important landmark within the town. On walking around the corner I realised I was being taken to his favourite football team’s home training ground. Next minute we jump the fence and I find myself being led to the centre of the hallowed turf. A football then magically emerges from his bag and I am challenged to have a kick. We then proceed to kick the footy for about 30 minutes, At this time I realise I have passed my Rite of Passage when David says “You would’ve been a mean footy player if you were a bloke!” Satisfied with my acknowledged ‘skill’ we then move on to coffee. It was not until our second meeting that he was prepared to reveal his life. At this meeting he spoke of his need to focus and orientate his thinking well in advance of our first interview, and how our physical encounter had enabled him to do that. With each meeting or telephone call he always had something to share, whether it be his most recent discovery, experiment, or book fuelling his passion for linking the brain and bodily functions to ‘dyslexic characteristics’, alongside his search for a cure.
Born the middle of three children, David spent the majority of his life working on the family farm. His mother provided him with, and encouraged, an interest in plants and animals. This directly influenced his interests as an adult.

His school life began early when he was sent to a convent school a year earlier than most because “I had issues ... I wasn’t picking stuff up like the ABC’s and spelling and stuff like that.” From this early age he was very self-conscious of his difficulties but it wasn’t until he attended his brother’s meeting with the school psychologist that he remembers his parents being told: “your brother’s got no issues, I’d be looking at that fella over there and all of a sudden I was labelled as not being good” and he was left with the memory of “I’m not quite right. I’ve got the issue.” However, he reveals that his father’s attitude was one of covering up any issues of any sort and not acknowledging them in any way and responding to his efforts in a negative way with the constant implication that he has a mental illness. This has had a profound impact on his emotional and psychological stability throughout his life. At one stage his father, as recently as 5-10 years ago, believed him to have bi-polar disorder and ‘got a shrink from mental health to go out to the farm ... so he could get me off the farm and she came out and she said ‘all he needs is love’”. On revealing the influence his father’s attitude had on him he became visibly upset and emotional. Anxiety was evident as his hands moved to his face and he began chewing, stuttering and pausing.

In a later conversation he spoke of the sense of disorientation he believed he was experiencing during that time.

He spoke of attending the local public primary school saying: “that period of my life is fairly hazy – I remember distinctly being embarrassed – you do things like being put in the corner and stuff and take a lot longer to finish things and I looked at a
school report and I noticed in it a lot of times it ... he shows promises but is not trying hard enough”. He remembers a solitary teacher who was an ‘absolute standout’ and made a positive impact on his learning. During Year 7 he was placed in a ‘special group’ that was taught by a first-year out male teacher who made learning fun. “I remember singing with him and laughing and I know the end result is that from being the bottom 15 percent he took me from there when I went to first year – year 8 – I was in the top percent.”

His efforts at high school were initially influenced by his Year 7 teacher who had given ‘me belief in myself ... that maybe I wasn’t a nutter and I could go if I worked hard’, alongside his own self-determination. He struggles to tell of being up until the early hours of the morning trying to complete homework and then getting back up again at 5.30am “and then you’d get stuff from the teachers like ‘we know you’re smart but you’re not trying hard enough and more dedication’ and stuff like that” and his memory of his mother ‘bawling and saying you don’t have to do this’.

Throughout his school years he recognised that he “wouldn’t be hearing things or it took awhile to get, I’d be making mistakes a fair bit you know and stuff like that and so in the end i learnt to be shy or quiet about it and go into my shell”. He spoke of the inconsistencies that plagued his thinking and his learning – being top 20 – 30 percent in a subject one year, and plummeting to the bottom 20 percent the next. His reasoning being not due to the teaching but attributing it to himself – “I couldn’t remember”.

Sport became his confidence booster and almost an obsession – constantly practising during every waking hour. His efforts were rewarded by peer respect in and out of the classroom, team success as well as individual success gaining the Best and Fairest
Award for Australian Rules Football (AFL), and then later on in his high school years captaining the state junior AFL side. He proudly states ‘I did kick the winning goal against Victoria’. This is in contrast to his memory of a picture of himself playing football as a young child ‘playing in the back pocket picking flowers, dandelions and stuff’. During his time as captain he pressured himself to go better on the field as his role as advisor to team selection and plays was inhibited by his difficulty recalling names of players and short term memory of plays. When the coach could see that “I wasn’t up to it ... they didn’t worry about” asking his opinion. “In the end my whole drive is ‘action is all that counts’ to prove what I’m all about. Words and memory and all that isn’t.”

During this time he was also dealing with a back problem diagnosed as Sherman’s disease. In considering the influence this was to have on his sporting and farming careers, based on the doctor’s diagnosis and suggestion that he would likely have to find an office job, he was determined to prove the doctor wrong. He consequently began swimming – dams, pools, anywhere – in temperatures ranging from zero degrees upwards throughout the entire year. So, he would be doing extra swimming, extra footy work and pushing himself at school. I was just overloaded.

After completing high school he went to work on the family farm. During this time he married and had two children. At the age of 27 his mother died and it was around this time that the farm was under financial pressure. In order to increase production, and determined to appease the banks and his father, he began experimenting with grains and growing techniques. The success of these techniques resulted in public acknowledgement by the state Agricultural Department as well as other researchers and scientists, both nationally and internationally. The techniques he developed, in
his trials with wheat, resulted in Australia’s overall wheat yield being increased considerably. Another of his alternative farming methods was so successful that an Australian university created a position in their science faculty for a scientist to further investigate his technique. The scientist was named after this technique. (position name not indicated for the purpose of anonymity). Despite this public recognition and success, and even after declining the offer of a Churchill Scholarship, his father failed to recognise his achievements or take any interest in his trials. “I was getting kicked off the farm for fucking around for being silly by my father. Three times I got kicked off and not being able to drive straight lines with the tractor …. so on one hand I was getting rewarded and the other way I was getting kicked off the farm for what I was being rewarded for almost like, and the consequences of dyslexia – like driving straight lines with a tractor I found hard, it took a lot of concentration and doing wheat trials and stuff”.

Having worked hard alongside his brother and wife and being financially successful, a downturn occurred in the industry. During slack time David went shearing despite his back problems. He believes this strengthened his back and made him realise that “doctors weren’t right so I could challenge who were perceived authorities because I had learnt other stuff that had helped me more than what mainstream had helped me”. This directly influenced his current passion about finding a cure for dyslexic characteristics – “the research as yet has not found it but I believe there is one … if I can’t cure it, I’ll find a way to improve it”.

When his relationship with his wife was breaking down and the ensuing divorce, accompanied by financial difficulties associated with the farm, he talks about being at his most vulnerable, particularly based on his dyslexia. Misinformation was being
provided and he was not able to confirm it due to his poor literacy skills and being computer illiterate. He spoke of losing his business because he couldn’t put requested information in writing and of being charged an extra $30,000 by the bank because he took four months longer to sign some papers because he couldn’t ‘read’ the small print. At this time his family network were non-supportive and he felt vulnerable to their manipulation of information.

After his marriage break down, and the loss of the farm, he sought counselling. He also discovered a book in which Richard Branson discloses his dyslexia, and decided: “shit that sounds like me”. On mentioning it to his counsellor she recommended the dyslexia course at the TAFE, as well as organising government funding to pay for it. The dyslexia course not only provided him with acknowledgment of his intelligence and understanding of his characteristics but also came ‘close to saving my life ... all that shit in the back of my head, there are a couple of deaths in the family, there’s bloody mental institution stuff, and that was always chucked at me ... I wasn’t a loony. I guess because it was pretty close almost the way my father portrayed it ... that gave me belief in myself”. The course enabled him to recognise similar characteristics in his son as well as being aware of the difficulties he was experiencing at school at which point he decided to get an official diagnosis for both of them. His determination and desire that his son would not suffer like he had drove him to seek an assessment by an educational psychologist who was an acknowledged dyslexia specialist. He continually phoned her until she agreed to see them both for free. As a result they both were assessed and she also gave them private lessons for free. He begins to break down as he tells of how she at times even paid their bus tickets – “I was that broke at times and the government system didn’t look after us I’d have to forge tickets to get a bus ... to catch her up”.
The impact of his father directly influenced David’s relationship with his son. He spoke of his father not wanting to understand and ‘running away from his own demons and truths or covering them up’. To his father it was “all about running and not facing and so that’s why I’m facing. Now I’m very determined to understand exactly, exactly, this is the time to understand exactly what I need to understand and my son won’t have to go through the shit again”.

Following on from the dyslexia course, and the discoveries he has made about himself and his understanding of dyslexia, he has now turned it into a real passion. “What haven’t I looked up?” he eagerly claims. “I’m seeing that there is a big need in the community to understand cause a lot of intelligent people that can do a lot for society but aren’t in actual fact, is hampered by the education system and with their self esteem goes down and they can’t – reading and writing’s everything in society, if you can’t express your intelligence in writing then it becomes very, very hard.”

He has remained in close contact with a number of his fellow students from the TAFE course and they have investigated alternative therapies. He also continues to conduct his own experiments and create his own hypotheses about how particular food and enzymes affect certain dyslexic characteristics. These experiments have made him attuned to his body.

His never ending determination and his adrenaline fuelled passion are evident despite the difficulties he has encountered in his life – in fact he believes that “the consequences of it are I’m really lucky cause its great character building so I’m really lucky to have these experiences ... cause I’m set up for the second half”.

“And did you know that Einstein is dyslexic and he’s the Patron saint of Learning Disabilities.”
**Participant 2: Joseph**

Joseph is 28, single and lives at home with his parents. He is currently self-employed as a painter. This is his second business venture after the first resulted in bankruptcy, which he attributed directly to his dyslexia. At the age of eight he was identified as having a ‘problem’ at school. However, even with ongoing support and pressure from his parents, he was given little educational support. He was identified as having dyslexia when he was 23 and with the encouragement of his mother and aunt enrolled in the dyslexia course at TAFE.

**Participant 3: Juanita**

Juanita claims to be ‘60ish’ and is a self-employed businesswoman specialising in function design. She has experienced a range of occupations throughout her life including parenthood, hairdressing and journalism. Her early educational experiences occurred in a convent school up until she was asked to leave at the age of 14 because of the school’s fear that her personal results in a government test for funding may bring the school’s overall results down. In her forties she was identified as having Scotopic Sensitivity Syndrome and continues to wear pink glasses to stop the print from moving. In her fifties she was identified as being dyslexic.

**Participant 4: Kim**

Kim is 59 and throughout the past five years has been studying at TAFE in a range of general education courses. As a result of a back injury during her previous job she went on a disability pension but refused to do nothing so she chose to go back to study. At the age of 12 Kim had a serious illness that resulted in a change in her educational placement. Testing indicated she was a ‘borderline case’, however she is
unsure as to what this meant. She left school at the insistence of her mother and was placed in a workshop that the then manager soon identified was an inappropriate placement for Kim. This led to employment ‘in the real world’ as Kim stated. At 55 she was identified as having dyslexic characteristics by her lecturer at TAFE and further assessments confirmed this.

**Participant 5: Kerrie**

Aged 46 and currently working in beauty therapy, Kerrie has two young teenage children – a daughter, with whom she has penned a draft of a book with, and a son, a talented singer and dancer, who has been diagnosed with dyslexia. It was when her son was struggling at school and she recognised similar characteristics to herself when reading and writing that she sought help from Dyslexia SpeldWA. The identification of her son’s dyslexia led to an identification of her dyslexia. Her involvement in the dyslexia course through TAFE directly allowed her to become an active advocate for her son’s educational needs.

**Participant 6: Robert**

Robert, 48, works as a grounds and maintenance person in a primary school and enjoys the challenges and interactions of working in an environment with young children. At 45 he was formally assessed as having ADHD (Type 1), Scotopic Sensitivity Syndrome (he wears blue irlen lenses) and dyslexia. To him, this answered a range of questions he had about himself. He has a supportive network of family members (particularly siblings) who read, write and negotiate on his behalf when it comes to paperwork demands. It was his second partner who drew his attention to the dyslexia course and encouraged him to attend.
Participant 7: Riley

Riley, 49, has four daughters and 2 grand daughters and enjoys taking to the open road on her motorbike when she needs to clear her head. She currently works in retail but continues to search for her niche in life including - a job that is meaningful, a relationship that is meaningful and a greater understanding of herself. At the age of 6 she experienced severe hearing difficulties that affected her learning. Although she has had a series of operations to assist her hearing she has always experienced difficulties with reading and writing and processing language. At the age of 43 she was assessed for dyslexia.

Participant 8: Sam

Sam is trained as a support person for people with an intellectual and vision impairment. Originally from the UK where she did her initial training, she now supports a young adult with autism and vision difficulties. She also does volunteer work at a literacy support private tutoring service. Aged 48 and married, she is a very strong willed, gregarious and articulate person. It was not until her later adult years that she was formally diagnosed with dyslexia, although she had been involved in adult literacy and support groups previously.

Participant 9: Christine

Christine, 31, has completed a psychology degree and is currently working toward a degree in counselling. With an official diagnosis of dyslexia at 28 she thought the barriers to learning may all dissolve. Her educational journey highlights the difficulties encountered in a tertiary context across a number of universities, as well as those throughout her earlier stages of schooling. More importantly her journey
demonstrates enormous persistence, resilience and determination to achieve despite the barriers she encounters.

**Participant 10: Sarah**

Sarah is currently employed as an Occupational Therapy Assistant, a job, which she thoroughly enjoys, however her ultimate dream was to become a nurse. This dream did not come to fruition. Her TAFE studies were regulated by an external nursing board that emphasised the importance of accurate spelling and literacy skills and as a result she did not complete her studies in this field. Sarah claims that ongoing family understanding throughout her schooling has been integral to her achievements, as well as supportive during times when she feels she has failed.

The following 10 pages present the individualised conceptual diagrams of each participant in the order previously presented. Viewing them in conjunction with the full individual narratives (Appendix F) will provide the reader with an insight into a range of life experiences linked to each participant’s dyslexia. The reader is not only encouraged to consider each individual’s lived experiences but also the similarities of contexts and experiences they present as a group.

This chapter has introduced the participants through narrative and a visual representation of their identified life experiences. The next chapter will reveal the perceptions of their educational experiences throughout their primary, secondary and post-secondary schooling. These perceptions have been informed by the knowledge
and understanding participants gained through their participation in the TAFE dyslexia course.
Figure 4.3  Juanita
Figure 4.4 Kim
Figure 4.5  Kerrie
Figure 4.6  Robert
Figure 4.7  Riley
Figure 4.9  Christine
Figure 4.10  Sarah
Chapter 5

EDUCATIONAL EXPERIENCES VIEWED THROUGH THE LENS OF NEW KNOWLEDGE GAINED THROUGH THE TAFE DYSLEXIA COURSE

This section focuses on the outcomes of a cross case analysis of the data that explains the participants’ primary, secondary and post secondary learning experiences. To provide a context for this discussion, each participant’s schooling experience is provided in a summary form (see Tables 5.1 and 5.2).

The key themes within this section have arisen from the perceptions of participants concerning how they viewed the role of the education system and the key stakeholders within that system. The key themes identified are:

- Perceptions of the educational setting as a system or institution;
- Perception of individuals (teachers and peers) within the educational setting;
- Perception of significant others; and
- Self-perceptions in the context of the education setting.

Participants were invited to share their perceptions of all aspects of their educational experiences. In so doing, they provided a wealth of memories and recollections of their experiences within the classroom, playground and family context. In light of the importance western society places on literacy, and the specific focus of education to create literate members, these individuals faced particular challenges in the education setting. Analysis of data across cases revealed similarities in participants’ perceptions.
about educational provision, teaching, interaction with teachers and peers and responses of family members to their participation in school. It therefore serves to identify the range of influences operating not only on an individual level but within the microsystem, exosystem and macrosystem of Bronfenbrenner’s PPCT model.

**Schooling Information about each Participant**

The following table (Table 5.1.) identifies each of the participant’s ages at the time of data collection, schools attended during their primary and secondary educational experiences, age/s at which they had a formal diagnosis of dyslexia, the type of remedial assistance they received throughout their schooling, the year they completed high school and whether they received family support throughout their entire schooling. The participants’ schooling experiences span the period from 1954 to 2002. Some participants were educated in the UK.

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<th>Sarah</th>
<th>Age: 23</th>
<th>Schools attended</th>
<th>Age of diagnosis</th>
<th>Remedial assistance</th>
<th>Year left high school</th>
<th>Family support</th>
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<tr>
<td></td>
<td></td>
<td>Public primary (country)</td>
<td>Tested at age 11</td>
<td>Withdrawal from class – one on one support provided (primary &amp; secondary)</td>
<td>Year 12</td>
<td>Yes: (Financial, Physical, Emotional)</td>
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<td></td>
<td></td>
<td>Private primary/high school (metropolitan)</td>
<td>Age 19 interpretation of results = dyslexia</td>
<td>Repeated yr 7</td>
<td></td>
<td></td>
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<tr>
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<td></td>
<td>From Year 7</td>
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</table>

<table>
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<th>Age of diagnosis</th>
<th>Remedial assistance</th>
<th>Year left high school</th>
<th>Family support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Independent schools – co-ed 2 x primary – 2 states 1 x high school</td>
<td>‘Problems’ identified yr 3 –aged 8 Diagnosis at age 23</td>
<td>Physical segregation Repeated yr 2 H.S = “special needs kids” classes except soc studs</td>
<td>Year 10</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Age 16</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1985-1996</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Christine</th>
<th>Age: 31</th>
<th>Schools attended</th>
<th>Age of diagnosis</th>
<th>Remedial assistance</th>
<th>Year left high school</th>
<th>Family support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Public Schools 2 x primary 2 x high school Year 10 selective HS for elite</td>
<td>28</td>
<td>Spec Ed unit (primary) – small group withdrawal each day</td>
<td>Year 11</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Age 17</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1983-1993</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Education</td>
<td>Early Life</td>
<td>Special Education</td>
<td>Diagnosis</td>
<td>Other Issues</td>
</tr>
<tr>
<td>--------</td>
<td>-----</td>
<td>-----------</td>
<td>------------</td>
<td>-------------------</td>
<td>-----------</td>
<td>--------------</td>
</tr>
<tr>
<td>Kerrie</td>
<td>46</td>
<td>UK – Independent Primary – Aus 5 primary 4 high schools 3 different states Public.</td>
<td>Adult – when son was diagnosed</td>
<td>Remedial reading classes – withdrawal Primary school – one on one Repeated yr 9</td>
<td>Middle year 9 Age: 15</td>
<td>Unclear – transient – frequent moves</td>
</tr>
<tr>
<td>David</td>
<td>47</td>
<td>Convent (pre-school) Public (rural) High school (metropolitan)</td>
<td>40</td>
<td>“special group” – Yr 6</td>
<td>Year 12 Age 17</td>
<td>No – considered a mental illness</td>
</tr>
<tr>
<td>Sam</td>
<td>48</td>
<td>Public school (UK)</td>
<td>Adult</td>
<td>Primary – withdrawal Secondary ‘special class for dummies’</td>
<td>Age 16</td>
<td>No</td>
</tr>
<tr>
<td>Riley</td>
<td>49</td>
<td>Public</td>
<td>Adult - TAFE</td>
<td>No remedial Repeated yr 2 (hearing) High school – “lower, basic grades”</td>
<td>Year 9 Age 15</td>
<td>No – other issues within family</td>
</tr>
<tr>
<td>Robert</td>
<td>48</td>
<td>Public</td>
<td>45</td>
<td>Remedial group reading – yr 5/6 Repeated yr 1 H.S – ‘basic classes’</td>
<td>Year 9 Age 15</td>
<td>Adult – family support Child – minimal from siblings</td>
</tr>
<tr>
<td>Kim</td>
<td>59</td>
<td>Public</td>
<td>Yr 7: IQ test – ‘borderline’ diagnosis Age 55 - dyslexia</td>
<td>Yr 7 – 9 – ‘Special unit’ for students with IM</td>
<td>Year 9 Age 14</td>
<td>No – mother Yes – father</td>
</tr>
<tr>
<td>Juanita</td>
<td>60+</td>
<td>Independent schools Single sex</td>
<td>No</td>
<td>50’s– SSS – Scotopic Sensitivity Syndrome &amp; dyslexia</td>
<td>Aged 14 – told to leave</td>
<td>No – ‘marry her off’</td>
</tr>
</tbody>
</table>

Three participants – Sarah, Joseph and Kim - were involved in formal testing for ‘difficulties’, but no official diagnosis of dyslexia was presented during their primary
school years. Kim’s results indicated that she was a ‘borderline’ case and she believed this was linked to intelligence testing. Nine participants were not formally identified or diagnosed as having dyslexia or specific learning difficulties until they were adults. Sarah was diagnosed during her late teens.

Five participants were required to repeat a school year – four during primary school and one in high school. Sarah and Joseph repeated because of a move between primary schools, Riley after her hearing difficulties were identified in year 2, Robert due to academic reasons identified in year 1 and Kerrie repeated year 9 but left without completing it.

**Remedial assistance**

Seven participants were withdrawn from the classroom to assist with their difficulties, although none indicated that they had been identified as having a specific learning disability. Christine, David, Kim, Kerrie, Sam and Robert worked in small remedial groups. Christine and Kim identified a special education unit where they worked. Sarah and Kerrie received tutoring one-on-one. This withdrawal was not ongoing for any of them but spasmodic or for a short period during a single year. Riley and Juanita received no assistance throughout their schooling. Joseph experienced segregated ability groups within the classroom.

It is important to consider the educational and social-based paradigms throughout the 48-year time frame that represents the participants’ experiences. Cultural and societal attitudes resulted in educational systems that adopted paradigms of segregation, integration and, currently, inclusion regarding the education of students with special needs or learning difficulties. These paradigms were reflected within the educational policies, operating within the exosystem, and their responses ranged from
segregation in special school settings based on intelligence testing, to fulltime withdrawal and exclusion from the classroom, to onsite delivery of teaching, removal of students from the classroom for individualised support, to individualised support or ability grouping within the classroom, the latter reflecting a move toward an inclusive framework.

**Year completed high school**

Four participants exceeded the compulsory leaving age for schooling in Western Australia. David and Sarah studied for their TEE and completed year 12, while Christine completed year 11. Joseph completed year 10, receiving his school certificate. Five participants left school during or at the end of year 9 and Wendy was asked to leave during Year 8. All three participants who attended school during 1984-2002 continued beyond the compulsory schooling age of 15. This age did not change to 16 until January 1, 2006 (WA School Education Act 1999, p 6). Juanita and Kim left school prior to 1966 when the Education Act 1928 allowed students to leave school ‘at the end of the school year in which [s]he attains the age of 14 years’. Kerrie, Riley and Robert left at age 15. Between January 1, 1966 and December 31, 2005 the leaving age for students in Western Australian schools was 15. Sam left school as soon as she turned 16, which was the leaving age at the school she attended in the UK. These decisions regarding compulsory leaving age reflected the political and economic decisions linked to employment demands and opportunities as constructed within their exosystems.
Post secondary education information (not including TAFE dyslexia course)

The following table (Table 5.2.) identifies the courses that each of the participants have attempted or completed post high school. It does not include the Certificate 1: Foundation Skills for People with Dyslexia. Any courses attended after the completion of the dyslexia course are also indicated.

<table>
<thead>
<tr>
<th>Name</th>
<th>Post secondary educational experiences</th>
<th>Completion</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>TAFE HSC English, Bridging Nursing course, Certificate: Nursing, Cert III:</td>
<td>Yes</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Allied Health (after dyslexia course) Individual tutoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kim</td>
<td>TAFE Housekeeping, CGEA: Adult Literacy (after dyslexia course) NOW: New</td>
<td>Yes</td>
<td>Adult</td>
</tr>
<tr>
<td></td>
<td>opportunities for Women Individual tutoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Riley</td>
<td>Night School – local high school - Shorthand Individual tutoring TAFE</td>
<td>No</td>
<td>15/16</td>
</tr>
<tr>
<td></td>
<td>Hospitality</td>
<td>Yes</td>
<td>Adult</td>
</tr>
<tr>
<td>Robert</td>
<td>TAFE Certificate in Panel beating (linked to Apprenticeship)</td>
<td>Yes</td>
<td>17</td>
</tr>
<tr>
<td>Joseph</td>
<td>TAFE Certificate in Spray painting (apprenticeship), Certificate in House</td>
<td>Yes</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Painting resulting in painter’s registration ticket Individual tutoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Juanita</td>
<td>TAFE Certificate in Hairdressing (Apprenticeship)</td>
<td>Yes</td>
<td>15+</td>
</tr>
<tr>
<td>Christine</td>
<td>TAFE Cert III: Human Services University University 1: Degree in Psychology</td>
<td>Yes</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>(3 years)(during dyslexia course) University 2: Grad...</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adult Diploma in Counselling (1 year) University 3: Degree in Counselling</td>
<td>Yes</td>
<td>Adult</td>
</tr>
<tr>
<td></td>
<td>(after dyslexia course) Individual tutoring Still completing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>David</td>
<td>Nil</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sam</td>
<td>Workplace Training EXCITE – enabling training (UK)</td>
<td>Yes</td>
<td>Adult</td>
</tr>
</tbody>
</table>
Nine of the ten participants have been involved in post secondary educational experiences, not including the Certificate 1: Foundation skills for people with dyslexia. David has not attempted any further education. Eight participants (excluding Sam and David) have completed a range of TAFE courses from Certificate 1 to Certificate III. Robert, Joseph and Juanita went straight from high school into apprenticeships and were required to complete the certificate linked to their specific trades. Attendance varied for each of their courses. Robert attended every Christmas break for six weeks. Joseph was required to attend for three weeks every three months, and for Juanita it was ongoing throughout her apprenticeship. Kerrie, Kim and Sarah have completed adult literacy certificates. Sarah and Christine completed Certificate III in areas linked to health services. However, Sarah was unable to complete her nursing certificate due to her literacy difficulties, but completed a Certificate III in Allied Health, qualifying as an Occupational Therapy Assistant. Christine is the only participant who has studied within the university system, completing a three year psychology degree and a graduate diploma in counselling at two separate universities and currently completing a counselling degree at a third.

Whilst studying, Sarah and Christine have paid for one-on-one tutoring to assist with the literacy demands of their course. Riley sought one-to-one assistance from her children’s teacher to help her ‘to learn to write’. Sam is currently having individual
tutoring to enhance her day-to-day literacy skills. She began this program after the completion of the dyslexia course. Throughout her life she has also intermittently attended night courses that assist with literacy skills but did not find them useful as “they were run by inexperienced volunteers”.

**Perceptions of the Educational Setting as a System or Institution**

“System failure” (Herrington, Hamilton & Mace, 2001) was perceived by all participants as the cause of their inadequate academic and social achievements throughout their educational experiences. The educational opportunities associated with literacy acquisition that individual institutions provided, were perceived as inefficient and inappropriate across a broad timeframe.

Experiences linked to the acquisition of literacy skills were at the forefront of participants’ memories of their schooling. The use and valuing of particular literacy practices reflected the political context in which schools were operating at the time. Anstey and Bull (2004) claim that literacy practices chosen by teachers shape students and “some students will be empowered and some will be constrained” (p. 6). These literacy practices are linked directly to the teachers’ learned discourses about literacy and are “a product of socio-cultural, political and economic influence” (p. 62).

Kerrie was involved in an educational intervention program that focused on improving her phonic skills, but as she had poor phonological awareness, which was not identified, she was unable to successfully learn through this program. She believed that the teacher lacked flexibility and knowledge of effective teaching techniques. Furthermore, she did not appear to understand Kerrie’s needs:
I just remember going to the remedial reading classes by myself and trying to get these sounds that this lady was trying to teach me and it was impossible, I just couldn’t, I didn’t know ... I couldn’t understand, it was all very confusing and she wouldn’t do it any differently to help me. (Kerrie)

Similarly, Sam spoke of learning the IPA (International Phonetic Alphabet) in primary school to assist students to spell and identify the sounds in words. However “we went to senior school and it was ‘what the hell’s this – we don’t spell anything like that, it’s normal spelling here’ and it stuffed us up completely ... we just couldn’t do it and nobody helped us”. Both techniques were reflective of the “bottom-up” phonics based approach (Konza, 2006) of literacy teaching that drove curriculum requirements during their primary years and was linked to prevailing academic research and educational paradigms of the time.

Juanita’s frustration was linked to educational provision that focused on academic skills that provided minimal explicit instruction and did not teach skills for individual successful learning - “you had to learn ABC ... I couldn’t learn the ABC – I couldn’t get past ABC – I didn’t know what came next and nobody would help me”. In Juanita’s case this was due to a lack of professional knowledge on the part of the paraprofessionals employed at the school. Sam, on the other hand, was placed on a levelled reading scheme that was used for all students in the class. As each student improved their reading, and read all the books in that level, they moved up to the next level. She was given the books and expected to learn to read without explicit instruction “... everyone else was [learning to read] and they were going up and up the levels ... I just couldn’t get it”.

These examples reflect the systemic concept of ‘one size fits all’ in that many of the strategies were based on 'popularity of a program’ and ignorance of effective teaching
strategies, which were linked to inaccurate acknowledgement or identification of needs (Ash, Bellew, Davies Newman & Richardson, 1997; Humphrey, 2002; Palfreman-Kay, 1998). It is these restrictive barriers that are linked to knowledge and understanding of learning disabilities by teachers, and opportunities for professional development within an institutional context, which Mortimore and Dupree (2008) and Riddick (2001a) claim exacerbate educational experiences. Barton (2005) suggests, within the social model of disability, if focus is on the restrictions linked to their impairments it is therefore linked to personal failure, as opposed to institutional failure, owing to the inequalities of the education system.

In a tertiary context the negative teaching strategies indicated were in relation to very specific experiences. They were perceived as being linked directly to literacy skills. While studying for her nursing certificate, Sarah experienced blatant exclusion based on her literacy skills from her choice of vocational study due to the requirements of an external board that regulated and determined set criteria under which the TAFE course operated and passed students. High literacy skills were one of the criteria due to the importance of appropriate recognition of medication terms in a ‘life threatening’ situation. She revealed that, after seeking extra external literacy support:

I only just started catching up and then they decided that my spelling - and when you looked at spelling and drugs and I got flustered one day and I misread two drugs. Cefalacton (sp) and Cefalaxon (sp) and one’s an antibiotics and one does something completely different and if you have gave the same dose of Cefa the antibiotic one you would actually kill a person. But I stopped and I looked at it and I went that’s ... and I’m checking the spelling. I’m looking at the thing going oh hang on that’s spelt wrong and the dose is not and I went hang on a second and I stopped and I grabbed myself. So I did catch myself - correct myself. And so you know but it was brought up as an issue. But then it was about two weeks before the end of the course and they said no we wouldn’t be recommending you to be registered at the Nurses Board of Western Australia. So that meant I couldn’t get a job as a nurse (Sarah).
During her psychology degree Christine indicated that she was required to complete a range of assignments. Some were very structured in their presentation style while others were predominantly essay based. All assignments had a high written component and no other method of demonstrating understanding. “As uni went on I think they started marking harder and harder and what I was finding was I was still getting depressed cause ... I had so much trouble writing – it took me so long.” She expressed her frustration at her marks as she could clearly articulate the concepts and explain them coherently to others, including the lecturers: “but I’d get my assignments in and I would fail.” In a study of students with learning disabilities in Australian universities Ryan (2007) found that “strengths [such as verbal communication] were rarely recognised in conventional university assessment methods, which generally entail large amounts of reading and writing” (p. 438).

Christine’s assessment tasks for her counselling degree, on the other hand, were a combination of journal and reflective written tasks as well as practical demonstrations. Where written tasks were required, students were taught the components of how they were to be structured. This approach allowed Christine to achieve success: “I got 91% once for an assignment for a journal cause there was a lot of journal and practical work as in participation and stuff.”

The provision of specialised placements or classes was perceived in a primary/secondary context as negative, from a segregation and exclusionary perspective, but positive in a tertiary context because it provided for specific needs. Eight of the ten participants, at one or more times throughout their primary education, were identified as experiencing difficulties with their learning, and were involved in small remedial classes or one-on-one instruction. This support was not ongoing throughout their schooling but, in most instances, for a period of one year only.
Participants believed that initial identification of learning difficulties was identified by classroom teachers, except for Kim, who had a formal IQ test after an illness, and Sarah, whose parents identified her difficulties at an early age based on family history and insisted on remedial assistance throughout her schooling. After a formalised assessment, Kim continued to have assistance in a full time ‘special education unit’ from primary to high school and her transition to the high school ‘special education’ class was automatic due to her being in a special class in primary school. She does not recall any assessment being conducted prior to transitioning to high school to see if she ‘needed to be in the special class’.

All assistance was based on a withdrawal philosophy and students were physically segregated from their mainstream class for short periods throughout the week. Joseph indicated that segregation by the teacher occurred within the mainstream class: “I was always with the slower kids in the class ... they always use to separate us.” Joseph, Robert and David also referred to ‘student instigated segregation’ where “pretty much the dumb shits go to the back and the good shits stay at the front” (David).

This philosophical belief, emphasised within the written policies of national and state education bodies, that withdrawal or removal supports and/or ‘fixes’ learning difficulties, confirmed for many of the participants the concept of exclusion through segregation. Christine referred to it as ‘institutional discrimination’, claiming that it increased her feeling of being different because of the treatment she received. Joseph also admitted to having this feeling. They both claimed that this exclusionary practice of segregation undermined their self-esteem and status among their peers.

Within the adult learning environment, where participants attended specialised adult literacy classes, they did not view this as exclusionary. Rather, they saw it as
beneficial to their learning needs given the inadequate education provided in a post secondary context. Kerrie, Kim and Sarah attended specialised courses for adult literacy. All three had individually sought out the courses, Kerrie and Kim based on personal motivation to improve their skills, whereas Sarah had been encouraged by lecturers in her nursing course. All three viewed these classes as assisting their positive self-development. In an adult context they did not perceive this as a form of segregation or exclusion, as had been the case during their primary and high school years. Nor did they consider the experience stigmatising, as everyone who attended was there for the same purpose. According to Kerrie: “I went to a spelling class to try and learn how to spell. It was a specially designed class for people that couldn’t spell. So I was fine in that cause ... I was in a class with lots of people that couldn’t spell.” The availability of these classes was also reflective of society’s belief and expectation that all people should be able to read and write. It also acknowledges that in the past the education system may have paid insufficient attention to this issue. A “functioning adult” according to Herrington, Hamilton & Mace (2001) requires ‘certain levels of literacy’ (p. 2) to function productively and efficiently within society. It also highlights the cultural belief that ‘literacy is best learned in the classroom” (McDermott & Varenne, 1995, p. 341) and therefore ignores the presence of other sources of literacies and acquisition methods that may be more preferential to those individuals whose early educational classroom-based experiences may have been traumatic.

