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A Narrative Inquiry into Primary Caregivers'
Understanding of their Child's Psychological
Assessment

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Jessica Niemand

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Abstract

This study explores the ways in which primary caregivers experience the process of having their child psychologically assessed. The research uses a narrative methodology to explore the accounts of seven participants who have supported their child through a process of psychological assessment. Caregivers were interviewed and their interviews were transcribed and analysed by outlining the sequential order of events and the main themes of each of the participants' narratives. Individual stories were then combined to present the overarching themes that emerged from the study. The main themes include the following: suspected "diagnosis" and own expertise, seeing "inside" the child, bittersweet labels, questions of guilt and blame, the "good parent", the distant professionals, problems with communication, challenging the system, inadequate measures, over-assessed, caregiver as the defender and advocate and the helpful professional. This research contributes to the limited literature on client's perspectives of psychological intervention and is intended to improve clinicians understanding of this area.

Keywords: caregivers, assessment process, experience, perspective, child

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Chapter One

Introduction and Literature Review

Psychological assessment has become an increasingly important tool in decision making around children's education and well-being (Reitman, 2006). Much has been written about psychological assessment and its value from the perspective of professionals (Reitman, 2006) but less is understood about how clients might experience this process or as in this case the caregivers of the children undergoing psychological assessment. The question that I ask in this study is: what is this process of psychological assessment like from the perspective of the primary caregivers of these children? What are their reasons for seeking a psychological assessment for their child and how do they understand it or envisage using the outcomes of the assessment process? This study uses a narrative inquiry methodology to better understand child psychological assessment from the perspective of the caregivers.

This chapter provides a background and context for this study and will begin with a brief definition of some of the more common diagnoses given to children today followed by an overview of what a psychological assessment is from the perspective of the clinicians administering them and within the context of Aotearoa/New Zealand. This is followed by an outline of those discourses that surround and inform the social construction of the psychological assessment of children. These include ideas about what Western societies say about childhood, childhood development, intellectual functioning, appropriate behaviour, family relationships, children's social relations and emotional development, all of which impact upon both clinicians and caregivers. Finally a rationale is presented for this study.

Common Psychological Problems amongst Children

New Zealand children are increasingly being assessed to diagnose a range of psychological problems including both those relating to mental health and education and learning. The Ministry of Health (1998) estimates that approximately 11 percent of children in New Zealand experience a disorder, including those of an intellectual or psychological

nature. Some of the more common of these will be described very briefly to provide a background understanding of these disorders.

The Ministry of Health (1998) notes that there is a rise in the incidence of mental health problems amongst children. The most common include depression, substance abuse, eating disorders and anti-social/disruptive behaviour disorders. Depression includes symptoms such as disturbances in eating patterns, sleep patterns, activity levels, concentration and thinking, decision making and energy as well as experiences of feeling guilty and regular thoughts of death or suicide (Sadock & Sadock, 2007, p.527-528). Substance abuse can be defined as the “use of any drug, usually by self-administration, in a manner that deviates from approved social or medical patterns” (Sadock & Sadock, 2007, p.384). Eating disorders include anorexia nervosa, or a dramatic reduction in body weight due to extreme restriction and/or purging of food resulting from a significant fear of becoming overweight, and bulimia nervosa, which involves cycles of binge eating followed by purging behaviours, such as induced vomiting, inappropriate use of laxatives and so forth (Sadock & Sadock, 2007). Finally, anti-social/disruptive behaviour disorders include the diagnoses of oppositional defiant disorder, in which children have angry outbursts, absolutely decline to abide by rules and display irritating behaviour which is not considered appropriate for the age level (Sadock & Sadock, 2007), and conduct disorder, which is defined as meeting the following criteria “physical aggression or threats of harm to people, destruction of their own property or that of others, theft or acts of deceit, and frequent violation of age-appropriate rules (Sadock & Sadock, 2007, p. 1220).

Some of the common diagnoses that are given to children in today’s education system include dyslexia, autism spectrum disorder, ADHD and ADD. Firstly, there is a great deal of discussion around whether dyslexia is a “disability, difficulty or difference” relating to issues surrounding literacy and it is yet to be given a definite definition due to it being such a wide reaching topic of which there are a great many opinions (Pavey, Meehan, & Waugh, 2010, p. 6). Brock, Davis, and Christo (2009) compare a number of current definitions of dyslexia and find that on the whole it is considered to be a neurobiological condition and is therefore not influenced by environmental factors, for example teaching instruction. It also involves difficulties with the deciphering and recognition of words and the fluency with which this is done. Reading comprehension is also impacted. These

difficulties appear to be relatively isolated to literacy and do not extend to other academic tasks and other areas of “intelligence”.

Secondly, autism spectrum disorder is the name given to a group of disorders that are classified under the umbrella of autism and with which there is a great deal of overlap. The New Zealand Ministry of Health (2008, p. 30) identifies these “subgroups” as being “classical autism”, “Asperger’s syndrome” and “pervasive developmental disorders”. All three of these “subgroups” share common “characteristics” which include “impairment in the ability to understand and use verbal and non-verbal communication, impairment in the ability to understand social behaviour, which affects their ability to interact with other people, impairment in the ability to think and behave flexibly which may be shown in restricted, obsessional or repetitive activities” (Ministry of Health, 2008, p. 30). Although all individuals with autism spectrum disorder experience these difficulties there is a great deal of range in terms of their severity and in terms of the individuals’ ability to function (Ministry of Health, 2008).

Thirdly, ADHD, or Attention-Deficit/Hyperactivity Disorder, is defined by Brock, Jimmerson and Hansen (2009, p. 1) as being a “diagnostic category currently used to describe individuals with clinically significant problems with inattention and/or hyperactivity and impulsivity”. ADHD is one of the most prevalent disorders among children today and can lead to a great deal of difficulty at school. ADD, Attention Deficit Disorder, is often used synonymously with ADHD and so is considered to be the same disorder (Peacock, 2002).

Psychological Assessments from the Clinicians’ Perspective

Psychological assessment is increasingly being used as a tool in determining whether a child may or may not be experiencing some of the problems described above. Clinicians who administer psychological assessments are likely to have a clear understanding of what it is that they are wanting to achieve. Their understanding is backed by a large body of research in the area of psychological assessments. The literature defines assessment as being the preliminary phase in every clinical setting involving children and their families as it enables the clinician and clients to pinpoint the areas of concern, establish a clinical diagnosis if necessary and make recommendations towards the treatment of these problems while aiding the primary caregivers and children in their cooperation and

engagement with the treatment (American Academy of Child and Adolescent Psychiatry, 1997; La Greca, Kuttler, & Stone, 2001; Reitman, 2006).

Typically children are referred for assessments by teachers, caregivers or medical practitioners who feel that the child is presenting problematic behaviour or is experiencing difficulties in a variety of areas, such as learning difficulties (American Academy of Child and Adolescent Psychiatry, 1997). The clinicians will then investigate these concerns further through the use of the assessment process.

The main aims or goals of the assessment process according to clinicians' understanding, is not to provide treatment from which change can be expected but rather to acquire insight into the presenting problems (Kanfer, Eyberg, & Krahn, 1992). The literature recommends gaining the following information in order to formulate an accurate diagnosis and treatment plan for the child: (1) intellectual and academic functioning, (2) developmental level, (3) personality functioning, (4) family functioning, (5) social functioning, and (6) temperament and affect. This information can be obtained by a number of means including formal psychometric assessments and undertaking structured, or naturalistic, behavioural observations, which are particularly helpful when working with children with conduct problems and attention-deficit difficulties, as well as assessing parenting styles (La Greca et al., 2001). Interviewing the caregivers and child is also helpful since it assists in identifying the difficulties and arriving at a diagnosis as well as building rapport (La Greca et al., 2001). In addition to this contact with other agencies or organisations that may have provided support for the child or family at present or in the past assists in the information gathering process (American Academy of Child and Adolescent Psychiatry, 1997; Kanfer et al., 1992).

The American Academy of Child and Adolescent Psychiatry (1997) identify a number of steps involved in the assessment process. The first is interviewing the primary caregivers to discuss any expectations and concerns that they may have as well as obtaining information on the frequency, intensity, duration and circumstances in which the problematic behaviours take place and investigating the primary caregiver, child and others' attitudes toward the issues. The second step involves gaining an understanding of the child's developmental history, which includes facts such as peer relations, physical development and medical history, interests, hobbies and talents amongst others. This is

followed by an assessment of the family and community background of the child, for example the culture in which the child has been brought up. Fourthly, the clinician interviews the child the aim of which is to investigate the child's understanding of the problems and to assess their developmental and mental status, through observation of physical appearance, orientation to time, place and person, motor behaviour, ease of separation and so forth. During this time the clinician makes use of a number of carefully chosen standardised psychometric tests, which "exist for systematically recording and assessing the development of children with respect to various realms of adaptive functioning" (American Academy of Child and Adolescent Psychiatry, 1997, p. 12S). Fifthly, data is obtained on the family's medical and psychiatric history, for example have there been family members with mental illness and so forth. This is followed by a diagnostic formulation, which outlines the presenting problem as well as the predisposing, precipitating, perpetuating and protective factors involved in the case (Eells, 1997). Finally, the findings are communicated to the family and child and the recommendations are presented in a way that is easily understood by both the primary caregivers and the child. This presentation includes the strengths and abilities of the child as well as the difficulties in order to provide a holistic picture. Once permission has been given by the primary caregivers the findings are communicated to the referring parties or organisations (American Academy of Child and Adolescent Psychiatry, 1997).

From this it appears that clinicians have clear guidelines based on the current research on how a psychological assessment should be conducted. We cannot know for certain, however, whether or not this theory translates into their actual practice. Nevertheless it is likely that they will, however, be deriving many of their perceptions from these dominant practice guidelines.

Child Assessment in Aotearoa/New Zealand

While there are generally accepted views on the purpose and practice of psychological assessment each practitioner, service or country may re-interpret these in different ways. In New Zealand there is considerable variation in the way that the purpose of assessment is envisaged and the administration of psychological assessments on children are conducted (Annan, 2010). Various health-related departments and organisations publish more specific descriptions of the assessments used in their particular area, for example

mental health, education and correction services, and clinicians select and adapt assessments according to the context in which they practice (Annan, 2010). It is beyond the scope of this thesis to describe the various assessment forms used within these sectors. It is possible however when exploring these various procedures to see that the general assessment processes within New Zealand, much like the processes in other parts of the world, involve the use of carefully chosen standardised tests and diagnostic criteria, such as the DSM-IV, observation, collaboration with the child's family, including extended family, teachers and any other adults or agencies involved with the child and gathering information from them relating to the child and family's history and the child's school functioning, this may be done by means of formal interviewing (Jimerson, Annan, Skoket, & Renshaw, 2009; Ministry of Education, n.d.; Ministry of Health, 2001; The Werry Centre, 2009). New Zealand therefore appears to be following very similar assessment procedures to those in America (American Academy of Child and Adolescent Psychiatry, 1997). Jimerson et al. (2009) found however that on one point New Zealand differs from the rest of the world in that there exists a general discomfort with the use of psychometric tests that have been developed overseas and may therefore not be culturally appropriate for New Zealand. When psychometric tests are used these are usually supplemented with New Zealand material (Jimerson et al., 2009).

In particular, there is a great deal of discussion around the issue of intelligence testing within New Zealand. Olssen (1988, p. 29) suggests that there is a political agenda behind the mental testing of children and that it is "not based upon neutral criteria". He suggests that the use of mental tests, such as IQ tests, imply inherent intelligence or lack thereof, which then allows for inequality within society and for some to be seen as advantaged and others disadvantaged. It also takes the blame for lack of performance off the school and onto individual children, who are seen to simply lack this natural ability. It is this thinking that provides the basis of the deficit model, which portrays the child who is experiencing difficulties as the problem; the teacher's role is then to attempt to change the child to better fit the environment (Thomson, Brown, Jones, Walker, Moore, Anderson, Davies, Medcalf, Glynn, & Koegel, 2003). The inclusion model however suggests that when a child is experiencing challenges in their learning it is as a result of failings within the learning environment (Thomson et al., 2003). New Zealand psychologists and those in related professions tend to reject the deficit model in favour of ecological assessment, which emphasises the impact of environmental factors on children's learning (Bartleet, 2009;

Ministry of Education, 1998). Herbert and Morrison (2007) also point out that psychological assessments prove inaccurate and inappropriate when working with Māori people and often do not adequately represent the difference between Māori and European individuals. In particular they mention the inadequacy of western IQ tests on Māori (Herbert & Morrison, 2007). There is therefore a great deal of debate within New Zealand around the appropriateness and validity of the use of intelligence testing and the decision to use them by clinicians is generally made on a case-by-case basis (Annan, 2010).

It is also important to note that Aotearoa/New Zealand is a bicultural country and that there is therefore a culture of “inclusion” and integration of cultural worldviews fostered within the assessment process and the conceptualisation thereof (Jimerson et al., 2009, p. 444). In particular the Māori culture has brought with it an emphasis on the addition of whānau/family (Ministry of Health, 2001; Ministry of Education, n.d.). The western view of family speaks mainly of the traditional, nuclear family but the Māori whānau extends beyond the household and into the wider, extended family and out into the community (Durie, 2001). Interdependence within this wide extended whānau is seen to be a positive thing (Harrington & Lui, 2002). The whānau shares the responsibility of child care and therefore it does not fall entirely on one or two parents as is the view among many western people. Psychological assessments in New Zealand therefore place a great deal of importance on the inclusion of extended family when working with Māori clients and it is suggested that clinicians receive cultural support when they are assessing children with Māori heritage (Annan, 2010; Ministry of Health, 2001).

In addition to this the idea of focusing on an individual because of their difficulties is not one that is compatible with the Māori worldview. When there is a problem with one member of the whānau it is seen as being symptomatic of problems within the whānau and there is a balanced focus on both the difficulties of the individual and those of the whānau (Durie, 2001). Question also exists around the appropriateness of using psychometric testing with Māori children and clinicians often tend instead to utilise cultural frameworking when gathering relevant information from Māori clients (Annan, 2010). Once again it is important for clinicians in New Zealand to receive cultural advice when working with Māori clients (Ministry of Health, 2001).

Practitioners are, however, cautioned against applying a one-size-fits-all approach when looking at issues of culture (Hirini, 1997). Not all Māori people will hold to these views and many have adopted a more western outlook. Māori people situate themselves broadly across the spectrum of cultural identity and so it is important for clinicians not to stereotype (Hirini, 1997). While these ideas are specific to Maori, it is likely that psychological practice in New Zealand is constructed with a stronger awareness of the significance of culture than some other Western countries.

Discourses in which Psychological Assessment is embedded

Burman (2008) critiques psychological assessments by arguing that they tend to associate the “cause” of the problem either with the family or the child and neglect to consider the context in which the individuals and family are situated (Burman, 2008). She argues that external social and political factors impact greatly upon the functioning of the family as a whole and should be considered when investigating problematic circumstances. For this reason it is appropriate for this study to acknowledge and explore these contexts. It is important to investigate some of the possible ways in which both caregivers and professionals may have formed their perceptions of psychological assessments. As a context and background for the study a number of discourses that exist around developmental psychology, the psychological assessment process and the concepts that are measured therein are identified and briefly summarised. The following discourses are discussed: childhood, development, intellectual functioning, family relationships, peer relationships and emotional problems.

It is also important to acknowledge that these discourses are, on the whole, discourses that exist within the context of Eurocentric western cultures that are more likely to be influenced by psychological ideas than other cultures (Rose, 1996). For example, the very notion of the self as being an autonomous being with an inner world of emotions, aspirations, abilities, beliefs and so forth is a uniquely Western one and it is out of this cultural context that psychology has been born (Rose, 1996). Psychology, in turn, has provided people with a way of conceptualising themselves. People construct narratives relating to their psyche as a means of coming to a deeper understanding of themselves and in so doing pave the way to an improved and more authentic self (Rose, 1996). The

very words that people use to describe themselves, others and their experiences are steeped in the cultural assumptions of their environment (Rose, 1996).

Eurocentric Discourses Relevant to the Psychological Assessment of Children

There are a number of discourses that may inform the social construction of psychological assessment with children. Particularly relevant discourses may include those around the topics of childhood, development, intellectual functioning, appropriate behaviour, family relationships, peer relationships and emotional problems. These particular societal discourses were chosen because these are some of the primary focuses of psychological assessments. These perspectives will be discussed in more detail below.

Discourses around childhood.

Ideas around childhood help to shape the way that psychological assessment is understood with this particular group of people. Although childhood is a physical state it is also an idea that is constructed through societal discourses around what it means and what it involves or is meant to involve (Moss, Dillon, & Statham, 2000). Burman (2008) argues that it is not 'reality' but particular discourses that have helped to shape childhood in particular ways. It is important to realise that these discourses are narratives created by society and form categories from which point comparisons can be made. The perceptions of childhood vary greatly across cultures and across time; they are not stagnant. These constructs have a significant impact on the advice that is given to those in charge of children and have an impact on the way in which society is managed, for example ensuring that we are raising children who will one day grow up to become "self-governing" and economically valuable adults (Burman, 2008; Hultqvist & Dahlberg, 2001, p. 4; Moss et al., 2000).

The concept of childhood has varied greatly over time. In more recent years two main discourses surrounding childhood have been identified (Prout, 2005). The first discourse around childhood is the notion that it is a time of dependence, purity and innocence (Burman, 2008; Cook, 2005; Prout, 2005). During this time children are to be free of cares and responsibilities and are considered extremely emotionally valuable and precious within the family context (Prout, 2005). They are also entirely dependent on adults to provide

their needs, protect them and to discipline and educate them (Moss et al., 2000). This discourse portrays a stark contrast between adulthood and childhood with childhood being viewed as a time of “incompleteness” (Cook, 2005). It is the caregivers who responsibility it is to lovingly guide their children into the maturity and “completeness” of adulthood (Cook, 2005). More recently a new discourse around childhood has begun to appear. In contrast to the view of children being weak, in danger of harm and dependent is the discourse around the empowered child (Cook, 2005). The empowered child is strong, symbolic of hope, significant, intelligent, and socially active and should be given a voice rather than being seen and not heard (Cook, 2005; Prout, 2005). The empowered child is also considered to be “more difficult to manage, less biddable and hence more troublesome and troubling” (Prout, 2005, p. 7). These discourses around childhood are relevant to this study because if a caregiver, teacher or clinician identifies that the child in question does not fit the “criteria” of what a “healthy” childhood is it raises concern.

Discourses around childhood development.

There are some very strong messages around what is appropriate for children to be achieving developmentally at what age and it is considered problematic when certain milestones are not reached within a particular timeframe (Burman, 2008). Weisner (2005, p.1) defines development as being “about children and families engaged in activities within a cultural and community context”. He goes on to say that these activities are prescribed to individuals by the culture and sub-culture in which they live and it is the individual’s choice to engage in these or not. Well-being for children, Weisner (2005, p. 4) argues, “can be viewed as the engagement by children and parents in everyday routines and activities, part of a life pathway of such activities, that are deemed desirable by them and their community”. Within the participant group of this study the culturally expected activities that the children should be engaging in include culturally appropriate academic achievement, appropriate behaviour, appropriate family and social relationships and appropriate emotional development while the caregivers are expected to fulfil a very particular parental role. There are some very fixed and clear guidelines set out for individuals to follow and when these are not met eyebrows are raised (Burman, 2008). Often children are referred for assessment because they have not reached the developmental milestones that are outlined in these kinds of discourses. Autism is an example of a developmental disorder

and may be assessed through the use of the Childhood Autism Rating Scale for example (Mental Health Commission, 2000).

Erica Burman (2008) critiques the assessments that have arisen out of developmental psychology. Through the standardisation of expected developmental stages, related directly to the age of the child, and by means of the tests used to measure these stages a social divide between that which is “normal” and that which is “abnormal” has formed. Each serves as a reference point for the other and steps are taken to create classifications through observation to ensure that the undesirable is rooted out. This Morss (1996) argues creates societal inequality, undermines the individual by grouping large numbers of people together and is contrary to liberty. The child then becomes scrutinised by assessments as well as the institutions in which they occur so that social control can be maintained under the guise of guardianship and shelter (Burman, 2008). Burman (2008, p. 22) argues that these notions are simply a socially constructed “myth”, “fiction” or “fantasy” based on philosophies and worldviews that are disguised as objective, scientific and standardised facts of normality.

Discourses around intellectual functioning.

The discourses around the notion of intellectual functioning or ability are numerous and familiar to most people in the general public. For the children, who are referred for assessment, questions often exist around their intellectual ability. We are told that the bulk of intelligence tests measure a child’s ability in a range of areas including vocabulary, word analysis, reading comprehension, language, mathematics, social sciences and science (Kamphaus, 2009) and are viewed as being connected to the age of the child. In other words there is seen to be an appropriate and acceptable intelligence level for different age groups (Burman, 2008). Research claims that an individual’s intellectual ability is influenced primarily by the genetic makeup of the individual but that this is mouldable to a certain extent by environmental factors up until the age of about ten or eleven years. According to this research the environment, or nurture, that the child receives plays only a minor role in a person’s cognitive abilities (Bishop, Cherny, & Hewitt, 2003). Caregivers are told, however, that learning begins at home and is fostered by supportive caregivers who provide their children with a wide range of experiences (Dowling, 2010).

While intellectual functioning is highly valued in our society questions are beginning to arise around this idea and some argue that there are other skills and types of intelligence that should not be undervalued (Elias, Arnold, & Hussey, 2003). Murdoch (2007) offers a strong critic of the traditional IQ test saying that it is not worthy of the weight that is given to it thus supporting the growing scepticism towards the notion of measuring intelligence. This idea is gaining in popularity as people recognise the existence of different forms of intelligence. This acknowledgement is evident in debates around disorders such as dyslexia in which it is suggested that the area of intellectual difficulty is limited to literary problems and does not necessarily extend to other areas of intellectual functioning (Brock, Davis, & Christo, 2009; Pavey, Meehan, & Waugh, 2010). In the assessment of autism spectrum disorder it is recognised that there is a great variability in functioning, including intellectual functioning (Ministry of Health, 2008), and in ADHD the issues are primarily around hyperactivity, ability to maintain attention and control impulses and not so much about intellectual functioning (Brock, Jimerson, & Hanson, 2009). Assessments today are therefore not simply determining the intellectual functioning of a child but also identifying specific discrepancies in their ability to learn that suggest a particular learning difficulty, such as dyslexia.

Discourses around appropriate behaviour.

In addition to the notion of academic achievement there is the question of what is considered to be appropriate behaviour. Often the children who undergo these assessments are deemed to have what is considered “inappropriate behaviour” according to the societal discourses that exist and tools such as Conner’s Rating Scales or Child Behaviour Checklist are used to assess this (Mental Health Commission, 2000). The discourses around the topic of appropriate behaviour for children say that caregivers need to teach their children to develop an understanding of what is right and wrong by considering the feelings of others and learning about the consequences of behaviour (Dowling, 2010). Children learn about what is appropriate behaviour from the example that is set at home as well as the behaviour of influential adults in their lives. According to this discourse the child’s personality and temperament also plays an important role in the way in which they behave and is largely influenced by the emotion that the child is experiencing at the time (Dowling, 2010). Therefore, the social construction of appropriate behaviour is created through our perception of that which is modelled to us by those in authority, by

what is communicated to us by others and also by the emotions that we experience (Dowling, 2010; Smith, Cowie, & Blades, 2003). Skelton and Valentine (1998) suggest that what is considered acceptable and appropriate behaviour varies from person to person and from group to group and that the person or group that wants their behaviour to be considered the “norm” will be intolerant of behaviours that deviate from this. Burman (2008) argues that these constructs exist to ensure that society is controlled and “good citizens”, that contribute economically, are raised.

Discourses around family relationships.

