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Parental Constructions of Autism
and the Impact of Autism on the Family:
A Critical Exploration

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A thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Clinical Psychology
The University of Auckland, 2011
Abstract

The majority of research on autism and its impact on the family have been conducted within the positivist paradigm theorising parental (predominantly maternal) experiences in terms of psychological stress mediated by coping strategies. The individualistic focus of such studies tends to underestimate or ignore the wider socio-cultural context, in which parental experiences and meaning-making about autism are embedded, implicitly locating the responsibility for poor coping within the parents. In this thesis, I seek to address such limitations by introducing other ways of theorising parental subjectivities and practices applying social constructionist and critical realist approaches to the study of autism. This research draws upon 26 interview accounts of parents of children diagnosed with autism. It is concerned with critically exploring parental experiences of their child’s diagnosis and their own identity as a parent as constituted by the cultural discourses available to them, and the ways parents negotiate these identities and experiences. I address this in two empirical chapters examining parents’ constructions of the causes of autism and stigmatisation they experienced. Following a general social-constructionist orientation, I utilise a form of discourse analysis which combines the attention to macro-level discourses with the rhetorical strategies used to negotiate subjectivity. As a background for my analyses, I review the current ‘expert’ literature on the causes of autism in a separate chapter, due to the large volume of data. To introduce the exploration of stigma discourses, I also provide a brief overview of theoretical and empirical research on stigma, and my own formulation of stigma for the purposes of this research. In my third empirical chapter I move away from constructionism, using a critical realist approach to give voice to parents and validate their experiences of the diagnostic process. I conclude with a discussion of the importance of approaching parents’ stories as constituted by societal discourses available to them, which I see as a means of de-pathologising and validating parental experiences. I reflect on the usefulness of the analytic and methodological approaches used in this thesis, discuss recommendations for practice and potential directions for further research. New theoretical understandings arising from this study, the first one based in New Zealand that utilises social constructionist approach to explore the impact of autism on the family, contributes to the extremely limited body of constructionist empirical research on autism and other developmental disabilities.
Acknowledgements

I would like to express my sincere gratitude to all the parents who participated in this study. This work would not have been possible without your involvement. Thank you for generously giving me your time and sharing your stories so openly in the interviews.

My deepest gratitude to my primary supervisor Associate Professor Nicola Gavey, for her unwavering encouragement and guidance. Nicola, you have been the most consistent source of intellectual inspiration, patience, and wisdom throughout the years – I can never thank you enough. I am also grateful to my secondary supervisor Dr Claire Cartwright for her support, advice, thoughtfulness, and direction.

Most of all, thank you to my family, friends and colleagues for their support, patience and belief in me. I could not have completed this project without you. To Karmyn and Anna – thank you for your friendship and for always being there for me when I needed it most. To Chris, Sarah, and Vicki – thank you for your camaraderie over the years – this has been invaluable. To Beryl – thank you for your support and wisdom. To Annette and Richard – much of this work is inspired by you.

I would also like to acknowledge the financial support provided by the scholarships and awards I have received: Kate Edger Charitable Trust Doctoral Degree Award and Winifred Gimblett Scholarship.

Finally, a huge thank you to Slava and Mike – it has been a long journey, and your love and encouragement have sustained me throughout.
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Chapter 1: 
Thesis Introduction and Overview

In order to make something visible you first have to notice its invisibility
(Grinker, 2007, p. 263)

Introduction

This thesis is about listening to parents and making their stories heard, or in Grinker’s (2007) terms – “visible”, within the landscape of medico-scientific discourses and practices through which autism and its impact on the family is currently “fashioned into an item of knowledge” (Bhaskar, 1998, p. 16). This thesis is also about noticing, and making “visible”, the complex matrix of discursive practices that shape the socio-cultural landscape within which parents’ stories are embedded. Although Roy Grinker (an anthropologist and father of a daughter with autism), used the word “invisibility” to describe the lack of interest, appreciation, and integration of children with autism into a ‘normal’ social world around them, I thought of it as a good metaphor for describing the place of parents’ accounts, their meaning-making, within the published research literature on autism. The approach I have taken in this thesis views all knowledges and accounts as storytelling (Burns, 2004). It recognises however, that some of the stories such as the ones told by “the science of the day” (Bhaskar, 1998, p. 16) carry more authority and have influence over other, less powerful narratives. I hope that adopting this approach while making the parents’ stories and the context of their creation the central focus of my research will help to increase their “visibility”.

Personal context

Objects of research scrutiny do not just land on our desks (Alldred & Burman, 2005, p. 183)

The idea for this research certainly did not just land on my desk. It was as a result of my work with children with autism as an applied behaviour analysis (ABA) therapist several years ago, that I became interested in various issues that I address in this thesis. In fact, it all began when after starting this role, I decided to improve my knowledge of the early history of autism, and in the process came across a 1949 article by Leo Kanner. In the article he stated (among other things), that fathers of children with
autism hardly knew their children, and that the mothers’ best efforts to take care of their children resembled a “mechanized service of the kind which is rendered by an over-conscientious gasoline station attendant” (Kanner, 1949, p. 424). The article made me ponder three questions. Firstly, how might it have felt for parents to have to deal with the stresses and strains of raising a child with a condition as serious as autism, while their personalities and behaviours were objects of scrutiny as potentially causing this condition in the first place? Secondly, how much time was needed for a discourse to become extinct (‘disappear’ completely), and whether that was in fact a possibility at all? Thirdly, did the more recent genetic and bio-environmental explanations of the causes of autism mean the end of parent-blaming? Over the years that I worked with children and their parents, I never ceased to be amazed at the enormous amount of love, energy, time, money, and sheer tenacity that parents were only too happy to ‘invest’ in bringing up their children, as the stressors and strains of their daily lives seemed unrelenting – a humbling experience for me, when I thought about my own fairly stress-less and uncomplicated experience of mothering. I also became quite convinced that many of those stressors were not inherent in the ‘reality’ of having a child with a disability, but were socially and culturally produced. For example, it appeared that the anxiety many parents (mostly mothers), felt about facing the world outside their homes (at least soon after the diagnosis), their fears of being excluded, considered ‘weird’, and ‘bad’ parents, had a lot to do with the history of autism and with the societal attitudes towards differentness and disability. There were also many more ‘practical’ issues, such as lack of funding, information, support, and treatment options within the public system that increased the overall stress for the parents.

For most of the parents I have worked with (as well as for those I later interviewed), the first full realisation of just how unsupported they were going to be came at the time of the ‘official’ diagnosis – the experience they frequently recalled as distressing for that very reason. Yet much of the available research on the impact of autism on the family has been conducted within a model which assumes “linear uni-directional causal relationships” between the child’s characteristics and parental stress (Avdi, Griffin, & Brough, 2000b, p. 242). The level of stress that parents experience is expected to be mediated by their coping (in the form of cognitions and behaviours), and personality correlates such as “hardiness” (Weiss, 2002), with few studies considering social and cultural contributions. Apart from decontextualising, and therefore oversimplifying a
complex process by which autism affects the family, such individual focus of the research appears to be inherently problematic for another reason – it implicitly blames the parents whose personalities or ways of dealing with stress are considered lacking, for their own distress.

Some years later, having decided on the topic of the thesis, and contemplating the general approach of my research, I knew that one question I did not want to ask parents was one about ‘coping’ or ‘adjusting’. My intention was to give careful consideration to the complex matrix of socio-cultural factors and institutional practices within which parents’ life stories unfolded. Two pieces of research inspired my choice of conceptual frameworks used in this thesis. The first was Avdi et al.’s (2000b) social constructionist analysis of parents’ construction of the “problem” during assessment and diagnosis of their child with autism – the first of this kind in autism research. The second was Burns’ (2004) exploration of bulimia, which successfully used a poststructuralist discourse analytic lens in combination with a critical realist framework to approach various aspects of the talk and text of bulimia. By applying constructionist and critical realist frameworks to the data in this study, I endeavour to resist the implicit parent-blaming attributions of the stress-coping paradigm and to validate parental experiences. My aim is to also bring the attention of the readers to the socio-cultural locatedness of parental stories, and to the societal discourses that parents of children with autism have to negotiate, in order to make meaning of their experiences.

I have introduced my research, described how the idea for it came about, and highlighted some of the issues with the existing research on parents of children with autism which I am addressing in this thesis. Later in this chapter, I will briefly review the history of how parents of children with autism have been portrayed in medico-scientific literature since autism was first described in 1943, and describe the position of this study in relation to this body of knowledge. I will then describe in more detail, my research aims and approach, and provide an overview of the thesis. However, to provide the reader with some background information on autism, I will begin this chapter by discussing the history of autism as a clinical entity, and the current state of research about its prevalence, treatment options, and the long-term prognosis for the individuals with this condition.
The history of autism as a clinical entity

Autism was first delineated in 1943 by Leo Kanner, an American child psychiatrist who reported on a group of 11 children with a “unique syndrome” that included social difficulties, communication problems, and repetitive and restricted activities. Kanner (1943) described these children as being “pure-culture examples of inborn autistic disturbances of affective contact” (p. 250). The history of conceptualising, researching, and treating autism, has been marked by controversies (Volkmar, 2000). Since the publication of Kanner’s original paper and until the mid-1960s to 1970s, there were two main “blind alleys” (Boucher, 2009, p. 6) in the conceptualisation of autism: 1) for a period of time autism was considered to be a form of psychotic condition (“childhood schizophrenia” or, in Creak’s (1961) definition, “schizophrenic syndrome of childhood”), and 2) within the dominant psychodynamic model, autism was formulated as ego-damage resulting from disturbed mother-child relations (Boucher, 2009). Subsequent studies challenged the association of autism and schizophrenia by demonstrating the disparity between the two conditions (e.g. Kolvin, 1971; Makita, 1966). Another group of studies emphasising the organic origins of autism made a strong argument against the earlier psychogenic formulations (Chess, 1971; Hutt, Hutt, Lee, & Ounsted, 1965; Rutter, Greenfield, & Lockyer, 1967). By the early 1970s, the notions of autism as a psychosis or as a psychogenic condition resulting from inadequate mothering had been generally replaced by an understanding that autism was “a neurodevelopmental disorder” (Rutter, 1999, p. 172). Returning to Kanner’s original view, autism became conceived of by the dominant medico-scientific discourses as a biologically determined developmental disorder characterised by a distinctive set of the abnormalities of behaviour (Boucher, 2009). However, as I will argue in Chapter 3, psychogenic attributions are not completely extinct even now.

As a separate diagnostic category, autism (then defined as “infantile autism”) was first mentioned in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980 (APA, 1980). In the most recent, fourth edition of the DSM with some text revised – DSM-IV-TR (APA, 2000), a group of autism-related conditions comprise the umbrella category of pervasive developmental disorders (PDDs). These include autistic disorder, whose definition most closely resembles Kanner’s original descriptions, Asperger’s disorder (a ‘high-functioning’ form of
autism), and a pervasive developmental disorder not otherwise specified (PDD-NOS) (APA, 2000). The latter category applies when some (but not all) of the diagnostic criteria for autistic disorder are present (Boucher, 2009), and is generally used for milder or atypical autism. Two other disorders included in the PDD category are Rett’s disorder and childhood disintegrative disorder. These are considered to be rare conditions involving developmental regression and some autistic-like behaviours (Boucher, 2009). The fifth edition of the DSM, planned for publication in 2013, may contain revised diagnostic categories and criteria for the conditions currently defined as PDDs. For example, it is proposed that Asperger’s disorder, PDD-NOS, and childhood disintegrative disorder are subsumed under a diagnostic category of autistic disorder (autism spectrum disorder), and that the diagnosis of Rett’s syndrome is removed from the DSM-V completely (APA, 2010).

In this research, my focus is on parents of children diagnosed with the type of autism currently termed autistic disorder. Although I do not consider the status of knowledge reflected in the DSM (or any other diagnostic systems) to be uncontentious, in this study I use some of its current diagnostic terminology as a heuristic ‘shortcut’ to clarify some of the concepts and aid communication.