Four participants were involved in one-on-one tutoring that required personal financial outlay. Although paid tutors individualised programs that acknowledged their specific needs and literacy skills and allowed them to work at their own pace, they believed that the fact they had to do this confirmed their belief that the system
failed to provide adequate educational training throughout their lives. Sam stated that individual tutoring was ‘quite expensive’ and she felt let down by the system: “... that didn’t teach me what I’m now learning – I’m now paying for what should have been free; what the teachers should’ve taught me when I was at school”. Sarah spoke of the financial outlay of her parents toward extra tutoring: “which could’ve been spent on things for all our family, not just me”. Christine is aware of free learning support at her current university but prefers to pay for a tutor who is not affiliated with the University out of fear of public humiliation if she sees them on campus, and a fear of failure, namely that they may not be able to cater for her needs.

**Repeating year levels**

Repeating year levels was a systemic response designed to address the individual learning needs of participants during their primary and secondary years. Six participants repeated a year level during their primary and secondary schooling. Repeating a year level was due to three reasons: (i) lack of academic achievement in literacy skills (3 participants); (ii) illness and absence (2 participants); (iii) interstate moves and differing state education structures (1). For Robert, the impact of repeating year 1 was the beginning of his sense of personal failure. As an adult, he clearly recalls the following: “Grade 1 – I remember the teacher and everything ... There was 38 kids in the classroom and only 2 of us got kept down in Grade 1 and I reckon that was the one that killed me – grade 1 and being kept back ... I can still feel it – not good”.

In an adult context, studying at a pace that suited individual needs (and allowed for repetition and repeating of skills) was perceived as being both positive and negative. This provision included one-on-one tutoring, as well as University and TAFE course
structures that enable students to complete subjects over a longer period of time.

Recognition of prior learning was also indicated, but not found to be consistent across these institutions, by one participant. From an institutional perspective, selection of students through an interview process was perceived as positive. Anecdotes linked to these points follow.

Sarah was accepted into a TAFE bridging course for Nursing to prepare her for the Certificate in Nursing. Entry was granted on the basis of her TEE results. A number of years later she was given prior learning credit when accepted into Certificate III: Allied Health. The credit was acknowledgement of: (a) her part-time work in an aged care facility; (b) units completed toward nursing certificate; and (c) completion of the bridging course discussed above.

In a university context, course structures allowed Christine to complete a minimal number of units each semester, thereby allowing her to study at a pace more suited to her needs. However, on moving from the second university after completing a Graduate Diploma in Counselling and being accepted into a Counselling degree at the third university, she was required to repeat components of the Graduate Diploma due to the course requirements, which do not give credit for prior learning. However, her excitement at getting an offer to study the course outweighed this additional work: “...they’re making me do the Graduate diploma bit again which – who cares. I really don’t care – it’s a small price to pay”.

In a TAFE context, Sarah took six months leave to ‘improve her literacy skills’ before returned to her nursing certificate. She felt it would be beneficial for her to redo the subjects she had already completed to consolidate her understanding and refresh her memory due to her time off. The ‘system’, which included the Western Australian
nursing board, said ‘no’, forcing her to continue on to semester 3. Sarah believed that the system was setting her up to fail, despite her willingness to take her time to ensure that she was on top of the program’s literacy requirements.

In a post secondary context, Christine and Sarah spoke of lecturers at university and TAFE acknowledging their individual needs in a range of ways. However, they were restricted at a number of levels, including financial considerations and the availability of sufficient courses to support literacy learning, factors that clearly reflected the economic and political influence and impact of service provision.

Christine claimed her second university had offered to put the text books onto a CD but they requested a fee – “there was one book they said you’d have to pay $100 to get it done”. Whereas, at University three where she is currently studying, she claims it is –

…one place where they’ve wanted to bend over backwards for me however I haven’t wanted them to because of my past experiences at Uni … they asked me what I wanted and I said well nothing cause I was too scared to ask for anything, but I said the one thing if anything could help me is just to have my books – I need the two modes, the written and the heard – auditory, and I combine the two and that would really help me to have that and low and behold someone called me from Sydney from Macquarie university asking me what format I wanted it in (Christine).

She also found that the equity support services at university three encouraged her to disclose to the lecturers that she had dyslexia. Her response was “No! So I didn’t do that cause I thought, particularly after university one and two’s experience, there is no way”.

Christine, with her highly developed oral skills, participated in interviews required for selection into two of the courses she has studied. These were beneficial in allowing her to demonstrate herself as a capable, passionate, intelligent and articulate student.
These attributes would not have been clearly represented if the selection process were based solely on a written component.

_Perception of Individuals (Teachers and Peers) within the Educational Setting_

Responses by teachers and peers to individual participants and, in particular their academic achievements, were highlighted significantly throughout the data. Participants perceived both positive and negative characteristics of educators. Of particular significance was the way educators responded both professionally (through teaching strategies), and personally to the needs of individual students (in the case of participants in this study to the identification of their educational strengths and difficulties). Participants attributed these characteristics directly to their own personal success or otherwise. The majority of peer responses focused on negative reactions to participants’ difficulties, and in many cases these mirrored the range of teacher responses in the classroom. The results clearly indicated that the basis of both educator and peer responses, as perceived by the participants, were clearly linked to participants’ literacy skills and associated difficulties, alongside the embedded societal attitudes and assumptions toward ‘difference’.

Teaching characteristics

A handful of educators, across all educational settings, were identified who overtly acknowledged individual needs. The personal and professional characteristics of these educators were positive and supportive. On the other hand, the majority of educators were identified by their negative characteristics. These educators were perceived as being the norm among all participants. It is interesting to note that it is only within an adult educational context that the majority of participants perceived educators as
being non-judgemental, and prepared to outwardly acknowledge their level of intelligence.

The following table identifies the range of positive and negative traits of teachers throughout the participants’ educational experiences (primary to adult). These characteristics become evident throughout this section as they are discussed in a range of participant experiences.

Table 5.3. Positive and negative traits of educators

<table>
<thead>
<tr>
<th>Positive Traits</th>
<th>Negative Traits</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patience &amp; respect</td>
<td>1. Lack of desire to help, acknowledge difficulties or understand</td>
</tr>
<tr>
<td>2. Willingness to listen &amp; communicate honestly</td>
<td>2. Targets vulnerabilities - bully</td>
</tr>
<tr>
<td>3. Provides individual attention – ongoing positive feedback</td>
<td>3. Ignorance</td>
</tr>
<tr>
<td>4. Acknowledged own limitations and expertise</td>
<td>4. Learned helplessness – “I don’t know what to do with you”</td>
</tr>
<tr>
<td>5. Expectation of success – “made an effort to help” &amp; “caring”</td>
<td>5. Attributes blame</td>
</tr>
<tr>
<td>6. Encouraged and rewarded skills in all domains not just academic</td>
<td></td>
</tr>
<tr>
<td>7. Genuine enjoyment for teaching and making it fun – sense of humour</td>
<td></td>
</tr>
<tr>
<td>8. Bullying not tolerated</td>
<td></td>
</tr>
<tr>
<td>9. Non judgemental*</td>
<td>1. Sadistic and cruel*</td>
</tr>
<tr>
<td>2. Acknowledged intelligence*</td>
<td>2. No acknowledgment of effort*</td>
</tr>
</tbody>
</table>

*Adult learning only  
*Primary and secondary only

Perceived responses to identification of strengths and difficulties during primary and secondary years

Throughout primary and secondary years of schooling, educators were perceived as responding more often to participants’ difficulties than to their strengths. In the adult
learning environment, on the other hand, educators responded more frequently to participants’ strengths.

In the primary and secondary schooling context where difficulties were identified, class teachers responded in the following ways:

- Referred the student to a support staff or remedial group;
- Attempted to support the student in the classroom context;
- Ignored or appeared oblivious to their needs and made no effort to support them.

These will be discussed further in particular reference to the perceived effectiveness of teaching strategies (see Appendix G) identified by participants.

In the high school context, the identification of non-specific-generic difficulties were linked to testing and ability group placements for individual curriculum subjects. Within these ‘lower ability’ classes, teachers were aware that individual students had ‘difficulties’ because of their placement in the class or program. In addition to the above responses, participants reported that teachers in a secondary context:

- Attempted to respond to difficulties but tended to ‘give up’; and
- Increased homework.

Kerrie spoke of teachers in high school being unaware of difficulties at first but when they did become aware they did nothing except: “I don’t think I was asked to read again”. The following comments by participants highlight the range of responses from teachers:

- Teachers didn’t even pick it up I had a problem” (Riley).
- ... like they didn’t care ... they’d see the problem but never help you with the problem (Joseph).
They were all aware of our problems because we were the dunces, some teachers couldn’t be bothered with us, and some would try and give up with us (Sam).

No-one didn’t pick me up[sic] ... I was just in basic classes – I was just absolutely basic (Robert).

Couldn’t do it – more homework – that would fix it they thought – couldn’t they see I couldn’t get it in the first place so how on earth was more homework going to help! (David).

Referred the student to a support staff or remedial group or attempted support in the classroom context

Where classroom teachers identified participants struggling in the classroom context or “didn’t know what to do with [them]”(Christine), they responded by referring them to support staff or support classes. Other teachers were identified as attempting to support the student in the classroom context through specific teaching strategies.

Both positive and negative strategies were identified and will be discussed.

Five categories of effective positive teaching techniques were identified by six of the participants (see Appendix G. Table G1). Eight of the thirteen techniques were used by teachers who were responsible for students with learning difficulties and had been used during withdrawal from their regular classroom. The majority of techniques were used by teachers who were identified as having a positive impact on their individual learning or who ‘appeared to make an effort’ rather than techniques used as a result of the teacher accurately identifying their learning difficulty. None of the techniques were ongoing throughout their schooling.

Christine identified two teachers who adjusted their teaching practice to support her needs. The remedial teacher used a ‘Token Economy’ system where students were rewarded for ‘good’ work. “We would work at our own pace, we weren’t compared against each other”. The second was a Year 7 teacher who used peer tutoring to help
her with her maths: “She was a really bright girl, brightest in the school, brightest in the class and ... she would go out with me ... and teach me maths.”

David identified a Year 7 teacher who worked with him in a “special group” and made learning fun by using laughter as a stimulus to learning. It helped to relax him and allowed him to process what was being taught. He claims that this experience was so removed from the rigid routine of board and bookwork that he had experienced throughout his schooling.

Kerrie remembered one teacher, “getting out a special reading book from the cupboard ... that was behind the other kids that was easy for me to read. I think I sort of felt ‘wow’ ... a feeling that someone understands me”. However, this one-off identification of needs did not continue into other aspects of the curriculum.

A range of negative teaching techniques and strategies were also indicated by all participants (Appendix G. Table G3). These highlight the inaccurate and/or insufficient identification of characteristics and needs of the participants within an educational context. These ineffective teaching methods not only provided a barrier to both learning and active participation in class but also indicate examples of public failure (Scott, 2003) based on the demands to publicly demonstrate literacy skills in a public forum.

David and Riley identified occasions in both primary and high school that, owing to a lack of understanding of their difficulties and knowledge of appropriate teaching and learning strategies by the teacher, resulted in them being required to stand up in front of the class and read aloud, resulting in public humiliation (Fink, 1998). This compounded their sense of academic failure and directly affected their social standing among their peers. Similarly, Joseph spoke of a year 2 teacher who “used to make me
write right-handed ... I’m naturally left-handed”. This is reflective of the institutional ‘one size fits all’ perspective. Sarah recalled being given workbooks and told to work through them “probably looking back now with knowledge of dyslexia [it] was the stupidest way to teach a student with dyslexia”.

**Ignored or appeared oblivious to participants’ needs**

Punishment was indicated as a teaching technique if you were unable to acquire or demonstrate understanding, particularly if you ‘got something wrong’. Forms of punishment included being hit (Riley and Sam), verbal punishment – “I’ve told you once how to do it so do it right” (David), or when requesting further assistance being made to “ … clean the cupboards, clean or tidy the library or book cases … I did more bloody cleaning than the cleaners” (Sam). This technique also reflected *public failure* (Scott, 2003) and resulted in *public humiliation* (Fink, 1998) in front of their peers. Sarah was punished by not being allowed to participate in art (which was her curriculum strength) in order to focus on her literacy skills. This suggested that non-literacy based subjects were not valued. It also confirmed that the school did not recognise her strengths.

Sam also indicated that a fear of the teacher and their unpredictable responses did not allow her to absorb what was being taught. She recalls an incident where she and a friend were made to stand up in front of the blackboard when they were unable to tell the time. The teacher “had pictures on the board and he was going over it and we spent the whole day doing this and he was shouting at us, saying we were dummies and stupid because he didn’t expect to spend the whole day teaching us how to tell the time” (Sam). She went home and her brother’s girlfriend sat her on her lap and demonstrated how to do it. On returning to school the next day she announced she
had learnt to tell the time because of her brother’s girlfriend. The teacher responded by yelling:

‘Nothing to do with me spending the whole bloody day yesterday trying to teach you?’ – Christ he went ballistic at us ... because we was so frightened of him and the way he was trying to teach us we couldn’t get it in, we just couldn’t understand it, but by sitting with someone that we trusted who knew was never going to hit is or shout at us we understood it (Sam).

Punishment techniques used as teaching techniques reflect not only the lack of knowledge and understanding that their teachers had regarding specific learning disabilities such as dyslexia, but also their individual belief systems and attitudes which Kerr (2001) states impacts on their “behaviours, philosophies and even their effectiveness” (p. 82). One variable within the exosystem that needs to be considered, and is difficult to determine, is the availability of ongoing professional development for teachers. This may or may not have existed within the time frame covered by this study, or within the educational institutions the participants attended.

**Perceptions of teacher responses in an adult learning context**

A range of positive teaching techniques and strategies used within the adult learning environment were identified by nine of the participants (see appendix G. Table G2). Strategies were identified within a classroom context, but also those set in place by institutions to support learners with a range of needs.

The eight participants in a TAFE or workplace training context identified a range of positive teaching strategies, the majority focusing on hands-on learning that linked directly to the career choice they were studying. Classes involved a range of demonstrations of trade-based skills and then being given the opportunity to practise with positive guidance. Written theory was incorporated into the practical with diagrams, labels and talking. Robert indicated that just by attending the class it
helped with revision and “you got a pass”. Joseph indicated that the TAFE teachers used different methods to high school teachers. They “focus on helping you to understand what to do, exactly how to do it and why - contextualising learning into real life ... they tell you the reasons why you have to do this”. Kerrie indicated that the “self development courses at TAFE were very effective because you were actually physically speaking and learning” and the lecturers encouraged interactive sessions where everyone’s view was valued. This reflected not only a systemic shift, which was influenced by the need for developing specific vocational skills driven by economic demand within the exosystem, but also a shift in teacher-student relationships at the microsystem level. Sam, however, perceives this relationship to be based on a power shift within the macro-system that acknowledges and supports the transition from a child to an adult learning environment. She claimed that with adulthood, a societal expectation exists regarding a power shift in the classroom environment, which saw the old child-adult relationship being replaced by an equal adult-adult relationship and, with this, comes the expectation of equal and ethical treatment. On entering the adult classroom she spoke of this cognitive shift in her transition from a child to an adult learning environment and claimed: “I’m not at school anymore. I am an adult and I’m in an adult environment and nobody can push me, hit me or bully me ... they have to treat me as an equal and support my learning, it’s my right” (Sam).

In an adult learning environment literacy difficulties were identified either by the teacher, or through self-disclosure by the participant. Where difficulties arising from dyslexia were identified, teachers and lecturers responded in the following ways:

- Referred participant to dyslexia course;
- Referred to other courses/forms of support;
• Attempted to support and adjust teaching and learning strategies;
• Identified job-related qualities; and
• Were non-supportive.

Referred participant to Dyslexia course

Kim and Sarah were identified as experiencing literacy difficulties during the TAFE course and their lecturers referred them to the dyslexia course. Both lecturers had previously participated in a series of professional development sessions about dyslexia in the classroom, run by the TAFE, and from this were able to identify learning characteristics that suggested they may have dyslexia.

Referred to other courses/forms of support

Sarah was identified by lecturers in her nursing course as experiencing spelling difficulties that would affect her in a medical environment that required correct spelling and reading of medication names and doses. The course co-ordinator advised her to: “go and work on your spelling and ... we’ll give you six months off ... if you promise to get some tuition”. This assumption that something needs fixing is reinforced by the Cadman report (1976) that indicates that learning difficulties can be overcome.

Attempted to support and adjust teaching and learning linked to identified job-related qualities

Juanita’s TAFE teacher recognised her job-related qualities but also was aware of her literacy difficulties and how these were going to impact on her success. She said to Juanita:

... you are a very very good hairdresser – you’re the best in the class, you’re a natural hairdresser. You have a natural flair with the people.
You’re doing everything – I have to give you 100 out of 100 except for your theory”. She identified her difficulties after a written exam – “... first exam comes up – I rule my page up and write my name in beautiful scroll writing and pretty coloured lines and handed it in. She said ‘Excuse me, you haven’t answered one thing!’ ‘Well, I don’t have to – that’s what you do, that’s what I’ve always ...’ She said ‘Well at school what did you do?’ ‘What I just did – you do, that’s how you do your exams’ She said ‘You’re supposed to write on it’ I said ‘Oh no you don’t, I never did any of that (Juanita).

Following this exchange, the teacher talked with her and willingly worked with her one-on-one to enable her to pass.

Sarah experienced both good and bad lecturers. Those that identified her difficulties were only too willing to talk about how they could support her and would actively do so “and then there were other lecturers that as far as they were concerned having someone that had learning difficulty or challenge ... was too much of a hassle and they didn’t want to know about it” (Sarah). The good lecturers were at all times positive in their responses.

Sam encountered work place trainers whose focus was on job-related qualities as the key to success, not literacy skills. Therefore, during each workplace training pre-interview stage, and at the beginning of each course, Sam would openly disclose that she found reading and writing difficult. “I told everybody at the interview that I was dyslexic and Tory, ex-teacher, said ‘I’ll help. It doesn’t matter if you can’t read or spell, it’s getting by and your qualities of being an enabler that count.” In a class context she recalls:

I would put my hand up and say ‘excuse me, excuse my ignorance but I don’t understand that” and I think it was Denis looked up and said ‘I don’t mind you asking but never say excuse my ignorance, never say that, put your hand up and say sorry I don’t understand that or I’ll go over anything, but you’re not ignorant”. [In response to the question: How did that make you feel coming from a high school environment to an adult learning environment? she replied:] Bloody good because I felt well, haven’t we come a long way, but then I thought they can’t treat me like a
child, they can’t put me down because I would be on them like a ton of bricks because I’m an adult ... because as a child you haven’t got a voice because adults look down on children, and in my day children did not have a voice (Sam).

However, she relates her partner’s perception that in a work-place training context a degree of economic accountability exists:

… people who are doing training course want people to pass because[of] the people who are paying them to do the training courses – if people aren’t passing, they want to know why... they will have a set number of who – a target to meet – passes – they just can’t let anybody pass but if you can scrape through, or they can help you, they will (Sam).

Non-supportive

Christine also spoke of the HECS debt she incurred, resulting in her not being able to complete a fourth year in Psychology, because of the attitude and treatment of the lecturers:

I have an 8 grand HECS debt but no 4th year degree to go with it. This is the part that angers me still because I’m going to have to pay 8 grand back one day for being treated that way ... I’ve done every single thing in 4th year except for the last semester of research – the last semester of my dissertation and they just won’t let me do it (Christine).

Christine experienced both negative and positive responses to her disclosure of her dyslexia and acknowledgement of her individual needs. During completion of her first degree in Psychology she had a diagnostic assessment done, which indicated she had dyslexia. She sought assistance from equity services at the University.

I had the recommendations what the dyslexia report said and I blindly and naively thought – oh, it’s written there, they’ll do that for me – thinking that was great ...’no sorry we can’t, no sorry we can’t, no sorry we can’t to pretty much everything – we can give you a scribe for your exams and a computer, but that’s it.’ The computer was useful but I don’t need a scribe. A scribe is not going to help me, it’s not where my problems lie. I think perhaps I was different from what their boxed dyslexia is unfortunately and it doesn’t work that way (Christine).

Christine believed that within an adult environment and particularly within a Psychology department, a degree of understanding and support would exist for her
cognitive abilities and different way of learning. She informed the course co-
ordinator that she had a psychologist’s report indicating she had been diagnosed with
dyslexia. Their advice was “tell your lecturers if you are OK with it cause they may help you”. She chose to disclose her dyslexia and the diagnostic ‘evidence’ to a
lecturer when she required an extension for an assessment task on cognition:

I put down that I had dyslexia and it was recently diagnosed and I was struggling to get the assignment done on time and I put down that dyslexia affected my ability to process things and therefore it took me longer to do things. I had a medical certificate and what have you, cause that’s what you have to do and the lecturer of cognition, I stress cognition. The lecturer said to me ‘yeah’ in an email – ‘I’ll be accepting it once but I won’t be accepting that excuse again!’ (Christine).

Further to this, the lecturer added: ‘Be very careful of labels they don’t always mean a lot’. Said Christine: “...from someone who’s come from this cognitive shift in thinking I was dumb to thinking I’m really smart. How does a person deal with hearing something like that? That kind of threw me.”

These negative responses throughout her three year degree culminated in her being told that she wouldn’t be accepted into a fourth year. As a result she became very selective about disclosing her dyslexia, even where there was clear evidence that positive support was available. Not only that, she withdrew from the university and changed her career focus, even though being a psychologist had “been [her] lifelong dream”.

At no time did any participants indicate that teachers asked for any information regarding what dyslexia was, or talk about characteristics in an informed way except for the TAFE teachers identified by Kim and Sarah who had attended the professional development sessions.
The responses of teachers to each of the participants’ individual needs throughout their schooling into adulthood fuelled very strong feelings. In particular, during primary and secondary schooling considerable discussion by all participants focused on the negative aspects of teacher responses. Where individual teachers were identified as having a positive impact on learning, participants acknowledged that these teachers reduced stress levels and fear of failure for all students through their acknowledgement of individual learning needs, teaching methods and personal traits. Their memory of these teachers is clear because of their positive impact. In a study of adults with learning disabilities, Reiff and colleagues (1993) found that “the influence of one positive teacher counterbalanced all the negative messages over years of schooling” (np).

Teachers referred to in a secondary context involved lecturers at TAFE and University level, workplace trainers and tutors. The participants who had post-secondary educational experiences tended to focus on the positive aspects of teacher responses, particularly in a TAFE environment and tutoring context. Only two of the participants identified negative responses directly linked to the attitude and knowledge of the teachers/lecturers regarding their literacy-based difficulties.

Where participants disclosed their dyslexia and identified specific characteristics, teachers were perceived as responding in the following ways:

- Positive attitude and attempted to support and adjust teaching and learning strategies;
- Identified job related qualities as key to success not literacy skills;
- Negative – non-recognition – claiming it to be an ‘excuse’ for lack of academic success.
Bullying

Physical and verbal bullying emerged as a common response by teachers to the efforts and abilities of all participants throughout primary and secondary. It was not indicated in conversations about adult learning experiences. The intensity of the memories for some during primary and secondary schooling was quite vivid, even 30 or more years after the event: “the one that slapped me across the face and growled at me – oh I can still feel it” (Riley). Physical and verbal bullying was quite often coupled with public humiliation. Its intention was perceived by some, as an inappropriate teaching technique, and 90% of responses cited were as a direct consequence of learning difficulties.

Seven participants cited examples of physical bullying during their primary and high school years. Examples of physical bullying included:

- open hand slapping (face/legs);
- hitting with an implement (feather duster, ruler, cane);
- hitting head against wall and ‘whack the back of your head’;
- physical removal from classroom;
- ‘scab duty’ (picking up papers in playground).

Physical bullying was used by both female and male teachers, in dealing with both female and male students. The following anecdotal examples of physical bullying were provided by participants:

I got slapped across the face in year 4 or 5 ... something to do with school work (Riley).

We had the most horrendous teacher, he was a sadistic bastard and he used to hit us, every single time we got something wrong he’d hit us (Sam).

The nun used to come around with the end of a feather duster and we used to’ get it’ if we got the sums wrong (Juanita).
Always up the back and always physically grabbed and thrown out and up to the office (Robert).

Eight participants revealed memories of verbal bullying all as a direct consequence of their learning difficulties. Examples of verbal bullying included:

- **Singled out and ‘picked on’** – “I remember being picked on cause I couldn’t spell the word ‘very’” (Christine).

- **Yelling** – “... huge verbal argument with Indonesian teacher – I can’t do English how do you expect me to understand to learn another language” (Sarah).

- **Threatened with physical discipline** – “... next time you come up in front of me you get the cane” (Sam).

- **Attributing blame** – “...you’re going to have trouble all your life if you can’t get these sounds” (Kerrie).

- **Threat of public humiliation** – “You’re not allowed to tell anybody that you’re leaving ... because they’ll know you’re dumb and stupid ... it’s our secret that only we know and we’ll never tell a soul” (Juanita).

Verbal bullying often resulted in public humiliation examples of which involved:

- **Public announcement to the class regarding difficulties** – “trying to teach you bloody maths is like throwing my head against a bloody brick wall” (Christine); “... go back to pre-primary cause your handwriting isn’t good enough – you might as well do finger painting” (Sarah).

- **Removed from the class** – “I remember being chucked out of the choir ... for having a droning voice” (Kerrie).

- **Stand in corner** – “... or sit in the corner with the hat on – the dunce hat” (Robert).

- **Stand on chair in middle of class and recite times tables** (Joseph)

- **Response to non-achievement – ignore and wouldn’t talk to student** (Christine)

- **‘Concept of the secret’** – see threat of public humiliation above (Juanita).

Out of the 24 anecdotes provided, only two were linked to non-academic skills, three were linked to concentration difficulties and the remaining 19 were as a response to specific learning difficulties linked to literacy learning.
Peer Responses

Peer responses during primary and secondary schooling revealed, on one hand, the importance of friendship, whilst on the other hand evidence of victimisation, bullying, public humiliation and stigmatisation as a response to their perceived failure in the classroom. Peer responses, in an adult learning environment, were indicated as being generally positive, acknowledging skills and enabling a sense of empowerment.

Primary and secondary years

Importance of peers

David and Robert identified their sporting achievements outside of the classroom as providing them with a degree of respect from their peers, particularly during high school. Christine, Kim, Robert, Sarah and Riley all indicated that close friends throughout school provided a buffer for their ongoing negative academic experiences. Christine spoke of her friend from primary school whom she followed to another school as being “a saviour”. During high school Robert had a group of friends that supported each other: “we were all about the same – some could do reading and some could write so we used to help and cheat ... [I’d] just ask them for the answers – they write it down for me... friends ... we all stuck together”. Riley, on the other hand, spoke of conditional friendship: “when you can’t keep up to them or anything they tend to not want to know you anymore”. As Kerrie moved throughout Australia she had developed a sense of independence and resilience and this demeanour enabled her to acquire the skills to break into friendship groups. These skills also resulted in minimal bullying. A coping strategy used by Christine, Sam and Sarah and Kim was to try and ignore peer bullying, or seek the support of close friends. Although this
appeared as resilience in the school setting, Sarah spoke of being “really upset’ in the home setting.

**Bullying**

Physical and verbal bullying was identified at both primary and high school and for seven of the 10 participants it was ongoing throughout their educational experiences. In primary school only one example of physical bullying, involving fist-fights in the playground (Sam), was identified. Physical bullying was more prevalent in the high school setting in the form of fist-fights, pushing, throwing things, destroying or defacing personal property (Kerrie, Sam, David, Christine). Three types of verbal bullying were used in primary and secondary school: (i) name calling; (ii) victimisation and public humiliation; and (iii) emotional manipulation based on difficulties.

**Name calling**

The underlying current/reason for bullying was due to their peers’ perceived belief that they were of lesser intelligence because of their learning difficulties. Because they couldn’t read, write and spell they were ‘dumb’ and this belief was underpinned by a wider societal belief that was perpetuated by teachers in the classroom and society’s responses to people with literacy difficulties. Withdrawal from the classroom was indicated as directly resulting in peer bullying: “...you’re a dummy, you’re not too good – you’re not bright enough to be in our class any more” (Kim). David claimed that this was enhanced by the teacher’s responses – he spoke of a principal who “would say ‘duuu...’ and call me ‘slow Jo’ and the kids do that too when you’re in class – mimic teacher”. Participants identified a range of derogatory
words referring to lack of intelligence. These words are discussed further in this chapter.

**Victimisation and public humiliation**

Christine spoke of organised victimisation and public humiliation by groups of her peers during years 8 and 9: “...cruel things were being done to me because I wasn’t smart”. On one occasion a group of ‘popular students’ placed a bogus Valentine’s Day card in her locker. On finding it she was pleasantly surprised: “then I went into class and they all broke up laughing”. She also indicated there were days when she “would catch a bus into town and out of town just to avoid the bullying and it took me an hour longer but I was prepared to do it”. The stigmatisation of her literacy difficulties was exacerbated by her peers’ responses.

Kerrie and Sam both indicated that they were prepared to support other students who were being victimised as a result of their personal increased sense of injustice through their own experiences and sense of resilience they had developed to deal with bullies. “I didn’t like anyone bullying other kids and I would always stand up for other kids – no-one would ever bully me because I always stood up to them” (Kerrie). “I was never a bully. I never picked on people because I was always being bullied at home ... but I didn’t let others be picked on and tried to stop it” (Sam).

**Emotional manipulation**

Riley indicated that her language and processing difficulties were misunderstood by her friends and resulted in her being ostracised or being manipulated.

... you say the wrong thing to them and you didn’t mean to say the wrong things to them and they’ve taken it in the wrong way and they’ve thought you’re being nasty to me and they’ll go off and you’re left standing there with no friends anymore ... or they’ll muse [sic] you to get around other people (Riley).
Yuen, Westwood and Wong (2007) identified a wealth of research linked to the prevalence of peer bullying experienced throughout their schooling by students with learning difficulties. Students with personal and behavioural characteristics, such as “passivity, feelings of inadequacy, diminished self-esteem, problematic peer relationships, and an external locus of control” (p. 37), were more likely to be bullied. Other research identified students who were experiencing academic difficulties and believed themselves to be stupid, powerless and failures to become the victims of peer bullying (Harris & Petrie, 2003; Hazler, Carney, Green, Powell & Jolly, 1997).

**Positive acknowledgement of skills**

Peer responses in an adult learning environment were recalled as being genuinely positive. Only three of the participants were able to give detailed accounts of encounters with their peers. The majority indicated that purpose, motivation and desire to learn was more important than relationships with other students. Joseph, Sam and Christine indicated a sense of empowerment when other students sought their advice or looked to them for assistance. Joseph stated that because his peers had recognised he “could do the basics – i.e. handwriting, spell, write a sentence ... better than the rest of them” they ’looked up to’ him. Sam found other students copied her work: “it was quite empowering but also quite frightening because I thought, well what if I get something wrong and everybody gets it wrong and we all fall flat on our face?” Christine told how she assisted others with their assignments and being asked for advice and clear explanations about course content because her peers recognised she could explain theoretical components more clearly than the lecturers.

Sam indicated the supportive nature and positive responses of all participants in a workplace training environment, particularly after disclosing her dyslexia:
Sat in this classroom situation that I hadn’t been in since school and how much did I hate school. So I decided the best thing for me to do is to actually tell everybody that I’m dyslexic. To be honest with them and perhaps if I needed help and I looked onto somebody for help they wouldn’t mind helping me. I said “well, I’m dyslexic and I’m petrified and frightened to death about keeping up with everyone else and Jane looked up and said ‘thankyou for sharing that with us ... and we’ll all help’ – “Yeah, we’ll help, we’ll help”. So nobody batted an eyelid (Sam).

**Perception of the part of Significant Others**

Although it was evident during interviews that Joseph, Christine and Sarah had been continually supported by their families, Sarah was the only person who was passionate about her parents’ ongoing concern, advocacy, financial and emotional support. They were aware of her difficulties from a very young age, based on personal experience (her father has dyslexia), and wouldn’t let her use her learning difficulties as an excuse. Rather, they made her see it as a challenge. When she attended a public primary school, her parents “pushed from an early stage for me to be tested but ... the Ed department was going through a phase when you don’t label anything, so they wouldn’t test me to give me an official label ... so mum and dad couldn’t get proper official support”. Sarah’s experience reflects the following three key ‘protective factors’ that have enabled her to continue with her studies and achieve a successful career:

- A family background that values education;
- Recognition of the learning disability at a relatively early age; and
- Intensive, effective intervention during the elementary school years (Hellendoorn & Ruissjenaars, 2003, p. 229).

Christine received family support that provided the first two protective factors in a primary and secondary educational context. However, intervention during her tertiary experiences was predominantly linked to the support of her adult partner.
Where Hellendoorn and Ruissjenaars (2000) state that “parental support appeared to be a powerful predictor of adult adjustment and well being” (p. 3) it was evident with Christine and Sam that their supportive partners, in an adult context, played a greater role during their post-secondary educational experiences in helping them by recognising their strengths and supporting their self-esteem. In Sam’s case, this also enabled her to overcome the lack of parental support as a child. This also reflects Goldberg et al (2003) who indicated that life stages determine the ‘nature of [and effectiveness of] support systems’ (p. 228).

Sam spoke of her partner’s open admiration for her achievements and ongoing belief in her efforts. She spoke of using her dyslexia as:

… a crutch ... I can’t learn because I’m dyslexic and I used that excuse not to try and push myself so I couldn’t fail and make myself look a complete idiot. By putting myself through the training with the ‘Enabling’ made me realise that I can. But Keith looked up to me and he said “I admire you” and I said “why” and he said “because you struggled so much but you never gave up it was never in your mind to give up. I said I haven’t bloody given up –he said that’s why I admire you because so many people would’ve given up and how many people that aren’t dyslexic didn’t pass ? 6 people didn’t pass (Sam).

Christine spoke of her partner being aware of the difficulties she was encountering with her study and suggesting that they investigate them further:

... he believed in me he had so much faith in my ability and I remember doing [this] personality unit which I failed by 2 %. I was ‘how did I fail this?’ I get this, I was teaching people this stuff, I was drinking this stuff in I loved it. Greg said ‘something’s not right here ’. So I rang the equity counsellor or equity co-ordinator or whatever they call themselves – they put me onto Dyslexia-Speld ... there is so much to be said for social support. My husband is the best husband... he just believed in me, he had just so much faith in me (Christine).

These “dyadic relationships with significant others” (Field, Sarver and Shaw, 2003) provided participants with acknowledgement and affirmation of their strengths, which had been overshadowed by ongoing and compounding negative feelings of self. This
also affirmed the importance of interpersonal support systems such as family and friends in encouraging self-determination.

On the other hand, a number of participants perceived a life-long sense of failing one’s parents. Kim’s parents were conflicted in their approach to her abilities while she lived at home. Her father was aware of the difficulties she was encountering at school and would provide learning opportunities at home. “He used to have these place cards to help me spell. He taught me the time ... and he’d teach me this and teach me that”. Her mother, on the other hand, denigrated her, constantly referred to her as being “stupid” or putting her down. “You can’t teach stupid people things because they’re too stupid to learn ... stupid people don’t belong at high school” and when encouraged by the teacher to allow Kim to continue for another year she responded “no, I’ve got another daughter to educate and she’s bright so we can’t have two at high school paying money when one’s stupid and one’s not”.

