

An interpretative phenomenological analysis of the experiences of parents of children with dyslexia in

Australia

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Abstract

Parents of children with dyslexia often feel powerless to help influence their child's education, frequently having their concerns and input dismissed by schools. Within Australia there has been limited research into the experiences of parents. What literature there is would suggest that parents do not feel engaged by their child's school, which is in contrast to Standard 7 of the Australian Professional Teaching Standards and many State and Federal parent engagement policies.

The recent debate surrounding the Year One Phonics Check (Y1PC) and its implementation beyond South Australia is focussed on the dichotomy of analytic or synthetic phonics, and has not yet drawn on parents' perspectives to inform the implementation of a new standardised screener. Given the direct impact of the Y1PC on students with dyslexia, there needs to be stronger collaborative efforts between schools and families to help the students achieve academically and improve their mental health outcomes.

This paper examines the experiences of parents of children with dyslexia and their relationships with their child's school. Interpretative phenomenological analysis (IPA) was used to explore the parents' values and beliefs of their experiences. The IPA approach allowed for a rich and detailed exploration of the systems and contexts that influence parental experiences when their child has a diagnosis of dyslexia. Three participants were recruited to share their experiences of their children's diagnoses of dyslexia and their interactions with their children's schools. Semi-structured interviews were held via teleconference and transcriptions were analysed for descriptive, linguistic and conceptual elements. Parental experiences were explored through a relational developmental lens giving insight into how parent and student well-being is influenced by the relationship between schools and parents.

Table of Contents

Abstract	2
Table of Contents	3
Acknowledgements	5
Acronyms	5
1. Introduction	6
1.1 Background	6
1.2 Statement of Problem	7
1.3 Purpose of Research Project	8
1.4 Underlying Assumptions	8
1.5 My Interests, Motivations and Biases	9
1.6 Philosophical Perspective	10
2. Theoretical Framework	11
2.1 The Microsystem	12
2.1.1 Biology	12
2.1.2 Parental advocacy	13
2.1.3 Schools	13
2.2 The Mesosystem	13
2.2.1 Interaction	13
2.3 The Macrosystem	14
2.3.1 Politics	14
2.4 Theoretical Pluralism	14
3. Literature Review	15
3.1 Silencing of Parents	15
3.2 Dyslexia & Mental Health	17
3.3 Politics of Year One Phonics Check	19
4. Research Methods	21
4.1 Methodology	22
4.1.1 Design	22
4.1.2 Recruitment and Participants	22
4.1.3 Procedure	23
4.1.4 Interviews	23
4.2 Analysis	24
5. Findings	25
5.1 Analysis of findings	26
5.1.1 People - Microsystem	26

5.1.2 Process - Mesosystem	28
5.1.3 Context - Macrosystem	33
5.1.4 Time - Chronosystem	35
<i>5.2 Interpretation of findings</i>	37
Research question: What values and beliefs do parents of children with dyslexia hold about their experiences with their child's school in the early years?	37
Sub-question 1: Do parents believe schools effectively respond to identification of SLDR (dyslexia) or mental health concerns?	37
Sub-question 2: Do parents believe their advocacy for their child is valued?	39
Sub-question 3: What influences do the meso, macro and chronosystems of the ecological model have on the parents' experience?	40
6. Future Research Opportunities	41
7. Limitations	41
8. Conclusion	42
9. Reference List	43

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To my dyslexic daughter, let’s go punch some tigers!

Acronyms

AITSL	Australian Institute for Teaching and School Leadership
CIS	Centre for Independent Studies
DSM V	Diagnostic and Statistical Manual (5th Edition)
IPA	Interpretive Phenomenological Analysis
ITE	Initial Teacher Education
MHC	Mental Health Concerns
NAPLAN	National Assessment Program for Literacy and Numeracy
SSP	Systematic and synthetic approach to phonics
PIRLS	Progress in Reading Literacy Study
RDS	Relational Developmental Systems
SLD	Specific Learning Disability
Y1PC	Year one Phonic Check

1. Introduction

1.1 Background

Currently there is a strong yet contentious emphasis on the literacy outcomes for students in Australia (Honan, Connor, & Snowball, 2017; Robinson, 2017; Tehan, 2019). While there have been calls to introduce the UK Year 1 Phonics Check (Y1PC) in Australia in order to improve academic outcomes (Buckingham, 2016), little has been systemically done to identify or reduce mental health problems in those experiencing difficulty with literacy, namely those with a specific learning disability - reading (SLDR), also known as dyslexia (American Psychiatric Association, 2013).

It is important that schools recognise that they need to address both the academic and social-emotional needs of children with dyslexia, as the latter is a significant barrier to the former. Parents often have a level of insight into and expertise in their children's disability and their contribution to improving the education provision would be valuable. Up until now, parental opinions, beliefs and lived experiences have been largely un-researched in Australia (Leitão et al., 2017) yet parental voice is presumed to be important by government policies and teacher professional standards in relation to the education and wellbeing of students with disabilities (Australian Institute for Teaching and School Leadership (AITSL), 2019; Queensland Government, 2019b). This project could help promote parental engagement by informing stakeholders of parental experiences, attitudes, values and beliefs.

Though I take the researcher position in the project, I am also the parent of a child with dyslexia. Her journey through early schooling was extremely difficult. My initial teacher education (ITE) had not provided me with knowledge of evidence-based reading instruction, however my experience as a learning support teacher allowed me to identify the cause of her difficulties. While I undertook specialist training to provide targeted intervention at home, my daughter experienced school refusal and somatic issues causing a high level of interference with daily life. I felt my initial concerns regarding her literacy acquisition and declining mental health were not addressed in a way that meaningfully supported her. I was responsible for identifying her learning needs, obtaining a diagnosis and recommending strategies for classroom teaching. Eighteen months after she began school, at 6 ½ years old,

my daughter had suicidal ideation caused by the difficulties in literacy acquisition. This very personal experience led me to research if it was a phenomenon shared by other parents.

1.2 Statement of Problem

The problem being explored is complex and multi-layered, involving children, parents, schools and politics. Ultimately, there is a lack of literature capturing the experiences of parents of children with dyslexia and the recent debate surrounding the Year One Phonics Check has not yet drawn on parents' perspectives as part of a collaborative process. The values and beliefs that parents have towards the education process will be shaped by them and their child's experiences with schooling, which is directly influenced by government policy and politics. While the outcomes of these interactions may include lower academic outcomes for children with dyslexia, it may also lead to increased stress and anxiety for them and their parents.

At the heart of the experiences in this phenomenon, from which meaning and perspective are found, lies a power imbalance. According to Poed (2016) parents often cite tensions around education adjustments in discrimination claims, tensions that relate to parental voice not being heard or honoured. Likewise (Reardon et al., 2017) identified dismissive professionals, limited confidence in professionals, recognition of the problem (and severity of the problem) as barriers to accessing help for mental health concerns in children. Table 1 outlines the research questions to be answered.

Table 1

Research Questions and Sub-Questions

Research Question
What values and beliefs do parents of children with dyslexia hold about their experiences with their child's school in the early years?
Sub-questions
1. Do parents believe schools effectively respond to identification of SLD or mental health concerns?
2. Do parents believe their advocacy for their child is valued?
3. What influence do the meso, macro and chronosystems of the ecological model have on the parents' experience?

1.3 Purpose of Research Project

The purpose of my project is to describe the experiences and highlight the values and beliefs of parents of children with dyslexia and a mental health concern. In particular the values and beliefs pertaining to the Year One Phonics Check (Y1PC) will be explored. By delving into the way in which different contexts or systems influence the phenomenon, a description of the processes that influence parental experiences can be created.

Furthermore I will make a contribution to the current Australian literature on dyslexia by including the voice of parents, which has been so far silenced. Conceptual Framework

The conceptual framework is intended to assist the researcher to develop a holistic understanding of the context in which the research problem exists (Smyth, 2004). The conceptual framework should provide a common language and guiding principles, and a structure for the analysis and conclusions drawn while also centring the research questions within the literature (Smyth, 2004). Ravitch and Riggan (2016) outlined a structure for the framework that addresses the foundational assumptions of the researcher. This includes investigating the researcher's personal interests and motivations that drive their ontology. Secondly it explores the researcher's identity and personality that underpin biases, ideological beliefs, epistemology and social location within the community being researched. Finally the philosophical underpinnings of the research and the researcher need to be explored.