The DSM-IV-TR diagnostic criteria for autistic disorder are cited in Figure 1 below:
Figure 1. Diagnostic criteria for autistic disorder

<table>
<thead>
<tr>
<th>DSM-IV-TR DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A.</strong> A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):</td>
</tr>
<tr>
<td>(1) qualitative impairment in social interaction, as manifested by at least two of the following:</td>
</tr>
<tr>
<td>(a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction</td>
</tr>
<tr>
<td>(b) failure to develop peer relationships appropriate to developmental level</td>
</tr>
<tr>
<td>(c) a lack of spontaneous seeking to share enjoyment, interests, or achievement with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)</td>
</tr>
<tr>
<td>(d) lack of social or emotional reciprocity</td>
</tr>
<tr>
<td>(2) qualitative impairments in communication as manifested by at least one of the following:</td>
</tr>
<tr>
<td>(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)</td>
</tr>
<tr>
<td>(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others</td>
</tr>
<tr>
<td>(c) stereotyped and repetitive use of language or idiosyncratic language</td>
</tr>
<tr>
<td>(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level</td>
</tr>
<tr>
<td>(3) restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:</td>
</tr>
<tr>
<td>(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus</td>
</tr>
<tr>
<td>(b) apparently inflexible adherence to specific, non-functional routines or rituals</td>
</tr>
<tr>
<td>(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)</td>
</tr>
<tr>
<td>(d) persistent preoccupation with parts of objects</td>
</tr>
<tr>
<td><strong>B.</strong> Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.</td>
</tr>
<tr>
<td><strong>C.</strong> The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder.</td>
</tr>
</tbody>
</table>

(American Psychiatric Association, 2000)
Although lower intellectual functioning is not a pre-requisite for the diagnosis, according to the DSM-IV-TR, in most cases of autistic disorder “there is an associated diagnosis of mental retardation” (APA, 2000, p. 71). The latter is defined by the DSM-IV-TR as an IQ of 70 or below and “deficits in adaptive functioning” – “the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group” (APA, 2000, p. 49). Intelligence in autism is commonly measured by performance on Wechsler-type intelligence scales, which are heavily reliant on competence in understanding and speaking language (Dawson, Soulières, Gernsbacher, & Mottron, 2007). However, a recent study by Dawson et al. (2007) found that when assessed by the Raven’s Progressive Matrices (Raven, Raven, & Court, 1998), a nonverbal test the authors described as “the most complex single test of general intelligence in the literature”), the children with autistic disorder were “not disproportionately impaired” compared to the typically developing control children (p. 661). Dawson et al. (2007) concluded that intelligence in individuals with autism had been underestimated.

**The concept of an autism spectrum and the terminology used in this study**

The concept of an autism spectrum, or, as it was initially termed “continuum”, was introduced in an early study by Wing and Gould (1979). The authors identified groups of children who would now be considered as fitting the criteria for autistic disorder, Asperger’s disorder, and PDD-NOS as defined by the DSM-IV (Boucher, 2009). However, they argued that the distribution of impairments among the groups of children “formed a continuum of severity rather than discrete entities” (Wing & Gould, 1979, p. 26, emphasis added). Wing and Gould (1979), therefore introduced the idea of autism as a multi-dimensional condition (with each dimension corresponding to a facet of behaviour, such as social interaction and communication skills, capacity for imagination, or language ability), where each individual had a unique dimensional profile of impairments and strengths (Boucher, 2009). In later publications, Wing used the term “autistic spectrum disorders” (ASDs) (e.g. Wing, 1996, 2002), which, as Boucher (2009) points out, “captures the lack of clear boundaries between different forms of autism” (p. 29). The literature on autism has over the years used a variety of terms such as “early infantile autism”, a term introduced by Kanner (1949), “early childhood autism”, and the diagnostic terminology from the DSM-IV, such as “autistic
disorder”, “Asperger’s disorder”, and PDD-NOS. The term “autism” is regularly used as a ‘shorthand’ generic term, indexing either all of the autism related conditions or only “autistic disorder”. The term “autism spectrum disorder” (ASD), is becoming widely used and has been proposed to be included in the new edition of the DSM (DSM-V), as a name for a more inclusive category subsuming the conditions that are currently categorised separately (autistic disorder, Asperger’s disorder, PDD-NOS, and childhood disintegrative disorder) (APA, 2010). Some researchers currently prefer the term “autism spectrum condition” as being less stigmatising and signifying not only impairments, but strengths as well (Baron-Cohen et al., 2009). The New Zealand Autism Spectrum Disorder Guideline (Ministries of Health and Education, 2008), define ASD as a term that “recognises that there are overlaps between the currently defined sub-groups within the spectrum of autism” and includes classical autism (in DSM-IV – autistic disorder), Asperger’s disorder, and PDD-NOS (p. 30). In this study, I interviewed parents whose children were diagnosed with autistic disorder. As the majority of the parents described their children as “having autism” (or being “autistic”), I use the same term as a ‘shorthand’ in my analyses. When discussing literature, I also use “autism” as a generic term following the example of many texts and review articles on autism, apart from those instances where using the exact terminology of the original is essential. When referring to the autism “spectrum”, I will use the term “autism-spectrum conditions”, apart from the instances when it is relevant to retain the terminology of the literature being reviewed.

The numbers: The increase in the prevalence of autism

More and more parents have to deal with the effects of an autism diagnosis, as studies have consistently reported a rise in prevalence rates for autism-spectrum conditions over the past decades (Baron-Cohen, et al., 2009; Rutter, 2005b). Compared to the first survey in 1966 reporting the prevalence of autism in children in Middlesex County in the United Kingdom (U.K.), as 4.5 per 10,000 (Lotter, 1966), today the prevalence of autism and autism-spectrum conditions is estimated as being much higher. Fombonne’s (2003) review reported a prevalence of 30-60 per 10,000 for “all forms of PDDs”, with more recent estimates in the U.K. being 116.1 per 10,000 for ASD, and 38.9 for
“autism” (Baird et al., 2006)\(^1\). In 2009, a U.K. school population study of autism-spectrum conditions argued that the ratio of known to unknown cases was approximately 3:2 (based on statistically weighted procedures), and therefore came up with an estimate of 157 per 10,000 (including previously undiagnosed cases) (Baron-Cohen, et al., 2009). The increase in prevalence is generally attributed to factors such as “improved recognition and detection, changes in study methodology, an increase in available diagnostic services, increased awareness among professionals and parents, growing acceptance that autism can coexist with a range of other conditions, and a widening of the diagnostic criteria” (Baron-Cohen, et al., 2009, p. 500). However, Rutter (2005b) suggested that a true rise over time due to some (as yet to be identified), environmental risk factors cannot be ruled out, and recommended an integration of epidemiology with basic science laboratory studies to test environmental risk hypotheses.

**Current opinions on the prognosis and treatment modalities for autism**

In this section I provide a brief overview of the published research regarding the prognosis (long-term outcomes) for individuals diagnosed with autism, and treatment options currently considered efficacious for this condition. Although as I show below, the information of the long-term outcomes for autism is still limited (Howlin, Goode, Hutton, & Rutter, 2004), and the prognosis according to the available literature is not generally optimistic, over the years there have been improvements in the levels of functioning and quality of life achieved by people with autism (Howlin, 1997). People with autism are now leading more independent lives, more of them have jobs, and far fewer spend their lives in institutional care – which is an encouraging message for the parents dealing with the diagnosis of autism. Another encouraging message for the parents, based on the available literature on autism treatments, is that there is currently a wide variety of treatments and interventions that can help their child’s development, and can have “a major impact on the quality of life in adulthood” (Howlin, 1997, p. 69).

**Long-term prognosis.** Early research showed that few individuals diagnosed with autism in the 1970s or earlier lived outside their childhood homes or institutional settings (Farley et al., 2009). In Howlin et al.’s (2004) follow-up study of 68 adults,

\(^{1}\) Baird et al.’s (2006) study used the International Classification of Diseases (ICD-10) criteria for “childhood autism” (WHO, 1993), which are essentially the same as the DSM-IV-TR criteria for the autistic disorder.
(who at the time of diagnosis were between 3 and 15 years old and had a performance IQ of 50 or above), only 22% were described to have a “Very good” or “Good” outcome on a rating scale for social functioning and independence used by the authors. The “Very good” outcome was described as “achieving a high level of independence, and having some friends and a job”, and a “Good” outcome stood for “generally in work, but requiring some degree of support in daily living; some friends or acquaintances” (Howlin, et al., 2004, p. 229). The majority (46%), were rated as having a “Poor” outcome, which meant that they required special residential provision, a high level of support, and had no friends outside residence (Howlin, et al., 2004). The authors found that although a higher childhood performance IQ was predictable of a better outcome, within the ‘normal’ IQ range the outcome was very variable. A recent 20 year outcome study of 41 individuals with autism with “average and near average cognitive abilities” (Farley, et al., 2009) found better outcomes. Using the rating scale described above, they reported half of their participants to be within “Very good” and “Good” range of overall functioning. Better overall social functioning was associated with gain in cognitive ability and better “adaptive functioning” (daily living skills, ability to care for oneself).

**Psychosocial and educational interventions.** A large number of focused intervention practices and comprehensive treatment models (CTMs) are currently being used with children with autism. At this stage, the “best prospects” (“evidence-based practices”) for autism treatment are considered to be behavioural, developmental\(^2\), or an integration of both modalities (Boyd, Odom, Humphreys, & Sam, 2010, p. 75). Focused intervention practices are specific teaching procedures used to promote learning and development or reduce problem behaviours (Boyd, et al., 2010). CTMs target multiple developmental or core behavioural characteristics of autism, and are normally implemented over an extended period of time (Boyd, et al., 2010). Recent reviews describe many focused interventions and CTMs that in the authors’ opinion show evidence of being beneficial for children, infants, and toddlers with autism (Boyd, et al., 2010; Odom, Boyd, Hall, & Hume, 2010a; Odom, Collet-Klingenberg, Rogers, & Hatton, 2010b). The most commonly studied treatment for autism (both in terms of

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\(^2\) Developmental approaches are child-directed. The child’s environment is organised to prompt communication, the child initiates interaction and the “teacher” follows the child’s lead “by being responsive to the child’s communicative intentions and imitating or expanding the child’s behavior” (NRC, 2001, p. 54).
CTMs and specific focused interventions), has been Applied Behaviour Analysis (ABA) (Volkmar, Lord, Bailey, Schultz, & Klin, 2004), however literature reports a “practical consensus” and a “formal consensus” from the National Academy of Science in the U.S (NRC, 2001) that “no single approach is the best for all individuals or even across time for the same individual with ASD” (Volkmar, et al., 2004, p. 150). The available research is optimistic about the progress that many of the children with autism may achieve with early intensive behavioural intervention (EIBI) (Dawson et al., 2010; National Research Council, 2001)³, however studies of long-term outcomes for children participating in EIBI programs are yet to come.

**Pharmacological treatments.** Children, adolescents, and adults with autism are frequently treated pharmacologically. Medications are not claimed to be curative, but it is suggested that they may be “of great benefit to children with autism and their families” (Volkmar, et al., 2004, p. 152) either directly – reducing aggression, irritability, inattention, mood/anxiety problems, and stereotyped and self-injurious behaviours), or indirectly – by reducing symptoms that impede educational and behavioural interventions (Leskovec, Rowles, & Findling, 2008; Volkmar, et al., 2004). Although described in some publications as “efficacious” (Lilienfeld, 2005), and used by approximately one third of people with autism (Leskovec, et al., 2008), pharmacological treatments used in autism, such as antipsychotics, stimulants, and antidepressant medication, have significant side effects (Leskovec, et al., 2008), and their efficacy is often questionable (e.g. Williams, Wheeler, Silove, & Hazell, 2010).