This social devaluation of Kim’s worth based on a perception of her intelligence, was also evident throughout David’s comments about his father. Both his parents were aware of his difficulties but his father believed them to be linked to mental illness, not to a specific learning difficulty. His father’s lack of understanding (and negative statements he made), during David’s schooling and throughout his life were fuelled by the stigma he attached to mental illness. “I couldn’t do anything right in his eyes ... I was just a failure to him ... there was a history of mental illness in my family and to him I was tarred with the same brush” (David).

Sam spoke only of her mother during interviews and claims she: “was always being bullied at home”. She also indicated: “I knew I was a dunce ‘cause my mum told me
so”. However, she did not feel she had failed her mother, but rather her mother had failed her.

Sibling support was not perceived as a key factor, however Sarah, Kim, and Christine all identified the support of their siblings in the school environment, particularly in regard to bullying incidents.

**Self-Perceptions in the Context of the Education Setting**

All participants claimed that they ‘felt inferior’ and ‘unwanted’, particularly in primary and secondary classrooms, because of their literacy difficulties and the responses of the system and people within it. In an adult context, this was dependent upon the course they were doing and their perceptions of the adult-teacher relationship as previously discussed.

Sarah, Christine and Kim highlighted the negative stigma attached to the institutional response of withdrawal from the regular classroom. Sarah stated:

> ...everyone knew you were going off to Mrs Such and Such’s class and you knew what it was for, and everyone knew why you were going there so automatically you’ve got this little label stuck on your forehead going – you know- ‘kid with problems’ – sort of thing – removal from the classroom was like a big light going ‘Alfonsos off to Mrs Such and Such’s class’ (Sarah).

Kerrie, Joseph and Christine claimed that removal from the mainstream classroom exacerbated their sense of feeling different and highlighted the differential treatment they were receiving. Christine claimed that the ‘school validated [her] dumbness” by adopting such an approach. Kerrie’s comments support this view: “I already had an idea that I was dumb ... I guess going to these remedial classes consolidated this”.

Kim spoke of being placed in a ‘special class’ as being an inappropriate placement for her needs. She said it was “very frustrating and very upsetting and very stressful
because I felt like I didn’t belong and I felt like that for many, many years”. All participants who were withdrawn from class or repeated classes claimed to have experienced increased negative self-talk and self-efficacy throughout their schooling and all claimed to experience it as adults, confirming that this exclusionary experience and strategy impacts across the lifespan.

Joseph perceived being ‘smart’ with being able to read and write and he claimed he had encountered this attitude throughout his schooling from educationalists, adults, media and even friends and, to a point, family. “They emphasise that you can only get a good job in life if you get an education ... you must go to year 12. You must go to uni ... but you must get an education that is based on reading and writing only”. Joseph’s frustration with this attitude was that it did not recognise other strengths, particularly practical based strengths, people may have. He cited:

... academic friends ... who went to uni who couldn’t change a tyre. Can’t change a light globe but are looked on more favourably than me cause they can read and write and have a piece of paper to verify it and I don’t! (Joseph).

Christine claims: “there’s an unspoken stereotype for people that have literacy problems”. The culmination of responses from teachers, peers and family across the lifespan, in particular those involving bullying, resulted in the participants experiencing physical, emotional and social withdrawal, as the following examples reveal.

David, Christine and Sam all considered self harm at different points in their life (both during the early stages and later on) as a result of the negative thoughts that resulted from ongoing public humiliation and psychological bullying, compounded by a lack
of academic success. At age 11 Christine expressed to her older sister: “I wish a bus would come and hit me ‘cause I’m so dumb”. This sense of worthlessness continued throughout her high school years, where thoughts and attempts at self-harm intensified as bullying increased. This resulted in a ‘breakdown’, and an inappropriate, inaccurate diagnosis and ‘labelling’ by a psychologist. David said his thoughts of self-harm were linked to his father’s responses to his difficulties, particularly the attitude and stigma he attached to mental illness. Sam indicated that public humiliation by the teachers got to the point whereby she recalls a constant dialogue with herself saying: “I’m not going to school tomorrow, I am going to die. I am going to kill myself. I am not going to school.”

Sarah spoke of public humiliation by a teacher: “that probably single-handedly destroyed my confidence ...I can remember her doing that, it was horrible. I felt so stupid and small.” Riley spoke of how she felt when physically bullied by a teacher: “I was just so humiliated and upset – very upset”. In response to peer bullying, Kim also spoke of “feeling terrible and so upset and I couldn’t cry but I wanted to cause everyone would see me and laugh so I just tried to ignore them”.

Linked to this fear of public humiliation was the ongoing fear of victimisation resulting in a number of participants choosing to withdraw, particularly in situations where they were required to respond verbally.

I always felt a lack of confidence and felt I’d be made a fool of by teachers and peers in class if I spoke (David).

If I keep my mouth shut my words won’t be used against me (Riley).

In a “fit of desperation”, after having chosen not to respond in the past, Sam used a technique of reverse humiliation in response to a teacher’s effort to publicly humiliate her and another class member. She described the following situation:
Me, I got something wrong so he said ‘right stand up in the middle of the class’ so he said ‘what are you girl?’ so I put my hand on my hip looked sideways over my shoulder and said ‘a beautiful young woman’ and I went like this (sensual body movement), well everybody creased and all the boys went ‘orrr yeahhh!’, ‘yeah, yeah, yeah’. Well, you could see him trying to hold his breath so he said ‘go sit down’. Then Andrew was made to stand up in class and he said ‘What are you boy?’ And he put his hand on and said ‘oooh I’m a handsome young boy!’ like this you see and it stopped. It completely backfired because that soon got around the classrooms and the school yard ... he stopped doing it (Sam).

**Self-perception as influenced by words and labelling**

Positive and negative self-perceptions within the context of the education setting have been influenced by a number of factors, including the language adopted by the individual student and significant others. This approach both reflects and perpetuates societal values regarding literacy skills. Language use, in particular the use of words indicating level of intelligence, is evident not only within an educational context, but among all people and across all contexts, places and timeframes. The perceptions of participants indicate that word usage has been used as an exclusionary and controlling device – one that has been driven by societal assumptions and beliefs originating within the macrosystem and permeating across all systems.

Commonality of negative words, which were used to label and describe participants, emerged throughout primary and secondary school experiences in particular. The following table (Table 5.4.) indicates the derogatory or humiliating words or statements that were used by teachers, peers and significant others toward participants, as well as those used by participants as part of their own self-talk. These words were frequently identified by eight of the ten participants. This table does not represent the context in which they were said, or the pragmatics involved during the utterances.
Table 5.4. Words and labels used to describe participants by key stakeholders

<table>
<thead>
<tr>
<th>Peers</th>
<th>Teachers</th>
<th>Family</th>
<th>Participants’ self talk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stupid</td>
<td>Stupid</td>
<td>Stupid</td>
<td>Stupid</td>
</tr>
<tr>
<td>Dummy</td>
<td>Dunce</td>
<td>Totally and utterly dumb</td>
<td>Retard</td>
</tr>
<tr>
<td>Dumb</td>
<td>Not trying hard enough</td>
<td>Retard</td>
<td>Dumb</td>
</tr>
<tr>
<td>Retard</td>
<td>Thick</td>
<td>Thick</td>
<td>Not good enough</td>
</tr>
<tr>
<td>Idiot</td>
<td>Pudding head</td>
<td>Slow learner</td>
<td>‘stupid and small’</td>
</tr>
<tr>
<td>Fuck wit</td>
<td>Not very good</td>
<td>Dunce</td>
<td>‘I don’t belong’</td>
</tr>
<tr>
<td>Dumb shits</td>
<td>No hoper</td>
<td></td>
<td>Dumb shits</td>
</tr>
<tr>
<td>Moron</td>
<td>Never succeed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never get anywhere</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not bright enough</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Totally and utterly dumb</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Slow Jo</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Idiot</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Slow learner</td>
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<tr>
<td></td>
<td>Dummies</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Slower kids</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Imbecile</td>
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</tbody>
</table>

The majority of words were used as a form of humiliation, thereby indicating the stigma associated with social devaluation. This is highlighted by the use of terms such as “pudding head”, ‘slow jo’, ‘no hoper’, ‘dunce’, and ‘not good enough’.

Examples of stereotypical terms are also prevalent that are linked to a lack of intelligence, these include ‘retard’, ‘dumb’, ‘imbecile’, ‘idiot’, ‘stupid’ and ‘moron’.

Each of these terms have been used by psychologists throughout the 20th Century to classify levels of intelligence by testing. The original Binet-Simon Intelligence Test developed by Alfred Binet (1905) classified intelligence using the terms ‘imbecile’, ‘moron’ and ‘idiot’ (Domino & Domino, 2006). While originally acceptable, these terms are now considered inappropriate and stigmatising.

Peers tended to be more direct in their use of terms whilst teachers tended to use body language and indirect put-downs by attributing the blame of failure to the student through comments such as: “you’ll never get anywhere”, or “you’re not trying hard
“enough”, or “dummies could read that”. Both the verbal and non-verbal reactions of
the teacher serve to disqualify the student and publically stigmatise their actions
(Goffman, 1963).

Five of the female participants identified words and phrases that make up their ‘self-
talk’ and exacerbate their sense of personal failure and self esteem and indicate
internalised oppression. One male used the term ‘dumb shits’ to describe how he
perceived himself based on the responses of teachers and peers, as well as how classes
were structured. These are words they have used to describe themselves from their
early years of schooling and continuing through life. All terms link directly to
‘intelligence’ and seven of the eight terms directly reflect those used by others toward
them. Juanita claims that the media, and in particular television shows such as The
Simpsons, that are continually using inappropriate terminology with humorous intent
to refer to people with academic and literacy difficulties as being intellectually
impaired, simply perpetuates this belief of intelligence being equated to good literacy
skills – “so what hope do we have?” (Juanita)

Clearly the implication to the flow from the use of these terms is that low intelligence
is directly linked to mental deficiency. Taken a step further, this view perpetuates the
misconception that exists within society that all people who experience literacy
difficulties must be intellectually impaired. Scott (2003) highlights the
internalisation of this implication and the impact that word usage through bullying,
humiliation and ridiculing has on defining how people with dyslexia perceive
themselves. Respondents are creating public experiences of social oppression through
their word usage. This in turn influences recipients on both the ‘inside’ and ‘outside’
and highlights the ‘psycho-social dimensions’ of failure (Thomas, 2003).
Summary of Chapter

This chapter sought to provide insight into the perceptions of participants regarding their educational experiences from their early years into adulthood. It not only highlighted the institutional and systemic inappropriateness of educational provision within the educational settings over a significant timeframe, but also how the perceptions and responses of key stakeholders such as teachers, peers and family directly influenced the psycho-social make-up of participants. Reflecting on their experiences through the knowledge gained from the dyslexia course allowed participants to evaluate the interactions and interplays that occurred within a range of contexts and across all systems and in so doing provided evidence to support the five sub types of failure as identified in the literature review. More importantly, for some, their perceptions of the challenges faced in the light of new knowledge and understanding from the dyslexia course enabled them to focus on the societal assumptions and beliefs that were embedded in those challenges. It also allowed them to reveal their perception of the overarching lack of awareness and subtle prejudices that are held and perpetuated by key stakeholders. The next chapter reveals and discusses the life choices participants have made in response to their perceptions of their educational and life experiences.
Chapter 6
LIFE CHOICES AND THE EMERGENCE OF REFRAMING

This chapter identifies the life choices made by participants in response to their perceptions of their educational and life experiences. These life choices appear embedded in their responses to the deficit-based pedagogies they experienced throughout their schooling and incorporate their perceptions of the responses of key stakeholders within this context. The life choices made beyond the schooling contexts appear to be influenced by their early experiences. The identified life choices are not products of single critical incidents but a result of a culmination of incidents, interactions and perceptions across a range of contexts. Individual dialogue and recollections reflect the interconnectedness and synergism influencing both environmental and psychological aspects.

The life choices that emerged from the data directly reflect the quantitative attributes of proactivity and reactivity that were identified in the literature by Raskind and colleagues (1999) and in a follow-up study by Goldberg and colleagues (2003) of adults with learning disabilities. The following table indicates identifiable characteristics of these attributes drawn from the literature.

<table>
<thead>
<tr>
<th>Proactivity</th>
<th>Reactivity</th>
</tr>
</thead>
</table>
| *Participant makes decisions*
  *Is actively engaged in the world, participates economically, socially in family and community*
  *Expresses belief that he/she has the power to make positive changes in his/her life* | *Participant responds to events rather than planning ahead*
  *Responds with passivity and avoidance to negative events*<br>  *Does not acknowledge that situations can be altered or multiple solutions to a difficulty might exist* |
Proactive choices, within an ecological perspective, refer to the individual’s ability to make decisions by taking into account all contexts and environmental influences. Proactive choices indicate an individual’s self-awareness of the perceived external and internal factors affecting their decision-making. Another key component of this attribute is the awareness of supportive others and their positive impact. The opposite choices are referred to as reactive choices.

Reactivity reflects a perceived sense of empowerment on one hand to make personal decisions, but a lack of control of external (microsystem, exosystem and macrosystem) and internal (individual) factors, on the other. Reactive choices are self-protective and used in an attempt to hide vulnerabilities.

Across all identified educational timeframes - primary, secondary and post-secondary (prior to the dyslexia course and after the dyslexia course) – similar life choice themes emerged that can be identified as proactive or reactive (Table 6.2). A further life choice labelled *Out of individual participant’s control also* became apparent.

**Table 6.2. Life Choices across the educational timeframe**

<table>
<thead>
<tr>
<th>Proactive</th>
<th>Reactive</th>
<th>Out of Individual Participant’s Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Personal motivation and perseverance</td>
<td>1. Withdrawal</td>
<td>1. Life choices made by significant others</td>
</tr>
<tr>
<td>2. Advocacy</td>
<td>2. Compensatory strategies</td>
<td></td>
</tr>
<tr>
<td>3. Disclosure of Literacy difficulties</td>
<td>3. Negative self-efficacy</td>
<td></td>
</tr>
<tr>
<td>4. Change in mindset and understanding</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Primary and Secondary Life Choices

Throughout their primary and secondary educational experiences, participants indicated a range of choices that influenced their social and psychological well-being. The life choices revealed the majority of participants’ responses to be reactive, as opposed to proactive, to the negativity they encountered throughout their schooling. Choices were also indicated that were ‘out of [the] participants’ control’. Many of the choices were a reactive response to an individual’s perceived lack of academic success and negative responses by key stakeholders. However, these choices could also be identified as proactive because of an individual’s desire to take control and change their situation. It is interesting to note that all choices throughout their educational lifespan are not either/or, but are based on the process and quality of interactions within particular contexts. A culmination of similar themes was identified throughout all stages. The following table presents themes from the primary and secondary context. Each theme will be further discussed using anecdotal recollections and perceptions of participants.

Table 6.3. Life Choices – Primary and Secondary

<table>
<thead>
<tr>
<th>LIFE CHOICES</th>
<th>Proactive</th>
<th>Reactive</th>
<th>Out of individual participant’s control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal motivation &amp; perseverance (5/10)</td>
<td></td>
<td>Withdrawal (10/10)</td>
<td>Life choices made by significant others</td>
</tr>
<tr>
<td>Compensatory responses (5/10)</td>
<td></td>
<td></td>
<td>- Moving states (2/10)</td>
</tr>
<tr>
<td>Negative self-efficacy (8/10)</td>
<td></td>
<td></td>
<td>- Moving schools (5/10)</td>
</tr>
</tbody>
</table>
Proactive life choices

Personal motivation and perseverance

Driven by personal motivation as a response to the negative experiences and responses by key stakeholders to their efforts and their learning, four participants made the following decrees:

Action is all that counts ... hard work + determination = success (David).
To succeed in life despite what others say and do (Sam).
To strive to find success – to find something I’m good at (Kerrie).
To complete year 10, no matter what (Joseph).

David and Sarah, in particular, spoke of their determination and desire to succeed within an academic framework and the effort and persistence they endured. David referred to his efforts as ‘torture’ and Sarah likened hers to a sense of ‘drowning’.

I’d have to do 2 or 3 more times than most guys and things like you’d be reading for about a minute or 3 or 4 and then you’d forget what you’ve just read and you’d have to go back over it and I remember distinctly saying that I’ll never put myself through this torture or this stuff again (David).

I remember going to school one day – I must’ve been near class and I turned to mum and I said I can’t stand this. I feel like all I do Monday to Friday is go to school, then Saturday and Sunday I study and study and study and turn around and it all starts again ... I felt like I was drowning (Sarah).

Although both made what appeared to be proactive choices, the negative consequences of their decisions resulted in panic attacks that they both experienced throughout high school. For Robert, these panic attacks continued into adulthood and his workplace. Their determination to succeed resulted in a sense of overload and anxiety.

Six participants indicated realistic and achievable life choices that they made – all of which appear reactive to their lack of academic success but proactive based on their desire to take control and change their situation. Robert and David experienced
recognised success in the sporting arena and therefore indicated that they would “pursue sport with vigour” (David) and “devote 100% effort to sport” (Robert), because sport does not involve reading or writing. Robert indicated that he would attend school just for sport:

I wagged school or went to school just to play sport and that was it. Morning tea came, same thing, after school straight down on the oval just to play sport ... homework, I just threw it in the bin. Any notes I got from the school were thrown in the bin as well – I couldn’t read them and if I couldn’t then nobody else was going to! (Robert).

David, however, made a further life choice to stop sport to concentrate on study due to: (a) Sherman’s disease and resultant back pain; and (b) TEE requirements and his determination to finish school. After completing secondary school, David “made a pledge” to himself that he would “never return to study or schooling ever again”.

Sam, during her secondary schooling became a goal-setter and identified 5 goals, which she has successfully achieved: (1). learn to drive; (2). to travel; (3). not have children (“so I can’t be a bad mother like my mother was’); (4). become financially independent; and (5). not marry before 30. In response to her experiences at home and school, Kerrie has developed a strong sense of injustice, choosing to become “a bully fighter” – sticking up for people being “picked on”.

Sarah’s life choice linked directly to her academic achievement and the positive responses of a number of teachers and her family. She chose to put in “110% effort and [to] try [her] hardest” and resign herself to lower marks as both her teachers and family recognised her efforts and positively acknowledged them. In doing so, she recognised and accepted the limitations of her learning difficulties, even though at this point she did not have a clear understanding of ‘her dyslexia’.
In the majority of choices participants’ decrees reflected a determination and personal understanding that the responses of others within their microsystem should not determine who they are and what they can achieve. This self-insight reflected a desire to change attitudes and assumptions of others toward their efforts. It also highlights Bronfenbrenner’s view that an individual can be an active agent of change within their environment.

**Reactive life choices**

**Withdrawal**

Negative reactive choices indicating a withdrawal response were revealed as a response to classroom experiences and their perceived personal sense of failure during this period in their schooling. It is interesting to note that a number of participants who adopted a withdrawal response were also identified as having personal motivation, determination and perseverance in a proactive context.

Five participants indicated that early on in their schooling they chose to withdraw from engaging within the classroom. They chose to ‘keep quiet’ in class to avoid risk taking, public humiliation and victimisation. For those who had given up academically their choice resulted in self-exclusion. The following recollections reveal claims of withdrawal and self-isolation linked to a sense of failure and self-efficacy:

I wouldn’t be hearing things or it took a while to get. I’d be making mistakes a fair bit ... in the end I learnt to be shy or quiet about it and go into my shell (David).

I began to withdraw when I was in mainstream class because I just felt like a failure ... high school, I was just withdrawing more and more (Christine).

I remember once I got to high school I sat in the back of the classroom because I didn’t want anyone to know how dumb I was or didn’t want to
be embarrassed ... by being asked a question I couldn’t answer or spell or whatever (Kerrie).

Kerrie, Christine and Riley claimed they gave up learning during their primary years as their experiences consolidated their internalised beliefs that academically they weren’t achieving on the same level as their peers and, possibly, they never would. Christine said: “Year 6 – academically not good ... I gave up by then. I wasn’t trying by then, I just thought what’s the point. I just didn’t do my work by then”. Kerrie claimed “I already had the belief that I wasn’t good at school and education and stuff ... I just assumed I wasn’t clever, things I did just weren’t good enough. So that was that”.

Eight of the ten participants indicated that they disliked school and that their memories of any good times were overshadowed by the ‘bad times’ and their inability to succeed. However, five of the eight indicated that they ‘hated school’ and this contributed directly to their choice of self-withdrawal. Comments included:

I hated school ... from about year 4 (Joseph).
I hated school ... 90% of it (Sarah).
Can’t remember good times – I hated school (Riley).
I hated school, I hated my life (Sam).

It was not so much the words and pragmatics in the delivery of these comments, but also the recollections of the experiences of school that reinforced this ‘hate’.

Participants indicated a range of critical incidents linked to negative responses by teachers, peers and significant others; inappropriate teaching techniques including withdrawal and the sense of ‘us and them’ through segregation; and ongoing academic difficulties linked to dyslexic characteristics, alongside the non-recognition of difficulties, resulting in a lack of academic success that led to their dislike and perceived ‘hatred’ of school.
Four of the participants - Kerrie, Riley, Robert and Sam - chose to leave school as soon as they reached the compulsory leaving age as a reaction to the culmination of negative experiences throughout their schooling. None had a life plan in place, apart from Sam’s five goals previously indicated. Juanita and Kim’s choice to leave school was decided by family and/or institutional input. Juanita left before age 15 as a result of the school’s choice. This was linked to the school’s fear of failure in regard to academic testing results and their consequent impact on the continued operation of the school. Kim left as a result of her mother’s attitude to her learning difficulties.

**Compensatory responses**

Five participants chose to use a range of strategies to achieve or avoid work. This included rebelling, cheating, wagging, self-placement/isolation in class and lying and bluffing. These strategies were used as direct responses to immediate situations and, in the majority of cases, were unplanned and reactive.

As a result of her opposed indifference to academic achievement, Christine would respond by “doing things like sewing my board short legs together and things like that, I just didn’t care anymore, I really didn’t”. She also recalls her sister forging notes for her and wagging school. “I remember by the time I was in year 11 I was waving to the teachers wagging and they would wave back to me.” Robert also indicated that he spent considerable time during his high school years ‘wagging’. Robert and Riley indicated they used cheating to avoid appearing dumb and not being able to keep up. Riley stated:

> As a child you like to try and keep up with the other kids and I found that very difficult – school, learning, spelling ... I used to cheat a lot too – I was so frustrated. I was so upset all the time and the teachers couldn’t understand it. I was just a failure (Riley).

Kerrie and Joseph saw self-placement as a self-withdrawal strategy in the classroom.
I sat at the back of the classroom because I didn’t want anyone to know how dumb I was (Kerrie).

All the dumb shits sit at the back (Joseph).

Juanita chose to focus on her appearance as it took the focus away from her academic attempts. “I arrived at school looking like the absolute perfect model so I looked good ... if you looked good and you dressed well, you could bluff everybody”. She continues to live by this credo today. She claims the superficiality of people’s thinking, linked to the way in which the media portrays the importance of visual image, “influences how people respond to you in social and work situations”.

**Negative self-efficacy**

Eight participants indicated that by the end of primary school they chose to believe they were a failure and this continued with them throughout their secondary experiences. There were ongoing incidents linked to negative responses by teachers, peers and family members, including inaccurate or non-recognition of difficulties, as well as institutional responses to difficulties, including withdrawal, repeating, ineffective teaching strategies and unclear labelling based on diagnostic testing. All participants highlighted and recognised the impact their personal characteristics had on this choice and the personal confusion that they experienced. Christine, David, Riley and Kerrie indicated that the culmination of all these influences led to ongoing emotional instability, including diagnosed depression:

> I was just so confused, I’m still confused ... you’re not clever enough ... you’re not a bright spark person, you’re not a genius ... I’m a failure ... that’s how they [school and society] make us feel and I still feel like that (Riley).

> My self-esteem and depression that is really major as a consequence of not being picked up as having a difficulty” (Kerrie).
Out of individual participant’s control

Life choices made by significant others

Life choices made by significant others referred predominantly to movement of the family group and were completely out of the participants’ control. Joseph and Kerrie’s interstate moves were linked to family employment choices whilst Riley’s local move was linked to a desired lifestyle change by her parents.

Sarah’s family chose to move from the country to the city and from the public school system to the independent school system owing to her parent’s belief that her difficulties would be addressed in a private school and that greater resources would also be available. Although this choice was made by supportive others, it linked directly to her identified learning needs and the lack of resources where they lived. Christine moved from one local primary school at the recommendation of teaching staff who identified a support program they believed may suit her academic needs. During high school she attended a selective sports high school for a short period based on her identified sporting ability.

Life Choices - Post Secondary Education (before Dyslexia Course)

The following table (Table 6.4.) indicates the life choices revealed by participants that occurred during their post secondary education experiences, but prior to their participation in the dyslexia course.
Life choices, in this section, indicated a marked shift from predominantly reactive choices to including a range of proactive choices. The continued themes of withdrawal, compensatory responses and negative self-efficacy continued within this timeframe however two new themes* of advocacy and disclosure of literacy difficulties emerged as proactive choices. Although the negativity experienced in their pre-secondary schooling continued to influence their choices, the shift from childhood to adulthood and the responsibilities that accompanied this shift, enabled participants to more closely consider and analyse their decisions, linked to their personal needs, even though the majority were not fully aware of the influence of their dyslexic characteristics. This indicated a shift in their locus of control. Linked to the majority of these decisions were also the overriding societal expectations of employment and economic demands, which in turn were dependent on achieving adequate literacy skills ‘required’ to be an active and productive participant of society.
Proactive life choices

Personal motivation and perseverance

Sam, Joseph, Christine and Kerrie indicated that educational success was ‘a dream’ as a child. But as an adult, one’s receptiveness to learning changes and is greater due primarily to an enhanced sense of motivation. For participants who chose to return to study as adults, the motivation was linked directly to their career choice, including the prospect of job promotion. For Joseph, Juanita, and Robert, whose desire was to learn a trade, the requirement of their apprenticeships included non-negotiable blocks of study linked to their trade. For Christine and Sarah, full time study was required over a period of years and their choice of career was linked to their desire to work with others within a nurturing environment – Christine, initially as a psychologist and then moving into counselling and Sarah, initially as a nurse and then becoming an occupational therapy assistant. Both choices reflected their empathic nature, along with a desire to use their personal skills to support others in a positive environment.

In his desire and motivation to learn a trade, Joseph successfully doorknocked for an apprenticeship ... “cause I really wanted it”. He was aware of the requirements of blocked study periods at TAFE and although anxious and fearful about returning to a classroom, he found a positive shift in teacher attitude and teaching methods. Upon completion of his apprenticeship he then chose to set up his own business.

Advocacy

Along with a shift into adulthood, for Riley and Kerrie came parental responsibilities and choices. Wanting to ensure that the education system catered for their children’s learning needs, Riley and Kerrie became active advocates for their children in an educational context. Neither wanted their children to experience the difficulties they
had encountered. Riley indicated that she made sure eyes and ears were checked regularly and that she was in constant contact with the school as to their progress.

She said: “I made sure that they were ok so they didn’t have to suffer like I suffered.”

She said that her decision was influenced by her own mother’s lack of time for her: “she never had the time ... never found the time ... didn’t know I had a problem”.

Kerrie, on the other hand, realised that the difficulties her son was encountering at school were similar to those she had experienced. She maintained ongoing contact with the school and insisted on assessment and support through the public education system, which was not forthcoming. She then sought external assessment that identified both her and her son’s dyslexia. But this assessment did not guarantee individualised support for her son within the school system due to definitional debates within the macrosystem that were underpinning ‘labelling’ of students, including the non-recognition of dyslexia.

**Disclosure of literacy difficulties**

It was not until this point that four participants made active, albeit selective, choices in disclosing their literacy difficulties. In the context of her involvement in a number of adult work-based training courses and being well aware of her literacy difficulties, Sam would publicly announce that she could require literacy assistance. This was as a result of positive responses by trainers who indicated that qualities other than good literacy skills were more important in the context of the training. Christine, on the other hand, chose to disclose her dyslexia in a university context, as she had ‘diagnostic proof’, only to be humiliated by the educators’ responses. Her disclosure was linked to the assumption that scientific/medical evidence was sufficient for a greater understanding by lecturers of her needs, but in reality she experienced the wider societal perception and institutional perspective that inadequate literacy skills
are not tolerated. She stated “there’s an unspoken negative stereotype for people that have literacy problems”.

**Reactive choices**

**Withdrawal**

Juanita was headhunted over a period of 3-4 months for a job with a local newspaper as a social columnist. On each occasion she would refuse the offer and provide a bevy of reasons until the editor asked what the ‘real reason’ was to which she replied: “I’m dyslexic ... I can’t spell, I can’t write!” The editor responded with “Oh for God’s sake is that all? I’ll give you a journalist and you can tell them what to write.” The newspaper wanted her for her knowledge and social contacts that would provide them with in-depth copy for their social column, not her literacy skills. As a result of the editor’s response, she accepted the position.

Joseph encountered bankruptcy with his first business because he refused to fill in forms or adequately complete paperwork because of his dyslexic difficulties. He also chose not to seek out advice or assistance through fear of embarrassment and humiliation.

**Compensatory responses**

When Robert began his panel beating apprenticeship he found he couldn’t stay steady when detailing cars due to his visual motor integration difficulties and therefore he experienced ongoing panic attacks. In order to keep his job he would try and bluff his way through jobs by getting someone else to do the difficult bits in the context of ‘demonstrating the skill’ or ‘helping with a tricky bit’.
**Negative self-efficacy**

Riley, as a reaction to a period in her life when she was experiencing significant employment, family and relationship difficulties that she believes were compounded by her dyslexia and language processing difficulties, alongside emotional confusion as to her own self-worth and self-efficacy, provided herself with two life choices: “suicide or go and learn to ride a motor bike”. Unable to make the decision she ‘flipped a coin’.

**Out of individual participant’s control**

While Kim was working at the non-for profit workshop after leaving school on her mother’s insistence, the director of the workshop indicated that she felt that, based on Kim’s level of intelligence, it was an inappropriate workplace for her. In consultation with her father they found a salaried position at an aged care facility. This change was suggested to, but not negotiated with, Kim.

**Life Choices - Post-Secondary (after Dyslexia Course)**

After identifying and analysing the life choices from the data prior to the dyslexia course the thesis now considers whether life choices indicated by participants after the course were similar or different to those previously identified. The findings are contained in Table 6.5.on the following page:
After the dyslexia course all choices were distinctly proactive and appeared to be a direct response to the learning that occurred throughout the program. Participants clearly articulated the choices they made and why, basing them on a range of experiences linked to their understanding of their dyslexia. Although there is an increase in proactivity over reactivity from primary school through post secondary to after the dyslexia course, the lack of reactive and out of control responses is surprising. The results, as indicated in this table, indicate proactive choices only and reveal a new theme,* namely of a change in mindset and understanding by all participants. This appears as an overarching component that has directly influenced the three other choice types. From a research perspective, it also prompted a return to the literature. What had happened as a result of the course? In particular, what led to a change in how the participants perceived themselves? What psycho-social process had occurred within the context of the course? Research in the area of dyslexia did not reveal any associated dialogues. However, within the research on learning disabilities, one interpretation emerged: that these adults experienced a process called

Table 6.5. Life Choices - Post-secondary (after dyslexia course)

<table>
<thead>
<tr>
<th>LIFE CHOICES</th>
<th>Proactive</th>
<th>Reactive</th>
<th>Out of individual participant’s control</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Change in mindset and understanding</em> (10/10)</td>
<td>Nil</td>
<td>Nil</td>
<td></td>
</tr>
<tr>
<td>Personal motivation and perseverance (Employment linked (5/10)); Other (1/10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advocacy (8/10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disclosure of Dyslexia (10/10) (different types of disclosure identified)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
reframing. These findings are similar to those found by Gerber, Reiff and Ginsberg (1996, 1997) and Reiff (2004) in their studies of people with learning disabilities.

Where Raskind et al (1999, 2002) and Goldberg et al (2003) focus on the importance of specific success attributes and proactive and reactive choices as impacting on life choices, studies by Gerber, Reiff & Ginsberg (1996, 1997), and Reiff (2004) refer to successful adults with learning disabilities as having used a process of reframing to work toward life success. It allows a transitioning from focusing purely on their perceived inabilities “to an emphasis on their abilities to confront and overcome challenges imposed by their learning styles” (Reiff et al: 1993) and, in doing so, enabling them to adjust from a reactive to a proactive stance as to how they perceive themselves. Within this process the success attributes identified by Raskind et al (1999, 2002), can be located and clearly influence the various stages of the reframing process.

What does the Literature say about Reframing?

Reframing encompasses four stages that allow an individual to view themselves within an holistic perspective, not just from the single perspective in which they define themselves by their learning disability. It enables them to identify ways in which to create positive expectations of themselves and to modify their beliefs and behaviours accordingly. Gerber and colleagues (1996) define reframing as:

... a set of decisions relating to reinterpreting the learning disability experience in a more productive and positive manner (Gerber et al, 1992, p. 481). It clearly allows for one to identify strengths and parlay them into success experiences, while still being aware of weaknesses that have to be mitigated or bypassed ... reframing promotes life adjustment and success for adults with learning disabilities (p. 98).
Further, Gerber and colleagues (1996) claim that from a psychological perspective reframing is a ‘change in reality’ (p. 98), brought about by a reinterpretation and change in life’s meaning, which allows an individual to take positive control of their life.


<table>
<thead>
<tr>
<th>Recognition</th>
<th>Ability to recognise:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Disability;</td>
</tr>
<tr>
<td></td>
<td>• Individual characteristics;</td>
</tr>
<tr>
<td></td>
<td>• Individual learning style;</td>
</tr>
<tr>
<td></td>
<td>Resulting in reflection and evaluation of this recognition which “will later lead to greater understanding” (Reiff, 2004, p. 190).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Acceptance</th>
<th>Acceptance of:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Learning disability – negative and positive aspects;</td>
</tr>
<tr>
<td></td>
<td>• Need to make changes based on individual limitations;</td>
</tr>
<tr>
<td></td>
<td>• Accessing support or assistance – personal and pragmatic based support.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Understanding</th>
<th>Process of:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Analysis, synthesis and evaluation of information gained, from previous components;</td>
</tr>
<tr>
<td></td>
<td>• “heightened awareness”;</td>
</tr>
<tr>
<td></td>
<td>• “As persons with learning disabilities come to greater understanding of their learning style, they move from the general and theoretical to a much more personal level of self-actualisation. Knowing about one’s own strengths, weaknesses and needs, helps forge a greater sense of uniqueness.” (Reiff, 2004, p. 192)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Plan of Action</th>
<th>Involves:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Reconceptualisation of learning disability that results in conscious attainable goal setting;</td>
</tr>
<tr>
<td></td>
<td>• Reframing negative to positive in developing and carrying out a ‘plan of action’;</td>
</tr>
<tr>
<td></td>
<td>• “Recognition, acceptance and understanding without resulting action may have minimal effect on day-to-day activities. On the other hand, when recognition, acceptance and understanding undergird a plan for dealing with and coping with life’s vicissitudes, the individual is forging strategies based on a systematic analysis of available information” (Reiff, 2004, p. 193).</td>
</tr>
</tbody>
</table>
In the original study by Gerber and colleagues (1996), the stages are cited in the following order: recognition; understanding; acceptance; and action or setting a plan of action. The characteristics remain the same. Gerber and colleagues (1996, p 100) also identify examples of statements to clarify each stage. They are:

Table 6.6. Reframing Stages and Characteristic Examples

<table>
<thead>
<tr>
<th>Stage</th>
<th>Example Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Recognition</td>
<td>You can’t overcome it if you don’t recognize it.</td>
</tr>
<tr>
<td></td>
<td>I know that I am LD and that poses opportunities and challenges</td>
</tr>
<tr>
<td>2. Understanding</td>
<td>I realize when I’m good I’m great, and when I’m bad I’m terrible.</td>
</tr>
<tr>
<td></td>
<td>I now know what I can count on in myself and what not to depend on</td>
</tr>
<tr>
<td>3. Acceptance</td>
<td>You can’t have success until you deal with the trauma.</td>
</tr>
<tr>
<td></td>
<td>You’ll never walk in a normal world; you must understand and accept that.</td>
</tr>
<tr>
<td>4. Plan of Action</td>
<td>You have to decide what you want to do and go for it.</td>
</tr>
<tr>
<td></td>
<td>There was now something that drove me to do something with my life.</td>
</tr>
</tbody>
</table>

Within the literature, individuals who were identified as highly successful used reframing. Those who were moderately successful “did not progress through all 4 stages to the same extent as the highly successful, and the marginally adjusted group did it unsuccessfully or not at all” (Gerber et al. 1996, cited in Kerka, 1998, pp. 2-3).