1.4 Underlying Assumptions

It is important to note that the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM V) uses the term Specific Learning Disorder (SLD) as an umbrella term to describe what has previously known as dyslexia, dysgraphia and dyscalculia (American Psychiatric Association, 2013). While the diagnosis given by a professional would be SLD in reading, writing or mathematics respectively, it is common (and also recognised by the DSM V) that the terms dyslexia, dysgraphia and dyscalculia are synonymous. As such, this paper will use the more commonly used and understood term of dyslexia.

The motivations underpinning my project are based on the assumptions I have about the nature of school experiences and educational policies, as well as teacher actions and how these affect children and families with dyslexia. Bronfenbrenner argued that

researchers conducting ecological research must take into consideration their own influence on the phenomenon (Rosa & Tudge, 2013). My assumptions as a researcher are largely influenced by my role as a learning support teacher, as the parent of a teenager with a disability and a young child diagnosed with SLD – reading, writing and mathematics, and mental health disorders. My own experience as a parent has shown that dyslexia is not understood or addressed through (ITE) and is not catered for in the classroom. It is my belief that this is part of the cause of comorbid mental health concerns (MHC) in young children with dyslexia. My experience also tells me that parental voice is often ignored and disregarded by schools, further exacerbating the difficulties.

Often in educational research, researchers come from a background of classroom teaching and educational practitioners (Berman & Smyth, 2015). As a teacher I have often found myself supporting students identified as having academic difficulties, but also experiencing mental health concerns. While provisions are made to improve student academic outcomes with the tiered response to intervention model (Catts, Nielsen, Bridges, Liu, & Bontempo, 2015), my experience and observations have led me to believe that schools generally lack an understanding that mental health in students with dyslexia is linked to academic instruction (Novita, 2016). Schools also seem to lack the processes to identify both the difficulties associated with dyslexia and mental health concerns at an early age. Both dyslexia and mental health illnesses/disorders are able to be formally diagnosed by the time the student starts schooling (Ozonoff, 2015).

1.5 My Interests, Motivations and Biases

This personal background, along with my role as a learning support teacher, grounds me firmly in the ideology of equality of access to education. I have seen the potential for education to marginalise vulnerable groups in society through a lack of quality provision of education. I also recognise that the process and the experience of education is as important, if not more so, than the outcomes (Dale & Hyslop-Margison, 2010). My parental concerns were misattributed by the school and my knowledge and experiences were devalued. My daughter has experienced micro discrimination through the deprivation of educational adjustments which has been described as being “more insidious’ than more overt or macro forms of educational discrimination (Cologon, 2013, p. 27).

1.6 Philosophical Perspective

These assumptions and experiences as a parent and a teacher are the foundations for my ontology as a researcher and have helped me to frame my conceptual framework (Smyth, 2004). Imenda (2014) stated that a conceptual framework was by necessity limited in scope so as to be immediately applicable to the research it was underpinning. On the surface it would appear that this would lean towards an interpretivist ontological approach, relying on an understanding that meaning is made through social experience and interpretation (Blaikie, 2004). This is grounded in the phenomenologist's understanding that experience is subjective (Luft & Overgaard, 2013). Friere's critical ontological position agreed that people were conscious beings and active participants in their own meaning making (Roberts, 2015). The nature of this phenomena, which involves highly emotive experiences and mental health concerns, requires both an empathetic and direct understanding to explore the attitudes, values and beliefs of the participants.

There is an essential acknowledgement of the fact that this is a social phenomenon, involving interactions between people, namely the child, parent and school. It is from these social interactions that the individuals derive meaning from their subjective experiences (Allen, 2017; Pauli & Reusser, 2015). Constructivism gives credence to these parental experiences by upholding the belief that reality is not distinct from the parent's interpretation of that reality (Allen, 2017). Though strict definitions are not found in educational or psychological literature, co-construction can be seen to have three main elements: social discourse or interaction occurs, there is a productive co-construction activity and there are expected outcomes of the co-construction, in this case knowledge and meaning making (Pauli & Reusser, 2015). Vygotsky believed that interpersonal co-construction occurred before it was transferred to intrapersonal understandings (Pauli & Reusser, 2015) and this is evident in the project in that the interactions between parents, children, schools and politics have already occurred (Apple, 2012) and the project is interpreting the intrapersonal meanings and understandings of the parent participants. Patterns in meaning and knowledge making can be established by observing the interactions between individuals and contexts (Leitão et al., 2017). This honours the phenomenological and idiographic approach of the project as the person-first point of view is the central point of data collection and analysis (Luft & Overgaard, 2013).

Guzzini (2005) warned against attributing power in constructivist research as there was a risk of politicising the issues, however in this case, politics cannot be avoided. The introduction of the Year 1 Phonics Check (Y1PC) in Australia has become a highly politicised topic with state governments, teacher unions and the Australian Institute for Teaching and School Leadership all contributing to a contentious debate around the role of phonics education (Robinson, 2017; Tehan, 2019). While the South Australian Government has adopted the screen (South Australian Department of Education, 2019) and the Australian Federal Government is encouraging schools to take up the check voluntarily, some individuals and groups within the education field are petitioning against any emphasis being placed on phonics instruction (Australian Association for Research in Education, 2019).

Many researchers have argued that the political and education systems are central in dominating and maintaining unequal relationships (Apple, 2012). Giroux described schools as contested arenas where competing and unequal groups struggled to achieve their perception of social order (Giroux & Robbins, 2015). They went on to argue that schools could only be fully understood when their relationship with governments were explored, as students (and by extension their families) were not responsible for the endemic failure of schools to meet the needs of students and families. There is clear evidence within the context of this project that there is a relationship between government policy, school level decision making, the experiences of parents and the imbalance of power influencing the co-construction of meaning. Without true collaboration with parent stakeholders and their experiences being brought to the forefront, the relationship becomes an unequal one, with the government and schools having power over parents and students. Alase (2017) concurred that IPA lent itself to combining a critical and interpretive paradigm to truthfully investigate, explore and interpret the lived experience of the participant within their social construct. This leads me to adopt a critical research paradigm, recognising the power relationship inherent in the transactions between individuals and systems.

2. Theoretical Framework

Both nature and nurture play a role in the developmental pathway of any individual (Lerner, Hershberg, Hilliard, & Johnson, 2010; World Health Organisation, 2012) and within my project this can be best understood by exploring the various contexts/systems that are evident in the experience of parents of children with dyslexia and mental health concerns.

Bronfenbrenner's ecological systems model describes life span development as involving the individual as an active participant within social and cultural contexts (Darling, 2007) and this is a critical element of a constructivist approach (Allen, 2017; Guzzini, 2005; Pauli & Reusser, 2015). Typically, children's dyslexia experiences are situated in the microsystem while parental experiences also extend to the exo-system (Leitão et al., 2017).

A relational developmental systems (RDS) perspective is an ideal lens through which to view this project, as it frames an understanding of human development and the bi-directional relations between individuals and the contexts they inhabit (Lerner et al., 2010). It builds upon Bronfenbrenner's model and as a process-relational framework it focuses on process, relational analysis, the use of multiple perspectives and explanatory forms (Lerner & Hilliard, 2019). RDS looks for change within and of the system and views individuals as active participants of "mutually influential relations between individuals and contexts' (p5). This is depicted as individual - context relations.

The impacts of dyslexia within the individual, family and community systems have been shown to impact on the micro-, exo- and macrosystems (Leitão et al., 2017). Additionally, RDS explains how the lived experience is influenced by genetic and biological traits, immediate relationships within families, and other face-to-face interactions and more distant social, cultural, and political climates, as it emphasises the causality as "reciprocal, bi- or multi-directional or circular (positive and negative feedback loops)" (Overton, 2013, p. 52).

2.1 The Microsystem

2.1.1 Biology

There is considerable evidence to support a genetic or biological contribution to dyslexia (Esmaeeli, Kyle, & Lundetrae, 2019; Thompson et al., 2015; Yu, Zuk, & Gaab, 2018). Research shows dyslexia has a neurological component and with a high proportion of children with the condition showing deficits across numerous neuropsychological domains (Hendren, Haft, Black, White, & Hoefl, 2018; McDowell, 2018; Morgan, 2011; Novita, 2016; Shaywitz & Shaywitz, 2016). These biological constraints are not in and of themselves the cause of the difficulties experienced by children with dyslexia. The difficulties arise when

their neurodevelopment interacts with external contexts, namely the school, where literacy is introduced (Novita, 2016).