**On the “complementary and alternative medicine” and “scientifically questionable treatments”**. Complementary and alternative medicine (CAM) has been defined by the U.S. National Center for Complimentary and Alternative Medicine – NCCAM (National Institutes of Health) as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine” (NCCAM, 2000, as cited in Myers & Johnson, 2007). The Cochrane Collaboration defines CAM as “a broad domain of healing resources that encompasses all health systems, modalities, practices, and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health systems of a particular society or culture in a given historical period” (cited in Zollman & Vickers, 1999).

³ See Chapter 3 for further discussion of early intensive behavioural interventions.
Lilienfeld (2005) described the same group of interventions, practices, and resources as “scientifically questionable treatments”, referring to their ‘non-preferred’ status within the dominant scientific discourse. Autism-related CAMs have been recently reviewed (Gupta, 2004a; Levy & Hyman, 2005), and include interventions such as nutritional supplements, special diets, avoidance of allergenic foods, treatment of intestinal bacterial/yeast overgrowth, and detoxification of heavy metals amongst many others. These treatments – generally termed ‘biomedical’, are used by many families in the current study, as well as in other studies that report on the uses of CAM (Harrington, Rosen, Garnecho, & Patrick, 2006). As the use of CAM in the U.S. is increasing, the committee on Children with Disabilities of the American Academy of Pediatrics (2001) suggested that it was important to provide the families with a balanced advice, establish and maintain a trusting and collaborative relationship with families, guard against bias, and “avoid dismissal of CAM in ways that communicate a lack of sensitivity or concern for the families’ perspective” (p. 600).

In the sections above, I have provided some introductory information on autism, addressing its history as a clinical entity, and the available research concerning its prevalence, treatment options, and the long-term outcomes for the individuals with this diagnosis. In the section that follows, I briefly review the history of how parents of children with autism have been depicted in medico-scientific narratives of the day since the first description of autism as a separate “condition” (Kanner, 1943). I then discuss the place of current research vis-à-vis the existing literature focussing on parents of children with autism and the impact of the child’s autism on the parents. I conclude this chapter by outlining my research aims, approach, proposed contributions of this work in more detail, and provide an overview of the thesis structure.

**Focus on parents: Parents of children with autism under medico-scientific gaze**

From the very first description of autism by Kanner (1943), parents of children with autism have become the focus of medico-scientific attention. Although Kanner concluded that the “disturbances of affective contact” were “inborn”, in the same paper he voiced that there were “very few really warmhearted fathers and mothers”, and questioned to what extent such coldness, as well as preoccupation with abstractions and “limited genuine interest in people” could have “contributed to the condition of the
children” (p. 250). Psychoanalytic perspective (dominant at the time), conceptualised child psychopathology as an early disruption of ego development. The child’s mother was seen as an all-important figure that “either enabled or impinged against” the infant’s struggle for the development of its ego and ‘normal’ relations with external environment (“object relations”) (Nadesan, 2005, p. 82). Therefore, “maternal failure due to absence, negligence, or ignorance, theoretically engendered psychoses at worst and neuroses at best” (Nadesan, 2005, pp. 82-83). Rutter (1999) noted that while being a remarkable clinician, Kanner was inevitably influenced “by the zeitgeist within which he had to operate”, and that by late 1940s Kanner’s vision had become “eroded” (Rutter, 1999, p. 170). In his 1949 article, Kanner depicted the mothers and the fathers of his “patients” as cold, perfectionistic, and obsessive – lacking “warmth that the babies needed”, and themselves “reared sternly in emotional refrigerators” (p. 423). By the mid-1950s, Eisenberg and Kanner concluded that although the existence of some biological predisposing factor cannot be excluded, “the emotional frigidity in the typical autistic family suggests a dynamic existential factor in the genesis of the disorder of the child” (1956). Other writers in the 1950s and 1960s (Despert, 1951; Kaufman, Rosenblum, Heims, & Willer, 1957; Meyers & Goldfarb, 1961) took Kanner’s argument further making claims about the solely psychogenic causation of autism (Rutter, 1985). In 1985, commenting on the early etiological attributions of autism, DeMyer described the idea that “defective nurture from parents” was either the main or the sole cause of autism as “most dearly held” in the two decades since Kanner’s original description of the condition (p. 209).

One of the widely popularised (and at the time highly acclaimed), accounts of the causative relationship between poor mothering and autism, using a blend of psychoanalysis and ethology, can be found in the book by Bruno Bettelheim “The empty fortress: Infantile autism and the birth of the self” published in 1967 (Nadesan, 2005; Silverman, 2008). Beginning the book with a description of autistic withdrawal due to a failure in ego differentiation (Nadesan, 2005), Bettelheim’s theorising develops into overt mother-blaming. He claims (for example), that “the precipitating factor in infantile autism is the parent’s wish that his child should not exist” (p. 272). The

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4 Although Kanner initially “succumbed” to the prevailing psychodynamic explanations (Boucher, 2009, p. 144), he later retracted his claims of parental causation (Mesibov, Adams, & Schopler, 2000). In an address at the National Autism Society Meeting, Kanner declared: “Herewith I especially acquit you people as parents. I have been misquoted many times. From the very first publication to the last, I spoke of this condition in no uncertain terms as innate” (Kanner, 1969, as cited in Mesibov, et al., 2000, p. 642).
prevailing psychodynamic ideas of the day were reflected in the approaches to
treatment. The treatment of choice for the children was play therapy “designed for
ventilation of the extreme stress assumed to be generated by the family” (Schopler &
Mesibov, 1984, p. 9). Changing parents’ (presumably dysfunctional) personalities so
that the child could overcome his or her autism was a common goal of ‘treatment’
(Schopler & Mesibov, 1984). Parents were often “required to submit themselves to
intensive psychotherapy with the threat that their child will be excluded from any help
unless they do so” (Schopler, 1985, p. 237). In Bettelheim’s widespread and influential
view (1967), “the only potential for the child’s improvement was to remove him from
his family in a “parentectomy” (Schopler & Mesibov, 1984, p. 9). Parents were given
the message that “society had no obligation for the special education of their child, and
the only way for them to partially discharge their guilt and responsibility was to
undertake exorbitantly expensive private therapy with no guarantees of outcome of
success” (Schopler, 1985, p. 237). In 1964, having reviewed the available outcome
studies, Rimland concluded that there was no evidence of efficacy of psychotherapy for
autism, stating that “writers who cite improvement in individual case studies as
evidence that autism was psychogenically induced are taking an untenable position”
(Rimland, 1985, p. 91). Bettelheim (1967) however, claimed high success rates. His
study reporting that 79% of the 40 children that he treated achieved either “Fair” or
“Good” outcomes in terms of social and academic functioning, was described by some
researchers of the day as “contrasting strikingly” with other available data, and the
accuracy of his claims was questioned (Treffert, McAndrew, & Dreifuerst, 1973).

In 1961, Ferster, working within behaviourist paradigm, came up with another
psychogenic theory of autism – theorising autism as a disorder of behaviour caused by
ineffective reinforcement by the parents (throughout the paper, Ferster uses the terms
“parents”, however his examples of poor parental performance mainly include the
“autistic mother”) (Ferster, 1985). Ferster suggested that “the conditions influencing
parents’ behaviour” include depression, various kinds of “somatic disturbances” (drug
addiction, hangover, diseases etc.), and the “prepotency” of other interests or activities
(house-cleaning, social activities and clubs, and “active telephoning”) over the child.
As a result, in Ferster’s view, “the autistic mother” might find her child unrewarding,
with the child acquiring the properties of a “conditioned aversive stimulus” (Ferster,
1985, p. 61). As behaviourism was not the dominant conceptual framework at the time,
the familiarity with Ferster’s theory outside research circles was limited (Schreibman, 2005b). However, many of his ideas paved the way for the design and implementation of effective behavioural interventions by clinicians who rejected the view of psychogenic etiology of autism and endorsed collaboration with parents in treating the child (Schreibman, 2005b).

Although the 1970s saw the general marginalisation of the psychoanalytic paradigm, and the accumulation of research contributing to understandings of autism as a biologically based, genetically determined developmental disorder (Nadesan, 2005; Rutter, 1999), parents’ personalities, and ‘deviant’ patterns of interaction in the family were still often the subject of the medico-scientific gaze. A number of factors have been postulated as figuring in the ‘pathology’ of autism, including “too much stimulation, too little stimulation, inadequate structuring of the environment, lack of family roles and identities, and lack of shared family pleasure” (Cantwell, Baker, & Rutter, 1979, p. 682). Psychoanalysis-informed papers continued to come up with causative explanations of autism such as “noxious or inadequate environment (mothering)” (Fraknoi & Ruttenberg, 1971, p. 727). Only by the end of the 1970s, following a number of studies involving the administration of personality inventories and observations of family interaction patterns (e.g. Cantwell, et al., 1979), it was generally concluded that parents of children with autism were “essentially similar” to parents of children with other (organic) brain disorders and “manifested no psychopathology which conceivably could induce the disorder” (DeMyer, 1979, p. 388).

With the biogenetic explanations gaining authority, research on parents of children with autism had changed direction. On one hand, parents continued to be the focus of medico-scientific inquiry into the causes of autism – this time in terms of genetic and other biological contributions including exposure to environmental toxicity, maternal infections, medication, smoking, alcohol consumption, and drug use during pregnancy. Due to the large volume of data, this body of literature is reviewed in detail in Chapter 3 of this thesis. On the other hand, the focus of family research in the area of autism has shifted towards studying the impact of having a child with autism on the family (Avdi, et al., 2000b). This impact has been conceptualised as high levels of stress and experiences of stigma associated with having a child with a disability. Many of the studies have been conducted within stress-reaction or stress-coping paradigms (Avdi, et
Parents of children with autism have been described in recent literature as having higher levels of stress compared with parents of typically developing children and children with other disabilities such as Down or Fragile X syndromes (Abbeduto et al., 2004; Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Montes & Halterman, 2007). The research on coping has been generally guided by the model put forward by Lazarus and Folkman (1984), which formulates coping as a dynamic process that involves “a parent’s appraisal of the event (stressor), individual factors (e.g. personality), personal and family resources (e.g. income), contextual and situational factors (e.g. other stressors), and cognitive or behavioural responses (coping)” (Pottie & Ingram, 2008, p. 855). This type of research has enhanced the understandings of parents’ strengths and resources (Montes & Halterman, 2007). It also highlighted the problems they are facing in the day-to-day life and their unmet needs, and therefore contributed to the improvement of service provisions (e.g. Bromley, Hare, Davison, & Emerson, 2004). However, focusing the inquiry on the individual parent’s ‘coping’ with stress and stigmatisation and making judgments about its effectiveness (while disregarding the broader socio-cultural context within which such ‘coping’ takes place), can come across as indirectly blaming the parents (yet again) for their own distress, and in some cases – their less than ‘optimal’ parenting. For example, Hastings et al.’s (2005) study linked parents’ increased stress and poor mental health with “maladaptive coping strategies” (“active avoidance coping”), and recommended an intervention “with parents” to focus on “enhancing their positive perceptions of raising a child with autism” (p. 388).

Another study, exploring maternal cognitions (and associated feelings) about parenting a child with autism, asked mothers whether they felt guilty because they believed they were not doing enough for their children. Mothers were then asked whether guilt interfered with their parenting. As many mothers endorsed both questions, the authors recommended that service providers “collaboratively discuss with parents how feelings and thoughts may interfere with optimal parenting” (Kuhn & Carter, 2006, p. 571,
emphasis added). The potential pathologising effects on the parents of such research and its practical recommendations are significant. Firstly, those parents who do not adopt a stoic and optimistic stance in relation to their child’s condition in the culture where disability and differentness are stigmatised and supports are scarce stand accused of being inadequate parents, culpably lacking in positivity and engaging in thoughts and feelings that are detrimental to the child. Secondly, in the case of Kuhn and Carter’s (2006) study, the way in which the questions to the participants and the recommendations are formulated reflect the dominant societal discourse of parental responsibility for the childbearing and child rearing with their implicit assumptions about the culpability of the parents who ‘produce’ less-than-perfect children, or parent in a less-than-‘optimal’ way. These issues will be discussed in detail in Chapter 5 of this thesis. Apart from the relatively large body of literature described above that has focused on the stress and coping of parents of children with autism, a limited number of studies have also addressed some more specific topics such as parental “perceptions” of (and coping with) stigma, and their experiences of the diagnostic process. These studies are reviewed in Chapters 5 and 6 of this thesis which address these two topics respectively.