One of the keys to an effective reframing was the individual’s identification and evaluation of ‘critical incidents’ (Gerber et al., 1994) throughout their life that helped them re-evaluate and change their perception. These critical incidents, whether negative or positive, “provided the catalyst for positively reframing learning disabilities” (Gerber et al., 1996, p. 187). Recalling and retelling personal events or experiences, particularly negative experiences, during the reframing process provides
“the likelihood of reconstructing a negative event into a positive attribution ... if the individual currently has a set of positive experiences that cast the event in a new light” (Reiff, 2004, p. 195).

In literature linked to dyslexia, “Life Stages” (Scott, 2003) and “Transition Stress Points for adults” (McLoughlin, 2001) that included education, employment and personal choices, were identified as constituting major critical incidents in an individual’s life. Scott (2003) and McLoughlin (2001) also included when and how dyslexia is identified and the resulting impact of individual/institutional responses throughout different stages as critical.

The notion of reframing is used in the next chapter as a tool of analysis to create a new conceptualisation of dyslexia informed by the insights gained from the adults in this study.

**Summary of Chapter**

This chapter has identified the range of life choices made by participants in this study linked to their dyslexia and society’s responses to it. This has influenced both their educational and post-educational experiences. Both proactive and reactive choices emerged throughout their schooling, however it was evident that reactive choices were found to exist only before their involvement in the dyslexia course. After the course, proactive choices only were identified.

This quandary led to a revisiting of the literature on learning disabilities. The literature revealed the existence of a process called reframing. Interviews with participants showed that each of them appeared to revise their views of themselves, their dyslexia and society’s perceptions of people with dyslexia as a result of the
course. This revision appeared to involve characteristics of the reframing process. This process will be used in the following chapter as a framework to consider the proactive change in perceptions of participants.
Chapter 7

REFRAMING DYSLEXIA

This chapter employs the notion of reframing to create a new conceptualisation of the experience of dyslexia. Previous chapters, focusing on participants’ perceptions of their educational experiences, have revealed individual responses to societal, institutional, individual and personal influences on their life choices. These appear to have stemmed from the narrow normative academic perspective of literacy perpetuated within society. Discussion of participants’ responses after the dyslexia course are discussed in this chapter to help understand the influence the program may have had in changing individual perceptions and self-awareness. In addition, there is a particular focus on the increased proactivity in their identified life choices.

The previous chapter posed a number of questions: (1). What occurred to increase the proactive life choices after the dyslexia course? (2). What led to a change in how participants perceived themselves? Further reading of the literature revealed another important question, namely, (3). What was the relationship of the dyslexia course to the reframing all individuals appeared to experience? These questions will be addressed within this concept of reframing.

The dyslexia course, particularly the module Understanding and Managing Dyslexia, appeared to act as a catalyst for participants to use a reframing process in increasing their knowledge and understanding of their own dyslexia and changing their perception of their self-awareness and how this links with society’s awareness and understanding of dyslexia. The specific content and delivery of the course, alongside
the social connections and supportive environment that emerged, provided key or critical contexts through a variety of opportunities for each participant to consider how they perceived their uniqueness. These contexts or ‘critical incidents’ (Gerber et al, 1996) provided triggers for participants to begin to reframe their understanding of their dyslexia and in doing so they experienced a range of ecological transitions (Bronfenbrenner, 1992), which refer to “shifts in role or context throughout an individual’s lifespan (p. 6)”. In addition to each participant’s culmination of life experiences, the course appeared to represent a transition point in their self-awareness. It provided a range of ‘critical incidents’, in the form of content and scaffolding of knowledge, for all the participants and their way of thinking about themselves, their interactions, and their dyslexia.

Life adjustment occurred for the participants, in the form of a ‘cognitive shift’ in thinking, and led to goal-specific action with all participants reframing their perceptions of their dyslexia from negative to positive, resulting in more proactive choices and ways of thinking.

The order of stages in the reframing process, as used in the analysis of this section, best reflects those indicated by Reiff (2004): recognition, awareness, understanding and plan of action. This differs from that proposed by Gerber et al (1996): recognition, understanding, awareness and plan of action. The analysis best fits Reiff’s ordering because, based on participant responses, one does not need to fully understand the complexities and nature of dyslexia before accepting it. It is possible to recognise and become aware of one’s own difficulties without a clear understanding. This is reflected in the compensatory strategies used by participants well before they gained a clear understanding of their dyslexia. In presenting this
order it is also evident within the analysis that the stages are not static and separate but blend together as well as are revisited throughout.

The first stage – that of recognition - in this study revealed a number of internal stages. Initial recognition of their difficulties by either themselves or others, accompanied by an assessment, enabled the participants to enrol in the dyslexia course. However, recognition of dyslexia as a specific entity with identifiable characteristics, did not occur until the participants had been immersed in the course. In their individual stories, all participants reflected on how they recognised their learning difficulties throughout their early years. Therefore, within the context of this study, three stages of recognition are suggested, with the third stage being the catalyst that operates between acceptance and understanding.

In this study, the second stage - acceptance - reveals the development of greater self-awareness and a re-perception of one’s dyslexia as opposed to a complete acceptance. Although participants’ comments indicated a degree of acceptance linked to the key components of Reiff’s (2004) characteristics, the point remains – do people ever completely ‘accept’ their dyslexia (particularly within a societal context) or do they re-perceive it? This section does not operate in isolation and crosses all stages. Therefore acceptance, for the purpose of this analysis, is presented as ‘degrees of acceptance’ that can be encompassed within the larger component of re-perception.

There appear blurred boundaries between each of the stages as indicated by participants’ comments. The following conceptual design indicates this by overlapping circles. The concept of re-perception, as a change in perception of self, encompasses all stages and is continually evolving, readjusting and with the
individual revisiting stages to clarify or adjust plans of action. This changing perception of self is indicated in the following diagram by brackets.

**Figure 7.1. The Stages of Reframing**

This chapter is presented in four sections. Section one will present individual recollections linked to the reframing process. It will be presented within the context of the four stages of recognition, degrees of acceptance, understanding and plan of action. Within these stages the evolving process of re-perception will be presented. Identified themes will be presented within each stage. The final stage, which involves the development of a ‘plan of action’, will discuss the proactive life choices that emerged in the previous chapter. The second section will consider the relationship
between the dyslexia course and the reframing process. This discussion will be presented within an ecological framework linked to the participants’ perceived experiences. A single case study – one that looks at the experience of participant David - will be presented in section three. The final section reveals a repositioning of the ecological framework in the context of the experience of dyslexia within a literacy-based society.

The Reframing Process

Recognition

Recognition is the first component of the process of reframing in which individuals are able to accurately recognise the unique characteristics linked to their dyslexia. It involves the recognition of the components that make up their dyslexia and the capacity to identify the characteristics unique to each individual. It also requires the recognition of one’s individual learning style based on these characteristics. This, according to Reiff (2004), will result in reflection and evaluation that “will later lead to greater understanding” (190). The individual narratives of all participants show that this recognition occurred at different stages of their life, alongside their lack of knowledge and understanding about their learning experiences. A series of three evolving stages of recognition became evident. Throughout the interviews a process of review, reflection and evaluation of their experiences, in the light of their new knowledge and reframing over time, began to surface.

First stage of recognition

The first stage - recognition - appeared early on in their schooling when they were aware of learning differences between themselves and their classmates. They acknowledged that this impacted on their schooling but felt disempowered through a
lack of self-awareness of themself (both as an individual and a student), and a lack of understanding and recognition by teachers. This recognition reflected comments linked to negative self-efficacy and self-attribution. Hellendoorn & Ruijssenaars (2000) in their study of adults with dyslexia claimed that “almost all participants ... knew that something was the matter with them long before they were diagnosed” (68) and Higgins et al (2002) confirmed this point in their study of adults with learning disabilities.

Reflecting on the recognition stage, particularly from a teaching perspective, Sam, Joseph and Christine indicated a no-blame attitude and recognised the possible limitations, based on a lack of knowledge by educators.

... cause they didn’t have dyslexia in those days, it was just that you were a dunce or didn’t try hard enough (Sam).
I guess when I was going through a lot of them didn’t know what this was (Joseph).
Some probably had more skills than they realised, but didn’t understand how to use them. They didn’t have the training, therefore they didn’t have the knowledge, but maybe had the skills if they knew how to use them (Christine).

Second stage of recognition

Stage two occurred prior to the course and involved the recognition that their difficulties had a ‘name’. This became evident as a result of formalised assessment and the subsequent identification or ‘labelling’ of dyslexia. For eight of the participants this occurred close to, or immediately prior to, the commencement of the course. For the remaining two this had occurred during high school (Sarah) and in adulthood (Robert). Christine indicated that, although formal identification of dyslexia was a turning point in her life, she still experienced a “lot of cognitive dissonance”. She found herself: “... going from retarded, dumb, stupid to intelligent, smart, bright” and it was not until the course that she was able to recognise her
dyslexic characteristics. It is armed with this name for their difficulties and very little knowledge about its constitution, that they began the course. Scott (2003) alludes to the fact that specific diagnosis of dyslexia is of utmost importance as “their problem is out in the open. Their perceptions and feelings are finally proven right ... the eventual diagnosis ... can do much to shift a lifetime – literally – of anguish” (90).

**Third stage of recognition**

Stage three, which has been ongoing since completion of the dyslexia course, involved the ability to recognise and articulate individual characteristics and learning styles, which were specific to each participant. Seven of the participants, when discussing their dyslexic characteristics, used diagnostic terms such as “disorientation” (David), “neurotransmitters” (Sam), “visual and auditory dyslexia” (Christine). The others were more general in their descriptions and recognition of the difficulties they faced, however they nonetheless indicated a sense of ownership by using the term ‘my’:

My dyslexia is mainly spelling ... read most things then I have days when it is just blank ... it just switches on and off (Kim).

My dyslexia well ... I can’t do it one way – it needs to come round this way ... so it hits me (Riley).

Can’t read, can’t write – oh I can, can write a little bit but not much – reading I read a little bit- spelling, no. That’s my dyslexia (Robert).

An important element of this process involved the recognition that their difficulties were not as a result of an intellectual disability or mental illness as they had previously believed. Furthermore, their language use indicated that they did not define themselves by their dyslexia but rather their dyslexia was part of their unique make-up. This process goes beyond labelling because it involves each individual having to:

- process precise information about what dyslexia is;
- reflect and analyse which characteristics are unique to themselves;
• identify characteristics within, and in isolation to their life’s contexts; and

• reconsider their self-belief and perception of themselves and the life experiences that had informed these. In this context they didn’t define themselves by their dyslexia but were aware of their characteristics associated with the concept of dyslexia.

These are reflected in the following comments.

There’s the proof there that I wasn’t dumb. I had dyslexia and I’m quite intelligent (Kerrie).

I thought I was a slow learner ... a dumb person ... it [course] opened a lot of understanding – why I couldn’t write letters, why I could not read to understand – why I was like I am (Riley).

I was always threatened with mental illness ... I was believing I was until that dyslexic course at TAFE (David).

If you’re a slow learner you do have got a problem but you’re not a slow learner ... I know what I’ve got and what I can do now (Robert).

In the context of the course, a number of participants spoke of how they had recognised the differences in the degree or severity of their dyslexia in comparison with others. Individuals not only recognised their own characteristics and learning styles, but found themselves making comparisons with other students in their group. Those who made these comparisons qualified them with a recognition of their prior experiences and support networks, which led to a development of further understanding and evaluation of their life:

I realised mine wasn’t as bad as most of them and I thought ‘hang on, my education was hard but it gave me a good grounding for what I needed to know (Joseph).

I’m classified as severe ... Mum and dad have fought tooth and nail for me where a lot of people there at the course hadn’t had that (Sarah).

It is within this third stage that the boundaries between recognition and acceptance become blurred as participants begin to see the link between the content of the course and how it related to them as individuals as well as the beginnings of the reflection process regarding their current self-perception.
Acceptance is the second stage of reframing (Reiff, 2004). Within this stage, it is proposed individuals develop an acceptance of the negative and positive aspects of their dyslexia and are able to make changes based on their individual limitations. In doing so, they willingly access support or assistance where necessary. This support may be personal or pragmatic-based support.

“As Adelman and Vogel (1990) and Speckman et al (1993) have argued, acceptance and self-awareness can help a person with a learning disability recognize strengths, accurately assess limitation and make appropriate accommodations to achieve personal goals” (Greenbaum, Graham & Scales, 1996, p. 171). It does not, however, guarantee that an individual will continue through the stages of reframing to achieve a positive or successful outcome. It represents a level of comfort as to the individual’s perception of themselves and their dyslexia. It does not necessarily create an absolute acceptance.

Participants in this study indicated the following changes in their comfort level about their dyslexia during this stage of acceptance:

- Changing one’s perspective of dyslexia from negative to positive;
- Acceptance of the need to use compensatory strategies;
- Acceptance of the need to access external support for pragmatic purposes; and
- The importance of the awareness of positive and successful well-known role models who have dyslexia.

Within these changes, aspects of acceptance were indicated but moreso a change in their self-esteem and self-worth became evident.
Changing one’s perspective of dyslexia from negative to positive

David’s acceptance of his dyslexia was linked to a reinterpretation of his dyslexic characteristics of which he was aware, but originally considered components of a mental illness. This belief had been perpetuated during his life by his father who:

Even as recent as 5 years ago the old man got me off the farm by thinking I had bi-polar and I couldn’t defend myself by writing and that he even got a shrink from mental health to go out to the farm ... and in the end he got a lovely lass out from mental health and so he could get me off the farm and she came out and she said “all he needs is love” (David).

The formal identification of his dyslexia and the information gained from the course, which enabled him to recognise his dyslexia, allowed a shift from a negative to positive acceptance of his characteristics.

I’m now really pleased I’ve got dyslexia ... I’m seeing it as a gift (David).

Accompanying this belief is his added challenge to ‘understand myself’. His acceptance of his dyslexia as a ‘gift’ suggests a ‘stigma shift’, although his overall willingness to disclose his dyslexia continues to be determined by audience and context. (This will be discussed further in this chapter). It also may be as a direct result of his interest in the book *The Gift of Dyslexia* by Ronald Davis (1997) that provided him with a tangible description of ‘disorientation’. David claims this to be one of his key dyslexic characteristics. He became aware of this book through the course.

Sam indicated a shift in her acceptance of her dyslexic characteristics in the following comment. Like David, it also reflected the influence of attitudes from significant others during her life that had led to a belief of personal failure. However, she indicates the influence of the course in changing this perspective and instilling in her a sense of self-belief:
I’m more comfortable with my dyslexia than at any other time of my life ... I always used it as an excuse not to achieve. I used it as a crutch because I was drilled into and drummed into from a young child you can’t do things. I can’t learn because I’m dyslexic and I used that excuse not to try and push myself so I couldn’t fail and make myself like a complete idiot ... [the course] made me realise that you can achieve (Sam).

**Acceptance of the need to use compensatory strategies**

Comments about individual acceptance included an increased sense of ownership of their dyslexia and, with it, an awareness of its limitations. This awareness revealed a realisation that practical and pragmatic strategies can be used to support the individual in dealing with their limitations. Many told how they had developed and employed ‘passing’ strategies (Goffman, 1963) to hide their dyslexia. However, they also conceded how, as a result of the course, they became more willing to openly use, and even identify to others, the purpose and reason for their adjustment. This indicated a personal shift in their “sense of shame” (David), “sense of failure” (Christine), and perception of ‘normalcy’, as well as their understanding of their personal and practical needs, thereby reflecting a re-perception of particular aspects of self. It continues to indicate their belief that their dyslexia does not define who they are, but is part of their overall make-up. This does not indicate clearly that they have fully embraced their dyslexia but that they are ‘OK’ with their dyslexia. Christine and Sarah made the following comments:

I realised myself there isn’t a cure for this so make it work for you and it doesn’t have to be a bad thing. Take it as it comes. Just be who you are with it ... I think I’ve learnt to compensate for things and I think that’s kind of a blessing or a gift (Christine).

It made me actually own up to owning, to having dyslexia ... Yep. I have dyslexia. It’s an issue but this is what I do (Sarah).

Juanita and Sam spoke of more pragmatic compensatory strategies that they use on a daily basis.
I’ll call someone darling or sweetheart cause I simply can’t remember their name (Juanita).

When I go into the bank I just pull out my card we made in the course with the numbers and things on it to help me – I can’t do it without it. In fact someone asked me about it one day and I told him and he said that it was a great idea and I ended up telling him about the course and how I’d learnt lots of new ways to do things (Sam).

However, dependent upon the situation or context, in particular those linked to social occasions where the expectation was that they were able to read, all conceded that they used ‘passing’ techniques to disguise abilities for which they believed they might be stigmatised. Responses to social situations reflected creative ways by which they could manoeuvre within and around exclusionary barriers. For example, when eating at a restaurant with a group of friends, Sam would request they eat at the same restaurant each time because they “catered for my food allergies” (socially acceptable response), however, she knew where to locate and read three meals on the menu. This pointed to a power shift, not only in their ability to find ways to participate in a ‘culturally acceptable manner’, but provided a shift in their ability to address the psychological and emotional barriers they had internalised throughout their life.

**Acceptance of the pragmatic need to access external support**

Where individuals realised that their limitations required more than a compensatory strategy, they were willing to access other support systems. For the majority of his life Robert had realised the limitations of his literacy difficulties and sought assistance from his siblings and other family members to read important correspondence and even to respond in writing, albeit in consultation with him. He claims: “No I don’t write. I get someone else to do it” (Robert).

Joseph recognised his limitations early in his working life, but was not willing to ask for help out of shame and fear of the stigma attached to disclosure, linked to his
acceptance of his difficulties. However, his acceptance changed through his understanding of his dyslexic characteristics that he developed while participating in the course. This enabled him to identify his strengths and understand that support systems and people exist, particularly to help small business operators. Components of the course focused on identifying specialist support and networks that have emerged to cater for the demands on small business, particularly from an administrative and legal perspective. It allowed him to recognise and understand that his strengths lie in his practical skills and that it is part of business ethic and practice to seek out and employ expertise to deal with legal and financial issues:

The way I now look at it ... these are the tools I’ve got. I’ve got to make the tools work so I put it into ‘OK I’ll do as much as I can and then I’ll seek help’ whereas for years I’d go ‘No bugger this’ . . . I’m good at what I do but not good at the paperwork – other people get experts to do that for them – so I now get people to do that (Joseph).

Awareness of well-known and successful people with dyslexia

Part of the course content focused on well-known and successful people with dyslexia in the real-world. This realisation was a ‘critical incident’ in the gaining of knowledge required to help each individual reframe. Although it was a very small component of the module, it proved to have a significant impact on all participants’ attitudes about themselves and, in some instances, provided a prop for disclosure or explanation of what dyslexia is.

Joseph and David stressed the importance of knowing that there were high achievers who also had dyslexia. Their following comments reflect a cognitive shift in their thinking and awareness of dyslexia, in particular the understanding that good literacy skills are not a precursor or pre-requisite to high intelligence.

Smart people ...The most powerful and successful people in the world ... could not write to save themselves (Joseph).
Learning that Einstein couldn’t read ... that was a big relief (David).

For Sam, the insight was particularly positive, highlighting not only how it was possible to achieve despite the odds, but importantly the realisation that no matter how negative one’s life has been, it can change. She says: “… Billy Connolly – he’s dyslexic. He had a terrible upbringing, very rough, very violent up bringing so that’s how he became a comedian because that was his way of dealing with it and things are a changing”. She also speaks of her admiration for Richard Branson: “He is the only person I actually look up and a[d]mire because he’s dyslexic and look at what he’s achieved and how he’s struggled.”

Juanita spoke of two Australian public figures with dyslexia – one a hairdressing entrepreneur, the other a media mogul for whom she had worked. Both had achieved international recognition and financial success. She claims they used their ‘dyslexic strengths’ to achieve their respective successes. Their success had not only inspired her professionally, but also the motivation to take on new challenges.

Kim, when selectively explaining to people about dyslexia, but not disclosing her own dyslexia, particularly if she senses a patronising demeanour, will use famous people to highlight that dyslexia does not mean a lack of intelligence. She uses examples such as Jamie Oliver and Richard Branson because they are frequently in the public eye and are presented in a “capable and successful light and no-one expects them to be” (Kim).

Gerber and colleagues (2003) believe:

[highly successful adults with learning disabilities have had and are having powerful effects on motivating other individuals with learning disabilities. In some cases, these successful adults with learning disabilities are creating opportunities for others that, in earlier times, would not have existed (p. 327).]
They are also providing a sense of hope for people with dyslexia that they too can succeed. These success stories also support the thesis that the mixed messages linked to intelligence and dyslexia are a product of underlying societal perceptions and misunderstandings, particularly when successful figures have succeeded in so-called ‘highly intelligent fields’ and impacted within a global context.

Understanding

Understanding is the third stage of reframing (Reiff, 2004). It is the process of analysis, synthesis and evaluation of information gained from previous components. From this understanding comes a “heightened awareness” (Reiff, 2004) of one’s learning disability:

As persons with learning disabilities come to greater understanding of their learning style, they move from the general and theoretical to a much more person level of self-actualisation. Knowing about one’s own strengths, weaknesses and needs, helps forge a greater sense of uniqueness (Reiff, 2004, p. 192).

Understanding constitutes a form of ‘sense making’ and a way of knowing about oneself. It is within this stage that evidence of a further change in the participants’ perceptions, about themselves and their life, occurred.

However, it is unclear whether this stage can be viewed as a separate entity that naturally develops from the previous stages. Within the stages involving acceptance and understanding there appears a continual process of ‘knowledge gain’ that influences the evolving perceptions of each individual. This ongoing acquisition of knowledge allows the participants to refocus on their strengths and limitations. As more knowledge is gained, a reassessment of acceptance and understanding occurs and can result in re-adjustments. According to Gerber and colleagues (1996), the stages of reframing: “were mostly discreet but still interacted with each other” (p.
100). However, on what level and to what degree was not made clear. A range of environmental and personal life experiences of participants need to be considered in the context and level of understanding that occurs in this stage.

The data reveals a range of themes within this stage that further highlights the ongoing development of re-perception as individuals develop a heightened awareness of their dyslexia through their analysis and evaluation of the knowledge gained through the course in conjunction with their life experiences.

**Membership of a unique group**

A shift from an egocentric and exclusionary perspective to a sense of belonging, both on an individual and group basis, was evident in the following comments by Juanita:

> I realised I’m sort of one of a group – I never thought anyone was like me so I was isolated. I’d heard there were dyslexic people. I’d never met them. They could’ve had two heads for all I knew (Juanita).

This sense of ‘differentness’ (Higgins et al., 2002) as a cohort, unlike in the study by Higgins and colleagues (2002), created a sense of belonging to a unique group for the participants in this study. David spoke of support groups within society that exist for people with evident disabilities. He claimed “other people have groups you can go to for help, like people in wheelchairs – but there’s nothing for us except this course and now we’ve got each other.” David, Juanita and Sam, along with some others from the course, formed a group outside of the course and searched for interest/research groups and methods to help them improve their learning, life style and personal well-being. This demonstrates their evolving understanding as to their ‘differentness’, as well as a resistance to the way in which they are perceived and how services within the exo and microsystems, perceive them. They created their own support group. “Unlike evident
disabilities, where there exists a culture of ‘support groups’ that represent political needs, as well as responding to personal needs, ‘support groups’ for non-evident disabilities such as dyslexia are not as prevalent or evident” (Tanner, 2009b, p. 795).

Dale and Taylor (2001) stressed the importance of the “significance of bringing people together in a group where they implicitly learn that they are not alone and can find solidarity with each other” (p. 1001). Whilst Choenarom, Williams and Hagerty (2005) cited an earlier study by Hagerty and colleagues (1996) that “showed that sense of belonging was related to both psychological and social functioning, with a higher sense of belonging promoting better functioning” (20).

**Self-understanding linked to understanding and confusion of mixed messages**

Mixed messages provided confusion throughout each participant’s lifespan. These mixed messages, as a result of the interplay within a range of contexts, were linked to intelligence and performance and did not become clarified or obvious until adulthood and an understanding of the uniqueness of each participant’s characteristics. At the root of these mixed messages was the overarching societal theme that *one’s degree of literacy skills equated to one’s degree of intelligence* [author’s emphasis]. Therefore, if you had inadequate literacy skills you must be ‘dumb’ or ‘stupid’. This was exacerbated by family, social, educational and personal verbal and non-verbal messages and expectations, but especially by school and family experiences.

David had grown up believing he had a mental illness, based on his father’s messages, and prior to the course couldn’t understand why his publicly acknowledged intelligence in one field was not reflected in other areas:
I guess I was pretty desperate to understand why on one hand I was pretty useless at certain things and the other hand I was equal to anyone in Australia ... now I know and understand (David).

Through her understanding of her dyslexia and analysis and evaluation of her previous educational experiences, Christine believes she has developed: “very good determination. Very good persistence. I’ve learnt how to have a fabulous resilience to things”. In so doing, she has become aware of, and learnt to deal with the mixed messages that have existed throughout her life. However, no amount of understanding and awareness can prepare her for incidents that occur while studying that remind her of earlier negative experiences:

The difficulties that you’re faced with when you’re studying as an adult now is ... when I have those troubles with assignments ... it throws you back into the past into where the difficulties of the past act as a trigger (Christine).

Although demonstrating such attributes of success as resilience and flexibility, perseverance and a high level of motivation (Gorman, 2003; Hellendoorn et al, 2000; Raskind et al, 2002) her degree of emotional stability continued to depend upon the resurrection of past negative experiences linked to educational experiences.

With both Kim and Riley it was not entirely evident that they had developed a clear understanding of their uniqueness and appeared unsure of the mixed messages they were receiving. Both indicated a sense of confusion. This is particularly evident with Riley who exhibits a co-morbidity of difficulties that are linked not only to dyslexia, but also expressive and receptive language processing difficulties and a mild hearing impairment. Her transition from recognition to understanding was in limbo as it appeared that the course provided her with insufficient content that linked directly to her individual needs. However, she said it provided her with emotional coping skills: “I want to do something and I turn around and go ‘oh can I cope doing this? I can
cope’”. Her coping strategy was linked to continual repetitive positive questioning and response self-talk.

Kim had the overriding impact of past and present family attitudes in which she was openly told or referred to as ‘stupid’. Although she acknowledges that as a result of the course she: “understood it [dyslexia] a bit more; before that, [I] didn’t know what it was”. Her ongoing confusion is reflected in the following comment:

I thought to myself I’m dyslexic, is that the same as being slow or is that better? I think it might be better ... knowing you’re a slow learner and then knowing you’re dyslexic – I think they’re two different things (Kim).

Kim’s response suggests a general level of understanding that dyslexia is not linked to intelligence levels, but a lack of knowledge about dyslexia, including complete recognition and understanding of the characteristics of dyslexia. To what extent this is influenced by her life-long perception of herself as determined by her early life is unclear, however she indicated that during her recent course at TAFE it was recommended that she talk to a therapist because of her negative self-talk and continual recollections of her mother telling her she was ‘stupid’:

From now on I hear that, I hear her saying it and then I like he said the chap said at TAFE said just tell yourself ‘no, go away you’re not stupid you’re smart, you’re healthy and you can do anything, you’re smart, you’re healthy and you can do anything and just repeat that of a day time and a list of things and tell yourself your smart, you can do anything … (Kim).

Even though she had gained knowledge about herself and her dyslexia, this appeared to be overridden by all encompassing emotional constraints and life-long mixed messages. Both Riley and Kim reflect McNulty’s (2003) term *LD trauma for persons with dyslexia* that:
... appears to involve gross misunderstandings of unexplained struggles with adversities related to hidden learning disabilities. Such misunderstandings publicly call into question fundamental qualities of the self, such as work ethic, emotional state, or intelligence, and lead to intense feelings of shame and humiliation on the part of the individual in question. Repeated episodes along these lines appear to result in heightened emotional insecurity and self-doubt (20).

**Engaging in a dialogue about dyslexia**

I can have conversations with people about what is dyslexia ... my dyslexia – if it wasn’t for the course I wouldn’t have become more open to let people know (Kerrie).

A critical (in a positive sense) incident that occurred during the course was the opportunity for Kerrie to talk on a local radio about dyslexia and its impact on her life. It also allowed her to analyse, synthesise and evaluate the knowledge she had gained from the course and contextualise it within her own life. She stated:

> Going on the radio and talking about my dyslexia was good for me – to hear what I said about my dyslexia and how it affects me and what I do – hearing my words and my understanding of myself made things even more clearer (Kerrie).

Sam developed the following literal explanation to describe her understanding of dyslexia to other people, particularly her work colleagues, who indicated “a lack of awareness and ignorance”:

> ... it’s when the neurotransmitters in your brain – you know the wiring system – do not work very well. It’s like a cord going into a light ... there’s a short circuit, there’s a nick in the wire so it’s short circuiting, it’s jumping across the nick so the light is flicking on and off ... that’s what [dyslexia’s] like (Sam).

Without the knowledge gained from the course she claims she “would not have this understanding to be able to describe it to others in a way they can understand” (Sam).
Plan of Action

Plan of action is the fourth stage of reframing and, based on the degree of recognition, acceptance and understanding, culminates in positive adjustments to life. It appears directly influenced by individual’s re-perception of the dyslexia. It is a result of reconceptualising one’s learning characteristics by identifying positive and negative aspects, and developing and carrying out a goal or plan of action, which has a positive impact on one’s life. This plan of action is realistic and achievable based on an individual’s understanding of their strengths and limitations. As Reiff argues:

Recognition, acceptance and understanding without resulting action may have minimal effect on day-to-day activities. On the other hand, when recognition, acceptance and understanding undergird a plan for dealing with and coping with life’s vicissitudes, the individual is forging strategies based on a systematic analysis of available information (2004, p. 193).

This section discusses the four life choices that were presented previously as occurring after the dyslexia course. They reflect a sense of goal-orientation that, within the reframing context, can be perceived as plans of action. These included:

- Change in mindset and understanding;
- Personal motivation and perseverance;
- Advocacy; and
- Disclosure of dyslexia.

All participants openly indicated that they had made conscious life choices and decisions based on their participation in the dyslexia course and, in particular, the Understanding and Managing module. The majority have made proactive and successful choices and their actions reflect the adoption of successful reframing strategies. Kim and Riley, although making proactive and clearly considered choices, appear to be in a state of flux that could be seen to be influenced by a range of
external and internal factors such as family support, employment/unemployment concerns, and emotional and personal difficulties.

Considering that initial interviews for this study took place up to two years after completion of the *Understanding and Managing Dyslexia* module, it is interesting to note that results indicate adjustments by participants initially commenced during the course, but appeared to have been on-going well after its completion. This two year time factor provided a period of reflection for participants regarding the extent to which the knowledge and understanding they obtained from the course has influenced their life decisions. The importance of this factor, that enduring change has occurred based on the time frame, and that individuals have responded to, and used this change across different and selective settings, reflects their role and self-perception of being ‘agents of change’. Significantly, Bronfenbrenner (1979), in his original presentation of his theory, was unable to find studies that reflected these enduring changes (p. 14). The implications of this outcome and how it applies to Bronfenbrenner’s research are discussed later in the chapter.

**Change in mindset and understanding**

A change in mindset (that is how individuals perceived themselves and their dyslexia) is the overarching umbrella that encompasses all participants’ life choices. This change of mindset particularly reflects the changing perception of self in society that individuals were experiencing. Of particular significance is the section on disclosure as it reveals three types of disclosure that participants actively chose to use, dependent upon the context within, and people with whom they were interacting at the time. Disclosure, although identified as a proactive life choice, is dependent upon individual responses to societal perceptions. The following discussion reveals the
degree of change and understanding of each individual and the context and interplay which has influenced their choices.

**Personal motivation and perseverance**

Similar to proactive choices made throughout the primary, secondary and post secondary (prior to course) timeframes, proactive choices were driven by personal motivation and determination to succeed. However, in these instances their choices were based on informed decisions that were linked to their increased self-awareness of their dyslexia. Choices or plans of action were identified as pragmatic and linked to employment and study or personal outcomes and linked to a sense of passion.

**Pragmatic plans of action linked to employment and study**

Five participants spoke of employment and study plans that had changed since their involvement in the dyslexia course. Within these plans it is evident that those with a well-developed awareness and understanding of their characteristics made choices that suited their strengths and limitations. Linked to this was their sense of emotional stability and flexibility that allowed them to cope with stress and frustration as well as their personal motivation and desire to be valued as economically productive individuals.

Niche and non-niche picking of employment that was “compatible and appropriate” (Goldberg et al., 2003, p. 226), to one’s identified strengths and limitations, was a variable that reflected a degree of reframing. Participants who did not demonstrate this self-awareness found it difficult to “find a niche due to the global nature of their disabilities which influenced their success across multiple contexts” (Goldberg et al., 2003, p. 226).
Riley, for example, expressed an on-going life dream to “get a career” because she is
“just simply determined to get one now”. Although she was, at the time of the course
and remains currently, being assisted by the Commonwealth Rehabilitation Service
(CRS) in advising and supporting her in finding a compatible job, no plan of action is
evident. She continues to have no idea as to what she could do, but indicated that she
is considering enrolling at TAFE to do a MYOB course. Choice of course indicates
‘non-niche picking’ in that she has not considered her strengths and limitations and
the global nature of her difficulties, but rather she is doing it out of an emotional
context and sense of being needed. She stated: “My partner’s got a business ‘cause he
drives his own trucks. He’s got his own trucking business and he needs somebody to
do bookwork now I’m thinking this MOYB[sic] – whether you think I can handle it?”
This emotional construct is evident throughout her life story and ripples through her
early family life, marriage and children and the desire to have a meaningful personal
relationship. This reflects research that indicates temperament, personal
characteristics and experiences in a range of contexts can impact on an individual
making realistic vocational plans (Gerber and Reiff, 1991; Hellendoorn and
Ruijssenaars, 2000; Morrison and Cosden, 1997).