There are also some very powerful discourses in our society around family relationships and how they should and should not operate and these change over time (Burman, 2008). When these are considered to be disintegrating the child may be assessed for its impact on them. Family relationships are generally assessed via interviews and observation (La Greca et al., 2001). These societal discourses around family relationships involve the notion that the family is a vitally important part of a child’s life, regardless of its imperfections, and will have a long lasting impact on the individual child. What happens at home, according to this view, teaches the child what is important in life, what is right and what is wrong, how one treats others and also how one can expect to be treated, which influences the child’s self-perception (Dowling, 2010). It is also recognised, however, that the child has a significant impact upon the rest of the family and the result is an interactive and reciprocal family dynamic to which all members contribute (Shanahan & Sobolewski, 2003).

There has also been a change in the way that the structure of the family is represented according to Burman (2008). In the past the woman has been portrayed as the primary caregiver (Moss et al., 2000) but in more recent years the expectation for men to become more involved in sharing the responsibility of childcare has become very evident. Men and women are now seen to be equally important in the role of raising children (Burman, 2008). Despite this idea that two parents are important in the raising of children Statistics New Zealand (1999) has found that there has been quite a dramatic increase in the number of single-parent families. These discourses around the advantages of having both father and mother participating in the parenting process presents a difficulty for single-

parent families, same-sex couples or other families that are not traditional nuclear families because it emphasises the need for a male and a female parent working together.

In addition to this caregivers may have considerable expectations placed on them through society's discourses around parenting to provide the ideal example and environment in which their children can flourish. Dowling (2010, p. 8) describes the "adequate person", from whom children get their example, as being someone with "good interpersonal skills", someone with a "clear moral code" by which they live, they are able to express their emotions and empathise with the emotions of others, they are confident, decisive, "brave in facing up to difficult situations", "enthusiastic" and persevering. In short these individuals are "equipped both to get the most out of life and to deal with problems". Under such a person's guardianship "the small baby lies ready to reciprocate and blossom in our loving care" (Dowling, 2010, p.8). Parenting is also acknowledged to carry an enormous amount of pressure and that this makes parenting a challenging task at the best of times (Dowling, 2010). This pressure is compounded by the discourse that an individual's childhood needs to be idyllic in order for them to grow up as psychologically healthy adults and avoid the "risk" of pathology (Burman, 2008, p.100).

The socially constructed, ever-changing and culturally and historically contextual purpose of a "good parent" is defined as being "to facilitate the child's optimal development within a safe environment" (Reder, Duncan, & Lucey, 2003). This notion of parenthood is threefold according to Hoghughi (1997). It includes care, which involves meeting the child's needs and protecting them from harm; control, which entails establishing and maintaining appropriate boundaries; and development, which requires fostering growth in areas of potential. Hoghughi (1997) expanded on these core ingredients of good parenting by arguing that in order to parent successfully every parent needs knowledge of their children's needs, how these can be met, their children's potential, what the child is communicating and any possible sources of harm. They also need motivation, resources and opportunity to implement what they have to offer.

Discourses around children's social relationships.

Sometimes children will be referred to services to be assessed because of difficulties in their social relationships. This is usually done by conducting observations of the child in

social situations and through interviews with caregivers (La Greca et al., 2001). The discourses that surround the issue of children's social relations include the idea that children's ability to relate to others begins when they develop a relationship with the primary caregiver and others within the family and these early relationships impact on their ability to build relationships later on in life (Dowling, 2010). It is important for children to have exposure to a wide range of people and to be able to develop relationships with adults and children that involve good communication skills (Dowling, 2010). In addition to this it is believed that children develop their social skills primarily before the age of six or seven and that the ability to understand someone else's viewpoint is critical to this process (Dowling, 2010). Being comfortable around others and feeling a sense of empathy towards others is important to society in general since it grows children into "good citizens" (Dowling, 2010, p. 46). Peer relationships also assist children in cultivating social competency by providing an environment in which they learn assertiveness skills, conflict management skills and investigate gender roles. Difficulties in this area, we are told, can have significant effects on the child and can result in depression, anxiety and loneliness (Ladd, 2005).

Discourses around emotional development.

When there is concern around a child's emotional development, for example the possibility of depression or anxiety problems, the child may be referred for assessment, which often under these circumstances includes tools such as the Children's Depression Inventory and the Children's Anxiety Sensitivity Index (Mental Health Commission, 2000). According to the cultural discourses emotional development can be achieved by ensuring that children are able to feel and express a diverse range of emotions, including negative emotions, in whatever way suits them and in a supportive environment (Dowling, 2010). Self esteem and confidence is fostered by influential adults, such as caregivers and if children are loved, recognised, understood, encouraged and supported to master tasks they will develop well in the early years of their personal growth (Dowling, 2010). In addition to this it is believed that children need to be independent. Independence is "an essential life skill" and involves being able to problem solve, make decisions, ask for information and contribute to group discussions (Dowling, 2010, p. 51). The children that are assessed are often thought of as lacking in the area of emotions.

Emotional development is often conceptualised in terms of Emotional intelligence (EI). EI is a concept that has long held the attention of professionals involved in psychology and the public, through its wide publication in the popular media, and is now considered by some to be a fundamental component of cognitive ability and personal achievement (Cassady & Boseck, 2008; Freeland, Terry, & Rodgers, 2008). EI is seen as something that can be grown in individuals and encompasses a number of qualities including being aware of ones own emotions and being able to control and adjust them, persevering in the pursuit of goals, seeing things from another person's point of view and having the ability to manage social relationships (Bar-On, Maree, & Elias, 2007; Chang, 2008; Elias et al., 2003). EI is also believed to impact on the way in which children are perceived by their peers, their academic work and their behaviour at school (Petrides, Sangareau, Furnham, & Frederickson, 2008). In addition to this EI has been linked to happiness, well being (Furnham & Petrides, 2008) and life satisfaction (Palmer, Donaldson, & Stough, 2008) and is perceived as being influential in individuals' ability to maintain positive interpersonal relationships and lead a fulfilling life (Chang, 2008). According to Bar-On (2007, p.12) by educating children around emotional intelligence "we will help to build more effective, productive and humane organizations, communities and societies". This, Burman (2008) argues, from a more cynical perspective, is part of a social agenda to ensure that society produces children that will contribute effectively to the labour market.

Laypeople's' potential views on psychological assessment.

Western society is saturated with psychological ideas (Rose, 1996). It is likely that the caregivers have some existing ideas about psychological work and it is also possible that these ideas are different from the way in which psychologists and related professions conceptualise their work. The primary caregivers of the children undergoing assessment may hold views of psychology, the study of human emotions and behaviour, that are different from those held by professionals working in the field and may influence their perception and expectations of the assessment process.

While there appears to be no research that focuses specifically on lay people's experiences of the psychological assessment process, research suggests that psychology and related fields have been conceptualised by the western public in very particular and sometimes stereotypical ways. These have influenced and have been influenced to a large

extent by the media and in particular the cinema, which has tended to present psychologists and related professionals as anything from the all-knowing oracle to the lunatic (Orchowski, Spickard, & McNamara, 2006) with a couch (Waska, 2005). Research does however suggest that the public is becoming more and more open to the help of mental health professionals (Angermeyer, Breier, Dietrich, Kenzine, & Matschinger, 2005; Angermeyer & Matschinger, 2005; Lauber, Carlos, & Wulf, 2005). On the other hand Zafar, Jawaid, Ashraf, Fatima, Anjum, and Qureshi (2009) found that although most of the participants in their study had positive attitudes towards psychotherapy as an effective treatment for psychiatric disorders almost half of them failed to identify the professionally accepted definition of the practice thus demonstrating a difference in understanding of the field of psychology between the public and professionals involved in psychological work. It is therefore possible that the primary caregivers involved in this study hold similar perceptions of psychology, which may influence their conceptualisation of the assessment process undergone by their children.

Aims and Rationale of this Research

Interest in this research was prompted by the suspected difference of understanding of the assessment process by the primary caregivers of the children involved from that of the clinicians. Little is known of the perception of caregivers who have brought their children for assessment. This study investigates the perceptions of caregivers after the completion of the psychological assessment of their children to gain further understanding of the experience from their perspective.

There are a number of reasons why an understanding of caregivers' perceptions of the psychological assessment process is relevant. Firstly, a study done within the field of social work found that, to a large extent, primary caregivers feel ill informed of the assessment process and in many cases feel patronised by mental health professionals (Cleaver, Walker, & Meadows, 2004). This research also suggests that increasing the involvement of families when working with children leads to better treatment outcomes. Therefore, this study may be helpful in increasing the families' level of involvement by improving clinicians' understanding of the caregivers' experience of the process. From there clinicians will be more able to provide relevant information to caregivers at the assessment stage in the hopes that it will increase their involvement in the treatment, thus

improving outcomes. It is believed that by having a greater understanding of the primary caregivers' experiences clinicians will be able to provide improved services to these caregivers by potentially addressing some questions that may exist.

Secondly, when looking at the literature on the psychological assessment of children there seems to be little research investigating the understandings, perceptions and experiences of primary caregivers whose children have undergone psychological assessments. There appears to be a gap in the literature regarding this particular angle and for this reason the current research will prove helpful in broadening clinicians' understanding of caregivers' experiences of the process. Thirdly, this study may be able to fill a need within services to gain insight into the service that they are providing and the way that it is experienced by the caregivers of the children they assess. Finally, qualitative research was chosen as the vehicle from which to operate since it allows us to better understand not only the caregivers' personal experiences but also appreciate and consider the context within which these experiences are situated, their significance to the individual and the complexity of these experiences (Gordon, 2000; Kazdin, 2008; Levitt, Butler, & Hill, 2006).

Summary

In summary, the goal of this study is to gain some understanding of the ways in which primary caregivers conceptualise the process of having the child in their care psychologically assessed. The clinicians who administer these assessments appear to be quite clear about what it is that they are hoping to achieve and these practices appear to be supported by a wealth of research. It is from these theories and literature that clinicians construct their perceptions of psychological assessment. It is possible that the clinicians' views of what is involved in the psychological assessment process may influence the caregivers' perspectives as well.

Due to the fact that individuals experience events within the context of their society, culture, beliefs and so on it is possible that the primary caregivers involved in this study are, like clinicians, drawing on a number of discourses surrounding topics such as childhood, intellectual functioning, family relationships, peer relationships, childhood development and emotional development to formulate their own perceptions of the experience. It is likely that caregivers and clinicians draw on many of the same discourses

around these topics. There may, however, be difference in the discourses that exist around the field of psychology in general between clinicians and the caregivers.

I believe that if clinicians are better informed of caregivers perceptions of the process they will be able to address some of the differences in understanding and in so doing increase the family's level of involvement and thus improve treatment outcomes

Chapter Two

Methodology and Method

According to Parker (2005) ethical qualitative research needs to have a good theoretical basis in order to make a study as transparent as possible and thus facilitate a greater level of understanding (Parker, 2005). The aim of this chapter is to describe the qualitative and social constructionist theoretical framework used in this study and provide a rationale for this approach. This is followed by a section which outlines the narrative methodology of this study and finally the method used is described.

Theoretical Framework of the Research

Qualitative research

Qualitative research allows us to explore the meaning of experiences from the viewpoint of participants, who are seen as the ones holding the greatest understanding of a particular experience, and it is from them that we glean some understanding of the phenomenon (Parker, 2005). This was considered an appropriate approach for this study of caregivers' experience of having their child psychologically assessed since it enables researchers to investigate perceptions of the participants within a collaborative partnership in which the participant is the expert on their own experience.

Social constructionism

This study uses an overarching social constructionist approach. According to Gergen (1985) social constructionism is interested in how people go about understanding and describing their environment as well as themselves. Firstly, it argues that every concept is the product of its social and historical context and the interactions among people while at the same time acknowledging the existence of normative rules (Gergen, 1985; Meier, 2002; McLeod, 1997; Speedy, 2000; Squire, 2000). Secondly, social constructionism acknowledges that the meaning making process is three-fold and occurs first by the person telling their story, then by the research and finally by the reader of the research. Each of these individuals will be drawing upon their social environments, their subcultures

and their languages in order to construct meaning (Parker, 1999). This results in highly complex and multifaceted levels of meaning which is appropriate when looking at any human experience. Thirdly, social constructionism asserts that language plays a role in the construction of concepts since it is through this means that people are able to represent their experiences to others and construct concepts within the context of social interaction, construct their futures by creating meaning and gain an understanding of themselves as people (Gergen, 1999; Polkinghorne, 1988; Schwandt, 2000). Fourthly, social constructionism views the researcher as equal to the researched, with no one of the participants in this partnership holding more or less control than the researcher, since they are equal in a social exchange through which new meaning is collaboratively created (Gergen, 1999; Lincoln & Guba, 2000; Snape & Spencer, 2003). Therefore social constructionism seems appropriate for this study since the aim is to engage in an exploration of how each individual caregiver has constructed meaning around the experience of the psychological assessment process and what contextual factors may have influenced this perception, how they have used language in this construction and the influence of others in that process (Crotty, 1998; Lincoln & Guba, 2000).

There are however two factors that may influence the construction of meaning in this study. Firstly, the context in which this study is done may also influence the information that is given by the participants. Parker (2005) argues that because of the general public's familiarity with psychological concepts and areas of interest, through popular media, they are already primed when recruited to participate in psychological research to discuss with the researcher issues related to their feelings, thoughts and psychological state in general. This limits to a certain extent the type of information that qualitative researchers, within psychology, will gain from their participants when interviewing them. Secondly, social constructionism makes the assumption that individuals are speaking freely about their experiences and that therefore the researcher is able to gain some, but not all, insight into their perceptions through the use of language. This is however complicated by relations of power. These power relations limit individuals by placing rules around what is appropriate to say and what is not (Parker, 1999). Therefore we are not entirely in control of the meaning that we create; we are restricted by the boundaries set in place by those in positions of power. Parker (1999) uses 'political correctness' as an example of this.

Methodology – Narrative Theory

The aim of this study is to explore the way in which caregivers experience the process of having their child psychologically assessed and this has been done through the vehicle of narrative methodology. The narrative methodology allows us to explore how people construct their own reality through story telling.

Methodology

What is Narrative?

Narrative research attempts to explore the way in which individuals have used narratives as a means by which to arrive at an understanding that creates meaning around the event for them (Parker, 2005). The 'narrative turn' in psychology began in the 1970's and 1980's (McLeod, 1997) and emerged out of a desire to move away from more traditional forms of research, which were felt to lack a deep understanding of the human experience, and began exploring narrative inquiry as a means of gaining some awareness of the richness of phenomena from the perspective of the ones experiencing it (Parker, 2005). Today narrative research is gaining in credibility and interest within the social sciences (Lieblich, Tuval-Mashiach, & Zilber, 1998; Phoenix, 2008; Squire, Andrews, & Tamboukou, 2008) and it is an appropriate methodology when exploring the ways in which caregivers have constructed meaningful stories around their experience of their child's psychological assessment.

Narrative inquiry has roots in constructionist theory since it calls into question that which was previously taken for granted and asserts that reality is created by the way in which it is represented (Andrews, Sclater, Rustin, Squire, & Treacher, 2000). There is much disagreement on the exact definition of 'narratives' (Meier, 2002; Riessman, 2008; Squire, et al., 2008). The term 'narrative' is often considered synonymous with 'story' but is far more complex than that since it endeavours to take into account the context, purpose and inconsistencies within the narrative. Narratives are also chosen by the teller according to relevance to the hearer and are connected and structured temporally, thematically or episodically (Andrews et al., 2000; Andrews, 2008; Dean, 1998; Gergen & Gergen, 1984; Riessman & Speedy, 2007). Therefore, within narrative research there is also no single

narrative that adequately represents an event; there are numerous possible accounts of an incident (Dean, 1998). Individuals are constantly re-scripting past events, both our own and others', in the light of later events and new ways of understanding the world thus demonstrating the multilayered nature of narratives (Andrews, 2008). I believe therefore that the stories that are told to me by the caregivers I speak to, in whatever form they take, will represent to some extent an aspect of their experiences and how they made meaning of them, thus facilitating the presentation of the complexity of human experience.

Narratives in Context.

In addition to this narrative methodology acknowledges that language and culture cannot be removed from the process of communicating experiences. The ability to be self-aware within a context of history and culture may be a uniquely human quality and these experiences are conveyed in the form of narrative plots (Hinchman & Hinchman, 1997). Narrative research holds that even the most unique stories occur within a 'cultural locus' and have been shaped by societal influences (Squire, 2000; Hiles & Čermák, 2008). Narratives both create and are created by their cultural contexts (Crites, 1997). In addition to this an individual's smaller stories link into the context of their larger life narratives as well as the collective narratives held by those around them (Parker, 2005). Riessman and Speedy (2007) argue that a central focus of narrative research is the interplay between individuals within the context of relationships and the way that individuals represent themselves and thus create yet another level of meaning (Andrews et al., 2004; Dean, 1998; McLeod, 1997; Polkinghorne, 1988; Rennie, 2004). Therefore human subjectivity is varied and fragmented due to the multiple contexts in which we live and as a result narratives can never be entirely coherent and may often appear inconsistent and disjointed (Andrews et al., 2000). The multifaceted character of narratives does, however, allow us to understand individual and social change more adequately (Squire, et al., 2008).

The Functions of Narratives.

Narratives perform a number of functions. Firstly, they allow individuals to organise the past as well as make sense of it (Riessman, 2008). Narratives perform the function of creating meaning and organising experiences, within the mental realm of reality, for both the teller and the hearer by arranging aspects of the past and providing explanation of the

present (Bruner, 1990; Dean, 1998; Gergen & Gergen, 1984; Hiles & Čermák, 2008; Mishler, 1986; Polkinghorne, 1988; Riessman, 1993). Secondly, they can be used to convince others of something, engage listeners in ones own experiences, entertain, mislead and motivate others into action (Riessman, 2008). Thirdly, narratives assist individuals in building identity, or the notion of the self, and understanding unique aspects of their lives while at the same time representing themselves to others (Andrews, Sclater, Squire & Tamboukou, 2004; Dean, 1998; Kerby, 1997; Lieblich et al., 1998; McLeod, 1997; Phoenix, 2008). Parker (2005, p. 71) describes narrative as being “the performance of the self as a story of identity”. Finally, values are communicated through narratives by providing examples of those behaviours that are acceptable and those that are best avoided (Polkinghorne, 1988) and by presenting practical and convincing responses to life experiences (Hiles & Čermák, 2008). These instances make a moral point (Riessman, 1993; Salmon & Riessman, 2008). For example the participants in this study may present value judgements on what it means to be a good parent through the stories they tell.

Characteristics of Narratives.

Narratives have certain core characteristics (Bruner, 1990). Firstly, narrative is always part of a social and meaning making interaction (Gergen & Gergen, 1984). They are generally described in a sequence (Gergen & Gergen, 1984), they often account for departures from the norm or an incident in which there has been a break between the idyllic and reality (Riessman, 1993) and they contain a level of ambiguity when assuming that certain ideas will be taken for granted by the hearer and therefore have a moral quality (Polkinghorne, 1988). They reveal something of the teller’s inner world and subjective experience and they have a dramatic quality in that they are made up of actors, goals, settings, plot, conflict, resolution etc. (Gergen & Gergen, 1984; Mishler, 1986) Gergen and Gergen (1984) describe a number of different narrative plot structures. The first is stability narrative. In this story the character remains unaffected by the events described. The second is progressive narrative in which the character is developing over time. Thirdly, in regressive narratives the character reverts to less functional behaviours. And finally, dialectic narrative refers to an account in which there is progress despite tension. Narrators also select certain plots according to how they understand the event and also how they wish their hearers to understand it (Riessman, 1993).

Multiple Interpretations of Narratives.

As was mentioned earlier narratives can have multiple meanings and interpretations. Meaning is not created solely by the narrator through the lingual representation of an experience but these narratives are then interpreted by their hearer as well as the reader, thus creating meaning in a collaborative way which ultimately results in the existence of multiple stories of the story rather than one true and absolute understanding (Riessman, 1993). Riessman (1993) describes six stages of representation in narrative inquiry. They include the primary experience by the individual, the individual attending to the experience, the individual telling the story of the experience, the researcher transcribing the narrative, analysing the narrative and, finally, others reading the result of the research. Riessman (1993) suggests that meaning and interpretations are created at each of these levels of representation and that the primary experience can never be re-experienced by anyone directly thus resulting in only vague representations of the event.

Narrative Research.

By studying the narratives of participants investigators gain an understanding of participants' conceptualisation of their experiences and lives (Keats, 2009; McLeod, 1997; Polkinghorne, 1988). Narrative research allows researchers to gain insight into both open and hidden stories of an individual's life (McLeod, 1997; Speedy, 2000). Therefore the study of narratives is complex because of the dynamic, contextual and uniquely individual nature of these stories (Polkinghorne, 2004). Narrative research involves taking a small snap shot of a participant's ever changing sense of identity, the experiences they have and that which influences these perceptions while all the time acknowledging that these will vary across time (Lieblich et al, 1998). For all these reasons I consider narrative to be an appropriate means of investigating the way in which caregivers experience the process of having their child psychologically assessed.

Narrative Analysis

When reading the literature around narrative analysis it became clear to me that there are not set rules about the way in which the information presented in narrative inquiry is analysed. In general narrative analysis involves investigating stories that have

commonalities, such as those of the participants in this study who have all had children undergo psychological assessments. Narrative research explores stories themselves as the primary object of study (Riessman, 1993) and the aim is to explore how experiences are recounted by identifying patterns of meaning making and justifications for the interpretations of experiences rather than individual words, pauses etc. (Andrews et al., 2000; Edvardsson, Rasmussen, & Riessman, 2003) and produce one unified story that accurately represents the main meanings, or key themes, that have been created by the narrators (Phoenix, 2008; Riessman, 1993). The analysis takes note of the way in which each participant chooses to present their narrative, the aim of the narrator, the characteristics of the hearer and the meaning of the account (Riessman, 1993; Riessman, 2008; Riessman & Speedy, 2007; Spencer, Ritchie, & O'Connor, 2003). It also highlights the complexity of individuals' lives and the social and cultural environments that impact upon these (Andrews, et al., 2004). Essentially it is an interpretation of a narrator's interpretation of an experience (Riessman, 1993).

Issues of Generalisability, Validity and Reliability

Narrative research faces a number of difficulties when it comes to traditional measures of generalisability, validity and reliability. Narrative research struggles with its ability to be generalised because of its relatively small sample sizes and unrepresentative pools (Riessman, 1993). Although this can be a limitation, history tells us that many persuasive and long-standing theories have developed through the exploration of just a few individual cases (Riessman, 1993). Narrative inquiry enables researchers to examine personal experiences and how they are conceptualised in a very systematic way that provides extremely rich data (Lieblich et al., 1998; Riessman, 1993). Riessman (2008) argues that the knowledge acquired through narrative cases has underlying principles that can be applied to a more general population and can form the basis for future work in the field.

A second issue faced by narrative research is that of validity and reliability. Advocates of qualitative research and specifically narrative research believe strongly that traditional definitions of these factors do not apply to narrative research or need to be altered dramatically (Parker, 2005; Polkinghorne, 1988; Riessman, 1993; Riessman, 2008). Since narrative research involves the investigation into complex and intricate events and experiences it is not surprising that there is often a great deal of variety in the results of

these studies (Parker, 2004; Riessman, 1993). It is often the changeableness and process of phenomena that grasps the interests of qualitative researchers and it is due to this variability in data that traditional views of reliability, or the consistency of data collected, do not apply in qualitative research (Parker, 2004; Parker, 2005). Validity and reliability have since been reconceptualised within narrative research. Narrative research is considered valid and reliable if the data presented is found to be trustworthy and significant by presenting a narrative that accurately represents the participants' experiences, meaning making, justifications and memories and examines how these have functioned in such a way as to form a unified whole (Polkinghorne, 1988).

As a result of this move away from the traditional methods of measuring the quality of research qualitative researchers have identified three criteria that good qualitative research should meet (Parker, 2004). The first is that the researcher locates their study within a wealth of sound literature and research and explores what has already been done on the topic. The second guideline is that the argument laid out by the researcher needs to be coherent and flow in a logical and natural way in order for the study to be considered of good quality. The final guideline described by Parker (2004) is that researchers need to make the study accessible by being explicit about their own background and that of the study, the process as well as other possible perspectives on the issue, thus ensuring pragmatic use, and by using language that can be understood by non-academic audiences as much as is possible.