Over recent years, some studies using qualitative research methods, have begun focusing on the parents’ perspectives, exploring their narratives, and the ways parents give meaning to their experiences (Avdi, Griffin, & Brough, 2000a; Avdi, et al., 2000b; Fleischmann, 2005; Gray, 2001; Rocque, 2010). Abandoning the linear associations of parental stress with their adaptation to the child’s condition mediated by ‘coping’ (Avdi, et al., 2000b), this type of autism research explores the social, political, and cultural context in which parents’ meaning-making occurs, and the ways their narratives are influenced by such context. The goal of this study is to contribute to this growing body of research.

In New Zealand, research on parents of children with autism is currently limited to one study – a qualitative exploration of Māori perspectives of autism (Bevan-Brown, 2004), described in a report commissioned by the Ministry of Education. Based on interviews with parents and whānau (extended family) of 19 Māori children with autism, this research focused on families’ stories of raising their children, on the practices they found helpful or unhelpful, and suggestions for the improvement of service provisions.
Apart from this study, the current research is the only one based in New Zealand that addresses the impact of having a child with autism on the parents.

**My research aims and approach**

In setting the research aims for this project, I was guided by the complex history of autism as a clinical entity, and particularly the roles or positions that have been ‘assigned’ to parents by the medico-scientific knowledges of the day over time. I refer to the early portrayals of parents as primary causal agents in autism, and their more recent positioning as individuals ‘coping’ (‘adaptively’ or ‘maladaptively’) with the stressors and strains caused by their child’s condition, as if unaffected by various influences exerted by their material and socio-cultural environment (as discussed above). I sought to address the limitations imposed by the individualistic focus of the studies investigating the impact of autism on the family within the stress-coping framework, with their tendencies to underestimate or ignore the wider socio-cultural context in which parental experiences and meaning-making about autism are embedded. Unlike traditional psychological research using positivist methods of enquiry, this research does not endeavour to generate new facts about autism and parental coping. Rather, its aims are to open up “new ways of making sense of the ‘ordinary but troubling’ (Gavey & McPhillips, 1999, p. 354)”, to “interrogate that in our contemporary experience which we take for granted” (Rose, 1996, p. 106), and to generate new possibilities in thinking about parents of children with autism, their identities, and impact the child’s diagnosis has on the family. This research asks questions about parental identities, practices, and experiences that differ from those traditionally asked by psychology or psychiatry. Rather than separating the individual (psychological) and the social, my focus is on making explicit the constitutive relations between individual subjectivity and socio-cultural processes and offering “an explanation of where our experience comes from” (Weedon, 1997, p. 40), by showing how “the social is taken up and made personal” (Burns, 2004, p. 3).

In this project I focus on language, which is understood as constructive of social reality. I analyse the interview accounts of parents of children with autism, and review the body of the current professional and research literature, representing the ‘expert’ knowledges about the causes of autism. This study was not set up as an attempt to provide a comprehensive investigation of all aspects of the impact of having a child with autism.
as constructed by the parents. Instead, this thesis is comprised of a group of analyses (whose topics were determined based on a combination of factors including the history of autism and the early attributions of its causes), my particular points of interest, and prominent themes and patterns of meaning that arose from the data. One of the specific foci of this research is an exploration of current parental understandings of the causes of their child’s condition as mediated by the contemporary (and historic) knowledges of autism etiology. Another focus is an examination of the nature of the often taken-for-granted issue of stigma in autism. Here I endeavour to investigate whether the change in the attributions of the causes of autism, and the predominance of biogenetic explanations have been associated with the change in stigma attributions in parental accounts. My final concern is to give voice to parents and to validate their subjective experiences of the process of the diagnosis, the “framing event”⁵ which transforms the child’s differentness and his or her unusual behaviours into a medical condition or a disorder, a clinical entity laden with emotional connotations and culturally embedded meanings. Broadly defined, the overarching goals of this work are to make the “invisible” (non-dominant) parental discourse more visible, to “de-inevitably”⁶ some taken-for-granted accounts present in the mainstream bodies of knowledge about autism, and to highlight the link between the talk or text, and the socio-cultural landscape within which it is produced. To achieve these goals, I use two epistemologically different approaches to interview accounts, namely social constructionist and critical realist frameworks.

Social constructionism is an epistemological framework that takes an anti-essentialist stance towards ‘reality’ and a critical stance towards taken-for-granted knowledge, emphasising that all knowledge (and ‘truth’), is socially produced, negotiated, and culturally specific (Burr, 1995). Claims about knowledge and truth are “brought into being by historically and culturally located groups of people” (Gergen & Gergen, 2003a, p. 2). Knowledge is also not considered to be neutral, but “represents the constructions of particular, value invested groups”, and is therefore associated with power (Gergen & Gergen, 2003b, p. 36). Education, research, and science are seen as representing “the subtle expansion of power” (Gergen & Gergen, 2003b, p. 36).

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⁵ (Avdi, et al., 2000b)
⁶ (Hacking, 1997, p. 2)
Language is understood to be constructive of meaning and of social realities, and our use of language is therefore regarded as a form of action.

As in social constructionism, in critical realism, language is understood as constructing our social realities, however, these constructions are viewed as “being constrained by the possibilities and limitations inherent in the material world” (Sims-Schouten, Riley, & Willig, 2007, p. 102). Critical realism therefore affirms that there is a material dimension to our lives that is (at least in part), independent of our understandings of it (Sims-Schouten, et al., 2007). It recognises however, that the representations of the material are mediated by culture, language, and politics (Ussher, 2000), and makes no claims about the truthfulness (or otherwise) of what is accepted as real. Although combining a constructionist lens with a more realist (albeit critical) perspective within one project appears to be a conflict of paradigms, I would argue, in line with Burns (2004), for the benefits of multiperspectival approaches in “illuminating different aspects of the topic under examination” (Burns, 2004, p. 207).

**Thesis overview**

In the next chapter (Chapter 2: Methodological issues), I describe the more practical methodological procedures utilised in this thesis, providing information about the participants, the recruitment procedures, and the process of collection and analysis of the interview material.

In Chapter 3: Medico-scientific knowledges of the causes of autism: Three levels of explanations, my goal is to foreground the first empirical chapter that follows by discussing the current ‘expert’ knowledges of the causes of autism. Due to the large volume of data, this review constitutes a separate chapter. I approach the data (mostly research and professional literature on the causes of autism), with a critical realist lens examining the state of knowledge of science and medicine that shape our understanding of the phenomenon of autism, while accepting the ‘reality’ of the research findings discussed in the review.

In the first and second of my empirical chapters (Chapter 4: Accounting for the causes of autism and Chapter 5: The differences that matter in people’s lives: Parents of children with autism negotiating stigma), I approach the interview data from a social constructionist perspective and use discourse analysis to explore parental talk. In
Chapter 4: *Accounting for the causes of autism*, I analyse parents’ portrayals of the causes of autism, problematising some researchers’ suggestions that the dominant biogenetic explanations of autism can be preferred by the parents as being less blaming. I explore current causative attributions of autism in terms of the discourse of parental responsibility, and discuss the ways parents negotiate this responsibility and blame to manage their identities.

I begin my second empirical chapter (Chapter 5: *The differences that matter in people’s lives: Parents of children with autism negotiating stigma*), with a brief overview of theoretical and empirical research on stigma, and introduce my own formulation of stigma for the purposes of this research. I proceed to discuss the portrayals of the diagnosis of autism in parental accounts, and the subject positions made available to parents by the societal discourses of disability, childbearing, child rearing, and parental responsibility. I conclude with the discussion of a number of strategies parents use to negotiate their subject positions and reduce stigma.

In my third empirical chapter (Chapter 6: “It’s autism, off you go”: Parents’ experiences of the diagnostic process), I move away from constructionism, using a critical realist approach to give voice to parents and validate their experiences of the diagnostic process. In this chapter, I begin by presenting a mini-case study of one mother’s positive (versus negative) account of a diagnostic process. This mini-case study serves as an introduction to the second part of this chapter, where I organise into themes and discuss parents’ reports of negative experiences and areas in need of improvement. The meaning of such experiences in relation to parental identities and practices are also discussed.

In my final chapter (Chapter 7: *Conclusions and recommendations*), I summarise my findings across the thesis and discuss the contribution of this research as a whole to existing understandings of the impact of autism on the family. I also reflect on the usefulness of the approaches employed in this study for research with families of children with autism and provide recommendations for practice.
Chapter 2: Methodological Issues and Analytic Approaches

Introduction

Having briefly introduced my epistemological frameworks (social constructionism and critical realism) in Chapter 1, this chapter will focus on practical methodological issues and procedures used in this thesis, such as the research participants, the recruitment procedures, and the process of collecting and analysing of the interview material. Although each of the empirical chapters in this thesis contain a brief outline of my conceptual and analytical approach to the data, in this chapter I provide a review of the methods and methodology of the study as a whole.

Participants and recruitment

This section describes the demographic characteristics of the participants and the process of their recruitment. For privacy reasons, specific details of each participant such as age, occupation, or the number of children in the family (including those with autism), that can identify this person to others (e.g. friends and relatives, professionals involved in the child’s care and education, members of the same support group, or spouses and partners) are not included. Instead, I provide general demographic information about the parents as a group. The participants were 26 adults, parents of children diagnosed with Autistic Disorder (APA, 2000), 14 women and 12 men, living in the wider Auckland, New Zealand area. Apart from one stepfather, the participants were the children’s biological parents. Ages ranged from 32-54 with a mean age of 40.7 years. Seventeen participants reported their highest educational qualification as a university degree (Bachelor, Honours, or Masters level). Eight participants described their highest educational level as “sixth form certificate”, “school certificate”, “university entrance”, “2 years at university”, “university papers”, and “nil”. One participant did not indicate their highest educational qualification. Participants’ ethnic identities, as identified by them, can be grouped into three broad categories: “Pakeha/European New Zealanders”, “Migrants from European countries”, and “Migrants from Australia”. Twenty-three participants were married, 2 described their relationship situation as “de facto”, and 1 was separated. The majority of the fathers (8) worked in professional occupations (e.g. teacher, engineer, accountant, consultant), 2
worked in trade occupations, and 2 were self-employed. One of the fathers worked from home, combining his job with full-time childcare responsibilities. Five of the mothers worked part-time in professional and clerical occupations (e.g. health practitioner, office worker), 1 combined childcare responsibilities with working in the family business, and 8 were not working outside the home and described their occupations as “mother” (3), “full-time mother” (2), “housewife” (1), “housewife/mother” (1), or “[name of the profession], currently “mother” (1).