Kim has an ongoing plan of action to improve her literacy skills and continue
attending general education classes at TAFE. She now believes she can learn if
educational provision reflects her needs. This plan reflects an active choice or
adjustment based on new knowledge about her learning style. However it may also
indicate a decision to stay within one’s comfort zone, particularly given her ongoing
confusion about dyslexia and ‘slow learners’. From a more holistic and societal
perspective, Kim’s decision-making may be linked to a range of other factors.
including age, lack of employment prospects due to injury, and receipt of a disability pension, which represents ongoing financial, health and transport support.

Joseph claimed that as a result of the dyslexia course he has: “changed [his] mindset to it [dyslexia].” He will now actively access both professional and personal support to assist with the running of his business. Prior to the course he would try to do everything regarding his business pursuits, even though he knew he had positive family support. He now employs a lawyer (for deciphering paperwork) and an accountant (for business bookwork) and acknowledges his family support, particularly his mother. “So how I now look at it now is – I can’t do this. I can do this to a point, now I’ll get someone else to do it.” He originally saw asking for help as an admission of failure based on his difficulties. His reframing has enabled him to compartmentalise his dyslexia through an awareness and knowledge of how his characteristics affect his functioning within the workplace, alongside his other strengths, which enhance his business skills and the productivity of his business.

After her official diagnosis of dyslexia, Christine made a plan to:

[k]now every single little bit of schrapnel there is to know about it ... I thought if I could learn everything and enjoy learning this stuff and learn about how it works and then I can apply it to myself to make life easier and to understand myself better – to understand it better.

At the time she was studying a Psychology degree at University and this fuelled her desire even further. She actively searched for and found the dyslexia course. She stated that she would like: “to do a study on it [dyslexia]”. However, she has since changed her plans to embrace a new career path – that of counselling. This choice, she believes, reflects her empathy with others and her well-developed social and communication skills. Her self-awareness has allowed her to compartmentalise her
dyslexia and select a career field that highlighted her strengths. In this context she was able to ‘niche pick’ (Goldberg et al., 2003).

After the completion of the course and with her return to study nursing, Sarah came to the realisation that the career path she had chosen accentuated her limitations. With this accepted self-awareness, which was also influenced by a fail mark for the certificate, she realised that her skills and knowledge gained in the field would be better suited to a different role in the health profession. She then changed her career path and sought prior recognition for her previous study. She credits the course with enabling her to: “realise ... I can go on and do other things. I have had the help. I have had the support. I don’t need to let this hold me back”. This comment reflects her change in mindset. It also enabled her to identify her personal strengths of empathy, sensitivity to others, social and organisational skills and niche pick a job within the health profession.

**Personal plans of action linked to passion**

Since completing the course, David has devoted his time to finding a cure for dyslexia. He is currently experimenting with natural elements claiming these may enhance long-term and working-memory. He identifies memory as one of the most difficult characteristics to deal with in terms of his dyslexia. He claims to have “turned it into a real passion and a real drive” which “I’m just working on day and night inside and outside of my head”.

This has been fuelled by a ‘group plan of action’ where the cohort of students who completed the module *Understanding and Managing Dyslexia* with David created a networking group outside of the TAFE. This group, which included Juanita and Sam, continue to meet, albeit infrequently, two years later. At each meeting they discuss
alternative therapies or organise guest speakers. Thought Field Therapy, biofeedback, chiropractic tapping and alternate medicines and nutrients have been topics at their discussion groups. David uses this group to: “confirm [his theories and observations about dyslexia and his ‘dyslexic cures’] with the guys in the group”. He has stressed the importance and benefits of this networking and feedback from the others in the group. It also appears to have added a renewed purpose to his life as the outcome will not only benefit his network but, more importantly, his son.

Sam has developed the personal belief that she can achieve if she finds the appropriate method that suits her learning style. She has made the decision to never give up. “In the past I would have given up ... but now I just have to learn the steps involved in completing whatever the task or challenge may be.” This adjustment in her reframing indicates the attributes of success, namely perseverance.

**Advocacy**

The dyslexia course provided the content and support to assist participants gain the knowledge and understanding to take on an advocacy role. Participants were presented with opportunities to disseminate current legislation and state policies and were involved in role play scenarios based on vocational, educational and daily contexts.

In the light of this it is important to remember that dyslexia can be hidden, with an individual portraying no visual or obvious signs. To contextualise this section it is important to state that in a pre-secondary educational context there is an institutional, as well as family, expectation that a student’s difficulties would be identified by teachers who would also act as educational advocates in supporting their learning.
In an adult context, a shift in advocacy roles occurs from the educationalist to the individual, who may choose whether or not to disclose their needs within the workplace or post-secondary educational institutions if they are aware of them. Even though the Australian Commonwealth *Disability Discrimination Act 1992* and current education policies such as *Disability Standards for Education 2005* (DEST, 2005c) require that employers, educationalists and equity services provide accommodations and adjustments to suit individual needs, it is ultimately up to the individual to indicate their personal requirements, not the responsibility of others to identify them in a post-secondary context. However, in order to advocate for oneself or others: “it is important to be conversant about learning disabilities generally, but also to have reframed successfully so the specifics of a learning disability can be expressed in terms of needs, reasons and adjustments” (Gerber et al., 1996, p. 101). But in saying this, where does this need for advocacy stem from? The exosystem provides support mechanisms with legislation that reflects a deficit perspective – this legislation is being driven by societal assumptions and beliefs about diversity. The macrosystem, and its hegemonic structure, is ultimately at the core of this need for advocacy.

Eight of the 10 participants indicated they were active advocates for creating an awareness of dyslexia and associated literacy difficulties and this advocacy had been closely linked to their gained knowledge and understanding of dyslexia and increased self-awareness. Three types of advocacy roles were apparent: (1) Public advocate; (2) Advocate for others with literacy difficulties; and (3) Self-advocate.

**Public advocate**

Sam, no matter what the context, public or private (with an exception of an identified relative), would disclose her dyslexia and provide a clear explanation designed to
help, educate and inform others. Her desire to inform was linked to the ignorance she had encountered in educational, social and work contexts, about the characteristics of dyslexia:

> It’s not an intellectual impairment. We’re not thick, our brains are wired differently ... I think the majority of people know about it but don’t really understand it ... I put them right (Sam).

Participants involved in the focus group discussion highlighted a ‘classmate’ who, inspired by the course, recognised that change was required at a political level to address the educational discrepancies and social ignorance regarding people with literacy difficulties. He was pre-selected to run for state parliament and ran a political campaign that highlighted this system failure that, he claimed, created academic failure and resulted in life-long failure. He highlighted his personal failure and publicly used this in his campaign as a platform for creating awareness of dyslexia. Although he failed to gain a seat, he still continues to campaign on behalf of people with dyslexia.

**Advocacy for others with literacy difficulties**

In the role of the caregiver, both David and Kerrie have actively chosen to advocate for their sons’ learning needs as a result of their negative schooling experiences:

> My young fella’s not going to go down my line and have a shit of a time at school like I did. I’m gunna make sure of that and do everything I can to help (David).

His determination and desire that his son would not suffer like he had drove him to seek an assessment by an educational psychologist, who was an acknowledged dyslexia researcher at a local university. The researcher was identified during the dyslexia course. He continually phoned her and his persistence paid off as she agreed to see them both for free. As a result, they both were assessed and given private lessons to “improve [their] dyslexia” for free. In his determination to support his son,
he claims that “I was that broke at times and the government system didn’t look after us [that] I’d have to forge tickets to get a bus ... to catch her up” (David).

Since the course, Kerrie also has actively fought for appropriate educational provision for her son:

I don’t want him to have the experience that I had growing up and thinking I was dumb and thinking that there was nothing there for the education ... a mother will do anything to protect their child (Kerrie).

Her advocacy and understanding of dyslexia has provided her with a confidence, on one hand, knowing that she has the knowledge to collaborate with her son’s teachers in supporting his needs but, on the other hand, encountering a brick wall linked to a definitional debate and non-recognition of dyslexia by the state and federal education departments within the context of the exosystem:

Why do we have to continually fight a system for something that he is entitled to – a good education and teachers who can help him to learn to read and write and understand him? (Kerrie).

Three of Sarah’s immediate family have dyslexia and all support each other both formally and informally. She stated that: “it’s just not me that’s an advocate, but my family that’s an advocate for each of us and for letting people know the real facts about dyslexia and a proper awareness.” She tells of the following statement, made to both her and her sister by a trainee teacher: “dyslexic people aren’t really dyslexic, they’re dumb and lazy.” Sarah chose to ignore it but her sister got: “really upset and said ‘So, Sarah is dumb and stupid then?’ to which they responded ‘No!’ ....’cause Sarah’s dyslexic!”

Juanita cites many occasions since the course when she has been aware of people with literacy difficulties and she has made a decision to provide emotional support from a personal recognition of the devastating impact low self esteem can have on one’s life:
I realised I was different in that I had accepted it and my heart went out to the people with low self-esteem. So I tried to lift their self-esteem by talking to them and highlighting their dyslexic strengths (Juanita).

She recalls identifying a young hairdresser with dyslexic characteristics and on suggesting to her that she might have dyslexia the girl became very angry. On a later occasion she said:

Look I’m sorry I said that to you it’s just that I’m dyslexic and really clever people are and really good hairdressers and people who are really switched on” so I said “You’re so clever that I feel that you think like we do” … “Oh really” and then about months later she was doing the colouring and I was talking to her and she said “oh yes, I can see colour” I said “see” and we started talking about colour and I said “I’m not being awful to you now but you’ve got the same ability that dyslexic hairdressers have with your colour” so I said “it’s a talent and you’re jolly lucky that you’ve got all the talented side and you’re not” and she said “actually I am, I’m very dyslexic” and she said “but I’ve never told another soul and nobody here knows and please don’t ever tell” I said “Of course I won’t … you’re just so damn clever” (Juanita).

Juanita’s advocacy stems from an emotional reframing whereas Joseph’s is predominantly from a practical perspective. In the context of his workplace, Joseph has many tradespeople whom he deals with daily. Many of these, he claims, have difficulty reading and writing so he actively tries to support their literacy efforts and will demonstrate effective compensatory techniques that he finds useful. “There is a lot of people worse off than me with all this and you could change it … you have to open people’s eyes.” This disclosure is linked to his reframing of his attitude to himself and his dyslexic characteristics. He says: “I can openly talk about it … I’m no longer embarrassed of what my problems … I know in how I believe in it, what I want and how to get it. It refreshes my belief.” The success of Joseph’s reframing in this instance is that he has developed a realisation of the expectations of the workplace and culture of business in the context of his dyslexia and is aware of the value and need to support others with techniques and strategies, even though they may not be
fully aware of their personal difficulties. His reframing has enabled him to shift from a self-absorbed self-awareness to an awareness of others in similar circumstances to him.

**Disclosure of Dyslexia**

Participants’ willingness to disclose their dyslexia in a range of contexts appeared directly linked to their perceptions of societal responses to their literacy difficulties whether it be institutional, or on a personal level. Three types of disclosure were indicated by all participants. These reflected their willingness to disclose their dyslexia and the contexts in which they felt ‘safe’ doing so. The three types are:

- non-disclosure;
- selective disclosure; and
- open disclosure.

These types of disclosure did not remain static and participants appeared to shift between types depending upon context and sense of vulnerability. These ‘types of disclosure’ are reflected throughout the stages of reframing, in particular the transition between each of the stages and the degree of cognitive shift made by participants throughout the course. The ‘types’ reflect a sense of self-belief, understanding and risk taking. In choosing to disclose, participants appeared to regulate the degree to which they disclosed. These degrees of disclosure were found to be linked within signposts or stages of dyslexia that emerged throughout interviews and on-going discussions (see Appendix H for further explanation regarding the signposts of dyslexia and dependency on the interplay between contexts).
The following diagram indicated the three types of disclosure that directly influenced the life choices of participants:

![Diagram of Types of Disclosure]

**Figure 7.2. Types of Disclosure**

Selective and open disclosures were as a result of informed disclosure based on acceptance and clear understanding of their dyslexia. Participants indicated the impact that the course had on their: (a) understanding and knowledge; (b) preparedness to disclose; and (c) willingness to support others. Selective disclosure involved requesting requirements or adjustments for personal/individual needs and was conducted within a selective audience. Open disclosure was linked to both individual/personal needs but also providing an educative component to inform people of dyslexia. It is within this type that advocacy roles were apparent.

Within selective and open disclosure two sub-types emerged – informal/personal disclosure and public disclosure. These were dependent upon context, audience and stage or signpost of dyslexia (see Appendix I). Public disclosure involved disclosure in contexts such as government agencies, educational settings, public forums,
employment based and daily life encounters whereby individuals openly indicated their dyslexia regardless of audience.

Gerber (2005) indicates that self-disclosure is “for decision making purposes [and it] fit[s] into two broad categories:

- Formal contexts, such as employment and education
- Informal contexts such as those involving family, friends, community and leisure.”

He claims that formal disclosure is linked to societal rights as supported by legislation to access opportunities, whereas informal disclosure is on a voluntary personal choice. This study supports this claim.

An individual’s choice of disclosure did not remain static but appeared dependent upon the context, audience and individual stage of dyslexia. The risk factor involved in disclosure and the stigma based on society’s perception to poor literacy that all participants had encountered, clearly influenced their decisions.

**Non-disclosure**

Non-disclosure was linked to: (a) bad experiences and/or (b) the participant’s degree or depth of understanding about dyslexia. Both these factors acted as a deterrent to disclosure. Riley and Kim expressed the difficulty that in a personal context: “you can’t control what people will say to you” (Kim) and “they just don’t care what they say” (Riley). Kim encountered a critical (negative) incident that influenced her desire to disclose. She does not disclose her dyslexia to anyone. She says: “I still don’t like to tell people that I’m dyslectid [sic] cause I just want people to accept me for who I am not for what I’ve got.” Riley, where possible, will not disclose although, if necessary for employment purposes, will reluctantly do so.
Gerber (2005) claims that in social and personal contexts: “there are no legal mandates and, therefore, no guarantees that people will look on positively or be willing to make allowances for the LD” (p. 2). However, Kim by virtue of her non-disclosure, appears to have compartmentalised her dyslexia as not being relevant to her social self. Her desire for people to accept her as an individual and not a person with dyslexia is reflective of her degree of understanding and reframing her dyslexia.

**Selective disclosure**

David, Riley, Christine, Sam, Jason and Kerrie indicated that dependent upon audience and context, they can be selective about their disclosure.

On one hand, David claims to be very positive about his new-found knowledge and confirmation of intelligence, claiming dyslexia to be ‘a gift’, and will self-disclose amongst other people with similar difficulties or for a specific purpose (i.e. when dealing with government agencies or as an advocate for his son). However, he expressed concern about public disclosure, through being identified within this study, and how it may impact upon his future plans. It is unclear whether his reframing is being undermined by the trauma associated with his fear of having a mental illness and the ongoing impact of his father and previous partner’s attitude, or whether the overriding stigma attached to disclosing literacy difficulties presents too much of a risk in the field in which he is working and in which he has gained recognition in the past. Fear of the stigma and the responses of others appear to be at the forefront of his disclosure choice.

Riley’s selective disclosure is based on an emotional context linked to her fear of risk taking and lack of resilience. She will only disclose: “to those you can trust”. After the course she went for an interview at a bank. Even though she was aware of the
legal obligations of the bank to make accommodations if she disclosed her dyslexia, she indicated she was extremely wary to do so, but on entering the interview she felt:

[H]e was a really nice guy ... I think his friendliness, his thoughtfulness, his helpfulness – he was prepared to give me the benefit of the doubt ... I was up front there because I knew what was what – he explained the lot involved ... I said to him look I have a problem with dyslexia and it’s to do with numbers and concentration. He wanted to help. He was prepared to give me the help I needed (Riley).

She was accepted into the training program. The bank manager had informed trainers that they should assist Riley, who: “told the girls that I had dyslexia that I didn’t understand a lot of things that’s happening. That I probably need one on one”. However, the training did not prepare her sufficiently for the final exam that determined whether she would be offered a position or not, and she failed. Her response to her failure was the recognition that in order to learn and understand she required repetition of knowledge:

... when I came to do all the exams and all the testing it just blew me, just blew me away. I couldn’t understand half of the things- you know like what to look for in your cheques, what to ... but if I went and did it again I could breeze through it. It’s like a second thing happening to me... [to] Pick [it] up ... I’m like a second hand Rose going around second round to get the gift[sic] of the understanding (Riley).

Riley, Kim and David’s comments suggest that their reframing is in transition as reflected in their fear of the stigma associated with disclosure of their dyslexia.

Open disclosure
Juanita and Robert both spoke of open disclosure in a personal/informal context whereas Sam and Rebecca indicated open disclosure in employment, educational and daily life contexts.
Juanita claimed the first stage in her willingness to openly disclose her ‘difficulties’ developed: “when I was mature enough to do it – when I wasn’t scared”. However, at this point she was not fully aware of her dyslexia. The second stage of her open disclosure became more informed, based on knowledge gained from the course: “...now I can tell them exactly what dyslexia really is and provide others with accurate knowledge and understanding rather than letting them make ignorant comments”.

Sam will assess a context and determine whether she is required to disclose her dyslexia. She is willing to disclose in both private and public contexts where a group of people may or may not know her. There is only one person to whom she will never disclose her dyslexia and that is her partner’s aunt because of her “narrow-mindedness and that will give her proof that she believed (Sam’s partner) got second best”. She indicates that her disclosure is to inform or educate others about dyslexia and to correct their misperceptions. She provides an example of her colleagues’ misperceptions. As the clients with whom she works: “can’t read or spell” (they have vision and intellectual impairments) she found that her colleagues attempted to put her “in that box”. She recalls her boss saying:

‘I never think of you as dyslexic because you’re far too intelligent’ he said and ‘I have to remind myself sometimes that you are’ he said. ‘But nobody in the office thinks of you in that way because you’ve put us right so many times’ (Sam).

She also discloses to support others with similar difficulties. She gives the following example in a job training course where she identified a number of other participants who were struggling with their literacy skills so she openly disclosed her dyslexia and asked the trainer to accommodate her needs: “I thought by me telling everybody and being open about it, it might make things easier for [others]” (Sam).
Robert directly attributed his choice of open disclosure to the dyslexia course. He said “the course gave me a bit more confidence. I wouldn’t tell anyone that I was dyslexic but now it’s my way of being and I will tell people”.

**Reframing in an Ecological Framework**

As evidenced in the previous discussion, the majority of participants were able to identify not only internal factors but the interrelationships with external components and how they could take control of them in a positive and meaningful way. Their perception of reality across their life span adjusted as they began to recognise the implications and limitations of their dyslexia, and how a lack of understanding and knowledge had had on all facets of their lives indicating reframing had occurred. For others, such as Kim and Riley, it added to their sense of confusion and therefore their reframing reflected incomplete understanding of themselves. Riley, in particular, was unaware of the extent of the co-morbidity of difficulties that extended beyond her dyslexic characteristics. However, both she and Kim indicated proactive goals.

The question remains: what was the relationship of the dyslexia course to the reframing that all individuals appeared to experience in varying degrees? More importantly: was the course the reason they were able to reframe? The simple answer to this question is ‘no’! It created a good “ecological niche [which] was favourable to psychological growth” (Bronfenbrenner, 1992, p. 113), and it acted as a catalyst that facilitated and supported their reframing. Their change in thinking and perception of themselves cannot be limited to the effect of one single event. All the participants had a sense of their ‘differentness’ from their ongoing interactions within their communities. From an ecological perspective, reframing is dependent upon the society in which one lives. The development of this perception is based not only on
the individual but the process of interaction between the person, the contexts with societal systems, the time frame and the interplays and interactions that occur between them. One needs to consider all the ecological factors that have occurred throughout each individual’s life and consideration given to the influence they have had on the degree each has personally reframed. It is important to consider both the individual and the systems’ components and the interactions and interplay between them and, the overall influence of the system. One interpretation is that the course provided an opportunity for individuals to gain knowledge to reframe their dyslexia but that they are at different stages in their dyslexia (Appendix H) and continue to choose different degrees of disclosure. Disclosure, in particular, is based on the functional independence between each of the participants and their surroundings, including both their past and present interactions. Interpretation also suggests that the participants may be involved in a continual conscious psycho-social ecological transition or perception as opposed to partial or full reframing, and that reframing forms part of this transition process. Reframing constitutes a sense of finality as a ‘process’ whereas transition indicates a movement between settings and perceptions and allows individuals to proactively move between different stages while considering the degree of disclosure considered appropriate in each context. Bronfenbrenner (1979) defines ecological transitions as “shifts in role or setting, which occur throughout the lifespan” (p. 6):

The developmental importance of ecological transitions derives from the fact that they almost invariably involve a change in role, that is, in the expectations for behaviour associated with a particular position in society. Roles have a magic like power to alter how a person is treated, how she acts, what she does, and thereby even what she thinks and feels. The principle applies not only to the developing person, but to the others in her world (ibid, p. 6).
Role transitions were particularly evident in those individuals who chose to fully disclose their dyslexia within the context of an advocacy role. They perceived a shift in their role that was directly informed by the knowledge and understanding from the course. This is particularly evident with Kerrie and David and their shift from their role as a parent to an advocate for their child and their educational provision. The term ‘psycho’ is used to emphasise the internal transition in thinking involved in the cognitive processes required for each individual to actively consider the interplay between contexts and settings and, in particular, reflect on and reassess their previous and current perceptions and thoughts, particularly influenced by those negative perceptions, which have been subconsciously embedded over a long period of time.

In considering each of the participants, the narratives and conceptual diagrams and school experiences provide an overall glimpse of each of their lives. The data and its interpretation in this study illustrates the change processes undertaken by each individual in the context of their life experiences as opposed to a single event such as the dyslexia course. However, the course provided a key to their personal understanding and self-awareness. It provided answers, knowledge and sense making to their personal insights and allowed them to contextualise it within the layers of their life experiences. The course itself allowed for a more personalised delivery and involvement. This degree of proximity, as indicated by Bronfenbrenner, directly impacted on their personal development and self awareness. Bronfenbrenner describes development as “the person’s evolving conception of the ecological environment, and his relation to it, as well as the person’s growing capacity to discover, sustain, or alter its properties” (p. 9). Influences such as the dyslexia course provided the knowledge base to allow individuals to do this.
The following diagram (Figure 7.3.) is based on Bronfenbrenner’s model that uses concentric circles to represent each system. It presents a culmination of the types of contextual influences throughout each of the systems, as indicated by participants in this study. The layers indicated, which surround the individual, are the microsystem, macrosystem and exosystem. Each layer appearing progressively further removed from the individual. The mesosystem is not diagrammatically indicated but does exist, in that it represents the broader context of the interrelationships between two or more layers. In this diagram the negative contexts and experiences are situated to the left of centre and the positive contexts and experiences to the right. The diagram presents influences across the lifespan of all participants, and incorporates a time span of 60+ years, hence the concepts in the macrosystem are linked by arrows indicating time direction.
Figure 7.3
The macrosystem is the outer most layer. It provides the infrastructure for how a society operates. It is not the physical infrastructure, but the cultural and political beliefs and values that underpins how a society views, organises and manipulates their members. This layer determines the criteria for the existence of the other layers and how members of a society view and interact with each other. This layer is of utmost importance in this study as all participants indicated their clear awareness of the overarching cultural view of how literacy is valued with good literacy skills being the key to the country’s economic productivity and success. “The politicians keep telling us that” (David). The second belief identified by all participants as coming from within the macrosystem was the view that one’s level of literacy skills equates to one’s level of intelligence and: “if you can’t read and write properly you must be dumb or stupid” (David). From an educational perspective, a range of beliefs were identified that underpin traditional educational paradigms. The first involves a range of conflicting paradigms in relation to the attitudes and acceptance of disability and diversity. The first is the need for scientific/medical evidence to determine disability but, on the other hand, the paradigm shift that is reflected in the exosystem within educational provision considers that “labelling is disabling”. Sitting adjacent to this is the view from the social model of disability perspective which believes that society is constructing barriers to people with impairments and has managed to influence legislation as well as educational thinking. Within an educational context participants indicated an historical shift in societal thinking about educational provision for people with specific learning difficulties ranging from a segregated paradigm (Kim), to selective withdrawal and integrative approach (Robert, Sarah, David, Kerrie, Christine), to limited support and adjustment in class (Joseph), which reflects movement toward inclusive practice. This also reflects the historical
timeframe. From an historical perspective Juanita, Sam and Christine perceived an attitudinal shift regarding women and the ‘tolerance of low intelligence as long as they were visually appealing’ (Juanita). They claimed the current expectation is that women need to be visually appealing, articulate and intelligent in order to be successful. This gender specific perspective was not identified by the male participants.

The next layer in the diagram represents the exosystem. It is made up of settings that individuals identified as affecting them, even though they are not actively participating or interacting with the settings within that layer. Participants claimed that decisions and events that occurred within this layer are influenced by the macrosystem’s overarching assumptions and beliefs and ultimately impact on the individual. Within this layer, a number of settings have been identified by participants. Negative and positive settings are indicated. The positive being: support and lobby groups for people with literacy difficulties; mass media; work place agencies that support unemployed workers; welfare support provision; commonwealth and state legislation; educational provision based on inclusive educational paradigms; and research institutes. Negative settings include: discriminatory financial expenses for services to support their ongoing literacy needs; the ever increasing literacy and paperwork demands within all aspects of society’s infrastructure; and non-diversity recognised educational provision and paradigm.

The layer closest to the individual is the microsystem and is made up of people, institutions and face-to-face settings, which directly involve and have influenced the participants. The contexts within this setting impact closely on an individual’s well-being due to the degree of emotional attachment they may have with others in this
level. Bronfenbrenner claims this emotional attachment with other people is “a powerful element in the process by which the microsystem wields its influence” (Bowes, Grace and Hayes, 2009, p 8). Within this layer the positive key elements identified by participants throughout their life include: role and the responses of supportive others; their individual role as a caregiver; dyslexia course; other educational experiences; health services; educational support services; work-related experiences and public recognition of strengths. Negative key elements include past and present attitudes and responses of educationalists, family, acquaintances, work colleagues, general public; childhood location; work-related experiences; and educational experiences.

The centre of the diagram represents the individual responses and analysis of new knowledge that leads to the psycho-social ecological transition involved in reframing their self-awareness of their dyslexia as influenced by the dyslexia course. It indicates the stages of reframing in which all inter-relate with each other depending upon the systems in which they are embedded. The study has revealed that participants actively choose their type and degree of disclosure and this does not remain static but is reflected within their current stage of reframing. An underlying layer that underpins, but is not represented in, this diagram, indicates the individual characteristics of each of the participants. These are presented in their individual diagrams in Chapter four.

**Case study: David**

The following section returns to David and seeks to contextualise his life experiences and interrelationships across all systems throughout his lifespan within an ecological framework. It analyses the life course of his dyslexia and how he perceives the
dyslexia course to have influenced his life choices. It contextualises his process of reframing focusing on his perception of himself and his life within a literacy based society.

David’s story and life experiences demonstrate that positive reframing has occurred as a result of his diagnosis and the dyslexia course. However, he chooses to isolate himself from societal demands. David’s story suggests his reframing constitutes an internal sense of general contentment and acceptance and understanding about his difficulties whilst in a social context his reframing is incomplete as he finds it difficult to live within a societal framework without feeling threatened by literacy demands.

Figure 7.4 Timeline of David’s key life experiences

David’s key life experiences indicated on a timeline identifying the positive and negative contexts within each of the systems.

- Above the timeline are the positive experiences within each system
- Below the timeline are negative experiences within each system

<table>
<thead>
<tr>
<th>Macrosystem</th>
<th>Positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Microsystem</td>
<td>Positive</td>
</tr>
<tr>
<td>Individual</td>
<td>Positive</td>
</tr>
<tr>
<td>TIMELINE</td>
<td></td>
</tr>
<tr>
<td>Individual</td>
<td>Negative</td>
</tr>
<tr>
<td>Microsystem</td>
<td>Negative</td>
</tr>
<tr>
<td>Exosystem</td>
<td>Negative</td>
</tr>
<tr>
<td>Macrosystem</td>
<td>Negative</td>
</tr>
</tbody>
</table>
His story reveals what Bronfenbrenner (1992) refers to as “synergism”, that is the “frequent occurrence of vicious or benign circles ... in which the joint operation of two or more forces produces an effect that is greater than the sum of the individual effects” (p. 117). Since completing the dyslexia course, he continues to live an exclusionary existence with minimal contact with anyone, apart from a handful of people from the dyslexia course and his son, living predominantly off the land and acquiring goods through a barter system. He chooses not to seek financial support or assistance from government agencies due to previous treatment and paperwork demands for which his literacy skills are inadequate. His time is devoted to experimenting with natural products to find a cure for dyslexia. Within the context of his networking with other people with dyslexia, he appears content and at ease with his dyslexia, but in the context of the demands of the exosystem his sense of reframing is determined by his inability to adjust to and cope with literacy barriers and the vulnerability and stigma attached to literacy difficulties.

David has lived the majority of his life with an underpinning emotional constraint, which came from his father’s belief and treatment of him. Well into his adulthood, his father believed he had a mental illness, even during those times when David was getting recognition for his farming innovations in a public forum. Within his microsystem, lack of family support, including the death of his mother during his adult years and the breakdown of his marriage when the farm was facing financial difficulties, exacerbated the demands on him within the exosystem, accentuating his dyslexic characteristics and limitations in the process. Based on his experiences - marriage breakdown, losing his business, fighting government and legal agencies for money which is owed to him – David believes that society and its members create barriers that focus on individual weaknesses and that having literacy difficulties is one
of the vulnerabilities used to deny individuals access to what could be rightfully theirs. He states that:

Dyslexia is probably an example of heaps and heaps of disadvantaged groups - and authority will play on weaknesses if they don’t want to hand out things that are earned by certain people and so they know their weaknesses so they’ll go down that line a lot of the time – it’s almost intimidating ... what I’m learning is that people with any type of disability – groups like Centrelink, like banks, they’ll play on it until you back off ... People that aren’t great with spelling and writing and got a strong constitution – the system will play on you ... they do their darnest to make you weaker and blame yourself and muck your self esteem up ... So, unfortunately as time goes by a lot more is put into paperwork and yet anyone that’s changed the world – I mean not anyone but there’s a helluva lot of people that have changed the world whose weakness was paperwork and their good as long as they’ve got secretaries and stuff (David).

He also provided an example within his microsystem of significant other’s actions as being used as a controlling measure. During the time of his marriage breakup his partner chose to withhold or purposely misinterpret information associated with the financial dealings of the farm knowing that David was unable to read the associated documents. He equates this with a form of abuse and stated the following:

What you are is you’re very open – unless you’re very strong and have got lots of money, you are very open to abuse – my missus, when the shit hit the fan and the old man let her know she’s getting nothing … sort of worked out she’s going to get out of the show as comfortable as she can get and anyway she actually stopped doing the books and then she’s giving us some misinformation at times and I was powerless to do anything with it – because I’m computer illiterate, I’m word and reading illiterate, and if you’re mostly still attached[married], you just drop your bundle and stuff so you’re very vulnerable if you’re not a ruthless type of person, you’re very vulnerable to the book keepers and book makers and your missus and stuff and all that. She was controlling the heart strings as well as the paper stuff and purse strings, so it was bad times (David).

David believes that society’s focus on the written word, and the overarching belief within the macrosystem of the linkages between intelligence and high literacy skills, perpetuates an ongoing fear of failure, no matter how hard you try. David was recognised nationally in his field of expertise, however he refused to do a state talk (because he had to write it down and then read it), and he declined the offer of an
international scholarship (it required a degree of literacy skills), because he feared his literacy difficulties would be exposed. Furthermore, he did not want to appear different or inadequate in front of his peers. “I didn’t do it because it would probably reveal that I couldn’t cover up properly – I didn’t want to look like and sound like, an illiterate blubbering bastard”.

David claims to have lost ‘a million dollar business’ due to his dyslexia and the requirement of government agencies that proof or accountability for one’s actions or financial status be documented in writing.

They can say ‘well put it in writing’ – wherever you go it’s ‘put it in writing’ and then it’s often several correspondence[s] are required the wrong way before anything happens. And then it can get down to wording such as ‘you spelt that the wrong way’ or ‘look it wasn’t clear what you had to say’.

I’m owed 30,000 bucks from Centrelink – all that muck you have to go through – paperwork after paperwork ... if I wasn’t dyslexic I could’ve put my ideas into writing and in conveyance and so I could’ve chosen to make the whole show good – but I couldn’t convey it into words (David).

He spoke of the attitude he had encountered that secretaries and advisers were easily available. However, he stated that one needed to be in a relatively good financial situation to employ them – which he wasn’t and still isn’t.

After a long period of unemployment, divorce and emotional instability, he was referred to a counsellor by Centrelink because he ‘appeared at risk of doing harm’ to himself. This counsellor referred him to the dyslexia course and recommended that he be assessed. The resulting diagnosis established he was not mentally ill and the course gave him the knowledge required to understand his situation. He claims that the course ‘saved my life’ and has provided a new focus in his life. From an ecological perspective, David’s actions and responses throughout his life can be attributed to a range of environmental issues, both past and present. They are not
simply reactions. It is the interaction between each of the systems that are of utmost importance and the result of reframing is dependent upon a range of relationships rather than a single one. In David’s case, his educational experiences appeared to be far outweighed by his adult experiences in which the demands on his literacy skills to demonstrate his economic productivity led to emotional turmoil and personal breakdown to the point where he considered taking his life. David’s story clearly highlights the societal impact of the assumptions and beliefs that underpin all systems built around the need for adequate literacy skills. His recollections and perceptions based on these assumptions and beliefs suggest that he views himself as being the focus of these demands and that it is his responsibility to change so that he meets society’s demands and becomes a contributing member.

According to Bronfenbrenner, this range of relationships and interplays is part of an overall developmental process. However, for this developmental process to occur on an individual and societal level, and for joint participation and communication to occur across all contexts and settings, Bronfenbrenner (2005) indicates the importance of the existence of positive information that recognises individual situations within all systems, as this will effect the process within which negative forces can be transformed into positive ones (p. 79)

However, David and the other participants do not believe that communication and appropriate positive information and understanding exist in our society. Why do questions linked to knowledge about dyslexia (for example: What is it? How does it impact on daily life? What legislation and provisions exist etc.) remain either unanswered or not considered within societal understanding and responses to dyslexia? This underpinning knowledge surely would “affect the subsequent course
of behaviour and development in the new setting?” (Bronfenbrenner, 1972, p. 6), as well as societal responses to people with dyslexia or, for that matter, other ‘difficulties’ that do not fit the mould.