In narrative analysis the goal is to discover the mutual ideas in the stories and other researchers given the same narrative should identify similar themes identified by the original researcher (Polkinghorne, 1988). There are, however, many possible interpretations and by getting the input of others the researcher increases the persuasive quality of their work (Squire, 2008) as well as providing a richer and more complex understanding of the phenomenon under investigation (Andrews, 2008). This was achieved by bringing transcripts, already having had identifiable information removed, to supervision meetings with other researchers so that ideas and interpretations could be exchanged thus providing an opportunity for the analysis of the interviews to be viewed from multiple viewpoints.

Reflexivity

In quantitative research the subjective experiences of the researcher are seen as obstacles to discovering knowledge and therefore efforts are made to eradicate their interference. Within the qualitative theoretical framework however researchers are reflexive and locate themselves within particular historical, institutional and personal worldviews, thus allowing the research relationship to be openly situated within these contexts and informing the reader to a greater degree (Parker, 2005). Reflexivity can be achieved by opening the research to other members of the research team so that the interpretations can be made subject to other individuals' conceptualisations of reality (Parker, 2005).

The notion of being explicit about our subjectivity has been questioned, however. This challenge has argued on three points (Parker, 2005). Firstly, Parker (2005) argues that by presenting the researcher's personal beliefs reason and logic is disregarded and therefore the viewpoints presented cannot be argued against. Secondly, they hold that the researcher is able to answer every concern by simply locating the origins of that reasoning and without providing solid justification. Parker (2005) argues, however, that the only alternative is for researchers to claim an imaginary objectivism. It is therefore preferable to simply acknowledge the presence of these difficulties along with the rest and attempt to maximise transparency.

Personal Reflexivity.

It is important to acknowledge when working within this modality that the researcher is not considered to be neutral or objective but rather that the context in which the researcher is situated has an impact on the research. I am a masters student at a university where a number of the participants in this study had their children's psychological assessments done. This may have affected the information that they gave me, for example feeling less comfortable conveying negative experiences of the service to me, and this association may also have prevented people from agreeing to participate in the first place.

The connection that participants may have made between myself and psychologists, psychological theory and related professions may also have had an impact on the

research. Participants may have felt that their parenting was under scrutiny by someone who knows all the “right” ways of bringing up children and as a result may have edited their communication accordingly. In addition to this it may have primed participants to speak to me about psychological concepts such as inner feelings, self-esteem and so forth that they may not otherwise include were they speaking to someone situated in a different context (Parker, 2005).

Another consideration in this study is the fact that I have no children and although most of my participants did not know this it may have impacted on the types of questions I asked and the way in which I interpreted their responses. A parent may have interpreted the interviews differently because of a potential feeling of shared experience.

Ethical Considerations

When thinking about ethics from the perspective of qualitative research there are five factors to consider according to Parker (2005). Firstly, it is important not to enter the research with predetermined judgements on the nature of individuals, whether inherently good or inherently bad, based on any one psychological stand point. Instead the investigation should focus on the ways in which these qualities appear and how they are evaluated. Secondly, researchers should refrain from assuming that they are the same as their participants. Rather researchers should have as their starting block the assumption that everyone is unique and different from one another and that there is no basis on which to expect that we would all be the same. Thirdly, it is advantageous to notice the differences that emerge during the investigation so that assumptions and those notions that are taken for granted can be challenged and in so doing bring about transformation in our research. Fourthly, ethical research does not involve pretending that discrepancies in the findings are not there or that they are the result of some erroneous practice but rather they should be viewed as a demonstration of the wide variety of experiences lived by individuals. Finally, researchers should not view groups of individuals as being homogeneous but instead examine the instances when members rebel against restrictive categorisation of their group as a means of exploring what it is that unites them as a community as well as the problematic areas that may be denied or glossed over (Parker, 2005).

Another ethical issue to be considered when conducting qualitative research is the language that is used in the representation of the data collected (Parker, 2005). Firstly, the participants of the study need to be referred to in a way that adequately describes their valuable contribution to the research. The traditional term “subject” is not acceptable in the context of qualitative research. Instead terms such as “participants” and “co-researchers” are considered more appropriate given the assumption that they are in fact the experts in the topic being explored (Parker, 2005). Secondly, researchers conducting qualitative research should refer to themselves in the first person, which results in the researcher taking responsibility for the work they have done and the decisions they have made (Parker, 2005). Thirdly, and finally, the researcher needs to consider the language that is used to describe members of certain communities. The terms chosen need to be sensitive to the members (Parker, 2005). Originally the participants for this research were referred to as “parents” but it was pointed out by the ethics committee that this is not sensitive to those people who are not the biological parents of children but are the primary caregivers to them. Therefore the language was changed to better accommodate those who do not fit the category of biological parent.

There is also a great deal of debate within the field of qualitative research around the issue of “sensitive topics” of research. Hydén (2008) suggests that there is no concrete definition of what a sensitive topic is but rather that whether or not a story is considered sensitive to the teller is dependent on a number of contextual factors such as the relationship between the teller and the listener, as well as other personal and cultural factors. Lee and Renzetti (1990) argue that any topic that involves investigation into the personal lives of the participants, as is the case in this study, should be considered a “sensitive topic”. It cannot however be taken for granted that it will therefore cause distress to the participants but rather an awareness of the potential for distress is necessary (Lee & Renzetti, 1990). Individuals will experience and perceive the sensitivity of the topic differently and to varying degrees and thus there is no fixed definition of what is and what is not considered to be a sensitive topic. Instead it is dealt with on a case-by-case basis (Hydén, 2008; Lee & Renzetti, 1990).

The current study gained ethics approval from the Northern Y Regional Ethics Committee¹. In addition to using the term “primary caregiver” instead of “parent” I made the interview as predictable as possible for the participants by sending them the interview guidelines beforehand so that they knew what to expect. I would also send them a copy of the transcript after I had finished advising them of the changes I had made in order to maintain anonymity and asking that they let me know if there is anything that they would like changed or removed. In addition to this I further disguised the participants’ information within the report by changing or generalising particulars relating to the participants and their children, for example age. Since this study has the potential to be considered a “sensitive topic” because it deals with the participants’ personal lives (Lee & Renzetti, 1990) there was clinical support available should the study bring up any emotional problems for the participants. This was not however necessary at any point during the study.

Method

This section outlines and describes the participants that were involved in this study, how they were recruited and the interview procedure, including how interviews were structured and the types of questions that were asked. This is followed by a critique of interviews as a data collection method and how I dealt with these difficulties. In addition to this the transcribing and analysis process is outlined.

Participants

The participants in this study were made up of seven caregivers whose children had undergone psychological assessments, thus using homogeneous sampling (Ritchie, Lewis, & Elam, 2003). The only criterion for this study was that they had had a child psychologically assessed. No specific assessment services were focused on.

The sample was made up of six women and one man. They were all the parents of the children they discussed. Most of these participants had experience either in education or in the mental health field and they had had their children assessed at a range of different services. All of the participants identified their children as having had a “psychological

¹ Ethics ref: NTY/10/04/035

assessment” although it became clear that for some the assessment process had involved other professionals including teachers, RTLBs, psychiatrists and social workers. I had initially planned to have a slightly larger participant group but it was difficult to find participants who met criteria. In any event, after the seven interviews, the data was generating some repeated themes and it appeared that data saturation had been achieved (Corbin & Strauss, 2008).

Procedure

The participants were recruited through letters that were sent out to individuals who were known to have had their children psychologically assessed. These participants were either recruited directly from a psychology clinic or via word of mouth and through snowball sampling. These letters informed potential participants of the study and invited them to participate.

Once I received word that someone wanted to participate in the study I contacted the individual by phone, answered any questions they had about the study, emailed them a copy of the interview guidelines and arranged a time to meet with them. Participants were given the option of being interviewed at the university or in their own homes. Most participants chose to meet at their homes, I met two individuals at their work place and I held one of the interviews over the phone and the participant emailed me the recording. The one phone interview meant that I was not able to read facial cues and body language but I was able to gain quite a lot of information from the participant’s tone of voice.

Interviews

The data collection for this study involved interviewing each of the participants individually since everyday language is the vehicle through which meaning is conveyed and since I was interested in hearing the stories that they had to tell relating to their experience and how they used the stories to make sense of that experience (Andrews, et al., 2000; Parker, 2005; Polkinghorne, 1988). These interviews were tape-recorded, with the permission of the participants (Robson, 2007), so that the content of the interviews could be correctly transcribed and analysed, thus increasing validity (Riessman, 2008). Immediately after each interview I mentally noted initial reflections and analyses (Dogra, Vostanis, Abuateya,

& Jewson, 2007). The aim was to collect the participants' experiences of the psychological assessment process undergone by their children and to ensure that the meaning conveyed is represented accurately through the use of interviews and a systematic analytic system (Polkinghorne, 1988).

During the interviews the participants were allowed a great deal of opportunity and time to describe their story of the assessment process so that I could gain a good understanding of the experience as perceived by the participant within their personal context (Legard, Keegan, & Ward, 2003; McLeod, 1997; Squire, 2008). If interviewees are given this kind of freedom to express their experiences it is likely that they will do so through the use of stories (Polkinghorne, 1988). In order to facilitate this flow of narratives I needed to renounce my control to allow for such unmitigated story-telling (Parker, 2005; Riessman, 2008; Squire, 2008). It has been suggested that having multiple interviews further assists in ensuring the accuracy of the information that is gained but due to time restraints this was not possible in the current study (Legard et al., 2003; Squire, 2008). The interviews were done collaboratively and in the form of a conversation so that both the respondent and I could work as partners in the pursuit of the meaning that is behind the stories (Polkinghorne, 1988; Riessman, 1993; Riessman, 2008; Squire, 2008). In addition to this note was taken of what both the interviewer and interviewee said and in what context, thus beginning the analysis process during the interview (Parker, 2005).

Although these interviews were in many ways conversational they differed from a conversation in that I had determined the kind of information that I wanted to receive from the interviewee beforehand. I was also interested in what extra and unexpected information would result from the interview (Parker, 2005). As the researcher I made it clear that I was interested in hearing about their experience of having their child psychologically assessed and in so doing determined the direction of the interview. There was, however, a great deal of flexibility in terms of what the participants chose to tell me about that experience and I allowed them to take it where they would like believing that whatever they said somehow related to what I was asking from them and was therefore relevant and serving a function in their meaning making process (Robson, 2007).

Questions.

I began the interviews by reminding each participant that I was interested in hearing how they understood the process of having their child psychologically assessed and then asking them to tell me how it all began thus creating a starting point from which a narrative can emerge (Polkinghorne, 1988; Riessman, 1993). I asked further open-ended questions around the topic when it was necessary (Riessman, 1993). The interviews covered the main areas of the study (Robson, 2007) and included such questions as: How did you understand the process of psychological assessment? Did it make sense? What was going on during the psychological assessments? Did the assessment make any difference to the child's situation? What do you see your role as being? What was the role of the professional administering the assessment? I asked questions that provided a facilitating environment and laid open the opportunity for respondents to develop answers that were meaningful to them and at the same time listened for the emergence of stories which manifest in the form of examples or instances in which a particular concept is obvious (Riessman, 1993; Riessman, 2008). Questions such as "tell me what happened", "can you remember a particular time when?" were used to create an opportunity for respondents to share narratives (Riessman, 2008, p.25). Questions that were answered by a simple 'yes' or 'no' were elaborated upon to create a narrative if I asked for examples (Riessman, 1993; Squire, 2008).

Critique of Interviews.

Interviews are not, however, without their faults. Firstly, the interviews conducted in qualitative research, such as the current study, are often then transcribed into written text for analysis. Thus the wealth of spoken word is in some ways limited by confining it to that of written text (Parker 1999). I attempted to translate some of the wealth of spoken word into written word by noting down any relevant hesitations, laughter, tone of voice and so forth. Secondly, according to Bevan and Bevan (1999) interviews themselves are problematic since the interviewee will be represented in whatever way is most appropriate within the researcher's chosen theoretical paradigm. When viewed from a narrative research perspective, for example, interviewees are conceptualised as constructing meaning within the interview through the means of story telling. This is the case in this study but because of the nature of narrative research other interpretations are acknowledged and this study does not claim to present the only valid representation of the participants' experiences. A third concern relating to interviews mentioned by Bevan and

Bevan (1999) is that interviewers can be seen by the interviewee as having a level of power, the power to take that which is secret and private to them and place it in the open for others to see. Interviewers may also be connected with institutions or groups, which may hold connotations for the interviewee and influence the relationship that exists between the two. It may have been the case in this research that some of my participants saw me as being connected with clinicians due to the fact that I am a psychology student and that may have influenced what they told me. I tried to minimise this by encouraging them to express their thoughts through non-verbal encouragers and an encouraging facial expression. Within narrative research it is not believed that these factors can somehow be “factored out” to ensure accurate and “truthful” information that comes from an objective viewpoint but rather that the best we can do is to acknowledge these difficulties and the impact that they have on the research and take necessary steps where possible (Parker, 2005).

Transcribing

I transcribed the interviews according to the method laid out in Riessman (1993), which involves identifying aspects of the narrative and the function they serve (Polkinghorne, 1988). This is done through multiple and meticulous listenings and systematic transcribing (Riessman, 1993). Firstly, the interviews were tape-recorded. This was followed by a transcription. I then read and re-read these transcripts to gain an idea of the most striking aspects of the interview and noted down any themes that reoccurred (Riessman, 1993).

I transcribed the interviews myself because it allowed me to take note again of the non-verbal cues that occurred during the interview (Parker, 2005). By identifying these non-verbal aspects of the interview I provide further context and meaning to what was said instead of focussing solely on the spoken word. This increases the level of complexity that is so integral to narrative research. I have also been explicit about what types of information I was looking for while transcribing instead of pretending to be an entirely objective transcriber which is in line with the qualitative theoretical framework (Parker, 2005).

Data Analysis

Analysis.

I decided to work with a version of the experience centred approach, which views narratives as having meaning, being unique to the human experience, representing and describing an experience and demonstrate change over time (Squire, 2008). The analysis of these narratives focuses on the sequence and progression of themes through the interviews, how these change and are resolved (Squire, 2008). This type of analysis also acknowledges that there can be multiple interpretations of a single experience (Squire, 2008).

In addition to this it was my aim that the analysis of the data collected be treated in such a way that investigates the role of thematic and other forms of narrative presented by the participants and what the purpose of that may be (Riessman, 1993). In this respect my analysis was very similar to the categorical-content perspective (Hiles & Čermák, 2008). Once I had transcribed the interview and noted the sequence of events and main themes I wrote individual analyses for each, which follow in the next chapter. This analysis involved firstly, a brief description of the wider context of the interview, for example where it was held, anything that occurred during the interview that was of interest and any contextual information relating to the participant, for example what they did for work (Squire, 2008). This was followed by the representation of events as they occurred across time. These events were seldom presented to me in order but incoherence and inconsistency was tolerated due to my acknowledgement that narratives are very complex and dynamic in nature (Squire, 2008). I therefore rearranged the order in which information was given to me in order to get a sense for the sequence of events. Finally, I identified themes that emerge from each of the individual narratives and these themes were often demonstrated in direct quotations. In the second layer of analysis I noted the themes that were common to the individuals' experiences and thus form the overarching ideas from which conclusions were drawn (Hiles & Čermák, 2008). I understand that each narrative is appreciated for its unique character while also understand that there are a limited number

of plots, due to a finite cultural collection of narratives that re-emerge in individuals' representations of experiences (Polkinghorne, 1988).

Summary

This chapter has outlined the theoretical framework, methodology and method of this study. The theoretical framework is based on qualitative research theory which endeavours to investigate experiences from the perspectives of the individual (Parker, 2005). Social constructionism argues that individuals construct these experiences themselves and these constructions are impacted upon by the context of the individual (Gergen, 1985). Narrative theory then states that individuals make these constructions for themselves and others through the means of story-telling (Parker, 2005). Narratives are also affected to a large extent by context (Squire, 2000), perform a number of functions (Riessman, 2008) and have multiple interpretations (Riessman, 1993). The goal of narrative research is to look at and analysing the commonalities within the stories told by people having experienced a similar phenomenon (Keats, 2008; Riessman, 1993).

This chapter also discussed particular issues of generalisability, validity and reliability as they relate to qualitative research. Parker (2004) and Riessman (1993) both argue that different standards apply to qualitative research and they outline some criteria that good qualitative research should meet. Reflexivity was also discussed in terms of the impact that the researcher can have on the research (Parker, 2005) and general ethical considerations relating to qualitative research, such as being as non-judgemental of participants as possible when going into the research (Parker, 2005), as well as the more specific ethical issues relating to this particular study were outlined. Finally, the method of this study involved seven participants that I interviewed. I recorded these interviews and transcribed them. I then wrote up their individual narratives, outlining the sequence of events and then drawing out the main ideas of each story, followed by an overarching analysis of the commonalities between all the narratives collected.

In the following chapter I present each of the participant's stories individually and begin the first layer of analysis. This involves portraying their narrative in a sequential order and following it with an outline of the main ideas that were brought forward by that individual. In the next chapter I analyse common themes generated in individual narratives.

Chapter Three

Participant Narratives

In this chapter I create individual narratives for each of the participants. This first layer of analysis relies largely on the stories they told to me but also involves some attempt to structure the main events in a somewhat sequential order. I have also attempted to highlight some of the main ideas and themes that emerged out of each individual story.

Anne: Gathering Ammunition

Anne and I met at her home. Anne's story is a tale of a mother who campaigns for her children. It all began when Anne's child was very young and she realised from her own observations as well as her background knowledge and experience in education that her daughter is especially gifted. Anne's daughter was identified as "gifted" by an organisation that provides schooling for gifted children. This was done through observation and not formal testing. Anne then had to go back to work for a few months and her daughter regressed. Anne gave up work as a result and since then has been desperately trying to regain access to her daughter's giftedness by means of a formal assessment but professionals have not been able to identify this in an assessment because of the "regression", which has involved becoming progressively "non-verbal". Her daughter has also received a diagnosis of autism. This assessment process has been a frustrating process for them because they have received a number of diagnoses ranging from extremely autistic to not autistic at all. They had a number of paediatric assessments done "to get anyone to find something that was vaguely close to what [they] thought was right". The most recent assessment was done, like many previous ones, in order to capture her daughter's "giftedness". This journey has been a long one and riddled with difficulties.

While speaking with Anne a number of themes began to emerge. Firstly, Anne suggested that the assessment tools that have been used are inappropriate. Anne believes that her daughter has become "resistant to testing". She described how when her daughter is being assessed she "switches off" and "does not respond", which makes it impossible to

“access” her and gain an adequate measure of her abilities. In addition to this Anne has found that because her daughter is far more non-verbal than she used to be many of the tests are an inappropriate means of gaining information from her because many of them rely on language and verbal communication. Anne also mentioned that her daughter has “got issues around oppositional defiance and compliance issues” and that she has to see the point to, or rationale behind doing the activities involved in the assessments.

Secondly, Anne and her husband had already determined what diagnosis they thought was appropriate for their daughter and wanted confirmation from a professional. Anne told me that she has a number of years teaching experience and had studied in related areas. In addition to this she has done a lot of her own research around the topic of autism and her decisions, for example the utilisation of therapy, have been based on a theoretical knowledge from both her professional training and personal study. Anne wants to be acknowledged for her expertise in the area and wants her views to be respected by professionals.

They were hoping that these formal assessments and their subsequent diagnosis would perform a number of functions. The theme of the assessment as being “ammunition” was a very strong one. Anne has used these numerous assessments as a way of gathering “ammunition” to fight the war against unsympathetic and suspicious professionals and against autism.

Firstly, Anne wanted these assessments in order to get a benchmark of just what her daughter is capable of so that they can stimulate her according to her full potential in order that the “window of opportunity”, during which time autistic children are likely to achieve the most improvement, can be maximised. In this regard the “early intervention”, which involves huge amounts of time, effort and money that is put into this “window of opportunity”, is seen as an investment that will hopefully “pay off in the long run” and is based on research that Anne had done on her own on autism. Anne’s mum goes to Anne’s home regularly and “she sees her role as just doing therapy stuff” with Anne’s daughter “she spends the whole time trying to get her to talk, trying to get her to do things”. Here she is using these assessments as a way of maximising her fight against this disorder that she feels is claiming her daughter. Her narrative emphasised the sadness and frustration

of trying to capture the capacities she knows her daughter possesses before she regresses further and becomes more non-verbal.

Secondly, Anne wanted this “ammunition” so that she can ensure that her daughter’s giftedness is not “overlooked” or “forgotten” particularly since her daughter’s “behaviour is not what is expected of a gifted kid” and may be misunderstood. She hoped that the “baseline” received from the assessments will “keep reminding people that she’s got two aspects to her”. Her concern is that “everyone’s so busy going on and on about her autism and forgetting that she was a smart cookie before it and she’s a smart cookie still”.

It’s frustrating. You know what your child is capable of but you cannot get it out, to get the world to know, to have it on paper, to have an objective, you know, standard to measure her by.

In the school context she hopes that it will result in the school respecting her and making sure that she is given the opportunities that will maximise her potential and so that she doesn’t get “bored”. Anne aims to use these assessments to give credibility to her expectations of the school that they give her child an individual education plan and acknowledge her abilities.

Anne also wanted to tell me “we’re not pushy parents, you know, we don’t flash card them and hothouse them” but they want them to get every opportunity available to them. She said this in the context of wanting to ensure that the school respects them and provides them with all that they need in order to do the best that they can academically. It seemed that Anne felt that because she has expectations of the school that she needs to defend herself against some kind of label or stereotype of being a “pushy parent”.

Thirdly, Anne hopes that the results of the assessments may give her “some basis to challenge” some parts of the therapy that her daughter is currently receiving “because some of it’s too basic”. This further demonstrates her concern that her daughter’s “giftedness” is being overlooked and ignored and that she is not being presented with the challenges that she is capable of. Anne hopes that by having a formal assessment that says that her daughter is gifted that she will have the “ammunition” to get the therapists to provide her daughter with the level of complexity that she needs.

Finally, Anne has had a number of instances where she has experienced the medical profession to be very suspicious of any claims she makes regarding her daughter, including reporting that her daughter was experiencing physical pain. This has resulted in her feeling “insulted” and that she is being spoken to as though she is “an idiot”. This makes her quite angry.

My only hope is that some of these [assessments] will give us some basis to go back to some of these guys and say “*I’m not making it up. Here is some other person who says this*”...if you’re not going to take *my* word for it please take the word of a professional, you know, who is not related to him

Anne hopes that by having another professional’s opinion she can go back to medical professionals with proof of what she is saying.

Anne’s protectiveness in relation to her daughter was evident in her narrative. She sees her role as protecting her daughter and advocating for her so that her giftedness is acknowledged and she is not misunderstood. She also sees her role as being one of “carer”, someone who resources therapies that will provide “stimulation”, “to keep her safe because she runs off, disappears, escapes all the time”, “to keep her routine” and to “monitor what she eats, monitor her moods” to ensure that she “keep[s] on top of things” and intervenes early to avoid “melt down and tantrum”.

Anne clearly feels a great deal of responsibility towards her daughter and is aware of the weight of her presence in her daughter’s life. She said that it “became very obvious that when I wasn’t here that she deteriorated”, which indicates that she is acutely aware of the link between her absence and her regression. Anne takes her responsibility as carer very seriously and this realisation resulted in her dedicating herself to her daughter’s care.

This assessment experience has resulted in Anne feeling very “frustrated”. She views it as having been “very very long” and indicates that the journey is going to be an on going one. This was made evident through statements such as “you know, you just have to keep working through and see where you get with her”, “we’ll probably have to wait until she’s a little bit older to try and get more” and when referring to a more appropriate assessment that is available she said “I’ll just have to paw around until we’ve got one”. Anne sees this as a “battle” that will continue for many years to come.

Anne's story took on a dialectic narrative form; she spoke of progress despite tension. For years she has campaigned and fought for the welfare of her children and she appears to anticipate that this will be an on-going process. This narrative focuses on themes of frustration at Anne's inability to have her daughter's abilities acknowledged and her desire to have assessment as a form of ammunition that will help her to take care of her daughter's needs in the future.