Of the 14 families, 13 only had one child diagnosed with autism, and one family had 2 children “on the spectrum”, with the second child diagnosed with Asperger’s disorder. The majority of parents did not use categorical terms (e.g. “mild”, “moderate” or “severe”) to describe their child’s autism. Rather, they constructed the severity of the child’s problems in terms of his or her position on the autism spectrum (“somewhere between mild and moderate”, “towards the mild end”, “more on the severe side”). This position at the time of the interview typically differed from the one at the time of the diagnosis, shifting away from the severe end towards the milder end of the spectrum, and reflected parents’ understandings of the child’s level of progress. Only one family consistently described their child’s problems as “severe” or “fairly severe”, both at the time of the diagnosis several years previously and at the time of the interview. All participants reported using at least one form of intervention for their child. Ten families were using more than one intervention, and one family of a recently diagnosed child were planning to use more than one intervention. Nine families used ABA interventions, either employing an ABA therapist (eight families) or working with the child themselves (one family). Nine families used biomedical intervention including diet, six families used RDI7, two families used speech-language therapy, two families used visual support8, one family used PECS9, and one family used music therapy. Although all the families were (at some stage) receiving services from The New Zealand Ministry of Education (Special Education), only one participant listed these services in the section “Treatment programs used for the child” on the “Background Questions” sheet given to the participants. Twelve families had other children, who were not diagnosed with autism.

7 Relationship development intervention (Gutstein, Burgess, & Montfort, 2007).
8 Visual support – “tools that enable a learner to independently track events and activities” (Odom, et al., 2010b, p. 279).
9 Picture Exchange Communication System – “a system for communicating that uses the physical handing over of pictures or symbols to initiate communicative functions” (Odom, et al., 2010b, p. 278).
The parents were recruited to the project in several ways: through an advertisement (see Appendix A) in Autism New Zealand\textsuperscript{10} (Auckland branch), newsletter (five), a postal mail-out by Centre for Autism and Related Disorders (CARD, a private ABA-based treatment provider) to the parents on their database (five), through a mail-out (via e-mail) by Children’s Autism Foundation, an Auckland parents’ support group, to their members (four), and through the author’s friendship networks (one). Apart from one family where both parents volunteered at the same time, all participants who contacted me initially were women. On my suggestion, they passed the invitation to participate to their husbands or partners, most of whom agreed to be interviewed (11). Some mothers contacted me after they had received advertisements from more than one source (e.g. Autism New Zealand and Children’s Autism Foundation, or Autism New Zealand and CARD). One woman who contacted me was unable to participate due to time constraints, and three women had children diagnosed with Asperger’s disorder, which was beyond the scope of this study. Information sheets (see Appendix B), were posted or e-mailed to the participants who responded to the advertisements, and to the one participant who had heard about the research by word of mouth through my friendship networks. The majority of the participants however, had already received the information sheets, as they were included with the initial mail-out by CARD and Children’s Autism Foundation.

\textbf{Procedure}

University of Auckland Human Participants Ethics Committee granted ethics approval to carry out this research in July 2006, Reference 2006/247. Semi-structured in-depth interviews were conducted individually with the participants. The majority of the interviews took place at the participant’s home (24), one interview was conducted at the University of Auckland, and one at the participant’s place of work after hours. The interviews were audio-taped in their entirety, although some un-taped conversation took place prior to each interview to establish rapport and to give participants the opportunity to ask questions, and, in some instances after the interview, when the participants spontaneously shared thoughts and feelings about the research after the tape-recorder had been turned off. Before the interview, participants were given a consent form (see Appendix C) to read and sign. Their questions if any, were answered and they were

\textsuperscript{10} Autism New Zealand is a non-profit organisation providing access to resources, support, training and information.
reminded that they could refrain from answering any questions during the interview, ask to turn the tape-recorder off, or discontinue the interview without having to give a reason. They were reminded that I would contact them in the week following the interview, to see if they would like the opportunity to talk about any issues or feelings that may have arisen in the interview, or to add further thoughts or comment on the interview.

The interviews lasted between 60-120 minutes. Mothers and fathers were interviewed separately, however on three occasions when the other parent walked into the room during the interview and spontaneously joined in the discussion for approximately 10-15 minutes, I was guided by the main interviewee’s reaction to this, and as they seemed to encourage the other’s participation the interview was continued with both parents temporarily present. The interviews included discussion about the participants’ ideas about autism, its causes, the treatment options, the support systems available, and the prognosis for the future. The participants’ experiences of parenting a child with autism, their contacts with professionals, choice of treatment, views on schooling (mainstream versus special), and stigma associated with autism were discussed. Topics such as the general public and “expert” views on autism, myths, and misunderstandings about autism, and the extended family reactions to the diagnosis were also explored (see Appendix D for the list of indicative areas of questioning). The main areas of interest were covered in each interview, and discussion was directed towards particular topic areas, which stayed the same for each interview (Gavey & McPhillips, 1999; Marshall & Wetherell, 1989). The questions however, were not considered to be prescriptive, but rather to guide conversation (Burns, 2004), and unexpected “leads” offered by participants were followed up. An informal conversational style was used in the interviews, and participants were encouraged to talk about the issues they were not asked about – but considered important. Occasionally, cross-connections developed whereby a topic introduced by a parent was used in subsequent interviews with others (Franklin, 1997). It was not assumed that the participants would come up with a single ‘correct’ answer to a question, and variability and contradictions in participants’ accounts were expected and considered as important and valuable feature of their talk (Wood & Kroeger, 2000). Rather than neutral tools of data collection, the interviews were viewed as active interactions between the participants and the researcher, yielding negotiated, contextually embedded results (Fontana & Frey, 2000). Therefore,
following the interview technique described by Gavey and McPhillips (1999), I sometimes shared my observations and reflections with the participant in the process of the interview seeking the participant’s response to these observations. Overall, I found this technique productive in encouraging interview participants to reflect in more depth on their experiences, either agreeing or disagreeing with the offered basic analytic reflections. It also (on occasions) stimulated participants’ interest in discussing topics that had earlier in the interview elicited less enthusiastic or indifferent response.

The interviews were transcribed verbatim in their entirety, 14 by the researcher and 12 by a transcriber who was employed for this purpose. All 12 transcripts were later checked by the researcher for accuracy. All the utterances made by the participants and the researcher during interviews were included, apart from one time when a participant was upset and asked to turn the tape-recorder off. As the analysis focused on the discourses and themes in participants’ talk rather than the minutiae of conversation, certain characteristics of participants’ speech, intonation, and the length of every pause (see Potter & Wetherell, 1987) were not included (although long meaningful pauses were noted in the transcript). The emphasis given to words or phrases, the expression of emotions (e.g. “tearful”, “laughing”), were also noted in the transcript, as was the intentional lowering or raising of the voice, changing of the tone of voice, or changing the rate of speech (see Appendix F for transcription conventions). Segments of transcripts that were unclear were omitted from analysis to enhance “readability”. To ensure anonymity, all the participants and their children were assigned pseudonyms. The names of other people mentioned by the participants were omitted to protect anonymity, and were indexed by their relationship (personal or professional) with the participant (e.g. “relative”, “husband”, or “Dr X, developmental paediatrician”).

**Generalisability**

Given the epistemological framework used in this study, it was not my goal to generate more facts or discover ‘the truth’ about the impact of autism on the family, but to enhance understanding of the phenomena and open up new ways of thinking about it. Similarly, I do not suggest that the experiences of 26 mothers and fathers described here were in any way representative of all parents of children with autism, as my epistemological framework renders generalisability problematic. I do however suggest that most of these parents’ experiences are not unusual, and that the interview data
represent themes and discourses not uncommon for the socio-cultural context of Aotearoa New Zealand and other similar cultures.

**Foundations of the analytic approach: Language, discourse, and subjectivity**

When people talk to each other, the world gets constructed (Burr, 2003, p. 8)

The shift towards a constructionist conception of language and representation did a great deal to displace the subject from a privileged position in relation to knowledge and meaning (Hall, 1997, p. 55).

**Language and discourse**

Developing on from the discussion in Chapter 1, my main analytic focus is on language. In social constructionism, language is understood as productive and constitutive of reality, meaning, and knowledge (Burr, 1995). The objects and events of the world are constituted in and through the language, and outside language ‘reality’ has no meaning (Sampson, 1993). Therefore, the aims (or claims) of research are not to ‘uncover’ the truth of reality, but to suggest “an interpretation or version which is inevitably partial” and constituted by language (Taylor, 2001, p. 11). According to Foucault (1972), language is always located in discourse, which is considered a social practice, a way of doing things, and not merely a linguistic concept used for description and communication (Wood & Kroeger, 2000). As Hall (2001) puts it:

"[Discourse] defines and produces the objects of our knowledge. It governs the way the topic can be meaningfully talked about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of others. Just as a discourse ‘rules in’ certain ways of talking about a topic, defining an acceptable and intelligible way to talk, write, or conduct oneself, so also, by definition, it ‘rules out’, limits and restricts other way of talking, or conducting ourselves in relation to the topic, or constructing knowledge about it. (p. 72)"

Discourses are not neutral, but promote certain (potentially competing and contradictory) versions of ‘truth’ and ‘knowledge’ (Gavey, 1989). Discourses are multiple, and not equally privileged – dominant discourses appear ‘natural’ and exert
their power through appealing to common sense, while their influence remains hidden, difficult to identify, and, therefore, resist (Gavey & McPhillips, 1999, p. 352). For example, in the case of childbearing, dominant discourses construct ‘production’ of ‘perfect’ babies as an achievable norm (Landsman, 2009). Therefore, maternal feelings of shame and guilt when the newborn differs from the ‘norm’ (is ‘less than perfect’) appear natural (Waechter, 1970).

**Subjectivity**

According to Foucault (1972), discourses construct “subject positions” for individuals to take up. These positions (or possibilities) for constituting subjectivity (sense of self, identities, behaviours, and ways of understanding the world) differ in terms of their power (Gavey, 1989). The subject in Foucauldian terms is constituted by multiple discourses, producing subjectivity that is “rich and complex, yet fragmentary and contradictory” (Gavey & McPhillips, 1999, p. 352). Discourses are also understood as constitutive of the materiality of the body, “unconscious and conscious mind and emotional life of the subjects which they seek to govern” (Weedon, 1997, p. 108).

**Discourse analysis**

The term discourse analysis has a wide reference, and can be loosely defined as “the close study of language in use” (Taylor, 2001, p. 5). Discourse analysis is an approach, rather than a single prescribed method (Gavey, 1989). There are no fixed rules about how to do discourse analysis, and the guidelines (e.g. Parker, 1992; Potter & Wetherell, 1987) are generally suggestive and open ended (Gavey & McPhillips, 1999). There is one “coherent theme” or restriction, that, according to Potter and Wetherell (1987) links a variety of discourse analytic styles together:

> Participants’ discourse or social texts are approached in their own right and not as a secondary route to things ‘beyond’ the text like attitudes, events or cognitive processes. Discourse is treated as a potent, action-orientated medium, not a transparent information channel. (p. 169, emphasis in the original)

In this research, I broadly followed the stages and recommendations for doing discourse analytic research outlined by Potter and Wetherell (1987). I use the form of discourse analysis proposed by Wetherell (1998; see also Wetherell & Edley, 1999), which
combines “the emphasis on the action orientation of people’s talk” (Wetherell & Edley, 1999, p. 338), and “the rhetorical strategies used to make and counter claims” (Lafrance & Stoppard, 2006, p. 129), with attention to macro-level discourses available in a particular cultural context – discourses “which have a history and which imbricate power relations” (Wetherell & Edley, 1999, p. 338).

To identify the discourses within the participants’ accounts, the interview transcripts were read several times to detect recurrent themes, similarities, contradictions, and discern patterns within and across accounts. The analysis did not aim at producing a “simple unitary summary” of participants’ talk, which was expected to be nuanced, fragmented, and contradictory (Potter & Wetherell, 1987, p. 168). I considered the variations in parents’ accounts to be as important as the commonalities. The inconsistencies, potentially indicating sites of contestation and negotiating of meaning, gave examples of fluid, non-linear, and transient nature of subjectivity and knowledge and indexed possible sites of resistance to dominant discourses (Burns, 2004). Links were then made to the macro-level discourses of autism, disability, and childbearing and child rearing. These were identified through reading of literature on the subject (for instance, the body of research concerned with causes of autism), and comparing my findings with the macro-level discourses previously identified by other researchers (for example, biogenetic and psychological discourses identified by Nadesan, 2005). Other analytic stages involved examining the action-orientation of the participants talk, identifying the subject positions made available by particular macro-level discourses, and exploring how participants negotiated their subjectivity. Following Gavey and McPhillips (1999), I approached the data from a standpoint that despite the impossibility of arriving at a ‘true account’ of what happened, “some appreciation of relevant aspects” of the broader context of participants’ life was necessary (p. 354).