2.1.2 Parental advocacy

Research into the protective factors for reading difficulties tends to focus on interventions within the school context, the role of early literacy in the home or the hereditary nature of dyslexia (Esmaeeli et al., 2019; Yu et al., 2018). What is missing from the literature is an in-depth investigation into how parental advocacy acts as a protective factor and whether this helps to improve literacy outcomes and mitigate mental health concerns. The literature does more broadly recognise that parents play a pivotal role in the diagnosis of and advocacy of their children's needs, but this can be limited to the families with the financial means to do so (Earey, 2013; Levi, 2017).

2.1.3 Schools

Schools are multi-layered organisations that influence multiple student developmental domains through organisational, social and instructional practices and can be seen as a bridge between the microsystem and macrosystem (Eccles & Roeser, 2010). While homes have been identified as needing to support early literacy acquisition through exposure to books and vocabulary, explicit phonics instruction in a school environment is recognised as being key to the success of all students, but particularly those with dyslexia (Buckingham, 2016). At a classroom level Hornstra, Denessen, Bakker, van den Bergh, and Voeten (2010) found that teachers' negative implicit attitudes towards students with learning disabilities affected both their instructional teaching and their expectations of the students.

2.2 The Mesosystem

2.2.1 Interaction

Gatekeeping, the process of schools deciding which information they deem relevant to determine a student's needs (Teather & Hillman, 2017), is a common occurrence amongst a variety of disability categories in Australia and maternal experiences of gatekeeping range from enrolment to classroom instruction (Lilley, 2013). Levi (2017) found that the disharmony over establishing the status of dyslexia is located in the interactions between parents and teachers. These difficulties begin when parents first engage their

child's school in a discussion about literacy difficulties and extend to the provision of resources. It is this level of the RDS that will be explored more thoroughly in this research.

2.3 The Macrosystem

2.3.1 Politics

International and domestic politics play a not insignificant role in influencing the way literacy is taught and the way parents and students engage with and experience schooling. The Programme for International Student Assessment (PISA) results for 2018 show a decline in the number of students achieving literacy benchmarks (national standards) from 2000 with 49% of 15 year old students not meeting minimum national standards (Thomson, 2019) with 20% of Australian students considered low performers (Thomson, De Bortoli, Underwood, & Schmid, 2019). This data is used to develop policies to target improving academic outcomes for students (Australian Government: Department of Education, 2018).

Domestically there is sufficient political rhetoric regarding engaging parents in the schooling process to suggest that there is a political belief in the value of co-construction of knowledge and meaning between the micro, meso and macro system levels (Australian Government Department of Education, 2017; Australian Government: Department of Education, 2019; Queensland Department of Education Training, 2016; Queensland Government, 2016, 2019b).

Each of these systems is seen within the phenomenon at the heart of this project, justifying the use of a relational developmental systems theoretical underpinning to explain the co-construction of the participants' lived experience.

2.4 Theoretical Pluralism

In seeking to establish a theoretical coherence for this project, it is necessary to adopt theoretical pluralism. Some argue that there is no single theory that one can completely and holistically describe any single phenomena or lived experience (Imenda, 2014). Hood (2015) supported the idea of a pluralist approach to compliment the phenomenological methodology stating that it could enrich the interpretation of discourses and social processes shaping the lived experience. In this project critical theory is the bridge between constructivism and relational developmental systems theory. Individuals may construct their own meaning based upon their lived experiences, and this is influenced

through the different systems and contexts that they transact with, however, when some of these contexts have inherent power over the individual, then the nature of the transactions are unequal. As such, a theoretical approach that integrates constructivism, RDS and a critical paradigm has been adopted.

Historically there has been a viewpoint that constructivism and a realist, critical paradigm could not co-exist. Elder-Vass (2012) argued that a pluralist view of using both constructivism and critical realism gave the researcher the tools to discern the structures that existed in and around the individuals as they constructed their meaning and knowledge. The understanding of any particular lived experience is enriched when the social processes that shape it are also addressed (Hood, 2015). In truth, constructivist claims can only be interpreted once the social mechanisms are understood through critical realism. This model of pluralism also recognises both the nature of individual agency and that the power attributed to causal processes within social structures (Elder-Vass, 2012).

While constructivism accounts for individual truths and interpretation of experience, these truths cannot be separated from the power relations inherent between individuals and social structures such as governments (and by virtue their institutions – schools) (Burr, 2015). By viewing the contributors to the lived experience through a relational developmental model, and applying a critical realism lens, it is possible to see how power is held in the macro and mesosystems.

3. Literature Review

Throughout the literature review, gaps will be identified, providing both a justification of the research problem (Berman & Smyth, 2015) and why it is worth investigating (Almadi, 2019).

3.1 Silencing of Parents

The IPA approach and its focus on phenomenology, hermeneutics and idiography lends itself to being a research design that gives its participants a voice by acknowledging that the participants' lives have worth and value (Castillo-Montoya, 2016). There is very little research both within Australia and worldwide on the experiences of parents of children with dyslexia (Leitão et al., 2017; Levi, 2017). While parenting a child with a disability often leads to parents engaging in disability advocacy, there can be a disconnect where they are

not seen as typical parents, and also not seen as being qualified to speak on behalf of the disability community (Runswick-Cole & Ryan, 2019). It is necessary to explore parent perspectives within this country as the policy and institutional influences over the lived experience are particular to this country and transference from other countries or contexts would be misrepresentative. Dyslexia is considered a disability as per the Disability Discrimination Act 1992 (Cth) but is not a disability as defined by state education funding schemes (New South Wales Department of Education and Training, 2019; Queensland Government, 2019a; Victorian State Government Education and Training, 2019) so it is important that research into dyslexia is reflective of the socio-ecological context within Australia.

Historically, research into parental experiences of parenting a child with a disability has ignored their voice and devalued their perspective when undertaken within the medical model of disability. When parents have presented a positive attitude towards parenting a child with a disability, researchers have described them as delusional or denying reality (Ryan & Runswick-Cole, 2008). Alternatively, parents can be seen as oppressors of their children who, as non-disabled people, are not entitled to speak about living in the disability community when they themselves do not have a disability. While the development of personhood for children has forced researchers and policy makers to see children as having agency, it has also moved to silence parents who are no longer allowed to speak on their children's behalf (Mallett & Runswick-Cole, 2014). This has the potential to also silence parents from speaking about their own experiences, living between the disabled and abled communities. In particular, when parents are primary and legal guardians, especially in contexts such as education, it would be repressive to silence parents on their experiences of interacting with the institutions and policies that so heavily influence their child's wellbeing.

Parental voice is also dismissed and silenced in the practice of interactions with their child's schooling. Griffiths, Norwich, and Burden (2004) explored parental agency, identity and knowledge and how this was created through interactions with their child's school and external support agencies. They noted difficulties in schools adopting commonsense approaches suggested by parents, school dismissal of a diagnosis or label of dyslexia and schools denying additional support when requested by parents. Further to this, they found that parents often had to escalate their methods of voicing concerns, from verbal

conversations with teachers, to written communication with the school and when this was still unheeded, communication with government agencies and politicians would occur.

This is despite schools being promoted as collaborative systems through departmental policy (Australian Government Department of Education, 2017; Australian Government: Department of Education, 2019; Queensland Department of Education Training, 2016; Queensland Government, 2019b). While shared goals might be rhetoric of educational policy and the desired outcome of co-constructionism, in practice it has been difficult for parents and teachers to achieve this due to differences in approaches to pedagogy and practice (Leitão et al., 2017; Levi, 2017). While parents seek to make meaning from a co-constructivist social model of disability, teachers and schools are often making meaning from a positivist medical model of disability (Lalvani, 2015).

More recent research has reinforced these findings of schools silencing parents when they advocated for their child with dyslexia. Earey (2013) had previously explored how parents are forced to repeatedly inform schools of their child's dyslexia diagnosis, despite often being better informed about the condition than the school. Here it is noted that parents' expertise in their child's diagnosis was not valued enough to give strength or credibility to their voice. Levi (2017) has most recently contributed to recognising parental voice in Australia, finding that classroom teachers dismiss parents' concerns for their children's difficulties in literacy acquisition and misattribute the difficulties to innate qualities of the child or to negative factors relating to the parents themselves. Again, there is a pattern of parental advocacy being dismissed, their presentation of official reports ignored and teacher expertise being valued as superior to parental knowledge.