Mary: "Total Faith"

Mary explained that for years she and her husband, who has been diagnosed with both ADHD and dyslexia, suspected that their son has dyslexia. They became especially concerned because their son would be doing his final exams for secondary school the following year and they knew that if he was diagnosed as dyslexic he would be entitled to a "reader-writer", someone who would sit with him through his exams and write down his verbal responses to the questions. Mary has an acquaintance that is an expert in special needs and suggested that they approach a clinic which conducts psychological assessments. Their son attended the assessments and was diagnosed as having dyslexia. As a result their son has been assigned a reader-writer and has learned some new learning techniques that assist him in his style of learning, for example that it helps him to be able to hear the material that he has to learn rather than simply reading it. Their son is now more hopeful of the future and is more "onto it" when it comes to accumulating credits and knowing how many more he needs and so forth. He is also making plans towards his future career.

During my conversation with Mary a number of themes and ideas emerged. Firstly, Mary seemed to view her and her husband's role as being that of a good parent, being "keen" and "happy" to provide whatever is needed to ensure that their child's needs are met. This was what motivated them when taking action and it was certainly not, Mary stressed, to "label" or "brand" the child. She does however suggest that the "labelling" of her child would be of assistance because it would open up the possibility of receiving the academic assistance that he needs. It seems that Mary was hoping that the assessment would give them some answers to questions around learning styles and diagnoses. She hoped that this would translate into a solution so that she and her husband can do what's best for their child.

Mary's narrative also focused on her concern that her son may have missed out in the context of a busy family. Mary also lamented her own role in relation to her son's difficulties. She felt she had not always said the "appropriate" thing to her son, for example comparing her own experience of reading with her son's. Mary also spoke about how her son was a middle child and described how he had had difficulties with his siblings and struggles at school.

Mary's narrative highlighted her and her husband's knowledge of the area of learning difficulties. Her husband has been diagnosed with ADHD and dyslexia and so has had personal experience of these disabilities and has been quite involved in the assessment process. Mary also mentioned that she has worked in the education field and as a result was able to recognise the dyslexia in her son prior to the assessment. She added that her husband had done a test in his adult life and had finally been diagnosed with ADHD but she had already seen it in him from when they first met and this test simply confirmed it for her. They have also done a great deal of reading up on the subject of dyslexia and so were not surprised when their son was diagnosed with it. Mary was however very surprised to find that they had not diagnosed him with ADHD

She repeatedly mentioned her surprise that her son had not been diagnosed with ADHD despite the fact that she had been quite certain of it, having been able to identify it in her husband and seeing signs of it in her son. She denied, however, having any doubts that something may have been missed, insisting that she had "total faith" in the psychologists, which she described as being "skilled" and "very thorough" in their "testing", as they fulfil their role of determining whether their son "fits this box or he doesn't fit that box".

Mary described their son as being "exuberant", "full-on", "active" and as having a good sense of humour. She also said that they believe him to be a "bright enough" boy and that the test had shown that he has been very resourceful in coming up with coping strategies to help himself in his learning. He is seen as being very capable but as having a different learning style and if they could just get advice on how to figure that out it would be okay. The assessment has allowed them to gain more knowledge on what their son's learning style is.

The tone of Mary's narrative was sometimes apologetic and unassuming. She appeared to hold professionals in high regard and did not question their abilities or skill. She declared having "total faith" in them, that they were "very skilled" and "very thorough". Mary portrayed the professionals in this story as heroes but in spite of this also revealed some dissatisfaction with a number of factors relating to the assessment process. The first was that although the assessment was "very thorough" Mary spoke of how they had expected it to be purely academic testing but instead they were asked the "type of questions they had never been asked before" on issues such as family dynamics and how their son's relationships with his siblings are. She was surprised by this and said that the friend who had referred her had not mentioned that this would happen but perhaps she did not know about it. In her narrative, Mary, however paired this kind of implied criticism with praise for the professionals for their very "thorough" testing which enabled them to get a full understanding of their son, which they would otherwise not have been able to access without the insight of a trained professional.

Finally, Mary said that quite a bit of "technical jargon" had been used during her meeting with the senior psychologist and she had asked for clarification but had been told that "it's not really important to define what it is but that if you can just understand this graph shows blah blah" and she left still feeling that she had not understood everything but did have some advice on what to do, which she was pleased with. Mary justified this by saying that it must be very difficult to put all that information into "layman's terms" to explain to a "parent who doesn't know a lot about that sort of thing". Again Mary had "faith" in these professionals despite having unanswered questions.

Mary's story took on the shape of a progressive narrative in which there is development over time. They sought help for their son, he has received the necessary assistance and his future is now looking more hopeful as a result. Although she clearly had some doubts about aspects of the assessment process, she professed faith in the psychologist's opinion and gratitude for the help she had received. When I thanked Mary for participating she said that she was only happy to be able to "give back".

Kate: The Pursuit of 'Normality'

Kate and I met at her home after she had finished work. Kate works in the education field. She was well dressed and had a beautiful home. Her story of her son's assessment conveyed her thoughtfulness and emotional insight. She is a single mum, who described herself as being busy. She and her husband divorced many years ago. Since then she has been in a long-term relationship which ended fairly recently.

Kate explained to me that her assessment journey had begun when her son first went to primary school and required a RTLB (Resource Teacher for Learning Behaviour) to assist him with some learning and behaviour difficulties he was having. This lasted for one or two years and then he no longer needed the RTLB. During primary school her son was also identified as being gifted and he attended a one day school for gifted children for almost a year. Kate described the experience of having her son in a gifted school as being a positive one because she was "pleased" at the thought that "perhaps one of the reasons for [son]'s difficulties was because he was very bright". Next her son moved on to intermediate school and once again required RTLB support as he was "having difficulties with the transition" and he "wasn't performing in the way that normal children do", which raised concerns for Kate. The issues her son was experiencing at that time involved "behavioural" difficulties, problems with "social skills" and an "emotional lack of maturity". The fact that her son required a RTLB also confirmed to Kate that he was having problems because RTLBs are not called in unnecessarily; having worked in the education field she is familiar of these processes.

At this stage Kate decided that she wanted to have her son psychologically assessed. She sought out this help for a number of reasons. Firstly, she was concerned about his progress at school. In particular her son "was doing a few silly things at school that were inappropriate, some behavioural things, making noises, disruptive, kind of, attention-seeking things" and having "behavioural" difficulties, problems with "social skills" and an "emotional lack of maturity".

Secondly, she wanted to make the right choice of college for her son; whether he should go into a co-ed school or a single-sex school. Thus, for Kate, the assessment was prompted by a turning point in her son's schooling career and she felt that by getting to know more about her son through the assessment that she would be better informed to make this decision. Kate sees her role as a parent to ensure that her son's educational

needs are met to the best of her ability. She wants him to be in an environment that facilitates his learning.

Thirdly, Kate wanted to find out if her son had Asperger's syndrome. When Kate and her ex-partner's relationship came to an end Kate said that things "came to a head because he indicated that he was having some difficulties with [son] and that he thought that it might be appropriate if I found out whether he was Asperger's". This suggestion was made because her ex-partner had been to his doctor and had discussed Kate's son with him and together, with the aid of google, had "self-diagnosed" Kate's son. Kate wanted to find out for herself whether this was true or not and if so what she was to do about it and what the school was to do about it. Here Kate indicated that by having this diagnosis of "Asperger's" given to her son that it would then result in action both by herself and also by the school, thus suggested that labels equate to solutions.

Finally, Kate also wanted to find out if it was her parenting that had caused these difficulties in her child. She felt solely responsible because she is a busy, solo parent and her son has little contact with his father. She felt that because he spends all his time with her and is raised entirely by her that the fault must also then lie with her. She also seemed to express some regret about the fact that her son had had to grow up without his father around and said "I didn't quite know the impact of that on a child". So as Kate said "there were lots of things that I just needed some answers to".

So the assessment was done at a clinic and Kate reports that the difficulties that they were experiencing have "improved significantly" and her son no longer requires a RTLB. She believes that this improvement is due to a number of factors. Firstly, the fact that they were able to spend a couple of months "really focussing in on everything that was happening for [son] and [son]'s life outside of school, inside of school, friendships, our home situation". This Kate said "gave him, and me also I think, a chance to really focus on what was necessary for [son] and why he was going through what he was going through, how he was achieving or underachieving or overachieving in some areas". In addition to this she felt that it was helpful for her son to be able to talk to someone about what was going on for him.

Secondly, Kate found the “guidance” that was given by the clinician very helpful. In particular her son was given some coping mechanisms and some recommendations were made such as developing a good routine, re-doing a previously tried bed wetting programme and providing an opportunity for there to be continuous dialogue between her and her son so that he is provided with the necessary support. Kate suggested that a professional’s guidance was very of great value and resulted in improvement. Thirdly, Kate spoke of feeling “stronger” in her ability to deal with her son and that she is becoming more consistent in her parenting. Fourthly, Kate attributed some of the improvement to environmental factors, such as her son having “grown up” and become “more mature”. In addition to this she thought that the fact that he no longer has the previous conflict with her ex-partner has also contributed to his progress.

Kate also found that the assessment was quite enlightening and that her knowledge of her son has improved. Firstly, she discovered that in fact her son displays “none of the features of Asperger’s” which at first she described as being “reassuring”. But when I enquired a little more on the subject Kate said “I suppose if there’d been a label that I could have put on him to explain some of his difficulties that might have maybe made it easier for me but then I didn’t really do this to make it easier for me”. She also indicated that this label would result in someone giving them a solution that she and the school could apply to the problem. This conflict between wanting a “label” and not wanting the “label” appeared a few times during our interview. On a number of occasions when she mentioned “Asperger’s syndrome”, “suffering from” or “normal” she would follow it immediately with the phrase “for want of a better word” implying some regret at having to use these labels.

Kate also found out that her son is very thorough in his work but as a result he works quite slowly. She said that she had been quite “surprised” to learn this and that there is “almost a bit of controversy there in [her son]’s ability”. It was also confirmed to her that “in some areas he’s very bright and in other areas he really struggles” and she described this as being “two extremes”, which she thought would be good for the school to know.

As a result of the assessment Kate has also decided to send her son to a co-ed school because the assessment found that he gets on well with girls because he finds them to be more mature and easier to talk to. He also tends to feel “intimidated” and “bullied” by “boy-

boys”, her son “is not a boy-boy”. He is more of an “intellectual” and “not at all sporty”. As a result she doesn’t “want [son] to get lost in the system” in a single-sex school where sport may be more of a priority and he may be perceived as different. Here Kate conceptualises her son as being “intellectual” rather than “sporty”, which places a positive light on the before mentioned difficulties.

When I asked Kate how she found the assessment experience emotionally she replied by saying that she was “proud” of her son. She thought that her son had “presented himself” well and “was able to talk reasonably articulately about things”. She had also mentioned earlier that she had found it “really reassuring for [clinician] to be able to say that [son] was actually a really nice, young boy who she found quite a delight to deal with and that had a lovely sense of humour and despite the fact that he would often be tired when he went to see her” “So that was nice to know that even when conditions aren’t optimum that [son] can perform in the way that you would want a child to”. She also said when describing her son’s behaviour during the assessment process that it was “good for me to know that, you know, that despite the fact that he has difficulties that he’s a good kid really”. Kate strongly desires that her son be acceptable to others and that he be perceived in a positive way.

This process of gaining insight into her son seems to have been a positive experience although it has not come without its struggles. She has now found that he “has a different approach” and “his way of thinking is different to many children”. She feels she now has to grieve the dream she had for her son. In particular she described her frustration at the fact that his “interests are very very limited” and she said “there are things that I think as a parent you wish for your children and then obviously I wish that [son] was more sociable and more involved in activities”. She said that at his age all she can do is encourage him and present him with options, which she has done for years with no success. Kate feels, however, that she cannot force him to do what he is not interested in. This has been a “challenge” for her since as a child she was “involved in lots of extramural things” and she sees “that as being making a *whole* person”. She desperately wants him to “have an all-round experience of being a kid and what it’s like being in a team, being a team player”. She is also concerned that “as an adult his experiences will continue to be narrow as well”. But after the assessment Kate said that she is “just accepting that [son] is who he is” and “just accepting the fact that [son]’s not ever going to be a sporty person or somebody who does extremely well or who is self-motivated in anything other than what he is particularly

interested in, which is computers [laughs]”. Again Kate presented a picture of what she had hoped for her son. Instead she has to grieve these dreams and reconceptualise her son in a way that fits him and reconciles his differences to her hopes, for example as an “intellectual”.

Kate was very clear about her role as a mum. She described her role as follows: “I’ve just worked my hardest to make him a helpful, respectful, kind, you know, trustworthy, honest person and just guiding him as best as I can” “For me as a mum I think it’s what I’d like to achieve with...my kids. To make sure that they grew into adulthood being respectful of others, and kind and helpful and honest and all those things that will help be good, reasonable human beings”. Alongside this she also seems, as was previously mentioned, to have an expectation that they have a wide variety of interests and abilities and that she provide these. Kate wants to provide all that her children need to be happy and productive in their adult lives. It may be that to her another form of provision is for her to see to their psychological needs and in order to do this she has ensured that her child has access to a psychologist. Kate portrayed her son as being problematic in terms of his behaviour and that she would like to see him being more sociable, outgoing and having more interests and activities but that she is learning to accept who he is. She also sees that he is a “good kid” despite all this.

Kate expressed to me that she “was *really* happy with the process that [they] went through” and that the clinician “welcomed [son] so warmly and built up such a lovely relationship with him very quickly, which was nice and in a nice environment that we were able to go to and [she] felt safe leaving him there with her”. She also had no problems getting her son to go along.

Kate’s story of the assessment process is a progressive narrative since the characters in this story improves over time. Her son has experienced improvement both through his behaviour and through her choice to accept him for who he is. As a result their home becomes more like what she would like it to be.

Amy: In the Dark

Amy and I met at her workplace. She reported that much of her daughter’s assessment had taken place a number of years ago and so her memory of it is not very clear. Amy

presented herself as being very familiar with mental health issues and with the systems and organisations that operate within this field. This familiarity comes as a result of working within the mental health field herself. She has not always been aware of the workings of this area, however, and it was before her mental health work that her daughter was psychologically assessed. Amy emphasised the importance of family involvement and “early intervention”, which further demonstrated to me her knowledge of the area.

Amy explained to me that it all began with her daughter showing signs of withdrawing and playing a lot of computer games. Amy had a sense that something was wrong but because her daughter “was actually getting up in the morning and doing that most days. [she] thought well, you know, she’s going to school”. And this comforted her until one day she received a phone call from the school her daughter attended saying that their daughter was in the counsellor’s office and was suicidal and appeared to be catatonic. Amy then had an interview with the counsellor. After this she made an appointment to see the principle and only then was she told that her daughter had been absent from school for two thirds of that year. This had not been communicated to Amy at any stage prior to the interview. “The school just really wanted, at that stage, [daughter] not to be there” and so Amy and her husband had to sign her out for health reasons. Amy then took her daughter to the GP who referred them to a local clinic which did an assessment on Amy’s daughter, including a neuro-psychological assessment, and diagnosed her as being clinically depressed. They prescribed medication but this made no difference to her daughter’s mood. She was then given the option of either one-on-one psychological counselling or family therapy; “One or the other”. Amy’s daughter went for the one-on-one counselling but because her sleep cycles were “upside down” she was often not able to attend the appointments due to being asleep. Amy described the process of “trying to pull a sleeping child out of bed to try and get to the counselling sessions” as being “very distressing for both her [daughter] and family members”. The clinic’s response was “well it appears that she doesn’t *want* our service so if she doesn’t come, then we can’t do anything”. They did some family therapy since Amy felt that family meetings “would be important to get us all on the same page and, because I had also come to suicide-prevention group at [agency] and...learnt that including families was important”. She also believed that “having everybody maybe change behaviours that were not proving fruitful or having a good outcome would be perhaps a good in road into learning how we could address some of the issues that maybe weren’t being helpful for our daughter”. The outcome of the family

therapy “wasn’t what [she] thought it would be” and her daughter was discharged from the service.

Some years later her daughter arrived at the decision to stop smoking, drinking and taking a drug similar in properties to marijuana. She did this without consultation with anyone, including family. “She thought that that was a good thing. ‘I’ll make a fresh start’” and the result was a sleepless three days and a psychotic episode. Amy once again took her daughter to the GP who referred her to the local mental health service and also to a drug and alcohol service. The drug and alcohol service said that she needed a psychological service and did not accept her into their service but the mental health service built up a good rapport with Amy’s daughter and used to visit her at home. She was then referred by the mental health service to a psychosis service and then on to a residential service. Her daughter left the residential service and has now moved to another city. She “hasn’t linked herself in with mental health”, which Amy feels she should do but she does appear to be doing better. “She’s going for job interviews. She’s eating well and joined a gym.”

From my conversation with Amy it appeared that there were a number of aspects to this experience that was very “distressing” for her as a parent. Firstly, she felt that the clinic at which her daughter was originally assessed had dismissed her because she wasn’t showing the expected behaviour. She explained that she “had a sense” that “because [their] daughter wasn’t showing outward signs of” wanting the service “turning up for meetings for example, or appointments” they just dismissed her because “[they]’ve got plenty of other people that do want the treatment so, you know, your choice sort of thing.” This was distressing for Amy because her daughter “wasn’t able to make those appointments due to “having sleep cycles upside-down”

Secondly, Amy felt that the process of having her daughter psychologically assessed was out of her control and she felt very much “in the dark”. She reports that she “would have liked to have had a bit more direction at the time”, “not knowing which direction or what support could support us as a family” and “what supports there are out there for [daughter]”. Amy paints a desperate picture here. She presented herself as seeking some control, understanding and direction and finding none.

When her daughter was initially referred to the drug and alcohol service and they dismissed her as needing a psychological service, when Amy felt that it was a “dual-diagnosis thing”, and they referred her daughter on without explanation and in a “very clinical” way. This only served to exacerbate the experience of feeling “in the dark”. Amy wonders “if I had had some more help, support, knowledge about that time then maybe the intervention process could have...had a better outcome”. Amy wonders even now if things might have been different had someone shed some light on that dark place and there is a sense of grief that comes with this question.

Thirdly, Amy found that the options presented to her at the time were very limited. This was evident during her first assessment experience when her daughter was not able to attend appointments due to being “too sick” and no alternatives were given. There were very limited options regarding her treatment. One medication was prescribed, they offered either family therapy or personal counselling, not both, and were only able to meet at the service itself and did not offer home visits.

Fourthly, lack of communication from the services providing the assessments was another aspect that was distressing for Amy. Firstly, when the school reported that her daughter had been absent for two-thirds of the year without any prior communication of the issue. And again in the original experience at the clinic Amy was not explained to about the medication her daughter was put on and she has no recollection of ever receiving a reported back from the psychologist, although she thinks that her daughter may have not wanted her to under the Code of Rights at the time. In addition to this, years later, when Amy wanted to be included in meetings regarding her daughter in the residential service, she asked for minutes of meetings, audits, plans and reviews but none were given. Amy also felt that to request to be involved was “frowned upon” because it was seen as “challenging the system”.

Fifthly, Amy repeatedly referred to what she considered to be “big gaps”. These appeared on a number of occasions. The first time was when her daughter was “too sick” to attend counselling appointments due to her sleep cycles being “upside-down”. She felt “the problem wasn’t really addressed” and that there was a gap in the system regarding treating people that were “too sick”. More recently this was evident when her daughter was referred to the drug and alcohol service and told that it was not appropriate for her despite

the fact that “she had obvious problems with drugs and alcohol” and Amy felt that the service would be a beneficial addition. Once again in the residential service Amy’s daughter’s flat mate was replaced by an individual who had “serious *drug* and *alcohol* problems and he caused a problem for the *whole* residential service”. These “big gaps” were also experienced in a “lack of fluency and continuity”. This was evident when her daughter was promised CBT at the psychosis service but had to wait for a number of weeks because the therapist was unavailable.

All of these experiences ultimately resulted in a feeling of broken trust. Being in a vulnerable position Amy explained that “you naturally put your trust, you want to put your trust in someone because you’re not able to do it yourself” and at the clinic this trust was broken when they were “too busy” to deal with someone as unwell as her daughter. Experiences of having her daughter referred to other services without explanation and services appearing “very clinical” served to break this trust for both herself and her daughter.

Amy’s experience of having her daughter assessed by the mental health service in more recent years was more positive, however because on the whole she felt that there was a more positive treatment of her daughter, there was better communication and that information that was transferred to herself was very good. This resulted in her feeling more “secure” and that she “could trust that they were actually genuine”. But on the whole Amy described these encounters as being an “alien type experience” in which as a family they were “thrust all together”, having expectations and yet not knowing what to expect and wanting to know “what can we do or not do or not say”. She found the experience “scary” due to “not knowing fully how the systems all work” “or what you can be doing to aid the person that you’re trying to care for”. She also found it “lonely and isolating” because she did not know what support she could have called on. She described herself as feeling “powerless and helpless” and the process as being “consuming” for them as parents and for their family as a whole.

Amy had a great number of questions that she wanted answered around their parenting by the experience of having her daughter psychologically assessed. They included: “what have we done wrong?” “what could we do better?” “How do we put things right?” “How can we be a...better support?” “What are some skills that we can take on board to improve our

relationship with our...daughter?". "You make mistakes and then you wonder, well, how can I change that outcome or *can* I change the outcome?" "Or is there something I can do to make whatever that outcome has been, turn it into a positive experience?". Amy appears to feel that their mistakes may have had a negative impact on their daughter and that they are in some way to blame. Unfortunately Amy never had these questions answered during the process of having her daughter psychologically assessed. Instead she has come to her own answers through her work in mental health.

Finally, Amy described her role in the process as a "support" and "advocate". She was an "advocate" in that she was there "asking questions" and being "somebody that can be the voice of someone who doesn't feel like they have a voice". In addition to this Amy saw her role as being quite practical as she attended meetings and tried to get her daughter to her appointments.

The siblings in the family Amy also saw as playing a role. She wanted her daughter to be able "to voice how they could support her". She wanted them to be given "skills and strategies" and "education around the whole psychosis experience, or clinical depression experience, so they could know...what they could say". She wanted them to be told if there was "anything that they were doing or not doing that would...make family life better for their sister". She also wanted them to know that there was "no blame" and she wanted someone to say this to her children. Amy wanted help but the experts that she so badly needed were apparently unavailable during this frightening and out of control experience and answers to these questions were never provided by the professionals involved.

Amy's story took on a dialectic narrative form as she spoke of progress despite tension. This journey has been a long, hard one and it continues to be. She felt she had had little support from professionals involved in the assessment process. She felt that there had been some improvement in her daughter's condition as she looks for employment, exercises and associates with better people but she feels that this is a result of factors other than the assessment process.

Emma: Guarding the Gates to a Heart

Emma and I met at her work place. Emma's story is steeped in emotion and at one point she was brought to tears as she told me of her experience. Emma paints a picture of herself as the guardian of her child as she beats back wave upon wave of professionals seeking to do an assessment or implement an intervention on her son, with little respect for either of them. The result has been that Emma is exhausted and feels that her son, despite her best efforts, has experienced damage to his ability to trust and his self esteem.

It all began when Emma's son was aged five and went to school for the first time. Within a very short space of time his teacher identified "behavioural aspects that she thought needed further investigation". The school wanted to bring the school psychologist in to assess him but Emma decided to get a private psychologist herself because she felt "no, I actually need some kind of control here". This psychologist "observed him in his classroom, in the playground, three times at different times of the day, in different settings" and wrote up a report to the school in which he said that in his opinion no intervention was required. The school disagreed with this decision and decided to do its own assessments. "They did assessments on sight, on sound, on hearing...spatial assessments were done on him, cognitive assessments were done on him. All sorts of assessments were done. It was just *on-going*". In addition to this teacher aids and a RTLB teacher was assigned to Emma's son and "every quarter" there would be a "big meeting were there would just be a *room full* of people, basically saying gobbledy-gook *stuff*, which you didn't really understand and then after *your* input there would be people that would come around to the house and you *knew* that you were being *observed at home*". This continued throughout Emma's son's primary school years and he saw the psychologist when necessary during that time.