**Other analytic approaches**

As discussed above, a discourse analytical approach informed by social constructionism does not treat things as having an extra-discursive reality in their own right, emphasising their constructed nature where language is seen as constitutive of reality. In two chapters in this study, I depart from the discursive/constructionist position and approach the data from a critical realist standpoint, which views texts and accounts as

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11 The term used by Yardley (1997a).
real (albeit not necessarily true), while recognising their socio-cultural and historical locatedness. My choice of paradigms in this study was data-driven. In Chapter 3: Medico-scientific knowledges of the causes of autism: Three levels of explanations, I review the current research and professional literatures taking them at ‘face value’ in order to inform the reader about the current state of ‘knowledge’ and research trends in the area of autism etiology, and to ‘set the stage’ for my analysis of parental constructions of autism causation. Although essentially realist, my narrative in this chapter is still critical, as it acknowledges the constructed nature of these texts “fashioned into items of knowledge by the science of the day” with its “antecedently established facts and theories, paradigms and models, methods and techniques of enquiry” (Bhaskar, 1998, p. 16), and its dominant discourses. In Chapter 6: “It’s autism, off you go”: Parents’ experiences of the diagnostic process, the choice of analytic focus is motivated by my intention to make the parents’ stories more “visible” (as discussed in Chapter 1). Following Sims-Schouten et al. (2007), I consider contextualising participants’ talk by positioning it within the “materiality that they also have to negotiate” (p. 103), to be an ethical stance as it does justice to their lived experience. For example, it appears inappropriate to treat a mother’s expressed dissatisfaction about the lack of even basic information about interventions for the child and support services for the family as “purely rhetorical” (Sims-Schouten, et al., 2007, p. 104). Lack of information at the time of the diagnosis often results in very ‘material’ delays in accessing funding and respite, and many hours of precious parents’ time spent in search of the vital information and services.

I utilise a mini-case study approach to present and analyse one mother’s positive experience of the diagnostic process, which is followed by a thematic content analysis of all parents’ accounts (including this mother who had more than one diagnostic encounter) of their negative experiences of receiving the diagnosis. The analysis, which followed the steps and recommendations outlined by Braun and Clarke (2006), was inductive and data-driven. I began by carefully examining each of the transcripts to identify all instances of talk related to parents’ experiences of the diagnostic process. The relevant extracts were read and re-read, and some preliminary analytic ideas were noted. I then manually coded the content of the entire data set, organising the text into meaningful semantic groups, which I collated into broader salient themes that re-occurred within and/or across interview transcripts. These themes were reviewed to
ascertain that they ‘accurately’ represented the meanings evident in participants’ talk, fitting together, and telling a “coherent and internally consistent” story about parents’ experiences (Braun & Clarke, 2006, p. 92). The extracts that I considered to be particularly salient and compelling examples of each of the identified themes were selected. A detailed analysis was conducted and written, linking the themes in the participants’ talk with the broader socio-cultural context within which parents’ accounts were produced, and which impacted parental meaning-making.

A note on reflexivity

How should we deal with the fact that our accounts of how people’s language use is constructed are themselves constructions? (Potter & Wetherell, 1987, p. 182)

Yardley (2000) states that for researchers who recognise that our subjectivities (in her terminology – our assumptions, intentions, and actions) shape our experience of the world, it is important to openly reflect on (disclose) the impact of such factors on the process and “product” of the research investigation. Such disclosure, known as “reflexivity”, may include discussions of the motivations (personal or professional) which have led the researcher to chose a research topic or research questions (Yardley, 2000), reflections on the interview style and process (Franklin, 1997; Warren, 2002), or writing analyses with self-referential qualities (examining at the same time the topic and one’s own investigation of the topic, or “accounting for accounts”) (Wynne, 1988). In this research, I recognise my constructive role in the whole process of its creation, from planning to the result. I therefore make my epistemological, methodological, and personal positioning explicit throughout the text of the thesis, and reflect on my authorial role in the research by including short “writing stories” within the body of some of the chapters. These are short narratives “that situate one’s own writing in other parts of one’s life” (Richardson & St. Pierre, 2005, p. 965), offer critical reflexivity, and serve as a reminder that research “is grounded, contextual, and rhizomatic” (p. 965).
Chapter 3: 
Medico-Scientific Knowledges of the Causes of Autism: Three Levels of Explanations

In this chapter, I provide a selective summary and critique of the ways in which the causes of autism have been portrayed in the current professional and research literature, and in literature conveying ‘expert’ knowledge for popular audiences. As the writings on the topic are extensive, this summary will necessarily be a selective, rather than a comprehensive in-depth account of the current ‘state of knowledge’ of the etiology of autism. It will serve as a background to Chapter 4 that follows, where I explore how the mothers and fathers of children with autism make sense of the ‘expert’ knowledges of autism causation, how and why they prioritise certain causal explanations over others, and what meanings they assign to them.

The idea of this chapter has come from my realisation that the analyses of constructions of the causes of autism in parental talk would be richer and more complete if they were set within a landscape of the current and historical medico-scientific knowledges of the etiology of autism. The majority of parents in this study reported doing regular extensive research (“keeping up”\textsuperscript{12}) and educating themselves about the latest knowledge in the area of autism. The excerpt below from one mother’s interview account demonstrates that parental exposure to various ‘expert’ knowledges could be substantial. Although not all parents in this study reported the same degree of involvement and interest that Anna did, many talked about using the Internet, reading books and journal articles, attending conferences in New Zealand and overseas, discussing issues with other parents and professionals, and subscribing to online information services that provide regular e-mail updates regarding the latest research on autism.

\begin{quote}
M.E.: Anna at this point of time how much um do you feel you know about autism its causes the treatment options and overall prognosis

Anna: in New Zealand?

M.E.: yeah /um/ well and in the world
\end{quote}

\textsuperscript{12} In this chapter and in the empirical chapters that follow, when I am using double quotation marks not otherwise attributed, I am using the words of participants. I am using single quotation marks to emphasise my critical distance from the term.
Anna: and in the world/and in the world yeah/ I think a lot... I do um I go to um conferences overseas and I go to- I am on the Internet all the time and belong to quite a few different e-mail groups um so yeah I think I prob- I really keep up... I spend- every day I’d probably would be doing something to do with autism whatever’s the latest research and books that have come out, yeah (emphasis added)

My goal as a researcher was to understand and show the reader what models and theories of causation were available to parents, and what was the nature of the information they were exposed to when they educated themselves (by reading books, journal articles, and accessing online recourses), or were educated by the ‘experts’ (while consulting specialists or attending conferences and workshops). My approach to the material in this chapter is informed by a critical realist approach. This epistemological paradigm considers ‘expert’ knowledges about the world (in this case – about autism and its causes) to be real and takes them at face value, while recognising their socially constructed nature as the stories of the science of the day (Bhaskar, 1998).

In the preface to the 2nd edition of Autism and Pervasive Developmental Disorders, Volkmar stated that precise pathophysiological models of the disorder remained unspecified, and that in an effort to specify such models “essentially all the theories of psychology and neurobiology have been utilized” (2007, p. ix). Literature on autism directed toward non-academic audiences, and particularly toward parents of children with autism tend to state the idea in far more simple terms, e.g. “nobody knows for sure what causes autism” (Ives & Munro, 2002, p. 37), or “no clear-cut answer exists on the question of cause” (Baron-Cohen & Bolton, 1993, p. 26).

There are currently three main directions of research into causation of autism spectrum disorders. The first area of research concerns itself with the “original” (Wing, 2002) causes of autism (“first” or “root” causes in Boucher’s (2009) terminology). This area currently concentrates on genetics, but also addresses broadly interpreted and mainly biological environmental factors, such as comorbid conditions, viral infections, pre- and perinatal conditions, environmental contaminants and so on. As I will demonstrate below, within the current ‘expert’ literature environmental factors are generally ascribed the secondary status of “triggers”, with ‘genes’ being seen as the main risk factors for autism, although environmental factors are currently under-researched. Since in their
accounts of the causes of autism, analysed in Chapter 4, parents drew predominantly on the discourses associated with these “original” or “root” causes, in the current chapter I will focus on this area of research in greater detail. The second area of research focuses on the pathology of the brain produced by the original causes. This area of inquiry, the “brain bases” (Boucher, 2009) or “autism brain science” (Nadesan, 2005), encompasses substantial bodies of neurophysiological, chemical, morphological and neuroimaging studies. The third area of enquiry concentrates on atypical psychological function (leading to the observable abnormalities of behaviour) produced by the brain pathology, which was produced by the original cause. Therefore, across various branches of science and medicine, the cognitive and behavioural differences associated with the syndrome of autism are broadly understood as epiphenomena of gene-induced (and possibly environmentally triggered) underlying organic disorder (Nadesan, 2005). However, constructing “a full explanation of autism from first causes up to what is known about brain bases, and thereon to psychological deficits or anomalies” is “not yet possible” (Boucher, 2009, pp. 228-229) due to the lack of knowledge in each separate area of research and poor understanding of the processes by which genes and environments contribute to brain development and thereon to psychological function and behaviour (Boucher, 2009).\textsuperscript{13}

The understanding of autism and its causes has changed since Kanner’s (1943) first description of the syndrome (Mesibov, et al., 2000). Originally defined as being “inborn”, a disorder later became construed as psychogenic, caused by (from the then dominant psychodynamic perspective) inadequate parenting, in particular – maternal ambivalence and rejection, and (in terms of learning theory) faulty reinforcement (as discussed in Chapter 1). However, since learning theory was far less influential than the psychodynamic paradigm, the impact of the latter parent-blaming conceptualisation of autism etiology was “quite limited” (Schreibman, 2005b, p. 84). Current medico-scientific discourse claims that autism today is “universally seen as a neurobiological difficulty, whose cause is organic and related to atypical brain development” (Mesibov, et al., 2000, p. 637). Nevertheless, it appears that the discourse of parents as contributing to pathogenesis, or, in Nadesan’s (2005) terms “the ghost of the refrigerator mother” (p. 176), still lingers. As Epstein (2000a) points out, “there remain

\textsuperscript{13} See Boucher (2009) for a review of some hypotheses concerning links from the “first causes” to brain bases, from “first causes” to behaviour, and one attempt by Belmonte et al. (2004) to construct a theory explaining autism as a whole.
numbers of psychoanalytic practitioners who maintain that there is a role for the idea of psychogenesis” (p. 632), with such notions being prevalent in countries with a strong psychoanalytic tradition, such as France (Chamak, 2008; Grinker, 2007; Howlin, 1998). Epstein (2000a) also mentions a textbook, which at the time of the publication of her article was assigned in graduate courses at an American university, that uses Bettelheim’s theories of autism as “its representative example of a psychoanalytic theory of development” (p. 633).