3.2 Dyslexia & Mental Health

The link between dyslexia and mental health disorders has been well documented and I have previously explored this in my postgraduate studies. Given that dyslexia is relatively common, affecting 10-15% of the population (Earey, 2013; Hendren et al., 2018; Levi, 2017; Whitehouse, Spector, & Cherkas, 2009; Yu et al., 2018), and that children with dyslexia are at greater risk of developing a mental health disorder than their neurotypical peers (Hendren et al., 2018), the implications for mental health concerns are significant. Children with dyslexia are more likely to exhibit internalising and externalising behaviours in

both the home and school context (Boyes, Leitão, Claessen, Badcock, & Nayton, 2019; Levi, 2017) with anxiety and depression often presenting as comorbid with dyslexia (Hendren et al., 2018). Other longitudinal research has shown that dyslexia is a precursor to the above listed behaviours and mental health conditions, highlighting the role dyslexia plays as a significant risk factor for poor mental health outcomes (Boyes, Leitao, Claessen, Badcock, & Nayton, 2016). Dyslexia creates difficulties in literacy and numeracy acquisition and this leads to feelings of inadequacy and inferior competency, negatively impacting on self-image (Alexander-Passe, 2015) and self-esteem (Boyes et al., 2019)

There is also evidence to suggest that the relationship is bi-directional, in that poor mental health then influences student engagement and outcomes, exacerbating the difficulties caused by the dyslexia (Hendren et al., 2018; Whitehouse et al., 2009). The classroom has been shown to cause a psychological stress response in students with dyslexia, where an individual student's self-image or self-efficacy may influence a fight or flight response to classroom tasks (Alexander-Passe, 2015). Stress is a response to learnt expectations within the classroom and when an individual feels they cannot meet these expectations then a physiological and chemical response happens leading to feelings of anxiety.

While there is a sparsity of historical research into the impact of poor mental health of children with dyslexia has on their parents, a recent study showed that there were increased levels of child monitoring, parenting stress and worries about their child's future and that parents of children with dyslexia had higher rates of anxiety, depression and parental distress than parents of typically developing children (Bonifacci, Storti, Tobia, & Suardi, 2015). Research seeking to evaluate the effects of cognitive behavioural group therapy for parents of children with dyslexia noted that the sources of the mental health concerns in the parents are socio-ecological – often stemming from concerns created by the schooling context (Multhauf, Buschmann, & Soellner, 2016). This study in particular highlighted the interaction between systems that influenced the experiences of parents and ultimately their mental health.

Ultimately the significance here lies in the relationships between the different systems and the crucial element of dyslexia. Children with dyslexia are at increased risk of

mental health concerns as are their parents. These lived experiences are heavily influenced by experiences in and transactions with the school setting. Ultimately, an approach to teaching reading that effectively supported the student with dyslexia would not only influence their academic outcomes but also their mental health, and consequently that of their parents.

3.3 Politics of Year One Phonics Check

As far back as 2005 Australia was investigating the implementation of systematic and synthetic phonics (SSP) as an effective way to teach reading. The National Inquiry into the Teaching of Literacy (Rowe Report) found that there was a dichotomy between educators who advocate for the traditional practice of whole language or analytic phonics, and cognitive scientists who relied on research to assert that SSP would be a more effective and efficient way to teach Australian school children (Australian Government Department of Education Science and Training, 2005). Similarly in 2006 the UK Department of Education released the Independent Review of the Teaching of Early Reading (Rose Report) which reviewed research into high performing schools and effective ways of teaching reading. The recommendations included a consistent approach to teaching and monitoring SSP as well as a curriculum that emphasises oral language development (Rose, 2006).

Another UK report released in 2010 showed SSP was the consistent factor in high achieving schools and was significant enough to overcome both socio-economic status and English as an additional language or dialect as potential barriers to learning to decode and encode English (Office for Standards in Education, 2010). These reports led to the introduction of a low-stakes, short phonic assessment in 2012 designed to determine if students had achieved phonetic decoding benchmarks by age 6 (Buckingham, 2016) commonly referred to as the Year One Phonics Check (Y1PC). Many schools were found to have made improvements to the teaching of phonics after the introduction of the Y1PC and as such there has been an overall improvement in the results measured by the phonics check within the UK (Buckingham, 2016). However in Australia, 11 years after the initial Rowe report, a nationwide, consistent approach to teaching phonics has still not been adopted, despite the introduction of the Australian National Curriculum during this time.

In 2016 the Centre for Independent Studies (CIS) released a report into the reasons why Australia should seek to introduce the UK Government's Year One Phonics Check (Buckingham, 2016). A lack of improvement in the National Assessment Program for Literacy and Numeracy (NAPLAN) tests in Years 3, 5, 7, and 9 and a decrease in Australia's ranking in the international Progress in Reading Literacy Study (PIRLS) (Thomson et al., 2019) were the main justifications for the call to take action. Most recently, Federal Minister for Education Dan Tehan announced a review into ITE and the Australian Professional Teaching Standards to be conducted by the Australian Institute for Teaching and School Leadership (AITSL) (Tehan, 2019).

There have been some vocal critics of the move towards an SSP and the use of the Y1PC. These criticisms centre around the use of non-sense or pseudo words (phonetically simple words that do not have meaning e.g. pib, vus, yop, elt, desh) and the move away from analytic phonics instruction (cued reading using pictures, word shape, initial sound and context to decode) (Clark, 2013). The Australian Literacy Educators Association made statements regarding their concerns over introducing a phonics check here in Australia and the move towards SSP as the prevailing instructional approach, largely citing their misinformed presumption of an over-emphasis on phonics as their reason (Honan et al., 2017). The Australian Association for Research in Education have criticised Tehan's announcement by accusing the taskforce of being biased towards SSP and the terms of reference to be too narrow (Australian Association for Research in Education, 2019). These criticisms show a misunderstanding of the implementation and intent behind both the teaching of SSP and a Y1PC as well as lack of understanding about the focus on teaching literacy in the early years. There also appears to be no acknowledgement of the mental health implications from the ineffective teaching of students with dyslexia.

There is ample evidence that an SSP yields better academic outcomes for students. It is not difficult to presume that better mental health outcomes for those who would have struggled or been left behind with analytic phonics could be improved by adopting an SSP. While there is evidence that the mental health risks for students with dyslexia increase significantly when the introduction of reading occurs (Boyes et al., 2016; Hendren et al., 2018; Whitehouse et al., 2009) there is little research on the link between SSP and the impact on the mental health of students with dyslexia. It is necessary for research to be

conducted into the relationship between the more effective teaching instruction achieved through SSP and the mental health outcomes for students, in addition to the improved academic outcomes.

4. Research Methods

Interpretative phenomenological analysis (IPA) is an appropriate research design due to its focus on exploring the rich experiences of individuals within the context of social and personal worlds (Shinebourne, 2011). IPA has at its core an integration of phenomenology, hermeneutics and idiography (Pietkiewicz & Smith, 2014; Smith, Flowers, & Larkin, 2009), making it a suitable research design for this project. The phenomenological approach is necessary when examining an individual's everyday experience and requires the researcher to take a reflective approach to events, thoughts, feelings and behaviours that have happened and are still happening (Shinebourne, 2011). IPA requires the researcher to adopt hermeneutics to uncover the meaning not apparent on the surface of the phenomena. The act of the researcher making meaning from the participants' own act of making meaning creates a double layer in IPA research (Hood, 2015). This allows the research design to both be descriptive, which facilitates participants to speak for themselves, yet also interpretive as it explores what the phenomena means in a broader context (Pietkiewicz & Smith, 2014).

Incorporating idiography allows the design to not only seek a rich and descriptive understanding of the phenomena using the words of the participant, but recognises that individual cases are fundamental to the researcher's understanding (Pietkiewicz & Smith, 2014). This qualitative design presents opportunities to investigate how the participants interpret their experiences and construct attitudes, values and beliefs pertaining to the phenomena being explored (Hood, 2015). By exploring a small number of cases it is then possible to identify commonalities and differences in experience and meaning making between participants. IPA seeks to explore and explain lived experience, but it does not seek to draw conclusions, make generalisations or to establish truths (Hood, 2015). The interpretation and analysis within IPA firstly draws upon interviews with participants, and then explores the social constructs and processes that influence the individual experience and understandings. This transactional or co-construction of experience is aligned with the epistemological and ontological foundation of this project. Data collection and analysis in

IPA research design is a crucial element as the integration of the phenomenological, hermeneutic and idiographic approaches need to each be evident, honoured and utilised to their full capacity (Smith et al., 2009).