**Repositioning the Individual within an Ecological Framework**

On an individual level, the process of reframing has empowered the participants to be active agents of change, both in terms of their perception of themselves and of their dyslexia. It has allowed them to reflect on the assumptions and beliefs underpinning society’s attitudes to individuals with literacy difficulties, and how these shape their life experiences. These reflections have revealed a change in their perception of self and how they see themselves fitting within society. However, why should it be that reframing occurs purely on an individual level? This suggests that the individual must adjust their self-perceptions to suit the requirements of society. If so, why are they referred to as individuals? In a society with an educational paradigm that currently preaches inclusivity, why is it that the individual is still required to fit the system? In this context I propose that a repositioning of the individual within the ecological framework should occur. Currently the individual is situated at its centre, thereby reflecting society’s embracing of a deficit perspective within a medical/scientific perspective. I purport that society should form the core of this framework and therefore reframing is also required at a societal level within the macrosystem. By instigating a change in assumptions and beliefs at this central place this, in turn, allows for diversity to be recognised and, with that, a positive adjustment of how society sets up ways in which to perceive and include people with dyslexia.

Bronfenbrenner’s framework, as represented in this study as a series of concentric circles, places the individual in the middle of all systems. The macrosystem is
situated as the overarching societal influence where assumptions and beliefs ‘trickle down’ through all systems to the individual. Although it allows an holistic perspective on the interplay and synergies between all systems, contexts and people, it still infers a deficit perspective as it places the individual at the centre. This positioning suggests that the individual changes according to the outer system’s requirements, particularly those societal requirements and norms that emanate from the macrosystem. Under this model, people with dyslexia whose literacy skills do not reflect societal assumptions and beliefs about literacy may not be viewed as productive members of society. Concentric circles also suggest a cyclical nature of interactions that infers repetition as opposed to dynamic evolution and ongoing change dependent upon diverse needs of individuals and their interactions.

The reframing process, as it applies to people with dyslexia, is inherent in the concept that an individual needs to change to fit the system as opposed to an inclusive perspective that the system should make adjustments to suit the needs of individuals. In this inclusive context I suggest that it is society that needs to reframe, not simply the individual.

While Bronfenbrenner’s conceptual framework was initially used as a framework to provide structure for the analysis, it has also assisted the researcher to make sense of the process of reframing. For example, society (as represented by the macrosystem) should be viewed as a living organism in which an individual is a key component to its survival. As in Bronfenbrenner’s framework the individual is surrounded by a range of contexts however, they are not necessarily layered. As opposed to being situated at the centre of the framework, the individual moves alongside of, and in and out of, contexts that relate to their being. These contexts are supplied by both the
micro- and exo-systems. The process by which they interact would be dependent upon purpose and time. Proximity to contexts may also be dictated by two additional elements: (1) purpose of the interaction; and (2) timeframe. This proposition acknowledges both the reactive and proactive choices made by an individual and their recognition as change agents. This repositioning fits well with Bronfenbrenner’s PPCT model as he claims the “power of the process-person-context – model lie in its capacity not so much to produce definitive answers as to generate new questions by revealing inadequacies of existing formulations in accounting for observed complexities” (p. 119).

**The River System Revealed**

In order to present and discuss these ‘observed complexities’, I have chosen to use an analogy of a well-developed healthy river system. Any river system can be understood as dynamic, having many components and influences. In the following discussion, two versions will be presented. The first conceptualises a full reframing across the components of the system, including the individual. The second considers the adjustments linked from a partial reframing perspective.

**A full reframing of the river system**

The land over which the river flows represents the macrosystem. It provides the framework underpinning the direction, depth and quality of water flow. The path the river takes and the quality of the water is influenced by a range of factors, including, but not limited to, the composition of the land. The river itself is representative of all contexts found within the microsystem and exosystem. It also includes individuals. The contexts and the individuals are not stationary or separate from one another, but
continually moving and evolving dependent upon their interplay with each other and
the landscape. While the landscape (macrosystem) can influence the direction and
flow of the river, the river can influence the way in which the flow occurs by shaping
the landscape. The construction of its surface also reflects the quality of the water.
The landscape (or macrosystem) generates the key principles and assumptions upon
which the river flows and evolves. However within this model the individual can
directly influence the macrosystem, dependent upon their role. That is, they can
employ their energies to redirect and even harness the river over time. This ongoing
evolution represents the chronosystem and suggests that the life of the landscape
(macrosystem) and the river (exoystem, microsystem and individual members) is in a
state of flux and not stagnant. The river, in particular its main artery, is based on
recognised and acceptable norms and follows the appropriate landscape. Within this
healthy flowing river system the uniqueness of individuals are acknowledged and
their role in maintaining the health and flow of the river is reflected in the way in
which the landscape accommodates by adjusting its path and flow and how it allows
the individual to be an active part of this adjustment.
This diagram represents the full reframing of both the individual and society. The assumptions and beliefs from the macrosystem are represented as an inclusive landscape that accommodates the diverse needs of all components of its river. This is reflective of the smooth river bed and strong supportive banks allowing both transparency and clarity of the water’s movement and interactions.

This diagram can be translated into a social context where the landscape represents the society and the norms and beliefs that underpin it. The river represents all components (microsystem, exosystem and individuals) and, in the context of the reframing process, the positive interplay between them.

**A partial reframing of the river system**
The first analogy may appear as an idealistic proposition whereby full reframing within a societal and individual context is occurring. A critical question, however, is what happens when society or individuals only partially reframe and a gulf remains...
between the assumptions and beliefs in the macrosystem and perceptions of individual differences? What happens to those individuals who still do not fit the norm due to these exclusionary beliefs and assumptions? Within this second river analogy we find that tributaries develop that work away from the main body of water. These tributaries are like those people within society who do not ‘fit the norm’. Their interplays within the main river may ‘force them’ to move or they may choose to self-withdraw. The tributaries, if considered from the perspective of the social model of disability, would therefore represent an exclusionary zone. However, the tributaries can play an important role in helping the river to either sustain or perpetuate itself (the latter via self renewal as they flow across the landscape). The tributaries can be interpreted a number of ways. On one level they can be equated with the non-conformists who are fighting against society. On another level, they can be seen as those who do not fit the system, but have an important contribution to make. Finally, there are those whom society excludes because of its beliefs and assumptions about normalcy. Each of these groups can fit the tributary model. Tributaries can play an important role in changing the path of the river, changing the landscape (the macrosystem), and in fact helping to sustain the river over time. However, this is dependent upon the degree of reframing that occurs. From the perspective of both river analogies, this highlights that over time, as the process and degree of reframing occurs, the landscape (society) can change to meet the needs of individuals (in this case people with dyslexia). The following three diagrams conceptualise how beliefs and assumptions are represented within the river analogy (Figure 7.6.); how tributaries are formed by individuals who are impeded by the exclusionary assumptions and beliefs (Figure 7.7.); and how, as reframing occurs within all systems the tributaries reform with the main body of water but a change in landscape and direction has adjusted in recognition of diverse
strengths and contributions of all individuals (Figure 7.8.).

**Figure 7.6.** Embedded assumptions and beliefs about people with insufficient literacy skills

**Figure 7.7.** Formation of tributaries by individuals
Maintaining sustainability linked to reframing on a societal and individual level

The use of the river system analogy prompts the question: how does the landscape (macrosystem) maintain its river so that firstly, it does not lose all its flow (its lifeblood) and secondly, so the outer tributaries are viewed as an important part of the whole river system and therefore remain sustainable? In order to maintain a healthy and productive river system all components need be aware of and recognise the diversity and contribution of all contexts and individuals. This acknowledgement needs to come from the landscape, as this provides and regulates the sustenance in the form of social, cultural, political and psycho-emotional expectations. If the landscape does not value, or take into account, all individuals’ contributions, including strengths and weaknesses, then certain components of the organism will not perform at their...
peak. For example, in the context of this study, society’s expectations regarding literacy levels can exclude those who struggle to read.

A reframing, from within the landscape, needs to occur that actively recognises current assumptions and beliefs about literacy levels, work as exclusionary barriers. It must be recognised that current attitudes are stigmatising and that expectations regarding literacy skills, currently regarded as one of the keys to an economically productive society, neither recognise nor draw upon the strengths of all members of society – instead highlighting deficits and limitations. Not only do assumptions and beliefs need to change but also the language used to describe diversity, particularly dyslexia, as it is more often the language that provides these exclusionary barriers.

Reframing at an individual level can be empowering as it allows individuals to become advocates and active agents of change at a range of points within the river system. Reframing at the landscape level would allow a reshaping that underpins and redirects the river flow as well as accommodating and adjusting to suit all river types and varieties of flow. This dynamic and inclusive reframing at the macrosystemic level would eliminate current exclusionary assumptions and beliefs that exist as barriers impeding the flow and health and well-being of the river. In the context of this study, those assumptions and beliefs include the importance of individuals acquiring and demonstrating good literacy skills in order to be viewed as productive members of society.

**Summary of Chapter**

This chapter has examined the process of reframing that emerged from the participants’ perception of their knowledge and understanding gained from the dyslexia course. Based on the discussions and findings it proposes a reinterpretation
of Bronfenbrenner’s model that not only repositions the individual within an ecological framework, yet also recognises the need for reframing to occur within all systems as a result of reframing at the macrosystem level.

To explain the reframing process the chapter has developed a model based that compares society with a river structure. The river and the landscape within which it flows represent Bronfenbrenner’s typology; the river as the exosystem, microsystem and the individual; and the landscape as the macrosystem. The redesigned model caters for reframing that takes place both at a societal and individual level.

The strength of this reinterpretation of Bronfenbrenner is that it moves away from a deficit model that implies the individual must fit the needs of society. In this model all systems work together and adjust according to the identified strengths of individuals and the contributions they can make to society.

The final chapter overviews the study and considers the implications of the research for educational and other research areas.
Chapter 8

CONCLUSION

This thesis set out to: (a) present the lived experiences of adults with dyslexia, with particular focus on their educational experiences, and highlight the multitude of influences that have shaped these experiences, including society’s perceptions; (b) reveal the perceptions of these individuals across their life-span in living with their dyslexia in a literacy-based society; and (c) analyse the influence of a customised course developed for adults with dyslexia on their self-perceptions and perceptions of life. Furthermore, its intention was to consider the educational and social implications of dyslexia within an ecological framework, as opposed to the medical-scientific approach that has dominated and perhaps even held back understanding to date. Furthermore, its intention was to add to the definitional debate in an Australian and wider educational context.

This thesis supports the notion that, based on the life experience of participants, the medical/scientific model and its dominance, serves to uphold and maintain a concept of failure among adults with dyslexia. It also provides evidence for the assertion that a process of reframing occurred in the context of the participants’ knowledge and understanding of their dyslexia. This reframing appeared directly linked to their participation in the customised dyslexia course offered by TAFEWA that they all attended.

This process of reframing had been previously identified within the literature on learning disabilities. The analysis and subsequent (and more explicit) discussion of a reframing process with participants led to a conceptual repositioning of each of the
individual participants within Bronfenbrenner’s conceptual framework to explain the concept of dyslexia. Further, the presentation of narratives, which are positioned within an ecological framework, has allowed an in-depth examination and analysis of each individual’s perceptions of their dyslexia across their life span. This has contributed to an understanding of the complexity of life influences across all systems. In so doing it provided an holistic perspective in which the reframing process, linked to individuals’ participation in the dyslexia course, emerged.

The interview process and resulting narratives produced a rich data source that provided a unique opportunity to explore first hand the personal experiences of adults with dyslexia across their lives, in some instances in excess of 60 years. This provided the opportunity to reveal the richness and reality of what it really means and feels like for the participants to live with dyslexia and how it influences their daily life. These narratives not only provided an insight into how the individuals dealt with their dyslexia, but also their perceptions of the exclusion barriers created by society for people referred to in the literature as having hidden disabilities.

The use of Bronfenbrenner’s conceptual framework emerged as critical in identifying and analysing the multiplicity of influences, beyond the personal, which have influenced the lived experiences of participants. It has enabled the study to focus on the development of the person and their individual characteristics alongside the social, cultural and political contexts in which they exist. It has been particularly beneficial in identifying and analysing the changes in individual self-perceptions within the reframing process, based on contextual influences both proximal and distal.

This study has reaffirmed research by a range of authors that dyslexia does continue into adulthood (Everatt, 1997; Fink, 1998; Gorman, 2003; Hellendoorn &
Ruijessnaars, 2000; Nosek, 1997; Miles, 1993; Raskind et al. 2002; Riddick et al. 1999). Ramus and colleagues (2003, p. 841) refer to this as “lifelong persistence”, which is supported by the perceptions of the individuals in this study.

The thesis supports Poole’s position (2003) that dyslexia, within an education context, should not be viewed purely within a medical/scientific perspective but within an ecological perspective. In addition, the results of this study extend beyond the educational perspective to embrace an inclusive lifespan approach. The strength of these ecological and life span perspectives are that they influence the language surrounding the concept of dyslexia, thereby shifting the discourse well beyond one of deficit, failure and homogeneity that is reflective of a medical/scientific perspective.

Elsewhere, I have identified this medical/scientific discourse as contributing to the conundrum of failure (Tanner, 2009b). In claiming this, I am aware of the proposition of the ‘Humpty Dumpty’ approach to definition (Beaton, McDougall & Singleton, 1997; Kavales & Forness, 2000; Riddick, 1996), which means that any definition can mean whatever we perceive it to mean, but this study does not seek to provide definitions. Rather it seeks to uncover perceptions of lived experiences, thereby reframing the way we talk about dyslexia by not defining participants purely in terms of their dyslexia but by presenting dyslexia within the context of their life experiences and the society in which they live.

Although this study uses Bronfenbrenner’s model as an analytical tool to identify and describe the factors that influence experiences, a finding of the study is that use of the concentric circles approach continues the portrayal of a deficit perspective of individual development. By situating the individual in the centre, as influenced by the outer layers, this approach perpetuates the non-inclusive perspective that an individual
needs to fit the requirements of the system. This study suggests a repositioning of the individual within the ecological framework, with reframing occurring at both an individual and macrosystemic level. This repositioning takes the conceptual form of a river analogy. As discussed in chapter seven the revised model compares society with a river structure; the river represents the exosystem, microsystem and the individual, and the landscape is the macrosystem. The redesigned model caters for reframing that takes place both at a societal and individual level. All systems within this model recognise the value of the diversity of individuals and the various roles they can play in a functioning society not necessarily linked to literacy strengths.

**Influence of a Customised Course**

For the majority of the participants, the dyslexia course was the first acknowledgement, within the education system and throughout their lifespan of the reality their dyslexia. One of the key factors about the *Understanding and managing dyslexia* unit around which this study is based, is the importance of providing a forum in which participants’ dyslexia is acknowledged and accepted. It provided an opportunity for the individual to gain understanding and knowledge about their and others’ dyslexia, and openly discuss issues within a safe educational environment (Tanner, 2009b).

The unit, and the course within which it was situated, allowed the participants to change the way in which they viewed and understood not only dyslexia as a generic learning difficulty (in the context of localised educational paradigms and policies), but their individual characteristics and how these influenced their life. It allowed them to change the lenses through which they interpreted and valued their characteristics and their individuality. It also allowed them to transpose their feelings
of negativity within a more positive internal framework. It enabled a sense of empowerment and control as they gained understanding of how their characteristics and difficulties manifest themselves and how they can work with them in a realistic and purposeful manner. Gerber and colleagues (1996) “concluded that success entailed a continuous process of confronting one’s strengths and weaknesses and making adjustments” (Kerka, 1998, p. 3).

The results confirmed research by Gerber and Reiff (1991) and Helledoorn and Ruijssenaars (2000) in concluding that dyslexia continued to have an ongoing influence on their daily lives, although in the case of this study, the course had enabled them to understand and take control over some of the difficulties they encountered. Considering whether these adults have been successful or unsuccessful in their pursuits is an attribute that has not been addressed. In the context of this study it was considered more important to highlight the process and complexity of decisions and level of awareness that has led to the participants’ life choices including those that appear to have transitioned through a reframing process.

**Importance of the course in the reframing process**

Results indicate that the course provided key elements for participants to reconsider and analyse their lifelong perception of themselves. It acted as a catalyst to enable participants to adjust their perception of their difficulties and take control of their personal responses. It provided the stimulus for the reframing process to occur as influenced by the knowledge and understanding gained from the course. Within this process each individual’s degree of reframing was dependent upon their self-awareness of their strengths and, more importantly, realistic expectations and limitations. This process reflected an evolving change in their self-perception. It
revealed that degrees of reframing were related to each individual’s comfort level associated with their change in perceptions and past experiences.

The course provided for both pragmatic reframing (for example: advocate for accommodations) and a personal reframing (for example: “I always thought I was dumb, now I know I’m not”). Within this pragmatic and personal reframing process ongoing attributional dialogue became an important part. Kozminsky and Kozminsky (2002) state that:

underachieving students (Carr & Borowoski, 1989), especially those with learning disabilities (Kistner, Osborne & Le Verrier, 1988) tend to attribute their success to external causes (eg. Task difficulty, significant others, luck) and attribute their failures to uncontrolled internal causes (eg. Personal ability). These faulty attributions block them from taking personal responsibility for their learning outcomes (p. 88).

Within the context of the course and the results of this study, the dialogue that participants engaged in allowed them to consider success and failure from both an internal and external perspective due to their: (a) self-awareness, (b) understanding; and (c) knowledge of their dyslexia linked to their degree of individual reframing. Therefore their comments can be referred to as holistic attributional dialogue that considers both the external and internal causes of the successes and failures throughout their schooling. This dialogue allowed them to acknowledge their personal responsibility as well as the controllable and uncontrollable influences within their individual ecological framework. The course enabled them to take control of their self-awareness and acceptance and, through this change in perception of self, become active agents of change in their personal development and reframing.

**Implications across all Educational Spheres**

The characteristics of LD are informed by but limited to our own cultural lenses, and values and beliefs of what constitutes success, normalcy and
(dis)comfort with diversity. From a sociohistorical perspective, we understand that constructs such as competence and success do not solely reside in the individual, but rather in the interaction of the individual with others in specific activity settings. It should be noted that the point being argued is not that individual differences do not exist, or that these are not important in ultimate academic and later life success. Rather, the argument is that these differences interact with the social organisation in a manner that mediates outcomes in significant ways (Gallego, Zamora Dura’n & Reyes, 2006, p. 2214).

Acknowledgement of diversity and difference is mediated by social constructs and judgments of competence. This study highlights the importance of educators in all educational contexts being aware of the range of influences on an individual’s learning capacity. These influences include the personal, social, educational, environmental and political.

In this study, inaccurate identification of needs and inappropriate and ineffective learning experiences culminated in negative educational experiences for all participants. This study recommends all educational stakeholders develop the following:

- An awareness and knowledge of the concept of dyslexia and other unique ways of learning, from birth to adulthood;
- An understanding of effective teaching strategies;
- A school curriculum that focuses on developing success attributes such as self-awareness, risk, resilience, emotional coping strategies, perseverance, making proactive choices, self-advocacy and respect for diversity. This is supported by Cummings, Maddux and Casey (2000) who suggest “that teaching self-awareness and self-advocacy as early as the elementary grades to students with learning disabilities may play a significant role in positive adult outcomes” (In Reiff, 2004, p. 186);
- An understanding of the influence of their responses on their students;
- An awareness of the beliefs and assumptions that underpin society’s norms and expectations particularly regarding literacy levels, and the non-
inclusive, selective acknowledgement of diversity dependent on economic and political attitudes.

Within an Australian educational context this research adds to the range of voices asking for the “clarity of terms in regard to learning difficulties” (Cunningham & Firth, 2005, p. 2) and, in particular, the existence of dyslexia to be recognised across all areas of education. It highlights the view that accurate identification and provision of specific teaching and learning strategies can influence an individual’s ability to learn and provide potential for achievement across their lifespan. Identification, along with understanding and knowledge, allows for educational provision that does not focus on limitations but rather on achievement. Although research, including this study, has indicated that the difficulties associated with childhood dyslexia exist into adulthood, it does pose the following questions; why is it that: (a) dyslexia is not recognised as a unique learning style; and (b) provision for people with specific learning difficulties such as dyslexia, who are critical stakeholders in understanding their needs, are not provided with the opportunity to be involved in developing educational services and policies?

The rhetoric that exists at a macrosystemic level does not reflect an understanding of their educational needs but further marginalises them by generic definitional banter. Denhart (2008) identified that: “within [USA] educational policy no mechanism exists for those labelled with LD to participate in creating new LD policies or critique existing ones” (p. 483) and therefore the ‘voice’ of those with learning difficulties such as dyslexia, are unheard or silenced through policy rhetoric.

Although this study confirms that dyslexia needs to be recognised as a discrete way of learning or a developmental learning difference within an Australian educational context, it also claims that we should move beyond the argument that this recognition
is disempowering because of the limitations it suggests regarding disability/difficulties. Current inclusive educational philosophies reflect an acceptance of diversity and development of curriculum and teaching practice to reflect the needs of all students.

In order to provide appropriate educational services for people with dyslexia, greater attention needs to be paid to the characteristics of difference, both within society and within an educational context. Knowledge of difference is empowering, not only for those who are educators, but also students with dyslexia and their peers. Using an ecological perspective allows knowledge to be viewed through a range of lenses. Awareness through all research lenses can support educators in understanding their students individual needs and break down the barriers that exist across all systems. It can also assist in dispersing the confusion regarding the range of definitions that make up the definitional debate and minimise inaccurate labelling.

Therefore this thesis suggests that educational providers need to address the following:

- **Pre-service teaching** – focus on knowledge beyond the generic terminology of learning difficulties and focus also on the characteristics of specific learning disabilities such as dyslexia and effective teaching strategies alongside an understanding of the psycho-social aspects.

- **Ongoing professional in-service development** for all practising teachers that focuses on characteristics and identification of students with specific learning disabilities within the classroom and effective teacher intervention to support their needs in an inclusive environment.

- **Ongoing knowledge-based educational intervention** throughout an individual’s educational timeframe that provides students with explicit information about the characteristics of their dyslexia and provides practical information that focuses on effective ways to learn and being learning-abled not learning disabled.
• Development and provision of specific courses for adults with dyslexia similar to that of the TAFE course – flexible delivery within a range of places and service providers, particularly where people with identified poor literacy skills are prevalent – TAFEs, Libraries, Job Rehabilitation services and providers, juvenile and adult justice system.

These recommendations not only allow for the rejection of inappropriate labelling but moreso the ‘abling’ of students by encouraging a continuous framing and re-perception of their abilities as opposed to re-perception based on negative experiences and misunderstanding of their abilities. While this appears to constitute labelling, it does, however, present all stakeholders with accurate characteristics and may avoid negative labelling and use of inappropriate derogatory terms that influence an individual’s psycho-social emotional self. As Riddick (2001) claims, the use of labelling “can mediate between the individual and their cultural context and explain certain difficulties they have and thus help to prevent inaccurate or negative attributions” (p. 231). Understanding of the label dyslexia and the concept itself was clearly beneficial for the participants in this study. Cunningham and Firth (2005) support this view of labelling. No matter to what degree arguments exist regarding definitions and support or otherwise of labelling, this study has highlighted the fact that there exists a group of people with dyslexia whose educational experiences have not addressed their needs due to insufficient and ineffective educational practices that failed to identify their dyslexia. This has had a lifelong effect on their lived experience and without the involvement in the dyslexia course may not have provided them with an understanding of their situation or even the mechanisms they require to ‘fit in’. Until there is a change at a societal level regarding the importance of literacy skills and the reframing of language used to reposition dyslexia it is important to equip educators with the knowledge they need to inform their teaching and thus improve their relationships with their students.
Implications for Further Research

On one hand, the data collected in the course of this study revealed a richness in the intellect of the participants, particularly in the ways they talked about their dyslexia and made sense of their experiences; whereas on the other, it revealed their low literacy skills. One key aspect at the forefront of participants’ recollections and perceptions was the attitude they encountered that because of their low literacy skills they were expected to have a lower cognitive ability. Failure to achieve expected levels of literacy was a sign of weakness, incompetence and low intelligence. The name-calling they experienced reflected this perception. As this thesis reveals, there is clearly scope for further research into why people perceive those with low literacy levels as having a cognitive impairment.

This research also revealed a divide between the extent to which students with dyslexia are recognised and catered for across a range of educational contexts. The experience of participants shows that the primary and secondary educational sectors do not recognise or adequately cater for students with dyslexia. On the other hand tertiary institutions were cited as providing equity services, learning support centres and disability support officers in recognition of the diverse needs of students. The TAFE dyslexia course was a key example of this recognition. Further investigation into revealing why the tertiary sector acknowledges, and makes provision for, students with dyslexia and other learning styles would be beneficial. More importantly, it is important to consider why this isn’t available at a pre-tertiary level. What are the underlying reasons for this? Is it based on educational paradigms, economic considerations or a social control mechanism? To what extent does the shift from child to adult, and the enhanced rights of the adult learner influence this decision? Further investigation into this conundrum is warranted.
**Limitations of Study**

It is important to note the study’s following limitations. The participants only represent approximately 10 - 15% of adults with dyslexia who had completed the TAFE course during the period 2003 - 2005. Using a small group, although limiting in terms of numbers, has provided in-depth and information-rich data that has allowed deeper analysis of perceptions. It has also provided ongoing opportunities to liaise with all participants throughout the research process.

Participants, unlike previous studies by Reiff and colleagues (1993), were not identified as ‘successful’ or ‘unsuccessful’ prior to the study and this distinction has not been taken into account particularly in terms of the reframing process.

**Insider or outsider?**

In conducting this study I struggled with my role as insider or outsider. On one hand I was an ‘outsider’ as a ‘non-dyslexic’ and therefore able to “pose questions that would not have been posed by someone [with dyslexia] … [and] not take things for granted or at face value” (Pole & Morrison, 2003, p. 37), yet on the other hand an ‘insider’ through the role of lecturer. Within this role as lecturer, respect and trust was previously gained. In the role of the researcher, based on this previous relationship, subjects felt comfortable disclosing and discussing sensitive issues that may not have been provided to other, unknown, researchers. Whilst enhancing credibility, as participants were very forthcoming with their experiences, from an ethical perspective it may have encouraged disclosure of sensitive issues. This was evident during the editing process when a number of participants asked for sensitive interview material to be deleted. It can be argued that whilst participants may have benefited from the opportunity to reveal untold or emotional experiences, this may also have encouraged
the emergence of unwanted hidden issues. This vulnerability was taken into account by counselling services made available to participants.

During the research process acknowledgement of the role of the researcher in each participant’s narrative was evident, however has not been included for the reasons cited above. This in itself may create a limitation of the replication of this study with others who may have completed the dyslexia course.

**Generalisability of findings**

Although the focus of this research has been on the lived experience of a small number of adults with dyslexia, the methodologies and analytical tools used could be applied to other groups of individuals, in particular those who may be vulnerable and marginalised within society for a range of reasons.

**Concluding Remarks**

This study has provided a unique insight into the lived experiences of adults with dyslexia. It highlights the importance of specially designed courses such as that offered by TAFEWA and targeted at people with dyslexia. The strength of such courses is that they help individuals understand their dyslexia and encourage a reframing of how they perceive themselves and their relationship with society. It also highlights the importance of knowledge about dyslexia both in the context of the individual and also from the perspective of educators and society more broadly. Knowledge provides the individual with the capacity to understand their dyslexia and how it influences their life choices and interactions within society. From the perspective of the educator, knowledge about dyslexia provides one with the tools required to cater for students with dyslexia and to help them understand their learning.
style and needs. Equipping educators with the knowledge they can use in a classroom context is also critical to changing society’s broader perceptions about dyslexia and the contributions people with dyslexia can make.

Critical to any push for change is the need for a reappraisal of society’s attitudes towards literacy skills, in particular the link between high skills and productivity. Until a reframing occurs at this level, as in the river system analogy discussed in Chapter 7, dyslexia will always be regarded as a deficit that holds back productivity.
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264


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Dear

I am a post-graduate student at Murdoch University. My research is about how *dyslexia* impacts on the *educational* and *life experiences* of adults with dyslexia.

I am under the Supervision of Dr Susan McKenzie.

I would like to invite you to participate in my project. You have been chosen because you have successfully completed the *TAFE* unit *Understanding and Managing Dyslexia*.

**The purpose of this study is to**

| (a) | identify the key features of the experience of living with dyslexia |
| (b) | investigate how participants perceive the ways in which society responds to their dyslexia. |
| (c) | provide insights into an understanding of the educational experiences of adults with dyslexia, and the subsequent influences of education on their adult lives. |

**How can you help?**

**By consenting to participate in:**

| (a) | 1 -2 individual interviews |
| (b) | 1 group discussions with other participants |
| (c) | Phone followups |
Interviews and Focus groups will be about 2 hours each and will be conducted in November, 2007 in Perth.

Interview questions will cover:

1. Educational experiences
2. Employment experiences
3. Family and Personal Relationships
4. Social Situations and compensatory strategies
5. Personal opinions and individual characteristics of dyslexia

At our first meeting you will be able to ask further questions. If you would like to help, you will be asked for written consent to be a participant.

Participants can decide to withdraw their consent at any time. All information given during the interviews is confidential and no names or other information that might identify you will be used in any publication arising from the research.

Feedback

Ongoing feedback about the research will be given throughout the project. At the completion of the project participants will be invited to attend a meeting to discuss findings.

If you are willing to participate in this study, could you please complete the details below.

If you have any questions about this project please feel free to contact either myself, Kathleen Tanner on (02) 42322853 or 0419 899 875 or my supervisor, Dr Susan McKenzie, on 9360 2527.

My supervisor and I are happy to discuss with you any concerns you may have on how this study has been conducted. If you wish to talk to an independent person about your concerns you can contact Murdoch University’s Human Research Ethics Committee on 9360 6677.
Covering Letter from Researcher

Hi
Remember me?
I was your lecturer at TAFE in the Dyslexia course.

I’ve gone back to University to do some study.
My research is about Adults with dyslexia.
I am hoping you might be able to help me.

I want to talk to you about your dyslexia and your experiences in school and in life.

I have attached an ‘official’ letter that gives you some more information.

I am doing interviews in November from the 4th – 10th and I would love to have you as one of my participants.

Please send the last page back and let me know if you are interested.

You can also ring me on (02) 42322853 or 0419 899 875

Many thanks

Kath Tanner
Please circle

YES – I would like to be a participant in the study. Please contact me about the meeting.

I am available on the following days for an interview:

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or

NO – I am not interested.

Name:

Phone Number:

Signed:

Please return in the envelope provided.
CONSENT FORM FOR RESEARCH PROJECT:

An Investigation of the Lived Experience of Adults with Dyslexia by Kathleen Tanner

I ……………………………….. have listened to an outline of the research project about An investigation of the Lived Experience of Adults with Dyslexia by Kathleen Tanner who is conducting this research as part of Post-graduate study supervised by Dr Susan McKenzie in the department of Education at Murdoch University. The information on the Participation Information Sheet has also been read to me and I understand the risks involved. Any questions I have asked have been answered to my satisfaction.

I agree to take part in this activity, however, I understand that my participation in this research is voluntary and I may change my mind and stop at any time.

I understand that all information provided is treated as confidential and will not be released by the investigator unless required to do so by law.

I agree to participate in two interviews and one focus group. I agree for the interviews to be taped.

I agree that research data gathered for this study may be used primarily for a PhD thesis as well as in summary form for journal publications provided my name or other information which might identify me is not used. I agree for a pseudonym to be used if necessary.

If I have any enquiries about the research, I can contact Kathleen Tanner on (02) 42322853 or 0419 899 875, or Dr Susan McKenzie on (08) 93602527. If I have any concerns or complaints regarding the way the research is or has been conducted, I can contact Murdoch University’s Human Research Ethics Committee on 9360 6677.

Name of Participant: ……………………………………………………………………………

Signed………………………………………….             Date: ………………………………

Investigator's Name:            Kathleen Tanner

Signed: ………………………………………..            Date: ……………………………..
Appendix B

Adjusted and Original Participation Involvement Sheets

Participant Information Sheet (Adjusted)

Purpose: To find out

- about your dyslexia
- about your educational experiences and,
- how they have influenced your life
- How we can improve educational provision for people with dyslexia.

What is required of you?

- 1 - 2 interviews of 1-2 hours each
- Interviews will be taped
- 1 Focus group: 8 – 10 people (next year)
- Total of 4-6 hours of your time over 12 months

I come to you!! Interviews are done close to you – in a coffee shop, library or park.

After the interviews I will send you

- CD or tape of the interview
- Typed copy of the interview

You can cross out anything you don’t want included and add any new bits.

Risks

- Involvement is voluntary – you can stop at any time
- You might be asked to talk about experiences that are unpleasant.
- Counselling is available at Murdoch University.

Benefits

- Helping to influence educational provision for people with dyslexia
- Helping to change societies attitudes
- Information will be used for:
  - Phd thesis
  - Journal publications
  - Conference papers

Important Factors

- Your name will **not** be used in the research at any time.
- You need to sign the consent form to participate
PARTICIPATION INFORMATION SHEET (Original)

Title: An Investigation of the Lived Experience of Adults with Dyslexia

INVESTIGATOR
Kathleen Tanner
PhD Student
Faculty of Education
Murdoch University
02 42322853
sjtanner@bigpond.com.au

SUPERVISOR
Dr Susan McKenzie
Lecturer
Faculty of Education
Murdoch University
08 93602527
smckenzie@murdoch.edu.au

PURPOSE OF THE RESEARCH

The purpose of this research is to provide insights into and an understanding of the educational experiences of adults with dyslexia and the subsequent influence of their experiences on their lives. The main aims are to:

• Investigate the contextual influences and prevailing attitudes which impact upon the life choices of adults with dyslexia. Its focus is to detail what it is like from an adult’s point of view to live with dyslexia on a daily basis and the culminating events which have occurred throughout their lives and their resulting life choices with a particular focus on how they perceive their educational experiences and attitudes.
• Deconstruct the ways in which society responds to people with dyslexia.
• Analyse the way in which messages concerning attitudes toward literacy are transmitted by people (educationalists/colleagues/peers/ family/general public), institutions and political agencies.

METHOD AND DEMANDS ON PARTICIPANTS

If you choose to be included, you will be required to participate in two interviews by the researcher. On this visit the researcher will conduct a 1 – 2 hour interview that will be audio taped. The interview will consist of a conversation about your experiences about living with dyslexia. There will be four main topics that you will be asked to discuss:

1. Educational experiences
2. Employment experiences
3. Family and personal relationships
4. Social situations and compensatory strategies
5. Personal opinions and individual characteristics of dyslexia.

After each interview you will be given a hand held Dictaphone to record any thoughts you may have after the interview that you would like included. As the researcher analyses the interview they may be required to contact you by phone for any clarification of information shared.
You will also be asked to participate in one focus groups. These may take about 1 – 2 hours. The researcher will lead you, and other participants in the study, in a discussion about the key themes that have emerged from individual interviews.

**RISKS, INCONVENIENCES AND DISCOMFORTS**

The project will require you to dedicate a total of approximately 4-6 hours of your time over a twelve month period.

It must be acknowledged that some of the discussions may involve talking about life experiences that may be unpleasant or of a sensitive nature. Your involvement in the study is voluntary and you can stop participating at any time.