**Original causes of autism: Genetic influences**

In 1976, Hanson and Gottesman entitled their review article “The genetics, if any, of infantile autism and childhood schizophrenia”, concluding that there was no strong evidence to implicate genetics in the etiology of autism (Hanson & Gottesman, 1976). As noted above, the current dominant viewpoint is completely different: autism is considered to be one of the most heritable of all psychiatric conditions. As Szatmari and Jones (2007) pointed out, “the issue today is not whether autism has a genetic basis but what that basis is, the specific genes involved, and how they act” (p. 157). The most influential development contributing to this change was a series of twin and genetic-family studies, the first of which (Folstein & Rutter, 1977) found a significant monozygotic-dizygotic (MZ-DZ) difference in concordance – 4 of 11 MZ pairs (36%) were concordant for autistic disorder compared with zero of 10 DZ pairs (0%), and 9 of 11 MZ pairs (82%) were concordant for a broader “cognitive disability” with only one out of ten DZ pairs (10%), providing “provocative evidence for heritability” (Newschaffer, Fallin, & Lee, 2002, p. 137). Further twin studies were seen to confirm the strength of genetic influences in autism, finding concordance rates of 96% for MZ twin pairs versus 24% DZ concordance (Ritvo, Freeman, Mason-Brothers, Mo, & Ritvo, 1985), 91% for MZ twins versus 0% for DZ pairs (Steffenburg et al., 1989), 60% for MZ pairs versus 0% for DZ twins (Bailey et al., 1995), and, more recently, 88% for MZ twins versus 31% for DZ pairs (Rosenberg et al., 2009). Bailey et al’s (1995) study also reported a 92% MZ concordance for a “broader spectrum of cognitive or social abnormalities” versus 10% of DZ pairs. Based on the summary of early twin studies (Smalley, Asarnow, & Spence, 1988) and studies by Steffenburg et al. (1989) and Bailey et al. (1995), Szatmari and Jones (2007) estimated the heritability of autism as in

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14 See Grinker (2007) for a personal account of consulting a psychoanalytically trained psychiatrist regarding his daughter’s autism.
excess of 90% and concluded that autism was “highly heritable” (p. 159). However, in addition to heritability, twin studies also implied a certain influence of environmental factors (Newshaffer et al., 2002).

Family studies utilising direct assessment of relatives have shown that between 2% and 6% of the siblings of children with autism experience the same condition (Rutter, Silberg, O'Connor, & Simonoff, 1999). The range of estimates of the prevalence of autism at the time in the studies that used the criteria comparable with those used in family studies ranged from 1 to 16 per 10,000, with a median value of 5, pointing to a very high rate of autism in siblings of people with this condition relative to the rate in the general population (Newshaffer, et al., 2002; Rutter, et al., 1999). Put simply, the evidence suggested that “autism can be inherited at least partially from pre-existing genetic variants in parents” (Zhao et al., 2007, p. 12831).

**Lesser variants/Broader phenotype**

Several studies suggested that ‘the genes for autism’ may also confer susceptibility to milder or incomplete manifestations of the condition, such as atypical autism or Asperger’s disorder (Szatmari & Jones, 2007), or a “lesser variant” – a “constellation of subtler abnormalities” which (Micali, Chakrabarti, & Fombonne, 2004) also referred to in literature as “broad autism phenotype” (BAP). BAP is considered to be characterised by similar ‘impairments’ than autism, but insufficient to meet the criteria for a psychiatric diagnosis. It is estimated that at least in the first-degree relatives the broader phenotype occurs in 10-20% of cases (Rutter, 2005a). Pickles et al. (2000) claimed that characteristics of BAP could be present not only in the siblings and parents of individuals with autism, but in second-degree relatives and first cousins as well, although in a substantially “milder form”. (In this study, the ‘presence’ and the ‘severity’ of BAP in extended family was ‘established’ by researchers based on behavioural descriptions provided by the parents of children with autism).

Studies comparing relatives of individuals with autism to relatives of people without this condition have reported a variety of subtle personality, social, and language “abnormalities” as well as “obsessional” and “repetitive” behaviours more commonly present among family members of people with autism (see Bailey, Palferman, Heavey, & Couteur, 1998, for a review). The following characteristics have been described as feature of BAP: rigid personality with preference for routine, socially reticent or aloof
dispositions with little interest in social interaction in the absence of clearly defined purpose, fewer and less reciprocal friendships, and some language difficulties, including impaired pragmatic language use (Losh & Piven, 2007). In a recent study, Constantino, Zhang, Frazier, Abbacchi, and Law (2010) argued that if autism is considered in terms of a broader phenotype, sibling recurrence may be significantly higher than previously published estimates. In their sample of 2,920 children, 20% of presumably unaffected siblings were found to have a historic diagnosis of language delay, one-half of whom exhibited “distinctly autistic qualities of speech” (p. 1349). The existence of BAP is currently seen as evidence for familial, and presumably genetic etiology of autism (Szatmari & Jones, 2007), however there is no consensus on whether it constitutes a common but qualitatively distinct category or a continuously distributed dimension (Rutter, 2005a). Although the boundaries and components of BAP are still debated, it appears that the ‘existence’ of the broader phenotype is not disputed within the field of biomedicine. Rutter (2005a) concludes that “the evidence on the reality, and relative frequency, of the broader phenotype of autism has been well demonstrated in numerous studies and the concept is no longer controversial” (p. 428). The “expansion of ‘the autism spectrum’ to include people with the mildest social deficits” has been critically challenged by Nadesan (2005), who argued that pathologising of personality eccentricities and broadly understood difference was a corollary of efforts of modern science “to explain and predict human variation using genetic explanation” and to link “socially marked forms of difference with genetic defects” (p. 215).

Although Folstein and Rutter’s (1977) study raised the possibility that what is inherited in autism is more broadly based cognitive impairments, particularly in language, more recent studies using direct assessment of parents and siblings failed to confirm this hypothesis (Gillberg, Gillberg, & Steffenburg, 1992; Szatmari, Jones, & Tuff, 1993). Szatmari & Jones (2007) posit that persistent cognitive impairments are part of the ‘autism phenotype’ only if also associated with social-communication problems. They conclude that “the genes for autism do not confer susceptibility to persistent learning disabilities or mental retardation unaccompanied by ASD-like social impairment” (p. 164).

Another active area of research concerns the question of whether the genes that may underly autism/ASD also confer susceptibility to qualitatively different disorders, such as mood disorders, anxiety disorders, and schizophrenia. Several studies have reported
that the rate of mood and anxiety disorders were significantly higher in relatives of children with autism (parents and siblings) compared with parents of children with other conditions such as Down Syndrome or various neurological disorders (Szatmari & Jones, 2007). A recent population based case-controlled Swedish study reported a twofold increased risk of autism spectrum conditions among children whose parents were hospitalised for a variety of psychiatric diagnoses. Schizophrenia was more common among both parents as compared to control parents (Daniels et al., 2008). In the Smalley, McCracken, and Tanguay (1995) study, the rates of major depression and social phobia were elevated among parents and siblings of individuals with autism, with 64% of the parents with major depression and all parents with social phobia diagnosed before the child was born. In Daniels et al. (2008) study the magnitude of the association between any parental psychiatric diagnosis and the child’s autism was found to be higher when a parent was diagnosed before the child was. The authors hypothesised however, that having a psychiatric problem might sensitise the parents and influence them to have their child evaluated, resulting in an increased rate of diagnoses of autism in this population. Szatmari et al. (1995) studied parents and extended relatives of children with autism spectrum disorder diagnoses and found no increase in the rates of psychiatric symptoms. Overall researchers in the area tend to agree that although the higher rate of psychiatric conditions in parents could not be fully accounted for by the stresses of having a child with autism, current findings are inconclusive. Further research is needed to clarify the connection between these conditions and the broad autism phenotype (Micali, et al., 2004).

Over the past 10 to 15 years the focus of genetic research has shifted from establishing the strength of genetic influences (by means of twin studies) and clarifying the boundaries and components of the phenotype of autism to systematic attempts to identify specific chromosomal regions and genes that may underly the condition (Volkmar, et al., 2004). Volkmar et al. (2004) posits that this change of emphasis has been influenced by “the general acceptance of the role of genetic factors and by technological developments that have enabled the molecular investigation of complex genetic diseases” (p. 149).
Known genetic medical conditions associated with autism (“non-idiopathic” autism)

A separate line of support for genetic etiology of autism is the overlap with known diagnosable genetic conditions and chromosomal abnormalities, such as Prader-Willi syndrome, Angelman syndrome, tuberose sclerosis, neurofibromatosis, and Fragile X syndrome (Muhle, Trentacoste, & Rapin, 2004). Many other rare single gene conditions have been linked with autism in case-studies (see Gillberg & Coleman, 2000 for a comprehensive list of these conditions). The genetic disorders, however, are linked with a small proportion of autism cases (<10 %), and the association is not universal in any one of the genetic conditions mentioned (Muhle, et al., 2004). Gilberg and Coleman (2000) also point out that the fact that these disorders are referred to as ‘genetic’, does not mean that other biological factors (e.g. second somatic mutation or an environmental biological factors) are not involved in the full expression of the clinical syndrome. They suggest that manifest picture of a ‘genetic’ condition should be viewed as a combination of several factors, which include modifying effects of other genes in the individual’s genome on the primary gene mutation and the effects of possible additional infections, exposure to toxins and other environmental factors. They also caution that the overlap between autism and the conditions described above may have occurred by chance.

Idiopathic autism: Continued search for the “elusive genes”

Despite the evidence from twin and family studies, indicating a strong albeit complex genetic component in autism, review articles and textbooks on autism tend to agree that “the identity and number of genes involved [in the etiology of autism] remain unknown” (Muhle, et al., 2004, p. 472). No individual gene has been clearly identified as playing a major role in autism liability. It is generally accepted that several and possibly many genes are contributing to the disorder (Yang & Gill, 2007). “Autism spans the genome” in that the chromosomal abnormalities or genetic mutations have been described in every chromosome (Coleman & Betancur, 2005, p. 17). More than 10 years ago Rutter et al., (1999) suggested that “the susceptibility genes of autism would be identified during the next decade” (p. 29), however, despite the accumulation of complex data, results remain contradictory, disjointed and unclear.

15 “Parents need to understand that they and their affected children are the only available sources for identifying and studying the elusive genes responsible for autism” (Muhle, et al., 2004, p. 473, emphasis added).
There appears to be, nevertheless, some convergence of the evidence. For example, Yang and Gill (2007) suggest that there is “at least some indication” that seven chromosome regions may contain risk variants for autism (p. 81). However, as has been pointed out above, some studies fail to replicate any of these regions, and instead name new regions that have not been implicated by other research groups (Monaco & Bailey, 2001). When a chromosome regions associated with risk variants for autism are identified, they are often reported to be associated with a small number of cases of autism, e.g. 1% in a study by Weiss et al. (2008), which the authors qualified as “substantial susceptibility” (p. 668).

**Mode of inheritance for “idiopathic” autism: Inherited or sporadic?**

There appears to be little consensus on the exact “mode of [genetic] transmission” of idiopathic autism (Szatmari & Jones, 2007, p. 172). Several complex models of inheritance have been suggested (see Szatmari & Jones, 2007 for a review), with the majority of researchers agreeing that autism is most probably a polygenic disorder, “but that epigenetic factors and exposure to environmental modifiers may contribute to variable expression of autism-related traits” (Muhle, et al., 2004, p. 472). One group of researchers, however, suggested that the majority of autism cases result from de novo mutations, presumed to be occurring in a parental germ line, the sequence of cells, which develop into eggs and sperm (Zhao, et al., 2007). This can occur in any family, regardless of the parental “genetic background”. For reasons so far unknown, female offspring are significantly more resistant to displaying the effects of such mutations than are males. Resistant individuals (particularly females) may become parents and in turn transmit the mutation to their children, who will display the symptoms with high probability in males. According to the authors, this model is likely to account for the majority of the cases of autism (Zhao, et al., 2007). Zhao et al. (2007), however, recognise that their model does not take into account environmental contributions. They emphasise that the model itself should not be seen as evidence for genetic causation, and that environmental factors contributing to the risk data cannot be ruled out.