In intermediate the school made a referral to a clinic to have Emma's son assessed again. The psychiatrist at this service saw the report and said that there was nothing wrong with him and that " he didn't know why he'd been brought in" but a psychologist at the service also read the report and said that she would like to investigate the possibility of brain injury. She met with Emma on a number of occasions and had someone from a brain injury service come and speak to Emma and they applied for accident compensation cover and did some tests but at that point Emma's son's father said that he would not allow the process to go any further. "His father has never been in agreement to anything, to any kind of intervention at all, ever. And he disagreed with everything that's ever been done."

There are a number of characters in Emma's story: villains, heroes, victims and defenders. Firstly, Emma presented the professionals, those with whom she met in the quarterly meetings, and some of the teachers as being the villains. Emma seemed to think of them as lofty in the sense that they presented themselves as being "so knowledgeable" and having very "educated opinions" and in front of whom she didn't want to "look like an idiot" by asking "excuse me what does that mean?". One way in which this power relation was played out was through a lack of communication from the professionals and consequentially a sense of lack of control for Emma. Every school term she would find herself in "a big meeting were there would just be a *room full* of people, basically saying gobbledy-gook *stuff*" and she found it "*scary* because you didn't actually really know what was going on". She said "I didn't know what was happening, I didn't know what was happening and it wasn't explained to me *properly*. It was more like "you son's got a problem and this person, and now he's doing this, and now he's doing that" and they're going" even to the point at which they asked her to "sign papers and say that [service] would have the say as to his medication". She refused to do this and when she asked if that meant that she wouldn't be able to appose an intervention they did not answer her. Emma, when talking about this lack of communication, explained that

It would have been helpful if they had engaged with *him* at *his* age-group level and said "this is what we're doing" or, you know, made it more *user-friendly*...it was always like all those little isolated satellites that were done and you were left to go and try figure it out, now why would they be doing that?...You know, so it was a bit confusing at times

Emma also reported that there was "a fair amount of jargon" and "for the first couple of years [she] thought "what *is* RTLB?". "And then you sit in a big meeting with a *whole* heap of people and their all giving their *educated* opinions on certain things and you're thinking "I don't know what that means and what's the acronym of that?"

These professionals also came across as being very cold and clinical in their interactions and Emma was left feeling powerless in the face of their interference. Emma described them as "doing their job, you know, they come in, tick the boxes, done the assessment, move on, next one, write the report, off we go" and that "they rather do *to* you rather than with you" and that her son perceived these professionals as being "another person coming in and *doing* another thing to him". Emma tried to regain some control by having a private

psychologist come in and also by acting as a protector and advocate for her son but there were times when it “wasn’t always in [her] power to do”.

These professionals also presented to Emma a picture of her son that she did not recognise and she found this very confusing. At times it even seemed to Emma that they were talking about a different person and she couldn’t “believe it”. She even went back to her son’s old kindergarten and asked them what they thought and the director of the kindergarten said that he couldn’t understand the reports that the professionals were presenting because Emma’s son had never presented these behaviours at the kindergarten. Emma said that it was “very confusing, very confusing”. At the same time she said that she didn’t “completely disagree with the reports, it was just a shock with the way they were given to [her] in the beginning”.

Emma also found that “it was *difficult* to get answers and it was *difficult* to get explanations and it was *difficult* to challenge because then you could be seen as being a difficult parent and that wasn’t the situation” and that “if you tried to actually put across that that sounded unlike your son because that wasn’t behaviour he’d displayed at home then they would almost brush you aside and discount”.

To cope with this Emma had to become strategic in her interactions with these professionals in these big meetings. She described how she learnt how to communicate with them so that she felt more heard and could voice her disagreement. She said that “it was almost having to *learn* how to speak their language to be able to get in and understand what they were saying about your child” and that “as a mother to actually try and understand the processes and assessments you actually have to, you have to learn the language, you have to get your head in the ring, you have to check and make sure that things are going fair and people are doing their job”. Emma’s use of the words “them”, “their” and “they” suggest that she views them as a collective, faceless enemy that she needs to overcome.

Emma felt that her questioning of the system did not come without a price however. She explained that she “*did* feel that when [she] *didn’t* comply with them there would be a *pulling back* in a sense”. She said that “if I didn’t comply with them completely and say “yes, yes, yes” and “I’ll do what you want” then the support for [son] in terms of when I

wasn't around didn't seem to be put in place". Emma felt that this was a passive manipulation to ensure that she did what the professionals wanted her to do. She refused to do what she did not agree with but would cooperate when she could see that something may be helpful.

Emma also described that even now when she has "approached the school and said that there are behavioural issues" and asked for support it has also been a struggle. They say "well he has to *want* it. He has to *ask* for it' or he has to do something seriously *wrong* when they can then force him into it". She has found this "extremely difficult" and "a struggle all the way through". When she hasn't wanted the help they have given it and when she wants it, it is withheld.

There was also a teacher that Emma spoke of who was a villain in this story. She described to me that this teacher wanted to put Emma's son on Ritalin and Emma was very apposed to this because her view of Ritalin is that "if your child doesn't sit and behave himself like a little *girl* we'll put you on Ritalin and *make* you behave like a little girl". Emma also reported that this teacher also caused a great deal of psychological distress in her son, that he was seen by the psychologist and that that teacher "was not allowed to have any further contact" with her son.

In addition to this teacher her son's father was portrayed as hindering her son from potentially receiving the help he needed in the form of the brain injury investigation. Emma also felt that his disagreement with the interventions that had taken place in the past had "rubbed off on" her son and this made this option even less likely to be pursued. Although the psychologist at the clinic offered a glimmer of hope and was "good in staying *linked* in" with Emma and continually saying "Are you *sure* you don't want this? Are you *sure* you don't want this?", when she hear that the father had refused to allow further investigation "she didn't really understand or attempt to understand the situation that I was in" and sent Emma on a "guilt trip". Emma felt that she "wasn't that *understanding* and if...she had attempted to *understand* there might have been another *way* that we could have engaged and brought him in". So as a result of her lack of understanding and empathy came a lost opportunity for Emma.

In this story Emma was the defender. During this time Emma saw her role “as a big *guard* dog at the door. That’s how I saw my role because I had the feeling that if I just let them all come in I didn’t know what would happen to him. I felt like a big guard ‘cause he’s so sensitive” Emma reiterates this protective sentiment later on when she said “I’m quite protective about him” and when the option of the brain injury investigation came up and her son did not want to engage she expressed that she was trying to “balance” all these “different elements”, including difficulties at home, and “all of that in the best interests of your son” and to her this meant to “still allow him to have some kind of self-esteem going ‘cause if I had overridden everything I would have just been either classified and put in the same box as he put everybody else who did that to him and undermined him. So I had to allow him to have some kind of feeling that he was of worth and that I believed what he said”. Her narrative expressed her strong desire to protect her son and his emotions. Part of this protecting, guarding role involved being an advocate. In addition to this Emma saw her role as “just to love him, just to *try* and encourage him and *try* reinforce and help him”.

Emma also presented her son’s strengths during our conversation together. She told me of how initially her son had “refused to read” and then when he “decided” to learn to read he jumped nine levels in one year, which the teachers said was “impossible”. She then told me that he has been “above average” in his reading ever since. In addition to this she told me that “the psychologists who did an assessment on him on the intelligence side said that he’s above average”. Emma equated the initial difficulties around her son’s reading as being as the result of a schooling system that doesn’t suit her son. Emma also suggested that perhaps her son’s difficulties were more to do with others’ perception of his behaviour than an actual problem when she mentioned that “if your child doesn’t sit and behave himself like a little *girl* we’ll put you on Ritalin and *make* you behave like a little girl and then we can teach you and the rest of the class” as if to suggest that he was behaving just as he should because he’s not a little girl, he’s a little *boy*. She also told me that “he’s a very popular boy today. He’s got heaps and heaps and heaps of friends” and “he’s got a *fantastic* sense of humour”.

This has been particularly hard for Emma because she is an immigrant and was unfamiliar with the school system in New Zealand at the time. This resulted in her feeling “a bit *overwhelmed*”. She reported that she didn’t “have the support structures so you actually draw *back* and let them *do*”. She also said that she didn’t have the opportunity to then take

the information and reports that she was given during this time and seek a second opinion from family members who knew her son well.

Emma described this process as being never-ending. She said “it just never stopped really. It *never* stopped”, “It’s *always* difficult”, “it just goes on and on, and the next step and the next step” and “in the end [she] just thought, “ah, this is just *so exhausting*”. And with this comes a sense of hopelessness and a feeling that she may never know what the problem for her son actually is. She asked “Does he have a psychological problem? I *still don’t know* with *all* the assessments that he’s had going over the years” and little hope of finding out because she no longer feels that she can “force” him to cooperate with assessments.

The emotions that Emma has associated with this experience are “sadness, deep sadness, weariness, anger...because...I was trusting the people in authority within the school and over the years there have been so many times they’ve failed me and failed my son. So I’m angry at myself as well for allowing myself to trust”. In addition to a sense of betrayed trust there also appears to be a level of regret here as well as she speaks of being “angry with [herself] for allowing [herself] to trust”. She also mentioned that the psychologist at the clinic had given her a “guilt trip” and she laments that “If [she] could [investigate the possibility of brain injury] [she] would *go* for it but it’s not that *easy*”. Emma also said “you never know if you’ve done the right thing or not”.

The result of these continual assessments has had severe consequences on her son. Emma portrayed her son as being the victim of the system. Early on in his schooling Emma’s son went for extra lessons for his reading and “from an early age he was always taken out the classroom for certain things, which made him *feel* like he was *different*, which just compounded the problem”. As a result of the constant assessments her son has become quite distrusting of professionals. She explained that by the time he was referred to the clinic he had become “pretty scathing” of professionals and saw them as people that had never “*really helped* in any way, they had just made his life quite difficult at school”.

These ongoing assessments have also had an impact on her son’s emotional development. Not only is her son distrusting of professionals but of most other people as well. Emma feels that these assessments have “just made him *very very* sceptical and he

doesn't trust easily...he doesn't let anybody get close. He will *not* let people get close to him" and "some of that has got to answer for it". Emma feels that the experience has "undermined who he is and...it's undermined his ability to try and to give it a go...I think he's scared to try in case he fails because he might get another intervention happening or another assessment happening". Emma also said that her son now believes that he is "stupid" because of the way in which he was treated differently during his years at school, for example having to "sit in the separate chair from everybody else...[being] put on the *edge* of the mat when everybody sat in the centre of the mat". Emma feels that "that a lot of damage has been done in terms of his...self image and his...perception of what he *can* achieve or not achieve".

Emma told me of an experience which reflects the bigger narrative but within a smaller story.

One day he had to see with some woman with spatial stuff and she had all these little pots of different colours and that looked really difficult...I thought "oh my gosh"... "he's not going to be able to put those in order"...she mixed them all up and gave him a stick and said "don't put your finger on this", she was really like really "rrrr, don't put your finger on the pots, use the stick and move it with the stick" [tone changed to depict a grumpy person]. And he sat there with one arm, had his chin in his hand and he took the stick in the other and he looked at her and he just like moved each on into exact order and the whole time he looked at her as if to say "and now?" and her attitude just became quite authoritative...he became disengaged but still gave what was expected but from a distance...I...actually thought "good for you my boy" because there wasn't any *empathy* there or trying to engage with him at his *level*...it was another person coming in and *doing* another thing to him and he was, in his defence, showing displeasure that way.

This tale shows all the above mentioned elements: an cold, clinical, authoritative, disconnected and insensitive professional, a clever, sensitive boy who has been victimised and misunderstood but is still fighting back in his own way and a protective mother who supports and understands him and admires and empathises with his feeling that he needs to challenge.

Thankfully there have been some heroes in this story. Emma told me that “there were some people along the way...in this journey that...did have a good understanding of him” and that “there’s been the odd person who...have been *amazing* but then you only have them for a while...so you do get those *breaks* where you have people who *will* explain to you, *will* listen, who will *try* and come on *board* and *understand* your son and his environment and work *with* that”. “Through the schooling system with him there have been some good teachers...If I could have had them *all* the way through with him, wow, what a difference”. The RTLB teacher played a particularly powerful role in this story because she validated Emma’s son and was encouraging and positive towards him.

The private psychologist that Emma got to assess her son during his primary school years is also a hero in this story. Emma saw his role as being her guide, “guiding [her] to what he felt would be best” particularly since she had no family in the country she “really relied heavily on his input”. He was also “non-biased, going in and observing [her son] in different situations, with different people and *professionally* putting forward his findings as well as suggestions for any resources or personalities in terms of teacher that [her son] might benefit from or not benefit from”.

Emma also wanted a label from the psychologist. She said “if you can classify [my son] as ADHD or having a mental illness or whatever, then I will work with you on that” but in the end “he wasn’t prepared to give him a diagnosis”. She seems to be saying that it would almost be easier to have a label because it can be seen as a “ticket” to some solution for her.

The story that Emma presented to me took on the form of a regressive narrative in that over time things have not improved in fact in some ways irreparable damage has been done. Due to these ongoing assessments Emma’s son has become progressively more fragile and emotionally damaged. This narrative almost takes on the form of a tragedy.

Mark: Action Plans

I had originally arranged to meet with Mark and his wife together because they had both been very involved in the process of having their child assessed but I received a call

before the interview that Mark's wife was not well and would not be able to meet with us. Mark suggested that we conduct our interview over the phone that evening.

His assessment journey began when Mark's daughter was in preschool. "There were some factors at preschool and one of the preschool teachers suggested that maybe she's ADHD". These difficulties were also apparent during her times with a speech therapist. Mark and his wife then decided to have their daughter assessed by a psychologist just before she went to school in order to find out "how she was going to work in a learning environment" but found that it was "a little bit too early to really determine every nuance...she was just a bit too young". Their daughter was also then involved with two programmes that assist people with ADHD, one of which she didn't finish because she was doing it "everyday twice a day" and it required a great deal of "focus and concentration" and eventually she was no longer "making forward progress" due to "choosing to be able to be distracted 'cause she didn't feel she wanted to do this anymore" but "fortunately there had been some improvement by that stage". Then in Year One things came to a head because the Year One teacher found that "she was very difficult for her to handle...because she didn't have her medication and just didn't stay anywhere near what she was supposed to be focused on at that point" and Mark and his wife felt at their "wits end". This pushed them to seek "external professional help, some more" and this resulted in a formal diagnosis of ADHD by a paediatrician that was suggested by the family's GP. Their daughter was then put onto medication. Since then she has had a second psychological assessment. During this assessment their daughter had to stop her medication for a day or two before the assessment so that the psychologist could see her in her "native condition".

Since this time their daughter has made some progress in reading and she is working on improving her maths skills and her ability to complete tasks without becoming distracted. Mark and his wife have to be careful not to "push" her when she does not want to do something to avoid "melt-down". Mark reports that "progress is slow".

Mark presented himself as being a very organised and involved parent who is familiar with what has gone into helping his daughter, knew just where to find all the information relating to his daughter's assessments and told me that each of their children have a "help file". He appeared to actively engage in what is needed in order to give his daughter all that she

needs. He also reported that he has acquired quite a lot of knowledge on ADHD by means of his own personal reading, listening to audio books and attending conferences. He also made use of some very sensitive phrases such as saying that his son had “made wrong choices” regarding his behaviour, which shows his familiarity with the language used in today’s education sector. Mark described their role as parents as follows:

I think our role has always been: “Let’s find out what we can about [daughter], she’s a special girl, and how she works. Let’s try to figure out what things we can do to most help her with...the way she works and how she approaches things and both through the resources that may be available...or techniques and information that can help *us*...I guess our objective is: “Let’s understand her the best we can and let’s do everything we reasonably can to give her the *best* grounding and the *best* opportunities to learn and develop and become all that she can be”

Mark and I also discussed the fact that their daughter has been diagnosed with ADHD and when I asked him how they had felt about the diagnosis he said:

in the beginning, I would have thought “well, I just want to be sure that...she’s not just being labelled for the sake of being labelled with something, what does it actually *mean*, what does this involve? And how does it affect her and how can we support her with this “*thing*” [laughter].

Mark makes a connection here between a diagnosis or label and what they can do about it. Here there is a direct link between labels and solutions. Mark then described how once they had received the diagnosis a lot of questions came up for them, including questions around “was it because of the way [they] brought her up?”.

I explored the question “was it because of the way we brought her up?” with Mark a little further and Mark said “I think one of the questions that...I think we probably imagined early on in the process of us being told that she has ADHD is ‘is there something that we’ve done? Could we have done things differently?’” But through his own research and input from their GP Mark has come to the conclusion that it is not due to anything that they have done wrong. Mark also mentioned that his wife had suggested before that there may be a connection to when their daughter was new born and there were difficulties with breast-feeding which resulted in their daughter being undernourished. She wonders if there is a link there and they do not have an answer to this at this point.

Mark also told me that he had found the reports they received helpful. He explained that the reports firstly outline the tests that were used, what the results and measurements of those were and how they compare to the wider average. Mark said that from this information he gain the following insight: “Ok she’s more capable in some aspects than others and she’s less capable in some aspects than others. And that’s sort of interesting and helps to give insights”. The next section Mark explained outlines some practical suggestions for what can be done about the difficulties identified. Here Mark demonstrates his knowledge of the assessments, how they are laid out and what they mean.

Mark feels that “the information is most useful when it helps us to a) better understand how [daughter] thinks, and b) better be able to do something that’s going to help things”. Neither Mark nor his wife have ever questioned the accuracy of the reports. They have found that sometimes their own knowledge of their daughter is confirmed and sometimes they gain more insight into the way her mind works.

It’s more been a case of some aspects that yeah, we can understand and relate to that and we see that particular factor and “oh, that’s something we hadn’t really known about. Probably it’s been there all along but it’s been measured in a more scientific way so that’s interesting”, sort of thing.

The main emotion that Mark expressed relating to the experience that they have been through was frustration. Initially, when their daughter first went to school and was taught by someone who they “felt was not at all suitable for new entrants, just in terms of her approach and strictness with them and things”. This teacher had a difficult time with their daughter and would meet with Mark and his wife regularly and would “draw a scale out of sort of 1 to 10, or something along those lines as to how well [their daughter] was staying on track or whatever. And [they] were always getting *right* down at the bottom of the scale and she’s disruptive and difficult and so on and that was emotionally...quite frustrating for [them]” and resulted in them feeling “at [their] wits-end” and asking themselves “What can we do?”, “well, what’s wrong with our child?”, “is this teacher going out of their way to make it difficult for us in anyway?” and “are we getting a fair run here sort of thing?”. This frustration lead to Mark seeking other options and it was out of this that they sought out the paediatrician and their daughter was diagnosed as ADHD.

Another theme that emerged while we spoke was that of concern for their daughter's self-esteem. Firstly Mark mentioned that the results of the assessments had helped them to be able to say: "Ah, well [daughter] you've got some areas that are challenges and you've got some areas that you're particularly good at too". He also mentioned that their GP had said that "there's kind of an age when she's not aware of what other's think very much and then as she grows up there could be a time that comes when she starts to brand herself as being "dumb" because she can start to see the contrast between her and her peers in some areas. And particularly if her peers at school came up with that idea and started to say derogatory things to her". The suggestion was that they work on creating "little islands of competence, little things that she can do well, that she can feel good about and sort of hang her self worth on". Mark has made an effort to spend some time with his daughter doing things that she does well and enjoys.

Mark also mentioned that the communication with the school over the years has been very helpful and that every term or two they "talk about strategy and compare notes with teachers", which "has been valuable". Mark also said that their daughter has not minded having so many assessments done and thinks that "probably to the extent that she can she sort of probably enjoys doing interesting and different things".

The story that Mark told me was a dialectic narrative because it spoke of progress despite tension. The process of having their daughter psychologically assessed, diagnosed as ADHD and assisted has been a long one and one that Mark expects will continue for many years to come. Although there has been progress Mark has described some issues that have made it a difficult journey, for example having unsympathetic teachers, slow progress with their son and questions around their own blame as parents.

Jenna: Second Opinions

Jenna and I met at her home and she told me of her experience of having her daughter psychologically assessed. Jenna told me that when her daughter was very little they had not thought that there was any problem with her ability because she appeared to be more advanced than other children in some areas, for example "she talked so early and she seemed really advanced". Then at age four they got her to do phoenix and at this point Jenna noticed that she was struggling to read and would often mix up d's and b's as well

as confusing words like “was” with “saw”. Throughout her early years at school her daughter had difficulty with reading and one year her teacher came to Jenna and said that she thought that her daughter may be dyslexic. Her daughter was then sent to the school psychologist, who said that she was not dyslexic but instead had some concentration difficulties, which were making it hard for her to read and write. She also identified “quite a few little issues”, including the fact that “visually...it’s harder for her...she sees things differently”. Jenna said of her daughter “she’s not stupid but it’s just she can’t sort of get it down what she’s trying to do” and that there are “quite a few little things that she needs work on”. The result of the assessment has been that the psychologist wanted Jenna’s daughter to see an occupational therapist and a paediatrician. The psychologist wants the paediatrician to give Jenna’s daughter an official diagnosis of ADD, which Jenna does not agree with. Since the assessment the psychologist and Jenna have still not met to discuss what can be done for her daughter, for example meeting with teachers and so on. This has been very frustrating for Jenna. As a result Jenna has decided to go ahead on her own and has arranged an occupational therapist herself. She has also discussed her daughter’s situation with a relative, who is very knowledgeable and holds a high position within the education sector and she is going to do her own assessment with her as well. Once Jenna has heard from all of the people involved then she feels she will be able to make an informed decision.

A number of ideas emerged during my conversation with Jenna which stood out to me. The first was her perception of labels, both that of “dyslexia” and “ADD”. Although her daughter does not have dyslexia and she doubts very much that she will be diagnosed as ADD the possibility of these diagnoses does not concern her at all. Of dyslexia she said “Probably not so bad *now*. I think years ago, it was kind of like “oh my goodness”...But now it’s...not so big a deal really. So I wasn’t too concerned” and of ADD she said “we’ve got a few friends with kids that have it and so it doesn’t worry me at all but I do know that some people do judge...Some people that don’t understand, like they haven’t had children with that or they’ve never heard of it and they’re kind of think “oh my goodness that kid’s”, you know [laughs]. But because I’ve been around it I don’t”. From this it appears that Jenna has come to a place where what some people may consider “abnormal” she is considering to be “normal” and is therefore not concerned about the possibility of either “labels”. In the end her daughter was not diagnosed as dyslexic and has not yet received a diagnosis of ADD, although Jenna very much doubts that she will be given this.

Jenna's only concern relating to the diagnosis of ADD was that she not be put on any "drugs" because of it. She said "it's harder to concentrate on things...I certainly wouldn't want to put her on drugs for it" and "I don't really want to put her on any medication". She seemed to see that as an imminent threat that would come with a diagnosis of ADD.

An issue that arose during our conversation was that Jenna was not satisfied with the report she received from the psychologist. She found it "very intellectual", that she felt that it was "a bit above [her]" and that the report was in language that "people like [the psychologist] would understand". In fact she had shown it to her cousin, who is a teacher and she had said "oh my goodness I don't even understand half that stuff' you know, and she's a teacher". She also said that others, who she had showed the report to, had thought that it was quite "negative".

Jenna presented the psychologist, who did the assessment, in both a positive and negative light. In addition to finding the report to be in language she struggled to understand she felt that a lot of time had been wasted. She had contacted the psychologist in term two and it is now term four and they are yet to come up with any concrete solutions, for example meeting with teachers, arranging an occupational therapist and paediatrician.

So it's...a little but frustrated 'cause I kind of think well if there's a problem the sooner we get onto it the better...it's more just how long it's taken that been frustrating because you kind of think "well, come on we need to help her".

Jenna also suggested that she had not received what she was hoping for from the psychologist when she said that she saw the psychologist's role as being "the professional that would hopefully...at the end of the day comes back with something for us...that we can see what's been happening, in [daughter's] little brain and come up with any solutions". This indicates that she was hoping for solutions and has not been given any. Jenna also implicated the psychologist when she said that "it's not really the school's fault because they've just got to wait for what [the psychologist] comes back with". Another frustration that Jenna brought up was that the psychologist had actually used an incorrect name in the report. She had said "Jane is not dyslexic" when Jenna's daughter's name is

not Jane. So Jenna is going to check that they have in fact received the correct information.