**BENEFITS OF THE RESEARCH**

The research will provide the basis for a post-graduate thesis as well as journal publications. If you decide to be part of this project you will provide valuable information and understanding about dyslexia and the way society responds to people with dyslexia through its attitudes and recognition/non-recognition of hidden diversity. In particular, its intention is that it may influence societal attitudes, but more importantly, educational attitudes and provision for people with learning difficulties such as dyslexia.

Confidentiality is assured and you will not be identified in any part of the research.

**ETHICS REVIEW AND COMPLAINTS**

This study has been reviewed by the Human Research Committee of Murdoch University. If you have any concerns or complaints regarding the way this research has been conducted, you can contact the Human Research Ethics Committee on 9360 6677.
Appendix C

Course Details

Certificate 1: Foundation skills for people with Dyslexia

The original certificate during 2003 - 2005, comprised of six modules:

1. Understanding and Managing Dyslexia
2. Identifying, selecting, using and evaluating different support mechanisms to assist adults with dyslexia
3. Strategies for developing basic literacy for adults with dyslexia
4. Maths Skills for Adults with dyslexia
5. Working effectively with others
6. Keyboarding Skills

To graduate with the certificate all modules needed to be completed. However modules could be completed as single entities. It was strongly recommended that all students complete the Understanding and Management component. This module was made up of five Learning Outcomes:

<table>
<thead>
<tr>
<th>Learning Outcomes</th>
<th>Topics and Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describe personal and practical problems associated with dyslexia</td>
<td>Discuss personal experiences – childhood and present.</td>
</tr>
<tr>
<td></td>
<td>Identify characteristics of own dyslexia in the classroom, home, workplace, social environment.</td>
</tr>
<tr>
<td>Describe current theories of dyslexia</td>
<td>Genetic vs acquired dyslexia</td>
</tr>
<tr>
<td></td>
<td>Differences in brain structure and activation</td>
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<td></td>
<td>Differences in processing</td>
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<td></td>
<td>Phonological deficit</td>
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<tr>
<td></td>
<td>Identify personal characteristics</td>
</tr>
<tr>
<td>Describe how dyslexia affects short term memory and working memory skills</td>
<td>Discuss how we use our senses to learn</td>
</tr>
<tr>
<td></td>
<td>Define short, long and working memory</td>
</tr>
<tr>
<td></td>
<td>Identify personal learning style and preferred modality</td>
</tr>
<tr>
<td></td>
<td>Identify characteristics of the processing</td>
</tr>
</tbody>
</table>
| **Identify strengths associated with dyslexia and apply this knowledge to self** | Identify typical strengths of dyslexics  
Identify areas of success and management strategies of successful dyslexics  
Identify personal strengths and reasons for these |
|---|---|
| **Identify and Use strategies for managing dyslexia** | Identify strategies for the workplace, home, place of study, social situations  
Identify programs and therapies designed to reduce impact of dyslexia  
Identify relevant sections of the Anti-discrimination Act and Disabilities Act  
Identify appropriate ways of being a self-advocate |

*Central TAFEWA, 2004*
Appendix D

Visual Timeline

*Visual Timeline (blue page = primary; yellow page = secondary; pink = post secondary

Timeline of ________________ ’s dyslexia

_____________________________________

Month/Year

*Original orientation = landscape
Appendix E

Patton Model of question types - (Madison, 2005)

1. **Behaviour or experience questions**

Questions which ask for “more information on action or behaviour” (p. 27)

For example:

When you go into Centrelink and they ask you to read and fill in forms what do you?

When you go out to a restaurant how do you choose what you would like? What happens if you are with a group of people that you don’t know?

2. **Opinion or Value Questions**

Questions which focus on “a conviction, judgment, belief, or particular persuasion toward a phenomenon” (p. 27)

For example:

What is your opinion, based on your experience, about the educational provision for people with dyslexia?

Why do you think people equate dyslexia with unintelligence?

3. **Feeling Questions**

“Feeling questions address emotions, sentiments and passions. The interviewer is concerned not with the truth or validity of a phenomenon, but with how a person feels about it or is emotionally affected by it.” (p. 27)

For example:

When you were at school and the teacher asked you to stand up and read out loud – how did you feel? What were you’re feelings towards the teacher?

You said that people would call you ‘dumb or stupid’ when you couldn’t read - what did it make you feel like inside?

Some people claim there is no such thing as dyslexia – how does that make you feel and why?

4. **Knowledge Questions**

Questions which focus upon the knowledge and understanding of a particular phenomenon that the participant may have.
For example:

Can you tell me about your dyslexia? What are the main characteristics?

I understand that you have investigated TFT (Thought Field Therapy) can you tell me about it and how it relates to your dyslexic characteristics?

5. Sensory Questions

“Sensory questions address the senses and human sensation. How does the body hear, taste, touch smell, and see a phenomenon at the purely visceral level in its contact with the phenomenon?” (p. 28)

For example:

What do you see when you look at print on a white page?

6. Background/Demographic Questions

Questions which identify how the participant perceives their individual characteristics and background.

For example:

Tell me about the schools you attended
Appendix F

Capturing the essence of each participant through a narrative of their life story.

Joseph’s story

Joseph is single, 28 and lives at home with his mum and dad and younger sister. A last minute change of arrangements, due to Joseph’s work commitments, found us doing the interview at his parent’s house soon after they had arrived home from a holiday. He had in fact forgotten to ring his parents to expect my arrival. Arriving on the door step I was greeted by his mother who upon being ‘filled in’, eagerly invited me in and prior to Joseph arrival home, willingly shared some brief anecdotes about him and the advocacy role she played during his schooling.

Joseph arrived home and in his bubbly and vivacious manner briefly explains my existence “you know – the letter!” and his mum knowingly ushers us off into the dining room. However, what begins as a two way conversation on a number occasions became a three-way conversation when Joseph invited his mother to join us to listen to, and clarify certain events. They both agree they have ‘a connection’ and that although his whole family are incredibly supportive, he and his mum “are very similar … I find it easier to come and see mum about a problem with how to read …. I can relate better to mum with my problem because she can understand it” to which his mother responds with fondness “absolutely … we’ve been through a lot through school and all that – the over the top mother”.

Aged 28, Joseph currently owns and runs a successful painting business, the second of two businesses that he has set up since completing his apprenticeship. It is from his previous experience as a business owner and an understanding and acknowledgment of his dyslexia that he has set up a network of support people to assist him with the paperwork side of this business which was the down-fall of his previous business venture. Three months after completing his apprenticeship in spray painting he decided to set up his first business – a panel shop. Sadly this
ended in bankruptcy, not from lack of enthusiasm, motivation and hard work but from his inability to understand the paperwork involved and at the time, being too embarrassed to disclose his difficulties and ask for help. He makes mention that this happened at a time “when my dyslexia was bad and I put it down partly to blame”. However, concurrently he was completing another apprenticeship at night to become a house painter, so he was pushing himself to the limits by working ‘7 days a week’.

When asked about his earliest memories of school he quickly responds with “I hated school”. This feeling began around about grade 4 when he remembers being segregated – “I was always with the slower kids in the class” and this continued throughout his school years. In high school, classes were based on ability but even within those classes there was a natural segregation occurring in that “… the dumb shits go to the back and the good shits stay at the front”.

In Year 2 he moved from interstate to a private primary school where he had to repeat year 2 due to the state education system based on age. It was from that point an awareness of ‘us’ and ‘them’ began to evolve – “I always knew that I wasn’t as cluey as the next one”. He remembers not being able to sit still – having to move – “I can concentrate on a subject that needs to be done but I can’t sit there”, so therefore he got into trouble a lot.

He recalls with laughter (although it was not funny at the time and caused considerable trauma and confusion) how one teacher made him write with his right hand even though he was naturally left-handed. He now thanks that teacher for his ability to play sport with both hands as well as his nice handwriting which enabled him to “jag it through high school because I always had neat handwriting”.

Smaller class sizes in high school - approximately 15 students with the majority being males – made a difference to his learning “I learnt more in high school than I did in Primary school”.
When asked about positive experiences from his schooling he laughs and says ‘Recess and lunch were always good!’ Although he “loved social studies ... I loved learning about history – that was the only course when I went to high school that I was above my mates. I’d split up and go to the smart guys ... you could feel the difference when you went into there, you felt the difference”. Even now he claims he can “sit for hours and watch the history channel”.

After completing Grade 10, with the help of his father he wrote a reference and door knocked for his apprenticeship. After a successful interview he had to sit a test at the Motor Trades Association. At this point he starts to laugh and calls on his mother, who then refers to his father as to one of the questions he had to answer on the test. In response to the acronym TLC in a multiple choice test, which stood for Trades and Labour Council in this context, Joseph had chosen the answer ‘Tender loving care’. After the laughter dies down his mother says ‘Tender loving care – you come from a tender loving care sensitive family – he’s a sensitive boy’.

Attending TAFE was a major component of his apprenticeship and he suddenly went from low school marks to high marks. He attributes this to the teaching strategies used by the teachers and the focus of contextualising the learning into real life. It was very practical and hands-on and the goal or purpose of the learning was made very explicit. After completing this course he went on to getting his “Painters ticket” as well as completing certificates in Book keeping, Business practices, Theory and Estimating. All of which he achieved high marks because he “wanted it”.

As a result of the failed business venture and the difficulties he encountered, not only on a personal level but also linked to external factors, his aunt and mother
encouraged him to attend the Dyslexia course at TAFE. He talks of how this course enabled him to change his mindset and focus on his strengths and to realise that there are other ways to overcome any difficulties that one may encounter and to use his strengths and do it ‘his way’ not necessarily the way others expect it to be done. Alongside of this came his willingness to disclose his dyslexia and support others who he recognised have similar characteristics to him. “I am a big believer in if something has to change you got to make it change first ... there is a lot of people worse off than me with all this and you could change it”. He observes that many of the trade’s people he works with have difficulty with reading and writing and he will go out of his way to show them strategies to help them. This self awareness also resulted in an interest in reading motivational books which have enabled him to believe in himself and know what he wants and how to get it. He also came to the realisation that there are people who provide support that are non-judgemental and that can be trusted. This has influenced the choices he has made about his current business venture where he has employed an accountant to help him with his bookwork as well as his parents.

During primary and high school he was continually bombarded with the attitude that academic success equals success in life and on reflection he says:

They always used to emphasise if you didn’t get a good education you’ll never make anything in life and the funny thing is when I went to school the guys that were at the top of the class – the roles are reversed – they’re all junkies or bums and stuff like that and the guys that were at the back of the class have all moved forward”

I’ve been down there. I’ve been rolling around in the gutter and I’ve picked myself back up, dusted myself off and said right let’s get going again ... I’ve developed better as a person. Every problem can be fixed, you’ve just got to find the solution. But that has taken me years and you can ask my mother she has seen me come home in tears and depressed and that’s the end of the world but I’ve learnt I’ve learnt this from my Dad, no matter how hard things get the sun is
still going to come up tomorrow. And that’s and I always put that down to I envied people that can be academic. I’ve envied people who can do this. I’m just an average Joe that’s doing his best and I’ve found out my problems as I’ve gone along and we’re slowly trying to work through them ... Being dyslexic is one of the hardest things I’ve had to come to. Come to terms with and um... openly know it’s a problem.

Juanita’s story

Everyone seems to know or wants to know Juanita. As we’re talking she’s continually aware of the passers-by and nods or waves in acknowledgment of their recognition. At one time during our conversation I witness the ‘Social Juanita’ in full flight when a gentleman interrupts and engages in a discussion about the next social function she is organising. During this time he gives her a name to write down and upon his leaving she looks at me and sighs “isn’t it lucky he kept spelling!” She also breathes a sigh of relief at having remembered not only his name but also mine and using the most incredible flamboyant and dramatic expression she says

I don’t know what I would’ve done then if I’d forgotten Kath – but I’ll be ‘yes sweetheart’ or ‘you’ve met, you know each other’ and they’ll go ‘No’ and then they’ll introduce each other and I’ll go ‘oh you do so! I can’t believe you’ve never met before”... and then I’ll go on and say ‘well I suppose maybe you wouldn’t have ... but Kath lived here!’... and I would be making up all this ridiculous nonsense to cover up.

Juanita moves in circles where these eccentricities are often observed, but she has developed them as strategies to support and bluff her way making her dyslexic characteristics not as obvious, as well as reflecting her social persona. Although she admits she’s never hidden her dyslexia as an adult – “I’ve always told people – so it makes it easier”. She also has a very friendly, confident and
open manner which is very endearing and contagious however, beneath this facade, glimpses of uncertainties and unspoken experiences are, at times, intimated.

Juanita tells of three known family members as being dyslexic - her brother, a successful property developer who “is a lot worse than me ... making a fortune” and she believes her father had characteristics as well as herself. Throughout her life she has married twice and has three sons – the middle one, a successful business investor, also has dyslexia - and three granddaughters.

Juanita grew up in an era in which girls were expected to finish school and get married and her parents were keen to “marry her off to somebody that [sic] can look after her ... so they married me off to the doctor so I could be the ‘doctor’s wife’ and swan around and never have to work for the rest of my life”. She went into the relationship completely unprepared and had no knowledge of the expectations that were required of her particularly in regard to sex.

But I think the dyslexia made me cope with that cause I thought after I left [my first husband] I thought I’d better go out and find out what stuff’s about called sex – then I thought if I can cope with dyslexia I can cope with sex! ... then I discovered it’s like putting on pink glasses – oh! Absolutely amazing! – it toughens you up.

Juanita started her school life in a small catholic school where she remembers ‘hanging onto the nun’s Rosary beads and following them around saying I want to be a nun – I don’t want to learn anything I just want to be a nun”. It was in grade 1 that she realised she couldn’t learn the sequence of the alphabet – “I couldn’t get past ABC – I didn’t know what came next” and that this was only the beginnings of her difficulties.
She was then moved to another school which she describes as a “posh school – the place to go for ladies”. “I arrived at the school looking like the absolute perfect model so I looked good. So I learnt very young that if you looked good and you dressed well that you could bluff everybody”. Throughout school she found that she struggled to read and write and where possible avoided work by ‘being good’. “I learnt very quickly to be a good girl and keep quiet and keep your head down and don’t look at anyone and they’ll ignore you”. She tells the story of exam time when she’d rule up her page – “3 coloured lines and 3 different ones and it was all ruled pretty” and she would hand it in without a trace of writing on it. She was later to discover that only one nun was a trained teacher and the others had no idea ‘what to do with her’ so they just passed her – 50/50 for every exam and she presumed this was the way to pass all exams. Later at TAFE during her apprenticeship she tried the same method and quickly discovered its inappropriateness.

At 14 the school requested that she leave immediately prior to testing of academic levels by the State Education department to determine ongoing funding for the school. Her mother was told “we won’t have her back because she’s going to bring down the marks of the school because she doesn’t do anything ... she’s a lovely child but she’s totally and utterly dumb ... marry her off because there’s no hope for her”.

Juanita said it was like a secret – she was told not to tell anybody she was leaving or say goodbye “because they’ll know you’re dumb and that you’re stupid... it’s our secret that you’re dumb and you must never tell anybody that you’re dumb ... it’s our secret that only we know and we’ll never tell a soul’ and I said ‘thank you so much!’”. She says she was accepting of this but also confused by not being
able to tell anyone. She was also pleased because they weren’t ‘cross ‘at her, and that she was also keen to get into the workforce.

She finished on the Friday and on the Monday put her age up a year ‘because I was still 14”, and went hairdressing. From the onset she was receiving positive feedback for her practical skills, being told she was a ‘natural hairdresser’ and having a ‘natural flair with people’ and being the ‘best in the class’. When she was at TAFE however, the written component could have been her downfall except the lecturer recognised her literacy difficulties and provided one-on-one tutoring.

The day she finished her apprenticeship she gave it all up ‘cause I was told you’ve got to marry’. This marriage lasted for 14 years. It was after this time that she was asked to take on the ‘biggest challenge’ of her life – writing a social column which appeared in a number of newspapers and magazines. At the time she was involved in organising large charity events and had an indepth knowledge of the ‘who’s who of wealthy socialites’ in the city. She was approached by a media representative about eight times over a period of four to five months to do a social column. Juanita continually refused until one day the rep said –

*Look I’m over this ... you’ve given me all this shit here, what is the real reason?* I said ‘well all right I’ll tell you the truth ... I’m dyslexic’ and she said “so! What’s the real reason?” and I said ‘well isn’t that a good enough one – I couldn’t spell the words. I can’t write it’ and she said ‘Oh for God’s sake, is that all? I’ll give you a journalist and tell them .... that’s even better, I’d rather a journalist write it cause then I don’t have to sub it. So now what’s your excuse?*

She talks of her experiences both from a writing perspective and relationships with colleagues, as well as the steep learning curve that she was faced with. She tells the story of one of her first reports where she gave verbal details to her allocated journalist to write up. Her oral recount included intimate defamatory
details of exactly who was doing what to whom as opposed to suggestive
innuendo and possibilities. It was published in full with her name as the author.
She learned very quickly and said to her employer “I deserved that ... I did learn
the hard way ... I learnt in one lesson” to which she responded “Right, there’s
nothing wrong with you ... you’re not dumb ... you learnt”.

Juanita currently is self-employed as an exclusive function co-ordinator. Her
innate ability to visualise things in 3d, have made her one of the city’s most
sought after designers and organisers. The day before our conversation, she had
transformed a local hotel for a Melbourne Cup function into Flemington
racetrack completely redecorated with instant grass inside and out. She had
visualised exactly in her head and its successful transformation and feedback
received enabled her to disregard the negative thoughts that she is continually
fighting to control. She talks of having lived with many negative thoughts linking
back to that concept of being dumb and not good enough. “I do a function and
it’s not working I can beat myself up about it and think ‘oh I should’ve done that
better and how can I do that? …’ Then I go into – ‘hang on – I can do anything, if
I can do that [write a social column] I can do this’ so I do keep grabbing onto
those thoughts”

Diagnosed with dyslexia and Scotopic Sensitivity Syndrome in her 50’s and now
in her early 60’s, she happened upon the dyslexia course. The course has
allowed her to reflect upon her life experiences in a more positive and open
context. Her attitude, which she openly spreads among fellow dyslexics as well
as anyone else, is one of “Aren’t we clever?” and it shouldn’t “hold anyone back”
and be accepting of genuine positive feedback even though you’ve been in a
downward spiral of negativity throughout your life – each positive comment is a building block for positive self-esteem.

**Kim’s Story**

I [have] felt like I didn’t belong and I felt like that for many, many years – I don’t know where I belong ... cause I can do everything everybody else does in society except my spelling and things.

Kim’s conversations of her life experiences reflect this sense of marginalisation that she has felt all her life, which appears to have been exacerbated by her mother’s lack of support and how her negative responses haunt her level of self-esteem which, only recently, has led her to seek counselling.

Kim is in her late 50’s, unassuming and quietly spoken. Over the past 8 years she has turned her interest to studying at the local TAFE college, participating mainly in Adult Literacy classes and completing a number of certificates throughout that time. She claims that the study has “woken some of the cogs up ... some things have improved and then sometimes they haven’t improved”. It wasn’t until her early 50’s that she was diagnosed with dyslexia, having thought she was ‘slow’ all her life. She was then unsure as to whether they were one and the same. “I thought to myself – I’m dyslexic, is that the same as being slow or is that better?”

Even having completed the dyslexia course after this time and knowing “they’re two totally different things” her life experiences continue to tell her otherwise.

Kim comes from a family with two elder step sisters, one full sister, a younger sister, father and mother. Both her younger sister and stepfather were very
supportive however her mother’s attitude toward her was one of disregard and continual put downs.

Half way through Grade 6 she fell ill with a mystery disease which saw her hospitalised for 3 to 4 months. She has no memory of her schooling or her life prior to this time – “I don’t remember anything before then”. Prior to grade 6 she believes that she was progressing and achieving at a normal rate but has no evidence as “I’ve lost reports”.

On returning to school at the end of the year, she was then moved into Grade 7 during which time she remembers being ‘tested’ and declared that she was “known as a ‘borderline case’” and was therefore placed in a ‘special class’ in which she just ‘cruised’ – “the work in the ‘slow learners’ class was too easy”. She then moved to high school and “because I had been in a special class at primary school, they put me in a special class at high school”. She stayed in this class for 2 years at which point her mother intervened when it was suggested she do a third year saying “no, I’ve got another daughter to educate and she’s bright and so we can’t have two at high school paying money when one’s stupid and one’s not”.

On leaving school she went to work in a ‘workshop’ run by a church based organisation. She was unable to recall exactly how she came to being there except she “was sent”. She quickly realised that her level of intelligence and competency skills were higher than the majority of the other people. The operators also recognised this and they would give her extra responsibilities including helping others. The lady in charge said “this is ridiculous Kim you being here, I’m going to get in some tests, get you retested, I reckon you should be out there in society in a job, earning money, you shouldn’t be here”. Once again she
was tested. While she passed the test she was still considered ‘borderline’ because of her literacy skills.

She struggles to hold back the tears as she speaks of this chapter in her life as being “very frustrating and very upsetting and very stressful because I felt like I didn’t belong”

She then applied for and got a job at a nursing home. Her father was very supportive of her leaving the workshop but her mother said “she can’t do that, she’ll fail, she’s too stupid, you can’t give jobs to stupid people”. Her father continued to support her by dropping her off at her new workplace every day as well as supporting her in her learning at home. She continued in this job for a number of years where she met her husband and they married and had two sons.

During her boys’ school years she stayed at home and supported them wholeheartedly. She enjoyed her time spent in their classrooms as a parent helper. During this time her relationship was breaking down and she was frustrated because they were always relying on unemployment benefits. So when the boys ‘grew up’, her husband went back to live with his mother. Now a single woman, Kim decided that she wasn’t going to rely on government handouts and went in search of employment. She successfully completed a housekeeping certificate at TAFE and found fulltime employment at a local motel. Although there was some written work involved in this position it was all conveniently coded – “VC – vacant and clean, DC – dirty and clean ... OC – Occupied and clean”. During this time she damaged her back and was unable to continue working in this field and although she attempted a variety of jobs which were classified ‘light work’, her back still played up. So she was put on a
disability pension. She was told she was not obligated to do anything but she took up the challenge when Centrelink suggested she do some study. Since that time she has completed a number of courses including the dyslexia course after she was assessed.

Kim has two sons – one who is married and the younger with whom she lives. She livens up when telling me that they spend a lot of time talking. “We have a wide range of subjects, discussion on everything from politics to movies to society to music, everything – we like the same shows on TV most of the time ... he likes Big Brother and I don’t! ... he respects my opinion and I respect his opinion”. However, she then goes on to recall an incident when she had seen the movie “The Castle” and was discussing it with her sisters over lunch and “they were saying they liked it and I was saying I didn’t like it and [one of the sisters] turned round and said to me ‘we’ll you mustn’t’ve understood it if you didn’t like it!’”. It is this confusion that has surrounded Kim’s life - that on one hand she knows she is articulate, independent and intelligent but people’s reactions to her have told her otherwise.

**Kerrie’s Story**

Kerrie’s story begins with an invitation to her house for the interview. Inside reveals a busy family environment and a comfortable inviting atmosphere. There are notes and schedules indicating her two children’s daily whereabouts, family photos and pride of place on the table – a sewing machine - “I love to sew - when I’ve got the time”.

She is married with two school-aged children. Kerrie originally comes from a large family of nine consisting of six girls and three boys. She was number six
and found the advantage of being a ‘middle child’ was that she “sat back and looked at what was going on between the older ones and the younger ones and took everything in”. At an early age she learnt about group dynamics and differing relationships and personalities. Very quickly she developed good people skills which involved diplomacy. She was the only one of the children to experience any specific learning difficulties. She was hesitant and visibly reluctant to disclose any details about family dynamics and personalities and became teary at times as obvious memories were stirred.

Born in England, she began her first years of schooling in a catholic school. From the beginning she developed a dislike of school because of the school dinners. “I was a very fussy eater and they made me eat stuff and I threw up … so I started avoiding school at a young age”. At the age of six or seven the family moved to Australia, a new school but “vegemite sandwiches – urrrghh! And I didn’t eat again”.

Throughout her schooling the family moved from state to state whilst her father followed work. She recalls attending six primary and four high schools and whilst this enabled her to develop independence and a sense of resilience it did not provide her with continuity of education and the extended opportunity for her learning difficulties to be recognised and addressed or life-long friendships to evolve. Although she says that “it was definitely my literacy skills that were more of an impact than moving because … I had already made up my mind that I was dumb at a young age and then life gave me lots of proof through schooling”. At age eight she was identified as having reading difficulties and placed in a Remedial Reading Class. She recalls the teacher saying “you’re going to have trouble all your life if you can’t get these sounds”. This was the beginning of her
negative self-efficacy and negative self-talk that remains with her today – that single comment “stay with me for life and I think that I made up my mind then at that time I wasn’t good enough”

Each school she attended she struggled to recall positive experiences, however she remembers being relatively good at maths and always coming second in the class in maths competitions “but being young I thought I was just not good enough, you know. I’m just not good at anything, and it didn’t register ‘hey you’re second!’”. On one hand she tells of how her creativity was acknowledged in sewing and cooking classes and she claims to ‘have a name’ for her creative ability and proudly says how her sister felt she ‘had to live up to her’ but then says as a consequence of her dyslexia she “always did things different to other people because maybe I didn’t understand the total instructions so when I made something it was different and it was done well I guess because I was very creative …”

Halfway through repeating Grade nine, due to another interstate move and varying state systems, “they shoved me out the door and said here’s a job go take it …” So she found herself in a solicitor’s office which required her to learn shorthand at TAFE. When she realised she could take it but not transcribe it she began skipping classes. The job developed into a receptionist position with responsibilities that were not linked to shorthand and writing.

Then the family moved states again and she found a job in a supermarket. She found success in this role and had a number of opportunities in management. This job provided her with proof of intelligence – “I realised that gee I’m good at this and I must have some intelligence”. But on the other hand even though she was motivated to move up through the managerial ranks of the supermarket she
realised that she would have “to study manuals and sit tests and I thought nah! I just, I would just fail miserably with it if you got marked for spelling or anything like that”. It is at this point that she reveals that she suffers from depression and experiences a lot of self talk in which she is continually putting herself down and ‘nothing’s ever good enough’.

This did however motivate her to go to Adult Literacy classes at TAFE in the hope that she could learn to spell.

After nine years in this job she had a car accident and damaged her back. To avoid lifting she changed jobs and went into retail selling. Her people and verbal skills enhanced her success in this area. She also became very interested in self development and attended classes at TAFE and tells of how she has ‘written a little book with my daughter about meditating and stuff like that but I never actually got it to publication stage. Maybe one day I will’.

Up until this point she did not realise she had a specific learning difficulty but rather she thought she just wasn’t good enough. It wasn’t until her youngest son went to primary school and she noticed that he was having similar troubles to that which she experienced in pre-primary and grade 1 and began what has become a long and arduous fight to provide him with adequate educational provision and recognition of his dyslexia, when she herself was diagnosed as being dyslexic as well.

The remainder of Kerrie’s story revolves around her role as an advocate for her son and frustrations she has experienced with the public education system and its non-recognition of dyslexia as a specific learning disability, the school and the way in which their funding for students with additional needs links directly to a medical diagnosis and the lack of knowledge and understanding that his teachers
have about dyslexia and specific teaching and learning strategies to support his learning needs. She expressed her determination to make sure that her son would not experience the difficulties she had –

*I don’t want him to have the experience that I had growing up and thinking that I was dumb and there was nothing there for the education did for me ... My self-esteem and depression that is really major as a consequence of not being picked up as having a difficulty so I [am] definitely not going to have his self-esteem [affected] or him thinking he was dumb – a mother will do anything to protect their child.*

After a formal diagnosis she began to research dyslexia determined to find all she could to help her son. She sought information from the SPELD association as well as encouraging one of her son’s teacher’s to attend a professional development session on dyslexia. She also got a copy of Richard Lavoie’s video about learning disabilities and encouraged it to be shown to all staff at her son’s school. However, she became frustrated because there was no continuity as the years passed by and teachers changed – “*I was doing all this work and every class I’m going to I’m educating the teacher on how to educate my son*” and the ‘school’ appeared disinterested. It was at this point she attended the dyslexia course at the TAFE which gave her a much greater understanding of dyslexia and particularly herself. It answered many of the questions she had been seeking answers and knowledge about. It gave her the confidence, self-esteem and renewed vigour in fighting for her son as well as taking on further personal challenges such as enrolling in an MYOB course at TAFE.

She talks with pride about both her children and their different personalities and interests in life. She tells me of her son’s dramatic abilities and that he is incredibly talented in both dance and acting and that they have just returned from auditions for an upcoming international musical production at which it was
indicated that he may be considered as an understudy for one of the main characters. “I don’t know where we’ll fit his school work in?” she giggles and sighs.

In a recent telephone discussion she proudly tells me that her son has been accepted into an AEP – Academic Extension programme for 2008 – “finally”, she sighs “he’s recognised and accepted for his intelligence, not his reading difficulties!”

**Robert’s story**

Having ‘slipped out’ from his job as a groundsman at the local primary school we first meet at the local watering hole where everyone else in town has also decided that it is the place to be. We find a relatively quiet corner and begin our conversation amidst the music and mayhem of the other patrons.

It takes a while for Robert to feel comfortable talking about himself and I realise that short statements and answers are his preferred responses. Processing the spoken word and then retrieving and expressing his responses don’t always come easily. He spoke of instances where the words he wanted to use are simply ‘not there’ but on the other hand if he talked about sport – one of his interests – the words would come more easily.

Our discussion begins with the results of the Melbourne Cup which had been run the previous day – funnily enough neither of us could recall the name of the winner. Sadly, all of the horses that Robert had placed a bet on were scratched.
at the last minute. When asked their names – he had no idea but he knew
exactly which numbers they were. “Names forget it, numbers I’m good”.

When asked about what he thought his dyslexic characteristics were he said
“can’t read … spelling, no … I don’t write!”. He then went on to say that he can
read and write ‘a little bit’ but it makes no sense – ‘it goes in one ear and out the
other’. He has a network of family members that he trusts and will do it for him.

Like if I want something done I go and see my brother and I say ‘here’s my mail,
look at it, if it’s any good, if it’s not, throw it in the bin’. And if it’s like my shares
and all that, he does all the reading, he just says ‘this is what we are going to do,
sign here and we’ll send it off’.

Robert’s story starts in a family of three elder siblings – two brothers and one
sister all of whom are still very close and throughout his life have been very
supportive when it comes to his literacy skills.

Robert attended the local public primary and high school and completed Year 10.
He spent a considerable time wagging school except where sport was involved.

“I went to school just to play sport and that was it … I played football, played
cricket, made the hockey team. I was captain of all the teams. Won all the
trophies in the athletics and all that – at school I was no good – sporting I was”.
He gave sport 100% and had good success and gained recognition with a variety
of trophies and awards. Sport did not involve any literacy-based skills and he
spoke of the explicit way they were taught set plays using pictures and diagrams.

His earliest memory was in Grade 1.

I remember the teacher and everything … there was 38 kids in the classroom and
only two of us got kept down in Grade 1 and I reckon that was the one that killed
me – Grade 1 … I just couldn’t do anything right. I just couldn’t sit still, couldn’t
concentrate …I would pull the girl’s hair and get a bit of attention and say ‘help
me, can you do this? Can you do that?’ I will always remember Grade 1.
He also recalls spending a great deal of his time being removed from the classroom or wearing a ‘dunce’s cap’ in the corner as a response to his behaviour, which in many cases was a result of him not “understanding what they were teaching”.

Having stuttered throughout his childhood, in Grade 5/6 it became considerably worse and it was at this time his teacher identified he was experiencing difficulties and, as a result, organised one-on-one ‘special classes’ with the ‘special teacher’ doing ‘lots of reading’. At this time he also had his eyes and ears tested which revealed ‘nothing wrong’. It was not until his early forties that he discovered that he had visual-motor integration and visual perception problems which affected his fine motor activities such as writing, drawing as well as his reading abilities. “I reckon if I had the glasses [when at school] I would have kept more inside I think”.

At high school he “was just in basic classes”. He located himself at the back of the class where possible and tried to keep quiet, however his concentration difficulties and his impulsive ‘loud mouthing’, which as an adult was diagnosed as ADD, once again caused him trouble. He also experienced panic attacks, which increased during the high school years, when he realised he did not understand or couldn’t do the work. His friends were very supportive and would complete his written work for him.

At the completion of Year 10 he went to work for his uncle in a panel beating shop and began an apprenticeship which involved going to TAFE. Although he had problems doing that – particularly as it was during the Christmas break for 6 weeks – “when it’s holiday time!”, he realised that by simply attending and doing
the revision ‘you got a pass anyway’. He claims he ‘wasn’t a good panel beater or spray painter’ which he links to his visual processing difficulties and due to his inability to ‘stay steady’ he continued to experience panic attacks like those in school.

After completing his apprenticeship he took off up north with a mate and for 3 months did soil surveying until uranium was found in the soil and ‘the government shut it down’. Then it was back down south where he ‘went roofing with dad for a while, painting and then I had enough of that and went and did floor sanding for 12 years and I’ve been doing this for 15 – 16 years.”

In his early 40s, when he was experiencing difficulties with his first marriage and was attending counselling sessions, it was suggested that he see a ADD specialist who prescribed medication for his concentration. She then recommended having an assessment for dyslexia, which he had and then the psychologist sent him to a vision specialist who identified eye-co-ordination difficulties as well as scotopic sensitivity syndrome (SSS). As a result of this he was prescribed glasses.

It was his second wife who drew his attention to the dyslexia course at TAFE which gave him not only increased confidence, but also the “understanding it’s not me that’s got the problem – it’s the other people that have got the problem”.

“And that’s about it. That’s my life!”
Riley’s story

Riley’s dream in life has not only been to have a career but also to have a meaningful relationship with a partner. But her life has been fraught with frustration through her difficulty processing written, receptive and expressive language. Her dyslexic characteristics have been exacerbated by hearing difficulties from a young age. These have impacted on all aspects of her life and even though she has a greater understanding, particularly of her dyslexia, she finds her co-morbidity of difficulties provide many challenges.

One characteristic of her dyslexia is a lack of word knowledge and particularly the comprehension of ‘larger words’ and even when she uses a dictionary to find their meaning she then forgets them. She speaks throughout our conversations of not having the ‘understanding of knowledge’ – being able to decode the written word piece by piece, but not comprehending it and similarly listening to a conversation but it ‘not registering’ and then not being able to find the words and correct linguistic structure to respond. “I can’t get it out, when it just won’t come out ... I change the whole sentence, [re]format the whole thing just to get it out” There are times throughout our conversation when she simply says “my head’s gone mad at the moment” or “I’ve lost it, sorry”

Riley grew up in a family with an elder brother and sister and a younger sister. Her main memory during her school years was her mother remarrying and the family moving in with her stepfather. She briefly spoke of the difficulties everyone encountered with her stepfather as he was very strict and ‘an angry person all the time’. Because her parents were establishing their relationship they were unaware of her difficulties.
Her earliest memory of school was Grade 2 which she repeated after having her tonsils removed and an ear operation due to an abscess. The ear operation resulted in some hearing loss and continued operations to this day. Throughout primary school she struggled to keep up with her peers both academically and socially. “I was so frustrated. I was so upset and the teachers couldn’t understand it”. When asked about the good times in primary school she simply says “... no ...no”. Although, she does recall being good at sport and enjoying singing which were activities that took her out of the classroom. Her grade 4/5 teacher (“the one that bloody growled at me and slapped me!”), looms dark in her memories and she bitterly describes the public humiliation and physical bullying she endured during those years.