4.1 Methodology

4.1.1 Design

A qualitative exploratory design was employed, and data was gathered using single semi-structured interviews. Semi-structured interviews are a common means of data collection from a small sample size. This allows for a detailed and intensive analysis of the transcripts (Hood, 2015). While an interview protocol was devised, it was used as a guide to allow ideas to be explored in depth as the participant raised them (Noon, 2018).

Transcriptions of these interviews were analysed using IPA. Analysis focused on the co-construction of meaning between the researcher and participants.

4.1.2 Recruitment and Participants

Participants were sourced from a social media support group – Dyslexia Support Australia. This group contains parents, educators and advocates who rely on evidence-based practices to inform their decision making and advocacy efforts. This research project focussed on parents and a request was made for participants who met the following criteria:

- have a child who has started at school (Prep or Foundation year) after 2015
- have a formal diagnosis of dyslexia (Specific Learning Disorder- Reading) for their child, obtained after the completion of Grade 1 of schooling.
- have experienced mental health concerns since their child's commencement at school

Four parents responded to a request to participate in the study. From this initial group, three were selected as one did not meet the criteria. The parent who expressed interest but did not meet the criteria was informed. As there is a high likelihood of literacy difficulties with the participants, given the genetic role within dyslexia, the consent process included a verbal discussion to ensure that participants were not disadvantaged by the wordy nature of consent forms.

4.1.3 Procedure

After obtaining ethical approval, three parents were recruited from the social media support group to participate in semi-structured interviews via Zoom after Term 1 of the 2020 school year. While some questions were prepared in advance, participants were encouraged to 'speak from the heart' in order to be able to use their words in the analysis. Once interview times were arranged, participants were sent email invitations with hyperlinks to the Zoom meeting. These sessions were recorded via Zoom and the recordings were initially transcribed using the automated transcription service on the *Transcribe* website (Transcribe, 2019). Corrections were made to the transcripts by listening to the audio and manually altering the automated transcription as needed.

4.1.4 Interviews

Interviews were conducted via Zoom, a software program designed for cloud platform video conferencing. There is some discussion within the literature as to the merits and disadvantages of choosing either a face to face or electronic (telephone, Skype, Zoom) interview medium (Cohen, Manion, & Morrison, 2017). Thoughtful consideration needs to be given to both the researcher and participant contexts in order to select the most appropriate interview style (Oltmann, 2016). Many good interviewing skills (Ivey, Bradford Ivey, & Zalaquett, 2017) can still be incorporated when using a visual electronic medium in order to create rapport. I was conscious of not sharing my personal experiences and knowledge prior to, or during the interviews as I did not want to influence the participants' contributions. Additional unscripted prompting and probing questions were used to encourage participants to talk in more depth and elaborate on points further. The schedule was not followed rigidly as IPA does not seek to guide participant responses. Not all questions were asked in each interview and the order of questions was also different, depending on the participants' responses.

In qualitative research interviews are best used when observations are not possible and when historical data is required (Creswell & Creswell, 2018). Critics of interviews claim that the data collected is never the truth because it is filtered through the subjective lens of the participant and it allows the researcher's bias to influence the data collection. These criticisms however, do not have merit in an interpretative phenomenological analysis as these attributes are considered to be a part of the double hermeneutic.

4.2 Analysis

While there is no rigid method of data analysis in IPA, the ultimate focus of analysis needs to be on the participants' ways of making meaning from their experiences (Smith et al., 2009). The process moves from particular to shared and from descriptive to interpretive using a close review of interview transcripts and the nuances of the participants' verbal and non-verbal language during the interviews. As the analytic process is one of co-construction, the double hermeneutic, there is no singular truth to be found. Analysis was subjective yet dialogical, systematic and rigorous.

Step 1. Reading and re-reading of the transcript of each interview was undertaken to create a focus on the participants' meaning making of their experiences (Smith et al., 2009). This process allowed for identification of surface level elements and sections. The act of multiple readings allows the researcher to understand the experiences from the participants' point of view (Pietkiewicz & Smith, 2014). Notations were made to identify non-verbal communication evident in the audio and visual recordings.

Step 2. More detailed analysis and notation was conducted examining the content of the data. This ensured identification about the particular ways the participants talked about an issue, experience or relationship. Three discrete notation actions were undertaken: descriptive, linguistic and conceptual (Smith et al., 2009). Descriptive notation looked for key words, phrases or explanations that evidenced the elements of experience that were important to the participant. The participants' thoughts and thought processes were identified here demonstrating their importance through the intensity of the words. Linguistic elements such as metaphor, idiom, simile, pronoun use and articulation were identified because they linked the descriptive notation to the conceptual. It was important to note the consistency between the language used and the content in this aspect of the analysis. The third and final level of the idiographic notation was more interpretive, seeking to conceptualise the participants' overall understanding of their own experiences. This level of notation also acknowledged the researcher's own experiences and understanding.

Step 3. At the completion of the exploratory commenting, a shift was made to identifying emergent themes from the notation made in step 2 (Noon, 2018). This was an act of co-construction of understanding the phenomenon using discreet sections of the

transcript, while also trying to reduce the volume of detail in the data. This shows the relationship between the participant and the researcher (Smith et al., 2009) reflecting the interpretation from the description. Emerging themes were identified to reduce the volume of data for the final stage of analysis and are expressed as phrases that express the substance of what was said in the transcript. Enough detail is kept to keep the data grounded in the participant's words, but equally it becomes abstract and conceptual (Smith et al., 2009).

Step 4. Exploring the emergent themes entailed identifying sub-ordinate themes through abstraction (similar themes brought together), subsumption (emergent themes become super-ordinate), contextualising within the socio-ecological model (identifying the different systems influencing the participants' experiences) and function (what is the function within the transcript) (Smith et al., 2009). This reflected my focus on the existence of the individual within a system and how they transaction with each other and its purpose to describe the ways in which different contexts or systems influence the phenomenon. It is how the participants' understand this influence and how they drawn meaning from their interactions (known and unknown) with other contexts that is of relevance to this study.

Step 5. This stage moved on to seeking connections across the transcripts. Any themes that were not evident across at least two of the transcripts were discarded. What evolved from this was an analysis that placed the sub and super-ordinate themes within different systems (ecological systems theory). It was possible to sort the themes based on what they were addressing within the micro, meso, macro and chronosystems. In this way the systems naturally became the superordinate themes exploring the people, processes, contexts and time. Bronfenbrenner's ecological environments need to be understood systemically or interdependently as "what happens or fails to happen in any given environment depends to a large extent on the events and relationships in other related environments" (Rosa & Tudge, 2013, p. 247). Importantly analysis of a phenomenon should consider the processes or interactions between people and their environments.

5. Findings

This section will first present an analysis of the data collected from the interviews. Following this analysis my interpretation of this data has been provided.

5.1 Analysis of findings

The emergent themes are provided below in Table 2. While there were many different concerns that came forth as the participants shared their experiences, those that were consistent across the participants experiences have been categorised according to the people, process, context, time aspects they represented.

Table 2

Summary of Emergent Themes

Categorisation	Emergent Theme
People - Microsystem	Child Parent School
Processes – Mesosystem	Relationships Communication Process External Agencies
Context – Macrosystem	Year 1 Phonics Check (Y1PC) Inequity Initial Teacher Education (ITE)
Time – Chronosystem	Early Intervention Lost Time Diagnosis as a Milestone Future Fears

5.1.1 People - Microsystem

Three entities were identified as existing within microsystem: the child, the parent and the school. Comments related to the values and beliefs about these entities and their actions/reactions to the phenomenon.

Child – The common theme with the children of the participants was the internalising and externalising behaviours described by their parents. Each parent relayed

concerns about their child's mental health and their academic progression. The children were portrayed by their parents as either victims of inactions of the school/teacher/system while at the same time, as having the potential to succeed due to the efforts of their parents.

Participant 1: *If he doesn't want to do it, he shuts down.*

Participant 2: *He's angry and he's anxious and he's sad and but none of that is at school.*

Participant 3: *I'm concerned about his mental well-being right now and they still haven't really got it.*

Parent – My analysis of the transcripts is that the parents were the source of the identification of dyslexia within their children. They were the persons who observed and noticed gaps between their child and other children. They were the ones who continued to observe and monitor both the academic progress and mental health of their child. It was the parent who initiated the conversation with the school, bringing the observation of the disparity to the teacher's attention. While they bore the considerable financial burden of supporting a child with dyslexia, this also led them to become experts, with sophisticated personal knowledge and understanding of their child that far exceeds the school's. Overall, the role of the parent was shown to be one that is proactive and vigilant.