In addition to these things Jenna appeared very doubtful of the psychologist's suggestion that her daughter may have ADD. She did not feel that the evidence that the psychologist gave to support her argument was valid. The psychologist said that:

she's got ADD because when the bell rung she was looking out the window, and you kind of think, "Well any kid's going to be looking out the window when the bell rings 'cause they think they're missing out on morning tea"...And then...she was looking at pictures on the walls so and it's like, well any kid if there things...around they have to sort of look at everything. So I kind of felt...any kids like that. You can't really say they've got ADD because of that...it's harder to concentrate on things...if she likes what she's doing, she can definitely concentrate".

Jenna would, however, balance her criticisms of the psychologist by saying "She's actually a *really* lovely lady and she was really good. She was very good. Yeah, she was really good" and "I think she was very good and she made [daughter] feel really comfortable." However, Jenna provided little evidence of what it was that she found so helpful and it may be that her praise of the psychologist's manner was a way of softening her critique.

Jenna described her role as a good parent who wants to find out what the problem is with her child so that she can find a solution and "help as much as [she] can, 'cause [she doesn't] want her struggling". If her daughter is given a diagnosis of ADD she said that "if they said, yes, there is a problem well then we'll have to do something about that to". Jenna described her role as "the one who has to kind of make the decisions". She hopes to make these decisions with the aid of as much information as possible. In order to do this she has gone ahead and arranged for an occupational therapist and her relative to assess her daughter so that she can have a number of opinions to consider. She said that "if they all say the same thing" then she will have to do something about whatever it is that they suggest. She has pursued solutions on her own because the psychologist has taken so long and she does not want anymore time "wasted". In addition to involving other professionals Jenna has discovered that she can motivate her daughter to read by paying her. She has therefore found a solution without the input of the psychologist.

Despite her confidence in seeking out external help because of the psychologist's apparent lack of involvement, Jenna appeared to desire confirmation from others. For example, referring to the report she received, she said "I showed a couple of people [the report] actually", "Like even my cousin, who's a teacher at [school], she was like "oh my goodness I don't even understand half that stuff" you know, and she's a teacher, you know", "so did other people that read it". When referring to the fact that she felt that her daughter was quite advanced as a baby she said that "she seemed really advanced to everybody else", which seemed to be a way of confirming that her own perception was correct.

Jenna's narrative fits the description: progress despite tension because although there has been progress in that her daughter has been psychologically assessed and there has been a little advice given as to how to improve her situation there have also been a number of difficulties. These tensions have included poor communication from the psychologist, very slow progress and the possibility of a diagnosis that Jenna does not feel is at all appropriate for her daughter. Jenna is doing her best, however, to ensure that progress does continue despite these difficulties. Thus Jenna's story takes on the form of a dialectic narrative because there has been some progress but there have also been a number of obstacles.

Chapter Four

General Themes Analysis

In this chapter I intend on moving onto the second layer of analysis, which involves identifying the overarching themes that have emerged from the previously analysed individual narratives and presenting them as a collective narrative that represents participants' shared experience. I approach this analysis from a categorical-content perspective, which emphasises the shared content of the individual narratives. Although each story was unique and individual in many ways there were also some commonalities in the participants' experiences perhaps because the participants were drawing on very similar social and cultural discourses (Polkinghorne, 1988). It is important to acknowledge these broader social discourses and contexts because they too have an impact on perceptions and experiences and should not be overlooked within the context of psychological assessment (Burman, 2008). The main themes identified are suspected "diagnosis" and own expertise, seeing "inside" the child, bittersweet labels, questions of guilt and blame, the "good parent", the distant professionals, problems with communication, challenging the system, inadequate measures, the over-assessed child, the caregiver as the defender and advocate and the helpful professional. I will expand upon these ideas in this chapter.

Suspected "Diagnosis" and Own Expertise

The first thing that I asked each of my participants to do when we first started the interview was to tell me how the assessment process all began. The vast majority told of a suspicion that was held, either by themselves or by others involved with the child, relating to specific diagnoses. Many of the participants in this study appear to have come into the assessment process having already made up their mind about what their child's diagnosis is, or should

be. Several participants had had personal experience and/or education in the areas of education, psychology and mental health. Participants explained how when their child had a particular difficulty that they would then go and read up on it to find out more information about the problem. By the time they had the assessment done, many seem to have already made up their mind about what the problem was that their child was experiencing. For these participants the process of having their child assessed was to get professional validation of their own views which would entitle them to services and ultimately to some kind of solution. In the following examples participants describe how they use the assessment as a form of warranting for their own assessment.

We had three paediatric assessments to get anyone to find...something that was vaguely close to what we thought was right (Anne)

Probably for a few years...my husband and I have been concerned that [son] may be dyslexic...and so we thought if we could have [son] officially tested (Mary)

It came to a head because [my ex-partner] indicated that he was having some difficulties with [son] and that he thought that it might be appropriate if I found out whether he was Asperger's...So I thought, well, I really need to find out for myself whether he is or not (Kate)

I saw [the psychologist's] role as confirming for *me*, my believe in that maybe there were issues and maybe there are still issues with my son, and probably always will be (Emma)

There were some factors at preschool and one of the preschool teachers suggested that maybe she's ADHD (Mark)

I had kind of wondered [if she had dyslexia] because she still gets her d's and b's mixed up...and it'll say "was" and she'll say "saw" or things like that (Jenna)

In the above section it is clear that many of the participants in this study already had an opinion as to what the diagnosis may be for their child. In some cases they had come up with it themselves or, in others, it had been suggested to them. Many of these participants appeared only to want confirmation of their concerns by a professional.

In addition to presenting their suspected diagnosis many parents spoke about their own knowledge and expertise in the area surrounding their child's difficulties, whether this was acquired through professional training or their personal research.

As soon as you get a diagnosis of autism you start researching it (Anne)

I mean, I've read a lot about dyslexia and my husband has it also...Being [involved in the education system] I'm aware of special needs in children so I believe that...I'd recognised the signs of dyslexia (Mary)

I thought well...having family meetings would be important to get us all on the same page...because I had also come to suicide-prevention group at [agency] and...learnt that including families was important (Amy)

A certain amount [was learnt about ADHD] from a couple of books I've worked through about ADHD and an audio book I've listened to about the whole thing. I went to a [conference] meeting once and a bit more about ADHD and so on at that (Mark)

The narratives suggested that the parents of these children either already had knowledge or expertise in the areas of difficulty that their child is experiencing or they have gone about obtaining it themselves. This finding is consistent with research which indicates that the activity of diagnosing is increasingly moving into the hands of the general public. A number of authors have noted increasing use of self-diagnosis, particularly of mental illnesses, and especially with the aid of the internet (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Emmons, 2010).

Many researchers have highlighted the way that lay people may feel disempowered in dealing with professionals (Jakobsen & Severinsson, 2006). It is possible that this

experience of disempowerment may have been actively resisted by participants in their narrative accounts of the assessment process. Their discussion of their qualifications and experience and use of psychological language may have been designed to ensure that their views had credibility and an attempt to counteract the experience that some had had of being disregarded by the professionals they encountered.

Seeing “Inside” the Child

In addition to already having a hypothesis about what was the matter with their child, many caregivers hoped that the assessment would give them some insight into the mysterious inner works of their child, those parts that only someone trained in psychological theory can reach. They seemed to be hopeful that this professional insight into their child would result in a strategy for dealing with problems and a helpful outcome. For many of the caregivers that I spoke to there was a hope that through the assessment they would come to a deeper knowledge of their child and that this would then translate into a formal, written document by a professional that would capture what the problem was for their child, what their child was capable of and what would be the best thing for them to do for their child.

We tried lots of different things to try and access her...To illicit the information from her that she knows because it's a matter of finding the right way to approach her to get the information out of her (Anne)

One participant seemed to want a professional to ‘see’ what potentials existed in their child in the hope of convincing others who were unable to see this:

It's frustrating. You know what your child is capable of but you cannot get it out, to get the world to know, to have it on paper, to have an objective, you know, standard to measure her by (Anne)

Participants seemed to be hopeful that an assessment could somehow be able to reveal to both themselves and others what their children are capable of as though psychological assessments have the ability to “access” that which would ordinarily be out of reach. Another participant found the assessment process quite enlightening and informative because for a couple of months they could spend time “really focussing in on everything

that was happening for [son] and [son]'s life outside of school, inside of school, friendships, [their] home situation" and these things were "captured" by an assessment.

It just gave him, and me also I think, a chance to really focus on what was necessary for [son] and why he was going through what he was going through, how he was achieving or underachieving or overachieving in some areas (Kate)

I did this to try and understand [son] a little bit better and...to have some knowledge to at least make good choices (Kate)

Again this participant hoped that the psychological assessment would be able to give her information and insight that she would not be able to gain without the assistance of a professional who can draw out this information through the process of talking, "focusing" on problems and so on. This idea is steeped in societal discourses which suggest that the process of speaking about our emotions and understanding ourselves better is helpful (Rose, 1996). Participants seemed to believe that professionals had particular skills and strategies that would allow them to understand aspects of their children that they were unable to access:

I saw his role as really being non-biased, going in and observing him in different situations, with different people and *professionally* putting forward his findings...And guiding me, I saw him as guiding me to what he felt would be best (Emma)

I was hoping that she would at the end of the day come back with something for us, you know, that we can see what's been happening, in [daughter's] little brain (Jenna)

It's more been a case of some aspects that yeah, we can understand and relate to that and we see that particular factor and "oh, that's something we hadn't really known about. Probably it's been there all along but it's been measured in a more scientific way so that's interesting, sort of thing"...I think the information is most useful when it helps us to a) better understand how

[daughter] thinks, and b) better be able to do something that's going to help things (Mark)

These participants present the psychology professionals as using “scientific”, objective and “non-biased” measurements to obtain “findings” that will reflect what is going on inside the mind of their child. The parents’ hope is then that these “findings” will ultimately result in a solution presented by this professional. Hughes (2009) suggests that by coming to a psychological understanding, with the help of psychological professionals, of the reasons motivating their child’s behaviour caregivers will be able to solve the presenting problems. Hoghughi (1997) also argues that in order for caregivers to fulfil their role of providing and caring they need to have a good understanding of their child’s needs and potential. It is interesting to note however that an apparent inconsistency exists between the earlier theme, which states that the participants felt that they wanted to be acknowledged for their expertise on issues relating to their child, and this idea that a professional is needed to gain a complete knowledge of their child.

Bittersweet Labels

Despite the fact that many caregivers had already come up with a tentative diagnosis themselves and were wanting to gain a greater level of insight into their child the experience of having one’s child given a “label” or a diagnosis, or even the possibility thereof, was often presented to me as being a “bittersweet” experience. Participants seemed to express some ambivalence about the value of a diagnostic label for their child. This may appear to be an inconsistency in their story but within narrative inquiry this is simply seen as an individual making sense of a deeply intricate experience that is multifaceted and as a result does not always at first glance seem coherent (Andrews et al., 2000).

When discussing the diagnosing of their child caregivers who had sought out the assessments themselves would often say, almost in their defence, that their motive was not to “label” their child and would often present these “labels” in a negative light. One participant in particular would immediately follow the use of terms such as “Asperger’s syndrome”, “suffering from” or “normal” with the phrase “for want of a better word” implying some regret at having to use such insensitive language.

I'd recognised the signs of dyslexia and so we thought if we could have [son] officially tested, not to much as to, you know, like brand him dyslexic (Mary)

I guess for me, in the beginning, I would have thought "well, I just want to be sure that, that she's not just being labelled for the sake of being labelled with something (Mark)

Clearly, many of the caregivers I spoke to had a negative initial reaction to the idea of "labelling" their child and, one in particular, wanted to assure me that that was not their motivation. It also seemed that when there was the possibility of a diagnosis of ADD or ADHD that the issue of medication raised some difficulties for participants.

If your child doesn't sit and behave himself like a little *girl* we'll put you on Ritalin and *make* you behave like a little girl and then we can teach you and the rest of the class...I'm not prepared to actually just have my son medicated for the sake of pacifying a teacher (Emma)

They also want her to see a paediatrician about her having ADD...but I'm sure about that because I don't really want to put her on any medication when it's *not* a problem (Jenna)

[Husband] has had bad experiences...he spent most of his teenage years on Ritalin. So that was always his thing: "I don't want my children to go on Ritalin"...I guess they don't dish it out as easily as they did back in the 60's, "ah your child may be ADHD, we'll put you on Ritalin", sort of thing (Mary)

From these quotes it appears that participants had a concern about medication being a possible consequence of a diagnosis of attention and hyperactivity difficulties. The administration of medication was portrayed as being the "easy way out" for professionals.

For one participant however the idea of a label was not something that she was at all concerned about. The reason from this was that she has become used to the idea of the

labels “dyslexia” and “ADD” specifically due to a lot of exposure to these disorders and they were no longer considered “abnormal” from her perspective.

Probably not so bad *now*. I think years ago, [dyslexia] was kind of like “oh my goodness”...But now it's...not so big a deal really. So I wasn't too concerned...we've got a few friends with kids that have [ADD] and so it doesn't worry me at all but I do know that some people do judge...Some people that don't understand, like they haven't had children with that or they've never heard of it and they're kind of think “oh my goodness that kid's”, you know [laughs]. But because I've been around it I don't (Jenna)

This participant appears to have normalised what others may consider “abnormal” because she has seen so much of it in the children of people she knows. It may be that normalising these diagnoses has helped her to cope with the possibility of these labels belonging to her child.

In contrast to the earlier notion of labels being a negative thing many caregivers seemed to also view the diagnosing, or labelling, of their child as being somewhat comforting and reassuring because it either absolved guilt or opened up possibilities in terms of solutions. For one participant it would indicate to her that it was not her fault that her child is the way he is but instead that it was because of this diagnosis or “label”.

I suppose if there'd been a label that I could have put on him to explain some of his difficulties that might have maybe made it easier for me but then I didn't really do this to make it easier for me (Kate)

Others portrayed these “labels” as being the key to a solution for the problems their child faced. That once one has a diagnosis one has access to services, one can be told what to do about the problem as though with a “label” also comes a list of solutions, for both the school and the caregivers.

I needed to know whether he *was* suffer from...Asperger's syndrome, what we would then *do* about it and what the *school* would do about it if he was (Kate)

If [the psychologist]...can classify him as ADHD or having a mental illness or whatever, then I will work with you on that (Emma)

Let's find out if he is ADHD so that we can put things into place for him if he is (Mary)

What does [this label] actually *mean*, what does this involve? And how does it affect her and how can we support her with this "*thing*" [laughter] (Mark)

Another participant considered acquiring a formal "label", which in this case was a "gifted" label, from a "professional" as being "ammunition" when dealing with the school, with the therapists and with other professionals. She saw it as a way of gaining credibility in the eyes of the professionals so that she could get for her daughter what she so desperately believes she needs.

I want the schools to respect them...they're...really smart and we don't want them to get bored at school...So I just want to make sure that they get opportunities at school and don't get bored and that their abilities are acknowledged (Anne)

My hope that it would give me some basis to challenge some parts of [the therapy] programme...we need to move faster in certain areas...they need to speed up on the things that they're doing because some of it's too basic (Anne)

My only hope is that some of these things will give us some basis to go *back* to some of these guys and say "*I'm not making it up. Here is some other person who says this*". You know, if you're not going to take *my* word for it please take the word of a professional...who is not related to him (Anne)

So, you know, you look to these things, the psychology, the assessments and things, you look to them to give you some evidence to show to some of these wankers, quite frankly, that you are not the only one who thinks that your child can do things, you know (Anne)

This participant is hoping that the label “gifted” will enable her to challenge and fight for what she believes her daughter needs. For many of the people that I spoke to this process of getting some kind of “label” or description of their child has in fact helped them to come to some sort of resolution, for example one caregiver found the assessment results helpful in making the decision of which school would be best suited to her child.

Just by knowing and reading some of the things that [clinician] had put into her assessment indicating that [son] at times doesn't like being with boys all the time because he found that they were all, [son]'s not sporty at all and he often found, he felt a bit bullied and intimidated by the big, sort of, *boy-boys*. He's not a *boy-boy* and it came out that he enjoys the company of girls. He finds them much more mature than boys...he's quite intellectual (Kate)

In this case although the child was never given a diagnosis the mother came up with her own label, by means of the assessment process, that helped her to better understand her son. The label of “intellectual” and “not a *boy-boy*” assisted her in coming to terms with who he is despite the fact that she had hoped that he would be different. She wished that he “was more sociable and more involved in activities”. This new way of looking at her son, through the use of a self-made label, also helped her to make the decision to send him to a co-ed school. The fact that issues to do with her son's social relationships is of concern to her shows that this participant is drawing on societal discourses which emphasise the importance of friendships in children's development (Dowling, 2010).

Another participant explained that by having their child diagnosed, or “labelled”, as being dyslexic, as well as identifying that their child had a different “style” of learning, the idea of which is drawn from current societal discourses around intellectual functioning (Elias et al., 2003), there have been some quite practical steps that have been put in place following the assessment that have helped him to achieve more academically, which in turn has given him hope for his future career.

He's very onto it...he's been earning lots of credits towards [his secondary school qualification] and he'll say “ah, I only need so many more credits to

get my maths or whatever and I've got this many" and so he's totally aware of his goals to achieve (Mary)

Not only buddying up with somebody but also they said actually recording it, having it recorded and played back and he listens to it and takes it in that way. So, those, although they may seem like little things, really sort of clicked with me and I thought "Oo, yeah, that sounds good". It's another way of learning for [son] (Mary)

Another caregiver told me that when they had their son diagnosed as ADHD they were then able to utilise a number of services, which have helped considerably over the years. Once again a "label" has served a function in that it is often followed by some practical assistance and help.

We felt like his involvement with the [ADHD organisation] made a significant improvement in some areas. Previously to that, we had *enormous* difficulties with her in trying to make progress in reading and now she loves reading and that's just been an *enormous* relieve for [wife] and I (Mark)

Caregivers may seek a "label", which they may already have suspected, from a professional as a means of gaining some assistance so that they can ensure that their child is given the best opportunities that they can. Current research confirms these strong views relating to the "labelling" of individuals particularly due to concerns around stigmatisation and discrimination (Jones, 2010; Overholser, 2010; Ho, 2004). The idea of labelling and diagnosing has similarities to the way in which developmental psychology has created categories and boxes or "normality" and "abnormality" and it may be this label of "abnormality" which may make people feel uncomfortable (Burman, 2008). It is also acknowledged within the research that despite the discomfort that the idea of a "label" can give caregivers because of the potential for discrimination diagnoses or labels often do result in a solution of some kind via various interventions or treatments (Haghighat, 2008; Ho, 2004).

Questions of Guilt and Blame

As well as gaining insight into their child, determining whether they meet the criteria for a diagnosis or not, many of the caregivers' narratives made reference to some feeling of guilt or remorse at the actions they had taken or that they are not good enough caregivers and that is why their child is having difficulties. They often reported wanting to be told by a professional that they were not to blame. "Have I done something wrong?" seems to be an extremely common question that caregivers are desperately seeking an answer to. While some participants did not speak specifically about guilt, a number suggested ways in which they felt they might have done more to help their child:

I kinda have a lot on my plate and so I actually really value the times at the therapist when I know she's getting one-on-one and that she's not getting a distracted parent who's still trying to, you know, pay the bills and sort out work from home and so on, so when she's with the therapist I know she's getting lots of one-on-one (Anne)

Then I had to go into full time work and there was no one to take her. So she stopped going [to gifted school] but we knew, we knew she was gifted before she was one so when she started to regress it was quite noticeable (Anne)

Others spoke about how they felt that, as parents, they may not have been able to give their child everything they needed.

So I left feeling that once that's put in place for him at school we're supporting him that way and lot of encouragement too cause [son]'s our middle child...even though he's got lots of confidence his older siblings really give him a hard time and so for [son] to have, to know that "oh, I do have this available to me" would also take some of the stress off of him (Mary)

It was particularly common for participants to express some questions around their ability and success as caregivers. They often wanted to know if they had done something to cause the problems in their child.

What have we done wrong?" "What could we do better?" "How do we put things right?" "How can we be a...better support?" (Amy)

Often the natural thing to do is to blame yourself and, you know, 'cause parenting doesn't come with a *handbook* [chuckle] so, you know, you make mistakes and then you wonder, well, how can I change that outcome or *can* I change the outcome? (Amy)

I'm angry at myself as well for allowing myself to trust [people in authority]...you never know if you've done the right thing or not (Emma)

I wanted to know whether it was something other than poor parenting (Kate)

Was it because of the way we brought her up?... I think one of the questions that...I think we probably imagined early on in the process of us being told that she has ADHD is "is there something that we've done? Could we have done things differently?" (Mark)

These parents all express a concern that it is due to their mistakes or faults that their child is having difficulty. It is interesting to note that often when parents spoke about this feeling of guilt they would change their language to include the use of the second person. It seems that they may be a bit embarrassed by the fact that they doubt their ability as parents and in order to cope with this they normalise it by speaking in general terms.

One participant seemed to find it reassuring that the clinician her son had seen had liked him. This may have made her feel that in fact she was a success as a caregiver. She reported feeling "proud" of her son and that

He presented himself well...was able to talk reasonably articulately about things...it was really reassuring for [clinician] to be able to say that [son] was actually a really nice, young boy who she found quite a delight to deal with and that had a lovely sense of humour and despite the fact that he would often be tired when he went to see her...So that was nice to know that even when conditions aren't optimum that [son] can perform in the way that you would want a child to...it was good for me to know that, you know, that despite the fact that he has difficulties that he's a good kid really (Kate)

This participant found it reassuring that at least in this sense she was doing a good job as a parent because she was fulfilling her role as she saw it. This comforted her because she could then set aside some of those questions of guilt and blame. In this she seemed to draw on societal discourses around what appropriate behaviour is within a particular context (Dowling, 2010; Skelton & Valentine, 1998). Seeing appropriate behaviour in her son was a comfort to this participant because it reassured her that she was doing a good job as a parent. The research that has investigated the experiences of parents whose children are experiencing difficulties of various kinds confirms that feelings of guilt and self-blame are extremely common (Hale, 2007; Nixon, 1993; Yingling, 1997). These feelings also echo societal discourses around childhood and parenting, for example the notions that unless a child has a picture perfect childhood they are at risk of becoming deficient human beings and that caregiver's mistakes and shortcomings can have implications for their child (Burman, 2008).

The “Good Parent”

All of the caregivers I interviewed described their role as being that of a carer, provider, the one who meets their children's practical needs and does everything in their power to ensure that they do the best that they can and reach their full potential. This may well be influenced by the societal discourses around what a “good parent” is and how that is played out (Hoghughi, 1997). Many of the parents conceptualised the assessment process as being yet another way that they meet the needs of their child. If their child needs assistance in an area relating to their behaviour or emotions then they need to take them to a psychologist in the same way that they may take their child to the doctor when they are physically sick. The quotes below demonstrate the various ways in which the participants verbalised their role.

Definitely her carer...So I see my role as keeping her safe... I try to keep her routine...trying to monitor what she eats, monitor her moods (Anne)

So we were very keen and happy to do whatever we had to do...Anything positive that we can do that helps we want to do...We're ready and happy to support him (Mary)

And just to love him, just to *try* and encourage him and *try* reinforce and help him...[to do] all of that in the best interests of your son (Emma)

I think our role has always been: “Let’s find out what we can about [daughter], she’s a special girl, and how she works. Let’s try to figure out what things we can do to most help her with her, the way she works and how she approaches things and both through the resources that may be available one way or another or techniques and information that can help *us*...I guess our objective is: “Let’s understand her the best we can and let’s do everything we reasonably can to give her the *best* grounding and the *best* opportunities to learn and develop and become all that she can be (Mark)

I want to help her as much as I can, you know, ‘cause I don’t want her struggling (Jenna)

Each of these parents appears to be motivated by a desire to do what is best for their child. Where there may be a need they want to meet it. One of the ways that this may have manifested is in their desire to see to it that whatever solutions come out of the psychological assessment that they implement them. The roles that these caregivers have assigned themselves are consistent with the discourses discussed previously around family relationships and particularly parenting, which state that a caregiver’s role is to care for, control and develop their child in an environment that is conducive to the child’s growth (Hoghughi, 1997; Reder et al., 2003). This theme also appears to be drawing from discourses that depict children as “needy” and entirely dependent on their caregiver’s provision (Burman, 2008; Moss, 2000).