She then completed 2 years at the local high school in which she ‘was basic ... in the lower, lower classes” and spoke of being given no assistance at all. She strongly believes this lack of assistance has resulted in her “struggling in life trying to get somewhere”. It was during this time she became aware of her vulnerabilities based on her language skills particularly in a peer context.

...when you can’t keep up to them or anything they tend to not want to know you anymore – you say the wrong things to them and you didn’t mean to say the wrong things to them and they’ve taken it in the wrong way and they’ve thought you’re being nasty to me and they’ll go off and you’re left there standing with no friends anymore ... Or they’ll muse [sic] you to get around other people.

At 15 she was “off like a shot” and got a job at G.J. Coles. This lasted only 6 weeks because her parents had decided to move away from the city and she was expected to move with them. She remains quite bitter as to the lack of consultation that occurred and that her needs and current opportunities had not been considered. Upon settling in the new town she had experience in a number of retail jobs and at the age of 16 – 17 moved back to the city. It was at this
point she met her husband-to-be on a blind date. They got engaged when she
turned 17, married at 18 and the following year had their first child. Coupled
with this was a move to a remote town in the country to be close to her
husband’s family. They had four children. During this time in her life she says –

I had a horrible time – I had my babies – took me 3 and a half years to have my
second one but in those 3 years I told mum I didn’t want this baby because I was
so immature, I was really immature. I didn’t want the baby. I wanted to get rid
of it so it gave us our marriage life a chance. Mother turned round and said ‘I
don’t want to know you’. Your husband says “I’ll divorce you’, so where was I
supposed to stand. I was very naive. I had no proper education, no
understanding.

When the youngest child was six she separated from her husband and moved
back to the city. In the small country town in which they were living “there was
nothing for the girls to follow on there, whatever” and “I didn’t want them to end
up like me”. One of her daughters found the move particularly difficult and
returned to her father after one term at school in the city. She was to return
three years later when her father died. Riley’s ongoing relationship with her has
been extremely torrid and she says “we’ve only just started coming back as a
mother and daughter only since November last year [2006] we’ve been coming
back”.

She struggled during her four daughters’ adolescent years in the way they
treated her, particularly their frequent use of put downs such as “you’re not
smart mum ... you’re stupid”. “The way they treated me, it was shocking”. She
was also involved in a number of relationships which compounded her negative
self esteem to the point where she contemplated suicide. “...suicide in my mind,
that’s what I wanted to do ... I didn’t want to be in this world anymore ... I didn’t
care about the kids, didn’t want anything – don’t want to be here anymore”. She
recalls sitting at her kitchen table with a coin that was to decide her fate –
“suicide or go and learn how to ride a motorbike”. The toss of the coin resulted in her now having “a motorbike sitting in my garage and every now and then I will get on it and I will ride down and ... brush everything out of my mind”.

It was at this point in her life that she was referred to the TAFE, through Centrelink, to do the dyslexia course. Involvement in the course “made me understand me for who I am and for what I am and what knowledge I have – why things are happening and why I’m like this cause I’ve learnt the dyslexia”.

Concurrently she was also working in the hospitality field and one of her work colleagues ‘picked up’ that she had difficulty expressing herself and “he knows that I’ve got problems of reading and writing. He knows that I’ve got problems of writing letters and everything else as well”. Since then he has continued to provide her with non-judgemental support with her reading and writing.

Recently she shared an AWA (Australian Workers Agreement) with him – reading it and explaining it to her.

Confusion and lack of understanding throughout her life – through school, through relationships, through family experiences, through work have compounded her negativity and self-worth.

I couldn’t understand why I was getting so frustrated – why I couldn’t write a letter, why I couldn’t understand things, why I – it’s got to do with understanding of life – the relationship with your children, the relationship with your partner, your relationship with yourself – I couldn’t understand why I couldn’t have a happy type life and why it was sort of ... why I was crying all the time, why I was upset all the time.

Her responses during our conversations continually come back to her ability to process language, comprehend beyond the literal and then find the words to express herself coherently. “My brains going ‘brrrrrrrrrrrrr’ – I’m having a fit ...
will say something and my body language will come out with a totally different sign and I...I say something and the next breath I say something else and I confuse – I get confused”. She refers to ‘the understanding’ and believes ‘the understanding of knowledge’ as being the key to a career and a happy life.

**Sam’s Story**

She’s confident and doesn’t put up with any ‘crap’!

It’s evident that Sam has always been independently minded and determined to achieve what she sets out to do despite the odds. In a manner of fact way she describes her birth as “dramatic ... my mum didn’t want me, she wanted to abort me and I was one of twins ... I was the only one that survived!” From that time on she intimates without giving too many details, that home life was never pleasant and that she needed to develop resilience and independence as survival techniques.

Well groomed, small in stature and with an ‘English Rose’ complexion, Sam would be a force to be reckoned with in any situation, particularly when it comes to speaking her own mind or in situations where she believes an injustice has occurred. Highly articulate and willing to provide her opinion and experiences on any subject she does so in her heavily English accent – on one hand very single minded, yet on the other hand, demonstrating genuine care and empathy with others which is reflected in her current work with people with an intellectual and vision impairment.
She was born and educated in the UK, the youngest into a family of six children consisting of four girls and two boys, with 16 years difference between her and her eldest sibling. She speaks of one of her brothers and his son as having dyslexia, as well as her mother. She made no mention of her father at all during our conversations.

School was not a time of good memories with the combination of her learning difficulties, compounded by her unhappy home life where she “was always being bullied”, she developed strategies to consciously withdraw from situations. She spoke on a number of occasions of the ability to ‘leave her body’, in a spiritual context. “I came from a very violent upbringing; it was like I couldn’t cope so I would leave my body and somebody else would come in and take over”. This particularly happened during school times when she was having difficulties with the task she was expected to complete. As a result of this ‘leaving’ she would face verbal and physical public humiliation by the teacher. She spoke of public humiliation to the point whereby she decided “I’m not going to school tomorrow, I am going to die, I am going to kill myself”.

Sam attended Infant school from aged five to seven, and it was during this time she realised her difficulties with reading when her peers were “going up and going up” with their reading levels and she remained on the bottom level. She was also continually being told that “you’re not trying hard enough, you’re thick, you’re stupid”.

After Infant school she moved to a different school for Junior school and it was there she “really, really learnt that [she] had big problems”. It was during this time she learnt how to be quiet cause “if you didn’t answer you didn’t get hit. But if you answered and something was wrong you got hit. So I wasn’t just
getting hit from being at home, I was getting hit from being at school and I just hated it; I just hated it.”

From 11 to 16 she went to Senior School and was put in the “special class for dunces. That’s what we were classed – dunces, because we all had problems with learning difficulties – reading, writing and spelling.” It was at this school that she remembers a male teacher who was supportive of her needs. However he left due to illness and was replaced by a less caring teacher.

During senior school she recalls a number of incidents where teachers publically humiliated her, however she did not allow the power play to be one sided in that she ‘fought back’ and stood her ground.

One teacher –

she’d have a go at you for something or ‘you’re just not trying’ or ‘you’re just not very good are you?’ and I’d throw something back at her - ‘you’re on detention’ – ‘try and make me” – you know and she’d come over and she would say ‘you will do it’ – ‘try and make me” - and ‘right you’re in front of the head mistress, deputy head mistress’. So I’d go up in front of her yet again and she’d have the cane then and she’d say ‘next time you come up in front of me you get the cane’ and I just looked at her eye to eye and say “and I’ll hit you fuckin’ back with it” and that was it – they just left me alone after that. They said you’re a no hoper, you’ll never succeed, you’ll never get anywhere, you know, we wash our hands of you.

It was at this point Sue left school and her mother, on receipt of her final school report said

S can’t read, she can’t spell, she can’t do anything she’s useless, she’s hopeless ...

... my mum said What do you want to do with your life? I said ‘I want to travel; I want to see the world; I want to do things with my life.” And she said “Don’t be so stupid”. She went so red in the face that I thought she was going to have a heart attack. People like us don’t do things like that! The only thing you can do is get married and have a family because you’re not any good at anything else.
As a result of these experiences S set herself 5 goals. She was:

1. Going to learn to drive
2. Going to travel
3. ‘never going to have children so I could be like a bad mother like my mother was to me and hurt them’
4. Be independently self-sufficient in terms of finances so that she wouldn’t have to rely on anyone – ever!
5. To not marry before age of 30.

All of which, she proudly states, she has achieved.

After leaving school she found it difficult to get a ‘decent job’. The combination of ‘being constantly drilled with ‘you’re thick, stupid, can’t get anything right, can’t do anything’ I believed that’ as well as having to fill in application forms as soon as “I said no I can’t do this, I can’t read or spell well – ‘we don’t want you here”’. Another factor was the small town in which she lived – everyone knew each other’s business! So she left and moved to another town for a fresh start.

The next chapter in her life involves new beginnings in which she speaks of a number of significant turning points in her life. The first being meeting and marrying her husband, whose love, support and admiration of her as an individual as well as her achievements based on her dyslexia, has transformed her belief not only in herself but also close relationships; the second, going back into the classroom in the UK, and doing the training to become an ‘enabler’ and third, moving to Australia and doing the Dyslexia course at the TAFE.

It was during her training to become an enabler to work with people with vision impairments that she thought it was simply “walking with somebody and being their eyes ... guiding them” that she didn’t realise how much was involved in the training particularly from a literacy perspective. Had she known she says she wouldn’t have attempted it. She says she has used her dyslexia as a ‘crutch’ “if I
say I can’t do that and I don’t try it I can’t fail”. Her partner played an enormous role in not only providing moral support but also acting as a scribe for written tasks. Of the 10 people who began the course only 6 passed and S was told she was their ‘best enabler’. She recalls her partner saying “I admire you ... because you struggled so much but you never gave up. It was never in your mind to give up ... because so many people would’ve given up and how many people that aren’t dyslexic didn’t pass?”

It was shortly after this that they moved to Australia, her partner’s birth place. She decided that “Australia is a land of hope and it’s a new country... it’s got to be a forward thinking country and they must have ... some sort of help here [for people] with dyslexia”.

It was at this point she enrolled in the dyslexia course at TAFE. Through the information and contact with other people at the course she then came to the realisation that her perception that ‘people with dyslexia never got anywhere in life like myself” changed. This shift in her thinking had an enormous impact on her confidence and willingness to try anything. At the end of the course she was keen to continue particularly gaining an understanding of the acquisition of literacy skills and she began one on one tutoring with Applied Scholastics, which she continues to do to this day. Their methods reflect those taught in the Literacy component of the dyslexia course and address her learning style. She has also successfully participated in further training courses, the latest involved her desire to go and drive dump trucks in the mines and she had to complete an Occupational Health and Safety course which comprised a variety of units. During this training course she openly declared her dyslexia and suggested specific methods to enable her to learn. She also found herself supporting other
participants who had difficulties with their understanding of the content and their literacy skills.

Concurrently, the qualifications and experience she gained in the UK were finally recognised in Australia and she became employed by the local Blind Society to support a young man with partial vision and autism. It is within this role she tells of the confusion her colleagues have expressed about her dyslexia. One of her bosses said “I never think of you as dyslexic because you’re far too intelligent”. The confusion she thinks arises from their ignorance and they equate literacy skills with intelligence.

Our work is working with people with blindness and deaf blindness and intellectual impairment – they class [dyslexia] as intellectual impairment. They associate me with our clients [who] can’t read or spell or very little so we should put S in that box – ‘but we can’t cause she’s too intelligent’... they felt they just couldn’t quite grasp why I was dyslexic and why I wasn’t intellectually impaired.

She does, however, emphatically state that she ‘puts them straight’.

Our final conversation finishes with a discussion about reading and she excitedly says “I actually take D [client] to the library in the bad weather and I read to him. I read to him!!!!!!”

Christine’s Story

August 6th – age 28 – “I know that date, that was a huge transition day”

Suddenly there was a reason for her life-long ‘internalised barriers’ – she had evidence - documented results indicating a high level of intelligence based on society’s norms, as well as a medical/scientific diagnosis which provided her with
logical and rational explanation about her characteristics. What a relief! But was it enough?

At the time Christine was at University studying psychology part time and with her academic knowledge in the field, and diagnosis on one hand, put her life’s experiences into a new perspective, but on the other hand didn’t erase the difficult memories associated with them throughout her schooling and through to her early 20’s. She sadly claims “my past is pretty black and it gets blacker and blacker until about the age of 20”.

Christine was born the youngest of three girls. As a young child she was identified as being developmentally delayed, which was the result of a stroke at birth affecting her cerebellum, and she didn’t walk until she was two. She was involved in Early Intervention programs at the local children’s hospital prior to attending full time school. During this time she recalls her mother ‘mollycoddling’ her and not giving her the opportunities to learn life skills. “I think I had a low self esteem before I went to school ... I thought my family thought I was a bit stupid cause mum would mollycoddle ... it wasn’t what I needed, it prevented me from learning”.

Although she began life with a developmental delay later in her school life she found success in sport. She was a state representative in both trampolining and diving and enjoyed also the tumbling challenges of gymnastics.

She began her schooling at the local public school. It was during Grade 1 that the teacher identified she was “not learning” and recommended that she move to a special education unit at another school. The unit catered for children with an intellectual impairment alongside learning disabilities and was located on site at a ‘mainstream’ school. She achieved success in this unit, which she not only
attributes to her own efforts but teaching strategies used by the teacher, as well as her attitude toward her students, but every time she was “learning things above and beyond what my mainstream class was doing they put me back in the mainstream class again and I’d plummet down again”. She moved between the unit and mainstream class up until Grade 4, where she remained in the mainstream class until Grade 6. By this time her self-esteem was quite low regarding her academic achievement – “I gave up by then. I wasn’t trying by then. I just thought what’s the point?” She was beginning to withdraw socially as well, as she found her peers responded to her efforts (academically and socially) in a negative way. She talks of her ability to do gymnastic flips and being excited about being chosen for a school play in which she was required to use her gymnastic abilities, and then being labelled a ‘show off’. “Something I was even good at was being knocked ... by peers, then academically I was being knocked – it was like ‘come at me from every angle why won’t you, come on!”

In her final year of primary school she moved “and [it was] probably one of the worst things I could have done – the picking on became worse. I no longer had friends. I had one close friend whom I still have ... she was a bit of a saviour for me too”. Her recollections of her primary years are filled with negative experiences particularly of the physical and emotional bullying and public humiliation inflicted upon her by teachers in particular. “Every year I withdrew more and more and I hated myself and I just loathed myself”. At age 11 she recalls saying to her sister “I wish a bus would come and hit me cause I’m so dumb”.

High school was no better either academically or socially. She began to withdraw more and more. Bullying increased and along with it, her self-esteem and
confidence plummeted which eventually resulted in depression and para-suicidal attempts. Even in Year 10 when she was chosen to attend a selective school for up and coming sporting achievers she only lasted a year because of the psychological and physical pressures that were applied in order for her to achieve. “I don’t think I was strong enough at this point ... mentally I couldn’t take it. I felt like I was a failure”. During this time her grandmother, who had provided lots of “good times”, died and compounded her feelings even further.

She then left school for 12 months and went into the workforce but a combination of her self-doubt, immaturity and life’s experiences up until this time, culminated in a break down. She returned the following year and completed Year 11. It was during this time she experienced an English teacher who made a huge impact on her life – “she had faith in me, she listened to me ... she had empathy, she would see how I was being treated in class and encourage me”. Her concern was such that she contacted Christine’s mother and suggested she seek medical help.

Around age 19 or 20, after meeting with a psychologist she had her first experience of labelling and without sharing that label, on reflection she realises how disabling that label became.

*I just remember seeing a psychologist and getting all these labels and crap put on me that I know are nonsense. There is one label in particular that was not valuable and sticks with me today. I still have a lot of trouble coming to terms with that label cause I work with some people like that have that label and I know how difficult they can be.*

After this time she had a number of ‘years of not doing much at all. I was bored, but I didn’t think I could get a job cause I just wasn’t smart enough ... and I was in and out of hospital with depression”.
She then decided to go to TAFE and successfully completed a Human Services Certificate 3. This also sparked a memory of her as a young child, wanting to be a counsellor. From there she heard about a course at the local University – “a foundation’s course for people with a mental you know, illness or whatever”.

With the help of her mother she wrote an application. She was accepted for an interview and they suggested the course would be totally inappropriate based on her level of intelligence and ability to communicate, and that she would be more suited for a course in the Social Sciences Faculty. She enrolled and then switched to doing Psychology with the aim of becoming a psychologist – at the time “psychologist and counsellor to me were the same thing then”. From there on her fascination with the cognitive functions of the brain and major facets of intelligence, began in earnest. Her passion for learning was also sparked.

On one hand she found that she absolutely loved what she studied and found she could explain them to others but she ‘couldn’t get the marks’ herself. She struggled with assignments – from a structural and writing perspective. Then she was diagnosed with dyslexia. Having documented evidence of her dyslexia and the understanding that accommodations were available she “blindly and naively thought – ‘oh it’s written there, they’ll do that for me’ – thinking that’s great”. The response in the Disability and Equity Services was ‘no, sorry we can’t: no, sorry we can’t to pretty much everything – ‘we can give you a scribe for your exams and a computer, but that’s it’”. She tells of a psychology lecturer, whose response to her email request for a weekend extension in which she stated she had been recently diagnosed with dyslexia and that “I was struggling to get the assignment done on time and ... that dyslexia affected my ability to process things and therefore it took me longer to do things”, replied “I will be excepting
"it once but I won’t be expecting that excuse again!". In which Christine’s responded to me - “In cognition!!!!?? And furthermore it’s not an excuse!!!”

Christine completed 3rd year psychology but was informed by the Head of the school that she “wouldn’t get into 4th year so I should try counselling”. She chose not to apply to that university to get into counselling because of the lack of support she had encountered. “I thought ‘no! I’ve had enough here, they’re not helping me, maybe another uni will help me’”. So she applied to two other local universities. She successfully got into the first and recalls during the interview, one of the interviewers saying “I have to say you have a really great counselling voice’. I just went ‘OK! I’ll just pick myself up off the floor’... I was just stunned. I didn’t expect to be complimented in an interview”. She completed a Graduate Diploma of Counselling whilst concurrently working as a volunteer phone counsellor at Lifeline.

She is currently continuing with her love of learning and is doing further studies in counselling at a third University. It is here that she experienced a complete shift in attitudes particularly in teaching style and recognition of needs both from the lecturers’ perspective and the services offered by equity services. She says that this university “is one place where they’ve wanted to bend over backwards for me. However, I haven’t wanted them to because of my past experiences at Uni”. Her ‘fear of failure and performance anxiety’ are continually at the back of her mind, particularly with assignment expectations. However, she speaks of her determination, persistence and resilience to deal with these thoughts, which are fuelled by her deep passion for learning.

With her knowledge and experiences Christine has reflected very carefully on her life and suggests that she has ‘reframed her thinking’ from focussing on the
positive aspects of her life and her dyslexia and disregarding or moving aside the negative components. She has moved from a pessimistic perspective to a more optimistic one continually using the statement “what are you going to do to make it work for you?” It has taken her a long time to do so however two factors have supported her reframing (1) her diagnosis of dyslexia and (2) her husband who she says “he says I’m his saviour but I say he’s my saviour ... my life changed when I got with him”.

She sums up her attitude and refocusing by saying with a sense of finality - “I’ve been a victim for a long time – no more, no more!”

Sarah’s Story

Our interview begins with Sarah outlining all the characteristics of her dyslexia and how they present themselves in her everyday life. She is very knowledgeable and self-ware as to her learning needs and the compensatory strategies that she uses on a daily basis particularly within the workplace. She believes her dyslexia has “improved over the years with tuition and training and hard work” but if she gets tired or fatigued then “it kicks in with a vengeance no matter what”. Remembering as a young girl her mother, “in vain”, trying to encourage her to read, to nowadays her “just about throttling me on the other side of the couch ... when I’ve got a good book and I’ve got my nose in it” she sees this as a positive transformation but she links this to her inner desire to access written information that has previously been out of her reach. This desire has come with age, maturity and knowledge. She tells of reading the Harry
Potter series of books about ‘six to seven times’ to gain the confidence and fluency in her reading – after this she “ventured out and read Jane Austin and Thomas More’s Utopia”.

Sarah’s early schooling started in a small country town in a multi aged classroom with one teacher as well as her two older sisters. At the age of 10 her family moved to the city and she was sent to a private school, where she remained for the rest of her schooling. School memories revolve around negative as opposed to positive memories. Her earliest memory is from Grade 2 when the teacher chastised her and humiliated her in front of the whole class and told her to “go back to pre-primary ... and do finger painting” because her handwriting wasn’t good enough – “that probably single-handedly destroyed my confidence ... I felt stupid and small”. Around this time she became aware of the differing levels of abilities in the class and defines them as “your smart kids and your dumb kids”. This was further exacerbated by withdrawal from the classroom to ‘practise our spelling’ during her favourite subject which she was good at – art. It also made her feel as though she had “this little label stuck on [her] forehead going ... ‘kid with problems’”. She experienced ongoing bullying by her peers but developed an aloof persona as a resilient response.

Family and in particular, parental support have been ongoing throughout her life. Her parents were aware of her difficulties, both her father and her elder sister have dyslexia. “I was never told I had a learning difficulty by my parents but I knew I had challenges and I needed to work at things but they never let me use it as an excuse”. Similarly her elder sister, who has dyslexia, grew up with this same attitude and Sarah proudly mentions she is now a school teacher and
claims because of her dyslexia she is able to relate to those children with learning difficulties.

From an early age her parents sought external professional support. She frequently visited an Opthalmalgic specialist at a local University with her sister, and when they moved to the city she attended a privately run centre which provided individualised fine and gross motor programmes as well as tuition for literacy skills.

Whilst she was attending the public country school she indicated that her parents, although concerned, felt reticent about ‘pushing too hard’ for support from the teacher and the school. She cites two reasons – the school teacher lived within the small local community and they could see negative implications for the family within the community, and secondly, the school refused to have her tested and ‘labelled’ because the “...Education Department was going through a phase when you don’t label anything”.

Moving to the city and to a private school brought with it a different attitude from both her parents in their advocacy role, and the response of the school and some of the teachers. Her parents insisted on formal testing and the school supported them and recommended an agency through which to do it. Her parents however had to pay the cost of the testing. With the paperwork indicating an official diagnosis of dyslexia came pages of documentary evidence “written in truly bizarre ways. You couldn’t understand it unless you had a Phd”. The school however provided a range of remedial support none of which addressed the specifics of Sarah’s learning needs.

In high school she recalls putting in 110% effort in all subjects and overworking herself to the point she felt like she was ‘drowning’ which resulted in panic
attacks in class due to the overload. She spoke of one teacher who reflected her parents’ attitude and recognised the enormous effort she was putting in and the marginal results she was achieving. The teacher said to her “... you know you’re always going to struggle but the one thing that’s good about you is you always hand everything in and you always do 110%”. This was a turning point in her motivation and her learning. Her parents had always remained focussed on encouraging effort and work ethic rather than marks.

After completing Year 12, having studied non-TEE subjects, she got into the Bridging into Nursing course at TAFE and successfully completed it. “It was there that I didn’t really want to hear it – I was told that I needed to work on my spelling”. She then moved into the Nursing course. It was during this course her literacy skills were questioned in the context of job-related tasks. Course co-ordinators recommended that she take six months off to improve her literacy skills, in particular her spelling. In her determination to succeed she actively sought and attended Adult literacy classes, support through the voluntary tutoring organisation Read, Write, Now as well as returning to her external tutor from high school who focussed on spelling of medical terms. It was at this time she found the Dyslexia course at TAFE which helped her in her self-advocacy as well as the realisation that she has had ongoing family support throughout her life which has enabled her to develop resilience and determination but more importantly take the risks to achieve.

After the six months she returned to enrolled nursing and requested that she repeat the previous semester to reinforce her understanding however both the TAFE and Nursing Board disallowed this. She did not complete her final semester because in an assessment she misread a drug and replaced it with a fatal drug –
although she self-corrected “it was brought up as an issue ... and they said no, we wouldn't be recommending you to be registered at the Nurses Board”.

Although very angry and upset (and still continues to be) as to the anguish and frustration and treatment she received she returned to TAFE to complete a Certificate 111 in Allied Health. She sought prior learning for the Aged Care component based on her voluntary aged care experience and further prior learning from her nursing studies. She is now a qualified Occupational Therapy Assistant and “absolutely loving it. Having a wonderful time”.

When applying for her current job she chose to disclose her dyslexia because she felt it was important that they understood. “I just warned them that this was the deal and all that and this is what my problem was and they went that’s OK – we understand”. She indicates that the job does entail a degree of written documentation but it is her job skills that are non-literacy based that they value and she is openly acknowledged for.

Her next challenge in life is an overseas trip which she is about to embark on with a childhood friend from school.

_Nursing was my dream. When I look back now I think yeah I would have been good at it ... but the therapy side of things now interests me more and intrigues me in other ways. I probably learnt to accept that it probably just wasn’t meant to be._
Appendix G

Positive and negative teaching techniques

Table G1. Primary and Secondary Education: Teaching techniques and strategies perceived as positive

<table>
<thead>
<tr>
<th>POSITIVE</th>
<th>PRIMARY – identified by 4 participants</th>
<th>SECONDARY – identified by 3 participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Literacy-based</strong></td>
<td>• #Provided appropriate levelled book</td>
<td></td>
</tr>
<tr>
<td><strong>2. Reward techniques</strong></td>
<td>• *Token economy – rewarded for work</td>
<td></td>
</tr>
<tr>
<td></td>
<td>– attempts &amp; completion</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Art displayed in art gallery</td>
<td></td>
</tr>
<tr>
<td><strong>3. Individualised techniques</strong></td>
<td>• *Work at own pace – individualised</td>
<td></td>
</tr>
<tr>
<td></td>
<td>program</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• *#Small group work – ability groups</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Peer tutoring</td>
<td></td>
</tr>
<tr>
<td><strong>4. Other</strong></td>
<td>• *Made learning fun – used laughter</td>
<td></td>
</tr>
<tr>
<td></td>
<td>* = during withdrawal sessions</td>
<td></td>
</tr>
<tr>
<td></td>
<td># = regular classroom</td>
<td></td>
</tr>
</tbody>
</table>

1. Literacy-based
   • *Flashcards
   • *#Repetitive learning – going over the same content - sounds in words
   • #English teacher - Break down tasks into manageable tasks - Teach strategies how to deal with lots of text

2. Individualised techniques
   • *one-on-one teaching
   • *individualised program
   • *Take time to explain, demonstrate and make sure you understood.

3. Smaller class sizes

Table G2. Post Secondary Education: Teaching techniques and strategies perceived as positive

<table>
<thead>
<tr>
<th>Classroom-based teaching techniques</th>
<th>Institutional strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TAFE</strong></td>
<td>• Specialised classes – content directly linked to life or work skills</td>
</tr>
<tr>
<td></td>
<td>• Availability of ‘Bridging courses’</td>
</tr>
<tr>
<td></td>
<td>• Credit for Prior Learning</td>
</tr>
<tr>
<td></td>
<td>• Hands on learning – linked to vocation/career</td>
</tr>
<tr>
<td></td>
<td>• Repetitive presentation of material</td>
</tr>
<tr>
<td></td>
<td>• One-on-one – individualised assistance</td>
</tr>
<tr>
<td></td>
<td>• Interactive classes</td>
</tr>
<tr>
<td><strong>Workplace Training</strong></td>
<td>• Assessment modifications – oral not written</td>
</tr>
<tr>
<td></td>
<td>• Practical – demonstrations</td>
</tr>
</tbody>
</table>
### University
- Distinct structure of genres for assessment tasks
- Multiple components to assessment tasks – written, practical, oral etc.
- Course inclusion based on interview selection process

### Tutoring
- Multi-sensory teaching techniques
- Individualised programs
- Work at own pace
- Make learning fun
- Taught assignment structuring

<table>
<thead>
<tr>
<th>Table G3. Primary and Secondary Teaching techniques and strategies perceived as negative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NEGATIVE</strong></td>
</tr>
<tr>
<td><strong>PRIMARY</strong></td>
</tr>
<tr>
<td>1. Literacy based strategies</td>
</tr>
<tr>
<td>- Working through workbooks – no explicit teaching</td>
</tr>
<tr>
<td>- Stand up and read in front of class</td>
</tr>
<tr>
<td>- <strong>#Phonics and alphabetic principle</strong> – rote learning – one single method</td>
</tr>
<tr>
<td>- IPA – International Phonetic Alphabet (primary – different method in HS)</td>
</tr>
<tr>
<td>- Left-handed – made to write with right hand</td>
</tr>
<tr>
<td>2. Punishment</td>
</tr>
<tr>
<td>- Physical or verbal abuse if got something wrong.</td>
</tr>
<tr>
<td>- Removal from lesson to do ‘cleaning’.</td>
</tr>
<tr>
<td>3. Large Class sizes</td>
</tr>
<tr>
<td><strong>SECONDARY</strong></td>
</tr>
<tr>
<td>1. Literacy based strategies</td>
</tr>
<tr>
<td>- Reading aloud to the class</td>
</tr>
<tr>
<td>- Given Extra homework – didn’t ‘get it at school’ – practice at home – no explanation or support</td>
</tr>
<tr>
<td>- Use of computer software – predictive text – inappropriate use – to use computer to retype work already completed with no support</td>
</tr>
<tr>
<td>2. Punishment</td>
</tr>
<tr>
<td>- if work not completed or incorrect = no sport</td>
</tr>
<tr>
<td>- Stopped art to concentrate on literacy and maths skills</td>
</tr>
<tr>
<td>Negative</td>
</tr>
<tr>
<td>--------------------------------------</td>
</tr>
<tr>
<td>TAFE</td>
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<td></td>
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<tr>
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<tr>
<td>Workplace Training</td>
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<tr>
<td>University</td>
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<tr>
<td></td>
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<tr>
<td>Tutoring</td>
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</tbody>
</table>
Appendix H

Signposts of dyslexia dependent on the interplay within contexts

The emergence of signposts of dyslexia that referred to their self-awareness of dyslexia, became evident during initial and follow-up discussions with participants. Participants identified themselves as being at certain stages of self-awareness with their dyslexia from both a cognitive and a practical day-to-day perspective. Christine referred to them as ‘stages of dyslexia’ and suggested that it is necessary to go through these stages in order to fully understand oneself and the impact that dyslexia has on one’s life. However she suggested that without knowledge such as that provided through the dyslexia course, this would become difficult and people would not be able ‘to move on and get on with life’.

The following nine signposts or stages of dyslexia and their components were identified. Participants are indicated within stages.

<table>
<thead>
<tr>
<th>Stages</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware but unknown</td>
<td>Aware of difficulties but not aware of dyslexia Belief that they could never learn (Riley - recalls being in this stage)</td>
</tr>
<tr>
<td>Closed Shop</td>
<td>Nosek (1997) – “knows he is dyslexic but conceals his dyslexia from himself through denial and from others out of shame and fear” Components as distinct from Nosek’s identifiers: - Acknowledges dyslexia (through participation in course) but will not disclose or discuss with others (even other participants) – fear of past experiences, fear of failure, fear of stigma, lack of trust. (Sam – observation of others in course)</td>
</tr>
<tr>
<td>Selective closed shop</td>
<td>Knows they are dyslexic but will only disclose with someone they are comfortable with – context and person dependent (Sam &amp; Riley)</td>
</tr>
<tr>
<td>Confused</td>
<td>Acknowledges dyslexia (through participation in course and within group Confusion exists as to understanding of dyslexia and own characteristics Unclear relationship between intelligence and dyslexia Fear of responses of others – fear of stigma Exacerbated by lack of understanding of co-morbidity of difficulties (Kim and Riley)</td>
</tr>
<tr>
<td>Victim to dyslexia</td>
<td>Victim to their dyslexia Caught in a negative downward spiral exacerbated by failure throughout life Negative self-talk over rides any positive external feedback or success Exacerbated by frustration and confusion linked to understanding of difficulties. (Riley) (Christine &amp; Kerrie recall being in this stage)</td>
</tr>
<tr>
<td>Frustrated</td>
<td>Internal frustrations - Inappropriate use and knowledge of compensatory strategies (Riley) External frustrations - Ongoing as new challenges are faced and adjustments need to be made (Sarah)</td>
</tr>
</tbody>
</table>
- Achieving job satisfaction through hurdles to study (Riley, Sarah, Christine)
- Lack of support and non-recognition i.e courses and assistance for people with dyslexia (Sam, Kerrie)
- Ignorance and attitudes of people (Sam, Sarah, Christine)

**Searching**
Comfortable with own dyslexia but searching for:
- A cure (David)
- Techniques and alternative methods to lessen impact of characteristics (Sue, Juanita, David) - Christine – ‘been there’

**Advocate**
Components:
- Recognition, awareness and understanding of own dyslexia
- Knowledge of legislation and policies
- Internal Desire and/or external motivation to bring awareness of dyslexia to others
- 3 types – Public, Selective public and/or personal (public consider Keith – ran for politics used dyslexia as his campaign forum)
- Similar to Nosek’s ‘Candid dyslexic’ who ‘knows he is dyslexic and is honest and open about his dyslexia when he deals with himself and others’, however, there appears to be a decision between being an advocate in a public and/or personal context.
  (Sam, Kerrie, Juanita, Joseph, Christine, Sarah, Robert)

**Accepted and content**
Components:
- Acceptance of dyslexia as a positive component of individual make-up
- Compartmentalised difficulties – as separate from other personal attributes
- Can identify strengths and limitations
- Transference of problem ownership – ‘not my problem – other people’s problem’ (Robert)
- Does not consume all life choices
- Able to self-advocate when necessary
- Accomplished plan of action
  (Christine, Juanita, Joseph, Sarah, Sam, Robert)

These signposts appear stage-like, but participants indicated being within a variety of categories at once, as well as having ‘been through’ particular categories. The stages or categories do not constitute a logical progression with individuals indicating they have passed through in a linear sequence. Some did not consider themselves in particular categories or having ever been in them. All participants within the **advocate** and **accepted** categories indicated it was as a direct result of the knowledge gained from the dyslexia course. All participants indicated being in the **Aware but unknown** category during their early schooling and for some, up until their participation in the course. Higgins and colleagues (2002) found a similar “recycling “ process of perceptions.
Appendix I
Types of disclosure and signposts of dyslexia

Signposts of dyslexia

Types of disclosure

Aware but unknown
Closed-shop
Selective closed-shop
Confused
Victim to dyslexia
Frustrated
Searching
Advocate
Accepted and content