Participant 3: *When my son was in four year old Kinder I noticed that his.... the way he addressed the activities were different to the way his friends did.*

Participant 1: *So it cost me a lot. The amount of money. I basically... 90%, 80% of my wage goes to the boys and their learning.*

Participant 2: *We can't just sit here and wait for someone to believe us. We need to be doing something.*

School – The parents identified the schools as the source and cause of their difficulties. This took a number of forms. Firstly it was the introduction of academic requirements on their children that brought to light the dyslexia. This in turn created mental health concerns for their children presenting as both internalising and externalising

behaviours. The second way in which schools were the cause of difficulties for parents was in their lack of knowledge and expertise regarding dyslexia and mental health. Teachers would misattribute the cause of the child's difficulties due to their lack of knowledge. While parents characterised themselves as active or proactive, they described the school as being passive and inactive.

Participant 3: *...and every year I see this sad withdrawn child and I could see it was school making him feel like that.*

Participant 2: *The school were really like, like "It's because he's a boy. It's because he's just started kindy. Kids take time to settle in. Nobody's meant to be able to hand write and read when they start school."*

Participant 2: *I like the school but their passiveness around actually doing something is infuriating and their inability to make reasonable accommodations is yeah soul-destroying.*

5.1.2 Process - Mesosystem

At the mesosystem level relationships, communication, processes and external agencies were found to be the prevailing themes. Each revealed the interactions between the parent and others.

Relationships- The defining feature of the mesosystem is the bi-directional nature of the interactions (or relationships) that occur between the entities within the microsystem (Sigelman, 2019). The participants depicted the relationships with their children's schools as inconsistent and one-sided. They would initiate communication, share reports from external agencies and ask questions of the teachers and school. On the other hand parents characterised the schools as reluctant to respond, dismissive of the parents' concerns and not transparent in their actions. In many ways the roles of the school and parent were reversed with the parent becoming the expert in dyslexia and educational adjustments and the school demonstrating. This is particularly evident when it is the parent who first identifies a concern of dyslexia, despite having no expertise in the area at this point. The parents firmly believed that it should have been the role of the school to identify concerns in literacy progression.

Participant 3: *And I said "Do you think he could be dyslexic?" and she said "Oh no, I've been teaching for 10 years. I would... I have never had a dyslexic child in my class". And I thought, ah, now she is lying. She is not able to work out what's going on and this is what the problem is.*

Participant 1: *The school doesn't even... they weren't even... everything you do you have to do it yourself. The school doesn't look at any of that.*

Participant 3: *It's like oh, well the mums dealing with it now, let's just let her deal with it, but it's like no you need to do it.*

The relationship between parents and the school/teachers are not equal relationships. The parents do not have any capacity to take action or make changes within the classroom.

Participant 2: *They keep coming back to us as parents and saying "Well, you know just do the best that you can" and I'm like fuck (emphasis on fuck) off, like, you know, that kind of like I'm a parent you can't ask me to modify the curriculum. I am a parent like you are the teacher, you modify the curriculum.*

Participant 1: *It frustrates me cause I'm spending all this money to do their job or make things easier like I can be proactive but it can't be just one person. Give, give, give. The other person has to give.*

Trust is a necessary component within a relationship. It seems as though the parents initially trusted the school and teachers, believing them to be experts in education. Over time however, this trust was eroded as the school/teachers did not act upon the knowledge that was shared with them. In particular, knowledge about the way the student learned, gained from psychoeducation reports and assessments, was not translated into adjustments to classroom teaching and practice that made meaningful differences to the student.

Participant 3: *I knew his brain works differently, but I trusted his teachers year after year to tell me if something was wrong. And they never, they never picked it.*

Participant 1: *You're constantly checking to make sure that they're putting in what SPELD has recommended. Now a lot of the times it's not.*

Participant 3: *I don't know whether they didn't pick it or whether they just didn't want to have to deal with it, didn't have the knowledge how to deal with it, which is what I think the actual thing is.*

Social isolation was another sub-ordinate theme of relationships that emerged from the data. Parents felt ostracised from the school community. Only when they had found others with similar knowledge and shared experiences, were they were able to find a sense of belonging and connection within the dyslexia community.

Participant 1: *I don't want to be the um, the odd one out, lost in the world.*

Participant 2: *I think we'd started to become labelled as, the like, annoying family, the pestering family.*

Participant 3: *The site (Dyslexia Support Australia – Facebook). You know, it's a community thing. It's not just an individual. It's a community thing.*

One positive regarding relationships that did come from the data was that the parents unanimously felt as though the experience had brought them closer to their child. Their increased knowledge of dyslexia, mental health and educational adjustments had given them insight into their child, strengthening that relationship.

Participant 1: *I would say it's made me a lot closer to (my child) and understanding how he sees things and I always say it's important to understand your child.*

Participant 2: *I think we've got quite a comprehensive understanding of what's going on.*

Participant 3: *The best experience for me is that I have really got to understand how (son's name)'s brain works and I found it fascinating.*

Communication – Communication was a significant element of relationships that was a constant theme to emerge in the three transcripts. While it is a sub-ordinate component of the relationships, it was discussed in significant detail on its own and emerged as a superordinate theme. Parents were able to identify many aspects of communication that had contributed to the erosion of the relationship with the school.

There were consistent concerns with the frequency, transparency and origins of communication between the school, teachers and home. Communication was also seen to be ineffective when it wasn't acted upon. This was one of the sub-ordinate themes within communication where the parents often did not feel heard by the school. Parents provided specialist knowledge that they had gathered from external agencies to the school to help inform practice however requests made of the school/teacher were not followed through. A bi-directional communication pattern between the parent and school/teacher was valued by the parent so that they could be aware of what was occurring in the class room.

Participant 1: *Well... did you guys (the school) listen to me at the beginning?*

Participant 3: *So we had this massive (emphasis on massive) meeting. Nothing came of it and at the end of grade four there had been no change from the school.*

Participant 1: *I don't know if they're doing the things properly... at school.*

Participant 2: *She's a lovely lady and she's always like "Oh, yes, like I'm always willing to talk". But then I'm kind of like "So talk to us". But then she seems bound by "but I'm not allowed to talk" like but so she keeps deferring to the whatever... the process of the school?"*

Participant 2: *Can I get a bit more information about that? But that I've received no correspondence about what it is he's doing, who he's doing it with?*

Parents felt they were the originators or initiators of communication regarding their children's progress. Consistently they requested communication however these requests were dismissed or delayed. There were no instances where the school approached the parents without the parent having first identified a concern or requested the communication, unless it was a part of standardised communication such as academic reporting or parent-teacher meetings.

Participant 2: *So we'd said at the beginning of the term... I was like, I'm like, we need to have more frequent communication between us part of the issues of the previous years is there's no actual communication. So we request a meeting, we request a meeting, we request a meeting.*

Participant 3: *I asked for two terms (slowed to emphasise) for an IEP meeting.*

The parents felt like they needed to rely on their child to inform them of what was occurring in the classroom yet at the same time acknowledge that relying on a child with dyslexia was not an appropriate channel of communication between the school and home.

Participant 1: *It's not till the kids get older when they can communicate.*

Participant 2: *And it's all very reliant on what he... a seven-year-old remembers and he... like, you know, I've just paid like \$3,000 for report to say he's got massive working memory problems. Like you know, that kind of he's, not he's not going to tell me like... it's not...*

Communication within the school was also identified by the participants as a concern for them. In particular was the way information about their child was or was not communicated to the new teacher each year. This is an example of the responsibility being placed back on the parent to manage aspects of their child's education that should be the responsibility of the school.

Participant 3: *So I said, "Have you had any feedback from the (school) psychology from last year?" And she said "No."*

Participant 2: *It's not the fault of the teacher that she was given no information like that.*

Process – The schools did not seem to have processes in place already to identify students at risk of having dyslexia. They also did not have processes in place to work with external agencies to obtain a diagnosis or recommendations to improve teacher practice. The lack of clear processes in part contributed to the role reversal between school and parent as the school lacked the knowledge of how to act and the parent actively sought to gain this knowledge.