The Distant Professional

Some participant narratives conveyed a somewhat negative perception of some of the professionals who were administering their children’s assessments, were involved in the intervention afterwards or were assisting the family in a more general capacity. They were seen as being very “clinical” and unsympathetic in their approach. In some of these cases the professionals involved in the assessments were within government funded

organisations and are therefore likely to have large case-loads and limited time periods with each client.

One participant told me of her difficulties with medical professionals and getting them to take her seriously when she spoke to them about her son.

Well, you know, you also get the feeling...from a lot of them...that you're *making it up*, that you're, you know, a very *subjective*, you know, that as a parent you can't be objective about your child's abilities or levels and as...years in the education sector person I find that quite insulting...And the number of doctors I've spoken to who have talked to me like an idiot...And I find the medical profession in dealing with her rude and abusive and, I mean the things they've done to her have been totally uncalled for and have caused more problems than anything else. I find their manner towards her absolutely upsetting and their manner towards me, their suspicions, their assumptions that I don't know what I'm talking about, that I am just making stuff up. I find that incredibly insulting (Anne)

This participant portrayed medical professionals as being insensitive to her plight and also suspicious of her claims. This has been a difficult experience for her and left her feeling invalidated and insulted. Jakobsen and Severinsson (2006) found that caregivers often feel that health professionals are "suspicious" of their involvement in the process and so this participant's experience is not uncommon. Another participant told me of their experience of professionals in government funded services.

They actually said "we've got plenty of other people that do want the treatment so, you know, your choice" sort of thing (Amy)

There were also appointments to go back and have some psychological counselling, which proved very difficult because...her sleep cycles were totally upside-down...and the response from [clinic] at the time was "well it appears that she doesn't *want* our service so if she doesn't come, then we can't do anything...it wasn't a case that she didn't want it, it was the case that she was too *sick*. She was too *sick* (Amy)

This participant found that when dealing with these professionals that they were unsympathetic, that there were large gaps in the system through which her child fell and that there was little communication and limited options. Another of the participants seemed to think of the professionals she dealt with as lofty in the sense that they presented themselves as being “so knowledgeable” and having very “educated opinions” and in front of whom she didn’t want to “look like an idiot” by asking “excuse me what does that mean?”.

Doing their job, you know, they come in, tick the boxes, done the assessment, move on, next one, write the report, off we go, you know...they rather do *to* you rather than with you, kind of thing (Emma)

When she first started at school she didn’t have medication at that stage, she also had a teacher, who...was not at all suitable for new entrants [chuckled], just in terms of her approach and strictness with them and things. And she was very difficult for her to handle as well...we met with the teacher a few times and...in our communication book with the teacher she’d draw a scale out of sort of 1 to 10, or something along those lines as to how well she was staying on track or whatever. And we were always getting *right* down at the bottom of the scale and she’s disruptive and difficult and so on and that was emotionally, I guess, quite frustrating for us and little bit of well at our wits-end here. “What can we do?”...“is this teacher going out of their way to make it difficult for us in anyway?” or “are we getting a fair run here sort of thing? (Mark)

[Psychologist] didn’t really understand or attempt to understand the situation that I was in, you know, it was really in the end it was, you know, “you *need* to do this” “do you realise what you’re doing if you don’t do this?” so you got that sort of guilt trip going on...wasn’t that *understanding* (Emma)

These participants presented these professionals as being mechanical in their dealings with their children and unsympathetic, uncooperative and negative in their

dealings with them. The result of this perceived coldness and lack of understanding was a break in trust.

You naturally put your trust, you want to put your trust in someone because you're not able to do it yourself but I quickly got a sense that...the service was too busy to, perhaps, cope with people that were *very* sick but I wondered, well, where, there must be a *gap*. My daughter was too sick to even get *up*, you know, nothings changed so, you know, what are the options? There didn't appear to be one (Amy)

A bit of anger there because...I was trusting the people in authority within the school and over the years there have been so many times they've failed me and failed my son (Emma)

The participants in this study reported that they felt very vulnerable during this process and in some ways at the mercy of the professionals they encountered.

It's quite an alien-type experience to be, sort of, *thrust* all together, having expectations or what do we expect. We haven't experienced this before so what's the expectation and what can we *do* or *not* do or *not* say or *not*, you know. The feelings are quite *high*, you know, as to feeling a bit helpless in the situation. You know, if you don't know how you can best manage the situation...you feel a bit powerless and helpless (Amy)

Quite...scary...not knowing fully how the systems all work. You know, not, perhaps, understanding how effective, or what you can be doing to aid the person that you're trying to care for (Amy)

I did feel quite just in the dark and not knowing which direction or what support could support us as a family and what...supports there are out there for [daughter]. So it was quite a lonely or isolating, I felt isolated and not knowing what other support I could call on that could support through that time (Amy)

When caregivers had their child psychologically assessed it was often a distressing time before which they have a lot of questions and often felt alone and “in the dark”. As a result they were seeking someone that they would be able to trust and in some cases this trust was felt to have been betrayed. This is not an uncommon experience since research shows that when professionals appear cold and unsympathetic their clients find it very distressing and it results in a breakdown of trust (Berwick, 2003; Westbrook, Nordholm, & McGee, 1984).

Problems with Communication

One way in which this power relation between these professionals and the caregivers played out was through a perceived lack of communication between the clinician and the caregiver. This was a theme that emerged a number of times in the narratives of the participants. When it was lacking, whether in the form of little explanation or the use of psychological jargon, the caregivers appeared to feel it sorely and it resulted in a feeling of lack of control. Many of the participants found the psychological jargon difficult to understand and that even when they asked for an explanation that it wasn't always given in a way that made sense to them.

I wanted to ask how can they say she doesn't have ADHD. She did explain it to me but I didn't understand...when we had the final meeting...she spoke in a lot of technical jargon, which kind of went over my head a little bit...So actually even when I asked her to explain things I didn't understand...I still left feeling a little bit like I didn't know... (Mary)

It was very intellectual...a bit above me...[it was in a language that] people like [the psychologist] would understand... (Jenna)

We would every quarter have a big meeting were there would just be a *room full* of people, basically saying gobbeldy-gook *stuff*...[it was] *scary* because you didn't actually really know what was going on...I didn't know what was happening, I didn't know what was happening and it wasn't explained to me *properly* (Emma)

A fair amount of jargon...you're thinking "I don't know what that means and what's the acronym of that?" (Emma)

Another participant told me that after being contacted by the school counsellor she had made an appointment to see the principle and only then was she told that her daughter had been absent from school for two thirds of that year. This had not been communicated to her at any stage prior to the interview. The medication her daughter was put on was not explained to this participant at all and she has no recollection of ever receiving a report back from the psychologist, although she thinks that her daughter may have not wanted her to under the Code of Rights at the time. In addition to this, years later, when she wanted to be included in meetings regarding her daughter in the residential service, she asked for minutes of meetings, audits, plans and reviews but none were given.

Another participant felt that the communication that she was given about her son by these professionals was not representative of him at all and resulted in her feeling very confused.

Hearing them talk about your son, and most of the time it was like another person so you didn't know *where* this other person came from that they were talking about...in the beginning you just can't believe it..."where the problems? What's going on?", you know, and *very* confusing, *very* confusing (Emma)

This participant chose to have a private psychologist, as a means of feeling more in control of the process, rather than a school psychologist assess her son because she felt that "no, I actually need some kind of control here". As an immigrant and "being new to the country" and with schools having a "different system" compounded the feeling of being out of control. This resulted in her feeling "a bit *overwhelmed* and you don't have the support structures so you actually draw *back* and let them *do*". She developed a strategy to cope with this lack of communication and confusion by learning how to strategically interact with the professionals who weren't giving her the information she needed.

over the years you learnt how to start interacting with them ...it was almost having to *learn* how to speak their language to be able to get in and understand what they were saying about your child...as a mother to actually

try and understand the processes and assessments you actually have to, you have to learn the language, you have to get your head in the ring, you have to check and make sure that things are going fair and people are doing their job...This is your son (Emma)

This lack of communication, particularly the communication of what resources and supports there are in the community as well as a lack of psychoeducation, often resulted in a feeling of lack of control for the caregivers of the children and a feeling of being “in the dark” and without direction.

I would have liked to have had a bit more direction at the time. Yeah, I did feel quite just in the dark and not knowing which direction or what support could support us as a family and...what supports there are out there for [daughter]. So it was quite a lonely...I felt isolated and not knowing what other support I could call on that could support through that time (Amy)

For [siblings] to have, to be given skills and strategies to have some education around the whole psychosis experience, or clinical depression experience, so they could know...what they could say...Was there anything that they were doing or not doing that would...make family life better for their sister (Amy)

If I had had some more help, support, knowledge about that time then maybe the intervention process could have...had a better outcome (Amy)

When participants did experience good communication from the professionals involved it was seen as being very positive. It made these parents feel “secure” and as though they had someone that they could “trust” who was “genuine” and wanted to help.

Communications between [daughter] and the service was a lot better and the information that was transferred across to me was very good as well...[this made me feel] a lot more secure. The fact that they were, you know, that I could trust that they were actually genuine (Amy)

So you do get those *breaks* where you have people who *will* explain to you, *will* listen, who will *try* and come on *board* and *understand* you son and his environment and work *with* that (Emma)

The school has been great and having meetings once a term or every couple of terms to talk about strategy and compare notes with teachers has been valuable (Mark)

Stewart (1995) published a literature review on the issue of communication between health professionals and their clients and found that communication is vitally important in this interaction and that good communication can have an empowering influence on the clients involved because they feel better informed to make decisions. The participants in this study also clearly found communication an important part of their experience of having their child psychologically assessed. When communication is absent or unclear it results in confusion and a feeling of lack of control but when there is clear communication these parents have really appreciated it. Effective communication with the psychologist seemed to give participants a greater sense of their own power and control over what could be an otherwise confusing and distressing experience.

Challenging the System

There were other ways in which participants narratives suggested an unequal power relationship between them and the psychologist who conducted the assessment. They described having experienced intolerance for any attempt to challenge the 'system'. A number of participants talked about how it was quite difficult to disagree with the professionals involved in the assessment process because it could be perceived as an affront and they felt that there would be negative consequences for doing so.

When we had tried to have family meeting it just appeared that it was frowned upon because we were challenging the system (Amy)

It was *difficult* to challenge because then you could be seen as being a difficult parent and that wasn't the situation...they would almost brush you aside and discount (Emma)

Not only did these parents find it difficult to challenge the system but they were worried that they would be labelled as being “difficult”. One participant said to me “we’re not pushy parents, you know, we don’t flash card them and hothouse them” and this was said in the context of wanting schools to respect their children. This implies that she feels that by having expectations of a school they may be labelled as “pushy”. In addition to this one participant felt that her son was passively “punished” for her challenging the system.

I *did* feel that when I *didn’t* comply with them there would be a *pulling back* in a sense...if I didn’t comply with them completely and say “yes, yes, yes” and “I’ll do what you want” then the support for [son] in terms of when I wasn’t around didn’t seem to be put in place...So it was almost a passive way of making you comply to what *they* felt was best but I didn’t agree with everything they said so I wasn’t going to comply 100%. I supported and complied with what *I* felt aligned to my son (Emma)

In this quote the professionals are presented as manipulating and blackmailing the participant into compliance. This participant felt that this was not only directed at her but also at her son, which she found very difficult since she too identifies with her role as being the caring and providing parent. Experiencing negative reactions to challenging health professionals and their systems has been reported in other research and appears to be a cause for great frustration among parents who want to be involved in the care of their children (Jakobsen & Severinsson, 2006). It is interesting to note that although caregivers may appear to be compliant they are likely to resist decisions that they do not support.

Inadequate Measures

One of the things the caregivers may want to challenge is the assessment itself. Some seemed doubtful about whether it was the best way of finding out the relevant information for their children. Some participants felt that in some ways the assessments they had gone through had been an inappropriate means of measuring the difficulties that their child is experiencing.

One participant felt that assessments that required a lot of verbal communication were not appropriate for her child, who has autism and is increasingly non-verbal.

I know that some of the stuff they were trying to get wasn't stuff that she can really *give* because she's not verbal enough. And of course some of the tests protocols use language or requests that are not something she can cope with (Anne)

Another appeared to feel that the assessments were a bit intrusive although she would not say so directly. Reading between the lines there seems to be an indication that there may have been some feeling that they were being asked for irrelevant information that they may not ordinarily feel comfortable giving:

It was quite thorough. Yeah it was quite long and thorough...Yeah, sometimes they weren't exactly black and white questions though. They would take a bit of thought. Especially when they were questions about our family dynamic and that sort of thing. I found I had to think a bit harder about that...I thought it was going to be sort of very focused on education but she, [clinician], also asked a lot of questions about our family, how [son] feels about his siblings and how they feel about him and the type of question that, you know, [son] and we had never been asked before. You know, to get a really thorough all-round idea of who this boy [son] is...I was surprised because I didn't think it was going to be like that although, I mean, my [acquaintance] had told me that it's a long thing, but she didn't go into much detail. I don't know if she didn't know or just, you know, that she knew it was long. And we had forms to fill out. My husband found that a bit difficult being dyslexic himself but it's good when it's like tick the box questions. He's very articulate verbally but when it comes to putting it in writing it doesn't reflect his ability (Mary)

This participant appeared to have questions around the ability of the test to pick up on what she seemed to be sure was there. Yet another participant felt that the psychologist's suggestion that her daughter may have ADD was based on a misinterpretation of her child's responses during the testing. She reported that the psychologist had described

behaviours that she felt were grounds for a diagnosis of ADD. Jenna, however, felt that these behaviours were appropriate behaviours for a child and not signs of a disorder. These participants appeared to feel that the assessments were flawed. It is not usual for there to be disagreement on issues relating to the assessment of children by caregivers and has been encountered in other research (Szatmari, Archer, Fisman, & Streiner, 1994).

The Over-Assessed Child

Some caregivers, whose children had undergone a number of assessments over years and years, reported that their children had reached a point at which they had been over-assessed, had become “resistant to testing”, were now no longer cooperating and, in one case, had suffered psychologically as a result.

When she might respond under normal circumstance she switches off when the testing process starts... so she is quite resistant to testing...she can't get her to respond (Anne)

She has issues around oppositional defiance and compliance issues so there's lots of things that make it difficult to get around her. She has to feel like it's a game or that it's something she wants to do. So, you know, you have to sort of tippee-toe around trying to get her to complete any tests. That's made it very difficult (Anne)

For one child this experience of being over-assessed has had some quite severe consequences for his psychological well-being. This participant's emphasis on the psychological impact that this has had on her son demonstrates the discourses around emotional development and what it means to be emotionally healthy or unhealthy (Dowling, 2010).

So he went for extra lessons for that...within the school and from an early age he was always taken out the classroom for certain things, which made him *feel* like he was *different*, which just compounded the problem (Emma)

He had had so many assessments over the years and he was pretty scathing of them because they always took him out of class, he would have people make fun of him because of that and he just saw another psychologist, psychiatrist or whoever doing another assessment on him as “*one of those people*”. No one had ever really *helped* in any way; they had just made his life quite difficult at school (Emma)

Did all the intervention make a difference? I think it's just made him *very very* sceptical and he doesn't trust easily. He's a *very* private boy. It will take *ages* for you to break through before he'll let you in...he doesn't let anybody get close. He will *not* let people get close to him...some of that has got to answer for it...I think he's scared to try in case he fails because he might get another intervention happening or another assessment happening (Emma)

he thinks he's stupid and he'll tell you that, “I am stupid so don't think I can do it Mum because otherwise I wouldn't have been pulled out of the class and I wouldn't have been isolated and I wouldn't have had to sit in the separate chair from everybody else and I wouldn't have been put on the *edge* of the mat when everybody sat in the centre of the mat” and, there were lots of little things that were done to him that he just says “I'm different” and “I'm stupid” and he's *not*...So yeah I do think that a lot of damage has been done in terms of his own self image and his own perception of what he *can* achieve or not achieve (Emma)

This participant's narrative suggested that the assessment process could in fact have a negative impact on children who began to see themselves through the lens of psychologists and other professionals. Some believed that their children had had strongly negative reactions to their experience of being over-assessed. The problems associated with over-assessment of a child seem to give weight to the arguments presented by Burman (2008) and Morss (1996) when they suggest that assessments create inequality by allocating labels of “normality” and “abnormality” to children.

For these participants for whom the process of having their child assessed has gone on for years and may well continue into the future at a later stage. They expressed a feeling of exhaustion and “weariness”.

Very very long...you know, you just have to keep working through and see where you get with her...we'll probably have to wait until she's a little bit older to try and get more (Anne)

It just never stopped really. It *never* stopped...It's *always* difficult...it just goes on and on, and the next step and the next step...in the end I just thought, “ah, this is just *so exhausting*”...Does he have a psychological problem? I *still don't know* with *all* the assessments that he's had going over the years (Emma)

We've just be working on [having her complete tasks without getting distracted] for ten years I think already [laughed]. And progress is pretty slow (Mark)

The words “very very long”, “it never stopped”, “it just goes on and on” and it's “so exhausting” speaks volumes. These parents have done the best that they can for their children for years and it has, in some cases, been a struggle. For many of them this struggle will continue and they do not know when it will end.

The Caregiver as the Defender and Advocate

Some of the caregivers that I interviewed responded to what they perceived as being distant professions, who didn't communicate adequately, would not tolerate the questioning of their findings, used inappropriate measures and, in one case, caused harm through the use of repeated assessments and interventions, by taking on the role of defender, campaigner and advocate for the children.

One of the participants that I interviewed was concerned that her daughter's giftedness is not “overlooked” or “forgotten” particularly since her daughter's “behaviour is not what is expected of a gifted kid”. She wanted the assessment to act as a means by which to “keep

reminding people that she's got two aspects to her". Her concern is that "everyone's so busy going on and on about her autism and forgetting that she was a smart cookie before it and she's a smart cookie still".

I want the schools to respect them...I just want to make sure that they get opportunities at school and don't get bored and that their abilities are acknowledged (Anne)

My main concern with going to [clinician] was to make sure that even with a diagnosis of autism I didn't want her giftedness overlooked or ignored because she is a very smart little girl (Anne)

This parent is clearly acting as an advocate for her child to systems and people that may not see her for all that she is. Another participant described herself as her daughter's "advocate" and that her role involved "asking questions" and being "somebody that can be the voice of someone who doesn't feel like they have a voice".

One participant in particular, whose experience of the assessment process felt especially out of her control, saw herself as the defender and guard of her child.

As a big *guard* dog at the door. That's how I saw my role because I had the feeling that if I just let them all come in I didn't know what would happen to him. I felt like a big guard 'cause he's so sensitive that I had needed to be really guarding who came near him and that wasn't always in my power to do that...I'm quite protective about him...you do advocate...this is your son (Emma)

This participant was concerned that without her being there to protect and defend her child that his vulnerable heart may get hurt. Many of the participants in this study would also tell me the good qualities in their children as though to defend them even to me in case the difficulties they were telling me somehow painted their children in a bad light.

Then when he decided to learn to read he jumped nine levels in one year, which the teachers said was "impossible"... and he's been above average

since then in reading...the psychologists who did an assessment on him on the intelligence side said that he's above average...he's a very popular boy today. He's got heaps and heaps and heaps of friends...he's got a *fantastic* sense of humour (Emma)

She also defended her son by suggesting that his perceived problematic behaviour was due to the fact that he was not a "little girl" he is a boy and that is why his behaviour is thought to be out of control.

If your child doesn't sit and behave himself like a little *girl* we'll put you on Ritalin and *make* you behave like a little girl and then we can teach you and the rest of the class (Emma)

Another participant told me of how her son is "exuberant", "active" and has a good sense of humour. She also said that they believed him to be a "bright enough" boy and that the test had shown that he has been very resourceful in coming up with coping strategies to help himself in his learning. He is seen as being very capable but as having a different learning style

Yet another participant told me how "proud" she was of her son and the way that presented himself during the assessment process.

Really reassuring for [clinician] to be able to say that [son] was actually a really nice, young boy who she found quite a delight to deal with and that had a lovely sense of humour and despite the fact that he would often be tired when he went to see her...So that was nice to know that even when conditions aren't optimum that [son] can perform in the way that you would want a child to...it was good for me to know that, you know, that despite the fact that he has difficulties that he's a good kid really (Kate)

Some of the participants that I spoke to saw their role as being the protector and defender of their children against the cold and distant professionals or systems that influence them. Some even appeared to defend their children to me by ensuring that they portrayed them in a positive way perhaps to ensure that I did not have a bad impression of their child

because of the difficulties they had told me about. This role presented by the participants again reflects the discourses around parenthood, which emphasise the provision of protection from harm (Hoghughi, 1997). It also draws on childhood discourses, such as those presented by Burman (2008) and Moss (2000), which depict childhood as being a very vulnerable period in which children need protection and defence.

The Helpful Professional

Not all of my participants had negative experiences of having their child psychologically however and those who did have experiences that were, on the whole, very distressing, did also have times when professionals were perceived to be very helpful and made a positive contribution to their child's development.

[Clinician] persisted *manfully* [laughter] and got as much as she could... she was very good (Anne)

[Clinician] was pretty down to earth and she didn't use a lot of technical jargon (Mary)

Had a very good GP, who had experience in the ADHD area (Mark)

There were things that he spoke to about with [clinician] that he obviously felt comfortable speaking to her. So I thought that was, that was really good for [son] to have somebody to talk to (Kate)

I was *really* happy with the process that we went through with [son], you know, [clinician] just welcomed [son] so warmly and built up such a lovely relationship with him very quickly, which was nice and in a nice environment that we were able to go to and I felt safe leaving him there with her and he always spoke positively (Kate)

They treated [daughter] a lot more like, better communications between [daughter] and the service was a lot better and the information that was transferred across to me was very good as well (Amy)

So that assessment process was very positive, they reviewed, although they didn't have the notes from the time she was at [clinic] but the process was quite different, there was quite a good rapport built up and they visited her at home (Amy)

There were some people along the way...in this journey that...did have a good understanding of him...there's been the odd person who has been *absolute*, they have been *amazing* but then you only have them for a while...so you do get those *breaks* where you have people who *will* explain to you, *will* listen, who will *try* and come on *board* and *understand* you son and his environment and work *with* that (Emma)

These parents have indicated that when a clinician is down to earth, speaks to them in language that they can understand, is positive and understanding and who makes the effort to build good rapport and make them and their children feel comfortable that they make a considerable difference. Professionals clearly have the power to take a vulnerable, confused parent and provide them with the reassurance that they need in this sometimes difficult situation. The narratives of participants did suggest that psychology professionals were, at times, able to provide their clients with the assistance and encouragement needed through their journey of making sense of their child's difficulties (Jakobsen & Severinsson, 2006).

Chapter Five

Discussion and Suggestions for Future Research and Practice

The aim of this study was to gain some understanding of the way in which caregivers experience the process of having their child psychologically assessed. The purpose of this study was to look more specifically, through the use of narrative inquiry, into the ways in which these individuals have made sense of the experience of having their child psychologically assessed and the stories that they tell about this. This chapter summarises the themes that emerged from the narratives in this study. This is done, firstly, by grouping narratives together in terms of their general similarities and, secondly, by outlining the overarching themes of all the narratives. The societal discourses and broader contexts that impact upon these themes will also be identified as they assist in the construction of meaning and should not be excluded when considering factors relating to assessment (Burman, 2008; Squire, 2000).