Participant 3: *She hadn't assessed him on his spelling and I said, "So you can't tell me what level reader he's on. You can't tell me where he's spelling and you haven't even assessed his spelling." So it all started to kick up.*

Participant 2: *The education system then doesn't seem to say it's our... it's our remit. Like they just ignore it. It's just like silent.*

External agencies –Psychologists, paediatricians, speech and occupational therapists and specialised tutors were engaged by the families seeking a definitive diagnosis and ongoing support. Only one family was able to access psychology through the school and this had no impact due to the poor communication between the school and their own psychologist. In other instances, the confirmation of the parents' concerns, open communication and provision of actionable supports were aspects that made the relationship between the parent and the external agencies a positive one. These were elements missing from the relationship with the schools. Interestingly, high school was seen as external to the primary school; a place where their child might be provided with the supports and access to education that they were not given in primary school.

Participant 1: *. So I rely on my tutors. They are really good tutors. I don't rely on the school.*

Participant 1: *I just I want the schools and I want people parents to realise don't rely on the schools.*

Participant 2: *..we've been forced to involve a cast of thousands outside of the school.*

5.1.3 Context - Macrosystem

A number of themes identified by the participants exist within the macro-system. The Y1PC, inequity and ITE were aspects of the phenomena that may not have directly impacted on their experience, but did so indirectly. The parents also identified aspects of the macro-system and their impact on the meso and microsystems.

Year 1 Phonic Check – The parents were largely unaware of the Y1PC and so I was required to give a brief explanation of what it is and what it hopes to achieve. I stated that the Y1PC was a screener completed at the end of year 1 that helps to identify students at risk of literacy difficulties and specific learning disorders. Interestingly the response from parents was to welcome the screener, not only because it may help to with earlier identification, but also because it places the responsibility onto the school to identify and then take action. The belief was that if the school made the identification then they would ultimately be required to have a process in place to follow through with targeted support.

Participant 1: *there's no... like you said, there's no 'what's its name' in place to diagnose or to get these kids... (pause) or understand what we're dealing with.*

Participant 2: *I think if there was a way that the school... (pause) could be like (pause) an active part of the solution... So I think if there was a phonics screener or a check or something that was the responsibility of the system the education system that they could administer that, it might empower them to be a part of the solution.*

In response to the role reversal identified earlier, parents welcome the schools taking responsibility for identification and believed that having a Y1PC might have helped them by reducing the burden on them to identify and take action.

Participant 1: *If I had that, it would have made my job so much easier and the school would probably be a little bit more understanding of what's going on.*

Participant 2: *And the way I kind of think about it is so, you know in the context of trying to get help for him and trying to still have enough money in our lives to like feed the family.*

Inequity – All of the participants noted the inherent inequity evident in the diagnostic process and support provided. Their concerns did not stop at their own child, but instead extended to other parents of and children with dyslexia. They believed that parents who were less privileged (financially, educationally) had difficulty locating external agencies to access services and that they might also have difficulty in being able to afford the high costs of diagnosis and therapies. In this way they noted the marginalisation of a twice vulnerable group within the school community.

Participant 2: *I don't know how families who don't have that capacity, I don't know how they're meant to succeed. I don't know how it's meant to work for them if they can't. navigate that process or pay.*

Participant 3: *There's a lot of kids at the school that I think are in the same position and aren't getting the help either and that's what I can see.*

Initial Teacher Education (ITE)– Linked to the concerns about the schools' and teachers' status as experts in education were concerns about the ITE that teachers received before

graduating. Parents felt that teachers lacked the knowledge of how to teach evidenced based reading strategies to students and that this should be a skill taught in ITE programs. Also lacking in teacher knowledge was an understanding of how to identify dyslexia, the educational adjustments that could be made and the link between dyslexia and mental health. They valued a qualification that would prepare educators to make decisions and take action based upon evidenced based methods of teaching reading.

Participant 2: *...(the teachers) push it to the parents. Which doesn't help because I'm not ughh.... Like what did you do your degree for then?*

Participant 3: *He doesn't get it. He doesn't know he's not the right... That's the other thing the principal isn't an educator. He's a businessman...*

Participant 1: *...because a lot of these teachers aren't... they, they don't know how to teach a child with dyslexia.*

5.1.4 Time - Chronosystem

The experience of the parents is one that spans a number of years. Their children have been in formal education for approximately 4-6 years and there have been numerous events that have helped to mark the passing of this time. The parents used communication with the school, the presentation of symptoms and the progression through school grades as markers of time. From this the three super-ordinate themes to emerge were as follows: early intervention, the diagnosis as a milestone, lost time and fears for the future.

Early intervention- The parents all believed that things would have been different for them if early intervention had occurred. There were significant time delays between when they first noticed their child's learning differences and their access to a diagnosis and educational or mental health supports. The delay in accessing intervention led to an escalation of the difficulties their children were experiencing.

Participant 1: *They leaving it till it's too late.*

Participant 2: *So why they didn't say that two years earlier? I don't really understand.*

Participant 3: *...when I could have started this process two years ago, and we could have been further ahead now and we could have avoided these horrible times.*

Diagnosis as a milestone – The parents believed that obtaining a diagnosis for their child should have been a milestone or turning point. They felt that they were led to believe that formalising their suspicions and concerns into a diagnosis would lead to an increase in classroom supports. This was not the case for the parents as obtaining the diagnosis did not act as a catalyst for the change they were hoping for.

Participant 1: *Unless they had it on paper, they wouldn't help. There's no way they were going to put it in the support.*

Participant 2: *We've got a thousand reports now that we have paid thousands of dollars for, but it doesn't help so, I don't know why we had to do it, because it doesn't get him any extra support.*

Participant 3: *They know that I'm frustrated with them and I have put in writing that I feel that even after a diagnosis. I don't feel that they have changed the way that they are teaching.*

Lost time- Another consideration of time was that time had been lost. The inaction and passivity of the schools led the parents to believe that time that could have been spent assisting their child was lost and gone forever. This feeling of loss extended beyond losing time, to having lost opportunities to act. These opportunities to act could have brought about a more positive outcome for their child.

Participant 1: *They don't realise he's already lost one term doing nothing.*

Participant 2: *...he spent a year doing nothing like argghhh (expression of frustration).*

Participant 3: *It was like they weren't listening to me and they weren't following up. That's the worst experience for me. Because it's made me (pause) not react as quickly as I probably should have.*

Future fears – The experiences that the parents had led them to be concerned about what the future holds for their children. They feared that the difficulties they are currently facing, both academic and with mental health, may continue for the length of their schooling. This relates directly to the negative affect they and their children have

experienced. The parents predicted that their future experiences will be similar to their past/current experiences and that no positive change would occur.

Participant 2: *You know, I look at it... I'm like he's only in year two... like it makes me feel sick to think that we've got 11 more years of this... like I just...*

Participant 1: *... sometimes I did feel like I was literally going crazy and I was fighting. Fighting for his future.*

5.2 Interpretation of findings

The aim of my project was to explore what are the values and beliefs of parents of children with dyslexia to capture their lived experiences with their child's school in the early years. The data revealed complex human development and relationships between the participants and the contexts they inhabit in line with the RDS model (Lerner et al., 2010).

Research question: What values and beliefs do parents of children with dyslexia hold about their experiences with their child's school in the early years?

Parents believed that there had been extraneous responsibilities placed upon them that should have been the responsibilities of the school. I perceived that while parents were unhappy with the role reversal, they valued their new found expertise in dyslexia and how this allowed them to advocate for their child. Parents of children with a disability actively pursue a range of activities to increase their knowledge and understanding of their child's diagnosis for the purpose of being a stronger advocate (Burke & Hodapp, 2016). For the parents in this study this did however lead to further frustration when the schools did not acknowledge this expertise. Bacon and Causton-Theoharis (2013) state that knowledge held by parents is often considered by the school to be subjective and inferior. Increased knowledge also leads to decreased satisfaction with school supports and poorer school-parent relationships (Burke & Hodapp, 2016).

Sub-question 1: Do parents believe schools effectively respond to identification of SLDR (dyslexia) or mental health concerns?

The overwhelming response was that parents did not believe that schools responded effectively to identify students with or at risk of having dyslexia. They thought that teachers and school administrators were not knowledgeable enough to identify dyslexia and felt they

routinely dismissed concerns that the parents brought to them by misattributing the symptoms. Schools and teachers are known to be lacking in their ability to identify and support students with dyslexia due to failings in ITE programs (Earey, 2013; Leitão et al., 2017). The parents believe the lack of a formalised process was a secondary concern to identifying dyslexia. The efficacy of the school response was largely hindered by their inaction. All parents noted that the school did not make educational adjustments that would support their children. Studies have shown that up to 75% of primary schools do not acknowledge a diagnosis of dyslexia or adopt the recommendations in psychoeducational reports (Earey, 2013).

The Y1PC was identified as a possible avenue for not only identifying dyslexia in students early, but as a potential catalyst for schools taking responsibility for following through with supporting those students. Parents believed that this would be a way for schools to effectively identify and respond to dyslexia. Among the justifications for implementing a Y1PC is its potential to influence improvements in teaching practice (Buckingham, 2016). In taking pro-active steps to adopt an early identification process, the parent in this study felt that this would prevent mental health concerns. Processes that facilitate early identification and academic intervention can alleviate the negative experiences that contribute to children's poor mental health by reducing their risk factors for developing a reading difficulty (Boyes et al., 2016).

Parents of children with disabilities do not inherently seek conflict and would prefer to work in a collaborative manner with the school (Bacon & Causton-Theoharis, 2013). The parents in this study valued communication that was transparent, frequent and bi-directional. They believed that adopting such an approach to communication with parents, external agencies and within the school itself would have greatly improved their experiences. As such the current communication practices of the schools and teachers were not believed to be effective. Beyond their own experiences, they believed that the lack of efficacy from the school would impact on other families who were twice vulnerable. The use of the Y1PC in the United Kingdom has in fact found that it has narrowed the academic achievement gap associated with socioeconomic status (Buckingham, 2016). In this way it identified children at risk when their parents cannot.

Sub-question 2: Do parents believe their advocacy for their child is valued?

The parents most definitely believed that they were experts in dyslexia. The literature suggests that parents reach a breaking point where they feel they must become fierce advocates in order to fight for their child (Bacon & Causton-Theoharis, 2013). Their experiences with obtaining psychoeducational reports and working with psychologists; speech and occupational therapists; and specialist tutors exposed them to new knowledge which they incorporated into their parenting of their child (Earey, 2013). It was due to the interactions with both the school and the external agencies that they became pseudo case managers for their children. Despite their belief in their expert status, the parents did not feel as though the school or teachers valued their input. Their concerns and requests were consistently dismissed or not acted upon. Similar to what is reflected in the literature, parents were required to remind schools of their child's needs and diagnosis year after year (Earey, 2013).

Other research has revealed the inherent inequality of power in the decision making process (Bacon & Causton-Theoharis, 2013). The parents spoke about their negative emotions associated with their dismissed advocacy, in particular the frustration they felt. The response of the schools to the parents desire to collaborate was less than favourable and in fact negatively impacted on the mental health of the parents. There was little data that suggested that the parents' advocacy was valued by the external agencies or by the children themselves, though these relationships were spoken of far more favourably than the relationships with the schools/teachers. This could be due to the scope of questioning during the interview. Certainly this could be an avenue for future investigation.

Sub-question 3: What influences do the meso, macro and chronosystems of the ecological model have on the parents' experience?

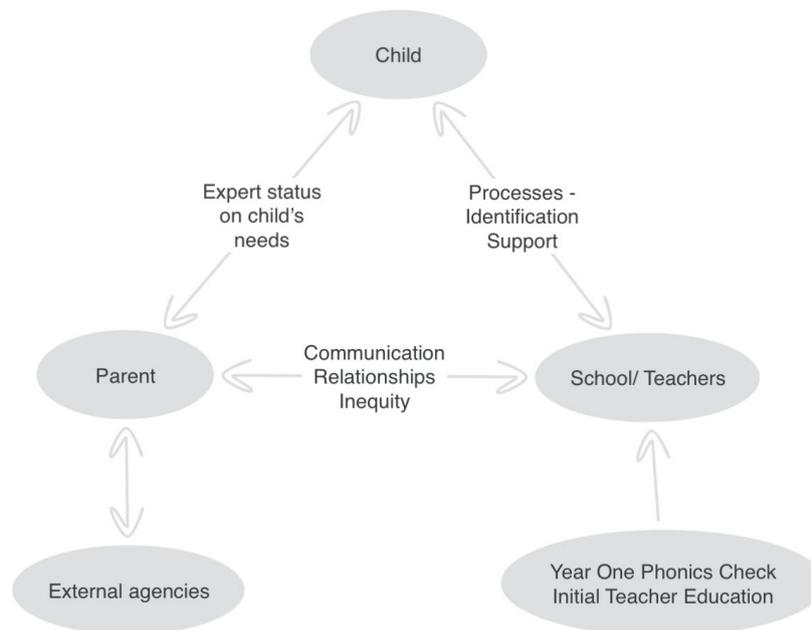


Figure 1

The influence of the emergent themes on the parent.

The parent experience is affected in multiple ways by transactions at different system levels as depicted in Figure 1. This was evident in the analysis of their claims and objects of concern (Larkin, Watts, & Clifton, 2006). At the mesosystem level parents are impacted by the relationships and poor communication with their children's schools. While they desired shared goal setting and decision making, this is not achieved due to the actions of the schools. Other influences at the mesosystem level included the support parents received from external agencies such as tutors, psychologists and SPELD (Supporting People Experiencing Learning Difficulties). This tended to be positive influences of the parents' experiences resulting in their increased knowledge and understanding.

Parents believed that formalised processes such as the Y1PC which would originate in the macrosystem could improve their experiences by relieving them of some of the responsibility to be an expert as well as the financial burden of identifying dyslexia. It could also formalise support processes and alleviate some of their concerns regarding communication to new teachers each year. Additional influences from the macrosystem

level, such as ITE, also negatively influenced the parents experiences. The lack of knowledge gained by teachers through their ITE programs had an indirect effect on the parents' experience by influencing their need to become experts.

6. Future Research Opportunities

The area of role reversal and the expert status of parents could be a potential area for future research. Given the negative emotional impact that occurred when the parents' expert knowledge was dismissed or not acted upon, it would be remiss to not take the opportunity to transform this experience into a positive one. Currently there is a policy rhetoric with state and federal educational bodies to engage and collaborate with parents (Australian Government Department of Education, 2019; Australian Government: Department of Education, 2019; Queensland Government, 2016, 2019b). The Australian Institute for Teaching and School Leadership has as professional standard for teachers at a proficient level "Establish and maintain respectful collaborative relationships with parents/carers regarding their children's learning and wellbeing." (Australian Institute for Teaching and School Leadership (AITSL), 2019, section 7.3). The Australian Federal Government has the vision that "families, schools and communities actively work together as partners to support learning, development and wellbeing of children and young people" (Australian Government: Department of Education, 2019, p. para 2). State government education bodies have similar policy directives (New South Wales Government, 2020; Queensland Government, 2019b). The experiences of the parents in this study, as well as my own personal experience, would suggest that schools are not actively seeking to engage parents and work collaboratively with them. Future research into the efficacy of communication between parents and schools/teachers would also be another avenue of research in this area.

7. Limitations

There were a number of limitations to the study. Firstly, all of the participants were mothers. This narrows the scope of the sample from parents, down to a singular parent, namely the mother. There is the potential that fathers may have been able to share a different perspective of their experiences. In this way it would be difficult to generalise and think that the experiences of the mothers explored here would be the same as the fathers in

these families (Cohen et al., 2017). Likewise all of the children were male. It would be worthwhile to explore if there are any differences or similarities in the experiences of female children rather than generalise the findings of this study to all children.

The limited time set aside to conduct each interview potentially reduced the amount of data that could be collected from each participant. IPA seeks to achieve an intensive analysis of the detailed personal accounts (Smith, 2011). While the data collected were rich and detailed, there were many aspects that could have been explored further if time had permitted. Another potential limitation came from the way language was used to elicit additional detail from the participant (Tuffour, 2017). The way I would summarise the participants statements as a way of demonstrating active listening and keeping the interview informal (Ivey et al., 2017) may have alluded to my personal bias on some topics due to unintentional emphasis (Cohen et al., 2017).

8. Conclusion

One of the aims of this study was to give voice to parents who, like myself, felt unheard by the schools our children attended. In this way I have sought to use IPA to move beyond simply describing what the participants have experienced, to interpreting these experiences within the contexts they occurred in. I identified a number of “objects of concern” (p. 111) by contextualising the lived experiences of the parents. This identification will help myself and other researchers to continue to explore the phenomenon and bring greater equity to the experiences of children with dyslexia and their parents. My goal was to give parents a voice by exploring, understanding and communicating both the experiential claims and underlying concerns of the participants (Larkin et al., 2006). In this way, my own experiences and concerns have been heard. My project has provided the impetus to conduct further research in this area, and to provide opportunity for parents of children with dyslexia to be heard.

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