Similar Narrative Groups

Although each of the narratives that have been shared in this study are unique in many ways and each individual has had differing experiences of the process it is possible to group the stories not only according to themes, which has been done in the previous chapter and summarised below, but also according to more general types. For two of the participants the experience of having their child psychologically assessed involved feelings of powerlessness. It was not something that they sought on their own but was instead thrust on them either by professionals or out of necessity due to a crisis. They felt that they

were “in the dark”, the process was out of their control and they didn’t understand a lot of what was going on or what the future held. Professionals, who were generally portrayed as the villains in the stories, came across to them as being cold, unsympathetic and distant at a time when they felt vulnerable and all they wanted was support and direction. For one of these participants there has been an improvement in their child’s mental health despite these difficulties and therefore takes on a dialectic structure. For the other there has in fact been a decline in her son’s psychological well-being and therefore has a regressive narrative structure.

For three of the other participants the psychological assessment process was initiated by themselves. They identified a need in their child and actively sought outside help. These participants portrayed the professionals administering the assessments as being the heroes of their stories and for most of these individuals the assessment equipped them with some practical strategies that had resulted in improvement in their child’s situation. On the whole these participants found the process of having their child psychologically assessed a positive experience that gave them some direction for the future. Two of these narratives took on a progressive structure in that the characters in the story experienced an improvement in their situation. Only one of these stories took on a dialectic narrative structure because despite these improvements there had been struggles along the way, such as difficulty finding appropriate assessment tools for her child.

The final group includes two participants who had not initiated the assessment process but who had been supported through it rather than left alone to figure it out. They had both been informed of their child’s learning difficulties by teachers and had in many cases been referred to a school psychologist for psychological assessment. Although both of these participants did seek outside help as well the primary source of the assessment was within the school their child attended and there was direct communication between the psychologist and the teachers. For these individuals it seemed that although there were some frustrations along the way, such as slow processing and lack of understanding from some teachers, the process of having their child psychologically assessed was supported by teachers and systems within the school and progress has been seen or is expected to be seen. These narratives have both therefore taken on a dialectic narrative structure in which the caregivers and some of the professionals are the heroes.

General Findings and Implications for Practice

A number of themes emerged from the narratives of the caregivers who participated in this study. The first was that of “suspected ‘diagnosis and own expertise’”. I found that some of the caregivers who had their child psychologically assessed had already made up their minds as to the diagnosis that they were expecting to receive for their child, at the very least they had a suspicion or hypothesis, and many either had personal or professional experience that had informed this hypothesis or they had taken it upon themselves to research these diagnoses prior to the assessment in order to be better informed. These caregivers then wanted confirmation of their concerns from a professional. This theme is quite consistent with the research that has found that the general public are increasingly making use of the internet to self-diagnose (Ahmad et al., 2006; Emmons, 2010). Once they had received the confirmation they were seeking this would then give them licence to pursue solutions, whether that be through personal means, such as ways of behaving at home, or through referrals to appropriate services. The difficulty that access to materials that allow self-diagnosis presents is that it can result in caregivers feeling uneasy about the diagnoses that are inconsistent with their own hypotheses and they may seek multiple opinions until their own is confirmed, which may lead to a great deal of frustration for the caregivers. A way that clinicians may be able to deal with this situation is for them to acknowledge the caregivers’ possible expertise and potential hypotheses regarding what the difficulties may be relating to their child and ask for their input. This more collaborative approach may inform the professional’s assessment of the child and in some cases the caregiver may be correct in their suspicions. When they are found to be mistaken the reasons for this should be clearly outlined so that caregivers do not feel that their insights have been disregarded. It is important for the caregivers of children to be very involved in the assessment process to maintain a “family-centred perspective” as this reduces stress and increases the family’s feeling of empowerment (Minke & Scott, 1995).

The second category was “seeing ‘inside’ the child”. Many of the caregivers that I spoke to sought an assessment in order to gain insight into their child. This insight appeared to be out of their reach without the assistance of a psychology professional, who apparently has the key to unlocking the inner mysteries of their child. Once they have acquired a greater knowledge of their child caregivers appear to feel better equipped to know what to do about their child’s difficulties and in one case the caregiver seemed to feel that the very

process of “focusing” on her son for an extended period had in itself been a helpful experience because she gained insight and he was able to have someone to talk to. Rose (1986) has discussed how people’s understanding of themselves is increasingly mediated through the ‘psy-disciplines’. While psychological discourses increasingly give people access to understanding motives and behaviour it can also lead to a situation in which people feel disempowered and less able to rely on their own judgements and perceptions even of those closest to them.

The third idea that surfaced during this process was that of “bittersweet labels”. There seemed to be some ambivalence around the topic of diagnoses as initially when caregivers spoke about diagnoses or “labels”, whether these were formally given by a psychologist or whether the caregiver had had a suspicion that they may be, they were portrayed in a negative light and described as “labelling” or “branding”. On further discuss, however, it appeared that although these diagnoses had unpleasant connotations for many of them they also held some aspects that were considered favourable. For one participant the “label” meant that she may not be entirely to blame for her child’s difficulties. For others it held the hope of a solution, almost as though once it has a name it also has a range of possible resolutions. For another caregiver it meant that she could get other professionals, particularly medical professionals, to take her seriously. For her the assessment and the subsequent “label” was “ammunition”. In many cases these diagnoses or the process of the assessment, and the suggestions that were made, did in fact result in positive progress and the caregivers have perceived some improvement. Thus the process of having a diagnosis assigned to their child was on one hand negative because it involved the label of “abnormality”, which Burman (2008) and Moss (1996) would argue is a social construct that creates inequality, and possible stigma (Jones, 2010; Overholser, 2010) but positive on the other hand because it brought with it answers to the problem (Haghighat, 2008). Thus there appears to be a sense of ambivalence around the issue of “labelling” individuals because it comes with both its advantages and disadvantages (Ho, 2004). In practice it may therefore be helpful to discuss with caregivers their thoughts and possible concerns around diagnoses and their child’s “label”. If they are having difficulty with the idea of a diagnosis it may be beneficial to work with them towards a new way of constructing it, for example, supporting them to see it as “diversity” rather than abnormality and deficit as well as emphasising the support that is now available to them (Ho, 2004).

The fourth theme that was identified in this study was that of “Questions of guilt and blame”. Most of the participants mentioned either directly or indirectly feelings of guilt and questions of blame. They wanted to know if it was because of something that they had done that their child was now having these problems. They also wanted to know what they could do to make things right if they had indeed fallen short of the mark. These concerns are extremely common according to the research on parent’s experiences of their children’s difficulties particularly since societal discourses tell us that children need to have perfect lives in order to grow up to be “healthy” adults (Burman, 2008; Hale, 2007; Nixon, 1993; Yingling, 1997). Caregivers therefore appear to seek answers to these questions so that they can rectify what they may perceive to have been mistakes or inadequacies. Nixon and Singer (2002) suggest that caregivers may take on blame as a way of feeling that the situation is in some way under their control and that there is someone to blame because it may be easier to deal with than to have no answers and no one to blame. They suggest that the best way to support caregivers in this position is to work with them on the false beliefs that they may hold regarding their involvement in the cause of their child’s difficulty and find more factual answers that will still allow them to feel a sense of control. In practice it may therefore be helpful to ask if this is a concern and to address it directly.

The fifth notion that arose, “The good parent”, was a unanimous one and was in response to the question: what do you see your role as being in the process? All of the participants in this study saw their role as caring for their children, both practically and through love and support. They also saw their role as providing all that their child needs in order to give them the best opportunity that they possibly can and so that they grow up to be the best people that they can be. Again these ideas are consistent with the discourses which prescribe the role of provider and carer of children to parents (Hoghughi, 1997; Reder et al., 2003) and depict children as vulnerable and in need of provision (Burman, 2008; Moss, 2000). This puts a tremendous amount of pressure on caregivers and may impact on the previous theme around guilt and blame. It appears that these caregivers felt guilty if they perceived that they had fallen short of being the “good parent”. In practice it may therefore be helpful for clinicians to acknowledge and applaud caregivers for their efforts to provide and care for their children.

The sixth theme that came out of the study was more negative and was that of “distant professionals”. Not all of the participants had had this experience but some perceived the professionals involved in the assessment process, whether they were medical professionals, psychologists or teachers, as being clinical, unsympathetic, patronising, lofty and distrusting of the caregivers’ views. This resulted a feeling of broken trust for many of the caregivers that I spoke to because when in this vulnerable position they were looking for someone to put their trust in and when they were disappointed in the response they received, broken trust was the consequence. Unfortunately these experiences are not uncommon, according to current research, and do often result in individuals feeling a loss of trust. Researchers have shown how some people have had difficulties with the perception that professionals are cold and lacking in empathy, which results in a breakdown in the client-practitioner relationship (Berwick, 2003; Westbrook, Nordholm, & McGee, 1984). Thus professionals administering psychological assessments need to be constantly aware of the culture that they create through their work. From this study it is clear that the caregivers of children being assessed feel very vulnerable and are seeking a professional who is warm, caring and empathetic.

One of the other ways that this apparent power relation is made manifest is through a lack of communication to the caregivers from these professionals. Therefore, “communication” was the seventh category that was identified. Many participants commented on the use of jargon and acronyms that they could not understand. Some said that they felt unfamiliar with how systems worked, what resources were available and what they could do as a family to help the situation but were not given the desired information. Some caregivers reported having had decisions made relating to their child’s treatment without explanation. This resulted in a feeling that they had no control which the caregivers found very distressing. There were however times when the communication between caregivers and professionals was present and effective and the impact of that on the caregivers was extremely positive. This further emphasises the importance of good communication. One participant reporting having to come up with strategic ways of interacting with these professionals in order to gain some information and in that way some control. It is therefore vitally important that professionals maintain good, clear communication with the caregivers of children they assess so that they feel empowered to make decisions and seek appropriate support (Stewart, 1995).

Another way in which the power relation between caregivers and professionals was played out was through the perceived disapproval when caregiver challenged or questioned what the professionals were saying. This idea is titled “challenging the system”. Some participants reported that it was difficult for them to express disagreement with the professionals because it was “frowned upon” and would often result in them being “discounted” or “brushed aside”. One participant in particular felt that when she did not “comply” with all that the professionals said that there would be a “passive” withdrawing of support. This experience of being disregarded because of challenging the system has been identified in previous research as well (Jakobsen & Severinsson, 2006). Being disregarded can have a very disempowering affect on caregivers because it results in a limited communication and therefore limited decision making ability (Stewart, 1995). Professionals need to ensure that they have an open, positive attitude towards challenges and questioning by the caregivers of child with whom they are working so that caregivers are not left “in the dark” and isolated.

A ninth theme that emerged was that of “inadequate measures”. Some participants expressed the idea that they did not feel that the assessments were necessarily relevant, for example asking for information that did not seem necessary, appropriate, such as using assessments that had a lot of verbal content with an autistic child who was becoming increasingly non-verbal or accurate, for instance suggesting the existence of a diagnosis what the caregiver was convinced was inappropriate. Once again the inconsistency of opinion between caregivers and professionals is one that has been noted in a previous study and therefore is not an unusual experience for these participants to have had (Szatmari et al., 1994). It is likely that caregivers’ increased access to diagnostic and related information has resulted in an increased likelihood of discrepancies between professionals and their clients’ opinions because their clients are now more likely to have an opinion on these topics than before (Ahmad et al., 2006; Emmons, 2010). It may therefore be beneficial for professionals to ask caregivers if they felt that the assessment was an appropriate means of gaining the relevant information and if not to discuss it with them. This may mean that the professional gains some insight from the caregiver and together they come up with a solution or for the professional to provide a more suitable explanation of what the assessment has entailed and address specific concerns.

A couple of participants also reported that their child had been “Over assessed”. This is the tenth theme in this study. This feeling of being “over assessed” has resulted in the children refusing to cooperate during assessments, “switching off” and becoming very “scathing” and “sceptical” of the professionals administering the tests. For one child in particular, these repeated and ongoing assessments have resulted in some permanent psychological damage, according to his mother. He now feels “different”, is fearful of trying new things lest he fails, thinks he is “stupid” and is distrusting of others. This damage according to Burman (2008) and Morss (1996) would be due to the process, typical of assessments, of classifying children as “normal” and “abnormal”. It also emphasises the importance that is given to emotional development within children by the societal discourses which have influenced this experience (Dowling, 2010). For many of these caregivers the assessment process has been “a never ending story”. It has been going for years and they expect that it will continue for many years to come. This thought leaves them feeling exhausted and weary. To address these concerns professionals administering assessments should consider carefully before assessing a child who has already been assessed numerous times. Being creative in their approach towards the collection of data may be helpful as well as making every effort to validate the child and praise them for their strengths and not simply focus on their difficulties (American Academy of Child and Adolescent Psychiatry, 1997).

As a result of these negative experiences many of the caregivers in this study identified yet a second role that they took on. This, the eleventh category, is titled “The caregiver as the defender and advocate”. It involves ensuring that their child is “respected”, acknowledged and not misunderstood. It also means that the caregiver acts as the “voice” for their child, who they feel may not be able to represent themselves in these situations. This role also entails being a “guard” for their child to protect them from the wave upon wave of assessments and interventions that were administered and seemed beyond the caregivers control in some instances. These caregivers even displayed this role in their conversations with me in which they would regularly tell me of their children’s good qualities and strengths as through to ensure that they were still really likable despite these difficulties. Here discourses around the parental role of protector are made evident (Hoghughi, 1997) as well as discourses around childhood being a time of total dependence on caregivers’ protection (Burman, 2008; Moss, 2000). By fostering a sense of trust and control in the caregivers through good communication and open discuss professionals are likely to

create an environment in which caregivers may no longer feel the need to defend and advocate for their child but instead will feel that they have an ally in the clinician. This sense of security could be facilitated further by speaking regularly of the strengths and abilities of the caregiver's child, which creates a more holistic picture for both the caregiver and the professional (American Academy of Child and Adolescent Psychiatry, 1997).

Finally, although many of the professionals that these participants encountered were perceived in a negative light there were some who had a very positive effect on the children and on their caregivers during this time. This category is entitled "the helpful professional". These individuals who helped both caregivers and children along the way included medical professionals, psychologists and teachers and seemed to have had a profound influence on the lives of these individuals. According to Jakobsen and Severinsson (2006) many people do report having positive experiences involving caring and supportive health professionals. The qualities that were described included good, clear communication, understanding, empathy, warmth and a willingness to support and listen to the caregivers. This serves as a good reminder to all professionals of the importance of these in practice.

Although each of the stories that were told in this study are unique in many ways one thing is common throughout and that is that for every one of the individuals the process of having their child psychologically assessed has had a considerable impact on them. For some it was felt more than others but for all of them it would appear that it was a significant event in their lives. This is a good reminder to clinicians working with caregivers in the context of the psychological assessment of their child that although this may feel routine within professional practice it is something that is having a profound impact on the caregivers of the children. This knowledge may enhance professional empathy in these situations.

Future Research

This study has brought with it some insights but it has also opened up some questions which could be explored in future research. Firstly, future research could explore the ways in which the children who are being assessed experience the process. It may be helpful to use methods of data collection that are more appropriate for children, for example drawing

pictures that represent their experience, since this is considered one of the ways in which children can represent their emotions and experiences (Sadock & Sadock, 2007), and comparing them. It would also be necessary to conduct the data collection as soon after the assessment as possible so that the experience is still fresh in their minds. Secondly, the same could be done with the teachers involved with the process. It would also be helpful for the same study to be done with parents but within specific services that deal with specific difficulties to determine if there is any variety between services and diagnoses.

Challenge

The main challenge that came up during this study was that of recruiting participants. This may have resulted, firstly, due to ethical constraints which prevented me from contacting potential participants from the clinic myself as their details are confidential. Had I been able to personally invite and talk to potential participants I may have had a better response. A second possible reason for this challenge, when thinking reflexively, may have been my association with psychologists and related fields. This may have prevented some people from agreeing to participate because they may have had a negative experience and did not wish to share this with someone they may have perceived as being very closely connected to the clinic or to professions with which they had had contact. In the end I applied to ethics and was given permission to use snowball sampling to recruit more participants.

Conclusion

This study has used a narrative inquiry methodology to explore the ways in which primary caregivers experience the process of having their child psychologically assessed. This study has a qualitative and social constructionist theoretical framework which allowed me to investigate these caregivers' perceptions and the way in which they constructed these in order to create meaning of their experiences (Gergen, 1985; Parker, 2005). In particular this study investigated that way in which these caregivers used narratives to construct meaning (Parker, 2005). I have endeavoured to note the context in which these stories take place (Squire, 2000), the function that they are serving for the participant (Riessman,

2008) as well as acknowledging that mine is only one of a number of possible interpretations of these narratives. The analysis has involved exploring each of the narratives individually by outlining sequential events and main themes. This was followed by identifying and analysing the overarching themes that are present within all the narratives as well as noting similar types of stories. Therefore, this study utilised an analysis method very similar to the categorical-content perspective (Hiles & Čermák, 2008). Burman (2008) has criticised psychological assessments for neglecting to consider the broader social contexts in which families and individuals are situated and instead tend to think of the root of the problem as being within the individual or family. For this reason I have identified social discourses around concepts, such as childhood and intellectual functioning, and their impact on the narratives in this study.

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Appendices

Appendix A

Information Sheet

Lead investigator:

Full Name: Jessica Niemand
Position: Masters Student, Massey University
Address: School of Psychology
Private Bag 102 904
North Shore City 0745
Auckland
New Zealand

Telephone: (027) 272 8006

Supervisor:

Full Name: Beverly Haarhoff

Position: Senior Lecturer, School of Psychology, Massey University

Address: Centre for Psychology

Private Bag 102 904

North Shore City 0745

Auckland

New Zealand

Telephone: (09) 414 0800 (extn 41223)

Title:

How do primary caregivers understand the psychological assessment process undergone by their child?

Introduction

I would like to invite you to take part in a study being conducted at Massey University to see what its like for primary caregivers to have their child psychologically assessed. This research is being done through the Centre for Psychology at Massey University and is a student project.

About the study

The aim of this study is to gain an understanding of the way in which primary caregivers make sense of the psychological assessment process undergone by their child. I hope that study will be helpful to you and other primary caregivers like you, because it will

help psychologists to have a better idea of the kind of information that they need to provide primary caregivers who have brought their child in for an assessment. We are hoping that if we understand your perspective better we can increase families' involvement in treatment later on, which, research says, helps to improve the effectiveness of our work.

You have been invited to participate because your child underwent a psychological assessment. We have invited all primary caregivers who meet these criteria.

If you agree to participate you will be interviewed. This can be done at your home, or wherever is more convenient for you. I expect that the interview would take around one hour. If you agree to do the interview I will send you your transcript of your interview to check to make sure it is accurate and to give you an opportunity to take out anything you don't want to include.

I will make sure that it is not possible to identify you in particular in the final report by not including any personal details and by disguising the information in such a way that you are not recognisable. I will let you have a summary of the report once the research is completed.

If you agree to participate in the interviews you do not have to answer all the questions and you may stop the interview at any time. With your permission all interviews will be audiotaped. Any information collected during the interview will be securely stored at the Centre for Psychology.

Once all the interviews have been completed the researcher will interpret the information by highlighting the main ideas expressed in the stories and writing one story that accurately describes all the participants' experiences.

More information on the study can be obtained by contacting either the primary investigator, Jessica Niemand or Dr Bev Haarhoff in the School of Psychology. Both of their details are given at the beginning of this document.

If you need an interpreter one can be provided. Details will be obtained on the consent form and arrangements made.

You may have a friend, family or whānau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

We would like to hear from you regarding whether or not you would like to take part in this study within the month.

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect any future care or treatment. If you do agree to take part in the study, you are free to withdraw from the study at any time, without having to give a reason, and this will in no way affect your future healthcare. Participation in this study will be stopped should any harmful effects appear or if the doctor feels it is not in your best interests to continue.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

Benefits, risks and inconveniences:

The benefits involved in this study include allowing participants an opportunity to express their story and experiences. It will also provide participants with information about their and others' experiences of the same event, which may be of interest to the participants and they will have the opportunity to contribute to the advancement of knowledge.

There is, however a risk that being reminded of the experience of having your child assessed and the events leading up to this may be distressing. This study may also

result in extra travel to attend the interview at Massey University, Albany, should you choose to conduct it there. There will be no compensation for these costs.

Confidentiality:

No material that could personally identify you will be used in any reports on this study. All the information collected during the interviews will be kept in a secure location at the Centre for Psychology, Massey University and will be held there for 10 years before being destroyed.

This material will only be seen by the supervisors of this study as well as the primary investigator, Jessica Niemand. Since some caregivers have had their children assessed at Massey it may cause some caregivers to feel anxious about sharing some information, particularly if expressing negative feedback about a therapist, for example. To deal with this a neutral third person, not within the Centre, will be asked to view the interview information after Jessica Niemand has transcribed it and remove all data that identifies the individual and the therapist as well as be available to facilitate any problems that arise (e.g. misconduct of the therapist etc.).

Results:

Each participant will be given a copy of the results of this research. There may be a delay of a few months between the interviews and the completion of the report.

Statement of approval:

This study has received ethical approval from the Health and Disability Northern Y Regional Ethics Committee, ethics reference number NTY/10/04/035.

Please feel free to contact the researcher if you have any questions about this study.

Appendix B

Participant Consent Form – Individual

<p>1) I have read and I understand the information sheet dated for volunteers taking part in the study designed to explore my understanding of my child’s assessment process. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.</p>	Yes		No	
<p>2) I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.</p>	Yes		No	
<p>3) I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future health care.</p>	Yes		No	
<p>4) I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.</p>	Yes		No	
<p>5) I understand that the investigation will be stopped if it should appear harmful to me.</p>	Yes		No	
<p>6) I have had time to consider whether to take part in the study.</p>	Yes		No	
<p>7) I know who to contact if I have any questions about the study in general.</p>	Yes		No	
<p>8) I consent to my interview being audiotaped.</p>	Yes		No	
<p>9) I would like the researcher to discuss the outcomes of the study with me.</p>	Yes		No	

Request for interpreter

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	lo	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	loe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	loe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	lo	Ikai
	<i>Other languages to be added following consultation with relevant communities.</i>		

I _____ (*full name*) hereby consent to take part in this study.

Date:

Signature:

Full names of researchers:

Contact phone number for researchers:

Project explained by:

Project role:

Signature:

Date:

This study has received ethical approval from the Health and Disability Northern Y
Regional Ethics Committee, ethics reference number NTY/10/04/035.

Appendix C



MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGĀ TANGATA

Letter of Invitation

Dear Sir/Madam

The Centre for Psychology is conducting some research aimed at improving our services. We would like to invite you to participate in a research project being undertaken by one of the Masters students in the School of Psychology, Jessica Niemand. In the attached Information Sheet is all the information on the study to allow you to make an informed decision about whether or not you are prepared to take part in the research.

I will be supervising Jessica's research but in order to ensure that the research does not impact on any future relationship you may have with our service, I will not be given the names of anyone who takes part in the study and any research data that I see will have all potentially identifying data removed from it.

If you have any questions about the research Jessica will be happy to answer these. She can be contacted through the administrator at the Centre for Psychology, Helen McMaster. If you have any issues related to the research that you would like to discuss with a senior member of the School of Psychology, you may contact Dr Bev Haarhoff at 414-0800 (41223) who will also be involved in this research project.

Thank you for your consideration. If you would like to participate, please Jessica Niemand or just sign the attached Consent Form and return it to:

Jessica Niemand
School of Psychology
Private Bag 102904
NSC
Auckland

Yours Sincerely

Dr Kerry Gibson

Appendix D

Interview Guidelines

The method of analysis in this study will involve interviews conducted in a manner similar to that of a conversation. A number of open-ended questions will be decided upon prior to the interviews but these may be adjusted and interviewees may be prompted during the interview to gain further information, in the form of a story if possible. This method of data collection is in line with the narrative methodology employed in this study.

The main questions that will be asked during the interview will include:

“Tell me when you first decided to get help. How did that all happen?”

“How did you understand the assessment process?”

“Did it make sense to you?”

“Did the assessment make any difference to the child’s situation?”

“What do you think the psychologist was trying to do?”

“What role do you think you, as a parent, played in this process?”

Prompts may include statements/questions such as:

“Can you remember a time when?”

“Tell me what happened”