**Original causes of autism: Environmental risk factors**

Environmental risk factors for autism began receiving some attention by researchers in the second half of the 1990s. In 1996, in a report to the National Institutes of Health,
Bristol et al. suggested that “it was not premature to investigate gene-environment interactions” as “there must be relevant environmental factors even in the face of the genetic evidence”, and that the role of such factors as “triggers” of pathophysiologic processes in autism “appeared highly likely” (p. 130). One of the main reasons cited was that even monozygotic twin pairs were not always concordant for autism. In 2000, London and Etzel described the current state of environmental research in autism as being “in its infancy” (p. 401), and expressed their belief that investigating environmental etiological factors would be a fruitful avenue to pursue. Newschaffer et al. (2002) explain this increased attention by the following three factors. Firstly, a single, parsimonious model of inheritance for autism had not emerged. Secondly, a Swedish study (Miller & Strömland, 1999; Strömland, Nordin, Miller, Akerström, & Gillberg, 1994) reported a significant increase in autism among members of a cohort prenatally exposed to thalidomide during days 20-24 of gestation, (a critical development period when the neural tube is formed), highlighting potential roles of teratogens in the genesis of autism. Thirdly, the general increase in the prevalence of autism also drew attention to environmental, non-heritable causes of the disorder. Currently however, the general consensus in literature is that environmental factors are unlikely to play a major and independent causal role in autism (Newschaffer, et al., 2002), and “more probably act as triggers in genetically susceptible individuals” (Boucher, 2009, p. 121).

Preconception factors

The idea that pre-conception chemical exposures may potentially be involved in autism etiology arose in late 1970s to early 1980s from two small retrospective case-control studies of autism, which found a statistically significant difference in parental occupational exposure to chemicals during the preconception period (Newschaffer, et al., 2002). In 1993 the hypothesis was revisited following a media report of a possible cluster of autism cases in the children of persons who grew up near plastic manufacturing sites near Leominster, Massachusetts. Spiker, Lotspeich, Hallmayer, Kraemer, and Ciaramello (1993) failed to find cytogenetic abnormalities for any of the 14 children involved, stating, however, that there could be abnormalities not detectible by the techniques they used. After investigations and follow-up case-finding efforts, the local Department of Public Health decided that further inquiries were not warranted since the estimated prevalence of children with autism among former and current
residents of Leominster was lower than the estimate of population prevalence at the
time (Karapurkar, Lee, Kresch Curran, Newschaffer, & Yeargin-Allsopp, 2004;
Newschaffer, et al., 2002). Beyond these studies there has been little interest in research
on the topic of parental chemical exposure (Newschaffer, et al., 2002).

**Prenatal factors**

**Maternal infections**

A number of studies have presented evidence both for and against the association of
autism with viral infection. Some of the ‘candidate’ viruses include measles, mumps,
rubella, and herpes simplex, including cytomegalovirus (CMV), (see Libbey, Sweeten,
(2005) conclude that the best association so far has been made between congenital
rubella and autism (Chess, 1971, 1977), however members of the herpes virus family
including CMV may also have a role in autism. Much of the published literature on the
associations of specific pathogens with autism has been composed of case reports, and
the results are often contradictory. The reviews of literature on the subject generally
agree that low frequency of reports associating maternal viral infection with autism
suggest that such infectious diseases do not constitute a major independent cause of
autism (Newschaffer, et al., 2002), but could “promote” the development of autism in
susceptible individuals (Libbey, et al., 2005, p. 4).

**Maternal medication (prenatal and intrapartum)**

Taking thalidomide (a medication prescribed to women for morning sickness until its
teratogenic effects became known in the early 1960s) during days 20-24 of gestation
was found to be correlated with an increased risk for autism (Miller & Strömland, 1999;
Strömland, et al., 1994). Animal and human studies suggest that maternal use of
valproic acid and other anticonvulsant medications during pregnancy also appears to
increase the risk of autism (Arndt, Stodgell, & Rodier). Regarding other prenatal and
intrapartum medication, the findings are mixed and often contradictory (Newschaffer, et
al., 2002). Wilkerson, Volpe, Dean, and Titus (2002) identified maternal taking of
prescription medication during pregnancy (the type/s of medication were not specified)

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16 Pertaining to the period of labour and birth.

17 The drug was also claimed to be helpful in treating “anxiety, insomnia, gastritis, and tension” (Miller & Strömland, 1999, p. 306).
as a possible risk factor for autism in the offspring. Earlier studies showed varying results: Deykin and MacMahon (1980) reported a slight increase in medication use among mothers of children with autism compared to controls, whereas Mason-Brothers et al. (1990) did not find any association. A Japanese study (Hattori, Desimaru, Nagayama, & Inoue, 1991) found a significantly higher frequency of autistic disorder among children born in one hospital, where 95% of children were born under general anaesthesia. Nineteen out of 21 children with autistic disorder born in that hospital were delivered by a method which included administration of a combination of sedatives, anaesthetic agents, and analgesics, and the routine use of oxytocin or prostaglandins to induce planned deliveries. In contrast, Fein et al. (1997) did not find a disproportionate number of autistic children with histories of labour induction with Pitocin (oxytocin). Other case control studies produced equally conflicting results regarding labour induction as potential risk factor for autism (Juul-Dam, Townsend, & Courchesne, 2001; Mason-Brothers, et al., 1990).

Smoking, alcohol, and cocaine use during pregnancy

Boucher (2009) in her book addressed to readers with little or no special knowledge of autism (including parents of newly diagnosed children) states that “heavy smoking or alcohol abuse in early pregnancy may constitute risk factors for autism in the child” (p. 122). The authors that she cites, however, are either quite cautious about the association of alcohol and autism, or offer a somewhat different explanation of it. For example, Fombonne (2002) discussing the available evidence from a few case series, concludes that it is not possible from these case series to establish whether there is a true association between autism and fetal alcohol syndrome, and that the description of the autistic syndromes in the studies were not based on standardised instruments. In his opinion, it is “very unlikely that there is a strong association between prenatal alcohol exposure and autism” (p. 243). Miles, Takahashi, Haber, and Hadden (2003) studied not just maternal use of alcohol during pregnancy, but the history of alcoholism in families of individuals with autism. They posit that 39% of family members “had alcoholism in patterns consistent with transmission of a genetic trait” (p. 403), hypothesising that autism and alcoholism share one or more genes that predispose to both disorders. Daily smoking during early pregnancy was found to be a significant risk factor for autism in one study (Hultman, Sparen, & Cnattingius, 2002), but in previous and subsequent studies maternal smoking was not associated with the increased risk for
autism (Bilder, Pinborough-Zimmerman, Miller, & McMahon, 2009). One study (case series) reported high prevalence of autism in children exposed to cocaine in utero, but the results have not been replicated (Gupta, 2004b).

**Perinatal factors and obstetric complications**

History of obstetric complications is not uncommon in children with autism. Several case-control-studies did not find association between obstetric complications and autism, others reported weak associations. Overall, the findings have been inconsistent, and “no single obstetric event has emerged as a pre- eminent antecedent for autism” (Gupta, 2004b, p. 51), see also Bilder et al. (2009). Short gestation length, low birth weight, low Apgar scores\(^\text{18}\), uterine bleeding, respiratory distress syndrome, hyperbilirubinemia, meconium staining\(^\text{19}\), and breech presentation were statistically significant factors in more that one study (Bilder, et al., 2009). Interpretation of the meaningfulness of the data is difficult as such risk factors represent “various forms of pathologic processes with no presently apparent unifying feature” (Juul-Dam, et al., 2001, p. e63). An observed association between obstetric “suboptimality” (adverse pre- and perinatal events) and autism risk have been discussed as either reflecting an independent causal contribution or being in itself a by-product of genetic susceptibility (see Newschaffer & Cole, 2005, for a detailed discussion of the possible competing causal models involving genetic susceptibility, obstetric suboptimality, and autism). However, the most commonly expressed view in the field is that obstetric and perinatal complications are unlikely to independently (in the absence of genetic predisposing factors) cause autism, but occur due to the foetus and pregnancy being compromised by the primary (genetic), cause of autism (Boucher, 2009; Gupta, 2004b).

**Exposure to environmental toxicity**

Given the high amounts of toxic chemicals routinely released into the environment (Nadesan, 2005) it seems likely that environmental toxicants contribute to the etiology of autism. Over 1,000 environmental agents have been found to cause developmental defects in laboratory animals (Lawler, Croen, Grether, & Van de Water, 2004).

\(^{18}\) The Apgar score is arrived at by scoring the newborn’s heart rate, respiratory effort, muscle tone, skin color, and response to a catheter in the nostril. Each of these categories can receive 0, 1, or 2 points. Perfect Apgar score of 10 means an infant is in the best possible condition.

\(^{19}\) Presence of meconium (the first stool of the newborn) in the amniotic fluid. If the infant breathes while still in the uterus or while still covered by this fluid after birth, the mixture can enter the lungs and partially or completely block the infant’s airways.
Grandjean and Landrigan’s (2006) review identified 201 industrial chemicals known to be neurotoxic in humans, five of which (lead, methylmercury, arsenic, polychlorinated biphenyls (PCBs), and toluene) had been recognised as causes of developmental neurotoxicity. As the study focussed mainly on identifying acutely toxic substances, the authors emphasised that neurotoxins that cause chronic or delayed disease were likely to be under-represented in their review, and therefore the overall number of toxicants that are dangerous for humans was likely to be far in excess of 201 (Grandjean & Landrigan, 2006). Although a variety of toxic substances have been linked to neurocognitive and neurobehavioural dysfunction in children, autism-specific associations are under-researched, and evidence is lacking (Lawler, et al., 2004; Windham, Zhang, Gunier, Croen, & Grether, 2006). Studies have reported contradictory findings: elevated concentrations of lead, uranium, and mercury in the hair of children with autism (Fido & Al-Saad, 2005), reduced in-hair concentrations of mercury (Holmes, Biaxill, & Haley, 2003), and no difference in hair and blood mercury levels compared to controls (Hertz-Picciotto et al., 2010; Ip, Wong, Ho, Lee, & Wong, 2004). Urinary porphyrin levels (a marker of heavy metal toxicity) were found to be significantly elevated in children with autism (Geier et al., 2009; Nataf et al., 2006), however, as the latter research team pointed out, not all children with autism had porphyrinuria and “some subjects with other diagnoses also displayed somewhat elevated levels of urinary porphyrins” (p. 106). One of the widely publicised investigations of the link between autism and neurotoxins took place in Brick Township, New Jersey. Drinking water and river water contamination due to landfills in the area was suggested to be linked with the increased local prevalence of autism. Two federal agencies (The Centers for Disease Control and the Agency for Toxic Substance and Disease Registry) examined these possible pathways. Although three contaminants were found in the drinking water at various times (tetrachloroethylene, trichloroethylene, and trihalomethanes), there was no evidence found of a link between the location and/or timing of the abnormal values and the location and pregnancies of autism cases (London & Etzel, 2000).

Recent research has reported a link between maternal residence near the areas of pesticide applications and autism (Eskenazi et al., 2007; Roberts et al., 2007). In the study by Roberts et al. (2007), risk for ASD was consistently associated with residential proximity to organochlorine pesticide applications in California’s Central Valley occurring around the period of CNS embryogenesis. Windham et al.’s (2006) data
suggest a possible association of autism with higher ambient air concentration of metals and possibly chlorinated solvents in the geographic area of birth residence. If environmental pollutants are contributing to the etiology of autism, the question arises why, given the widespread exposure of the population, only a proportion of children develop autism. Lathe (2006, 2008) hypothesises that children who later develop autism may be especially susceptible to toxic damage due to genetically explained deficits in detoxification. Available evidence suggests that early life periods (gestation, and possibly lactation) are likely to be the relevant temporal windows of exposure (Lathe, 2008; Lawler, et al., 2004). Addressing the complexity of gene-environment interaction in the genesis of autism, Newschaffer (2006) comments:

We know that hundreds of chemicals have the potential to disturb basic brain development processes …. What we don’t know is how harmful those chemicals can be at low levels of exposure, and which specific genes might make some children more vulnerable to low-dose exposure than others. However, if genetic susceptibility and environmental exposures interact, many of the epidemiologic studies done to date that have characterised only genes, but have not measured environmental exposures, have little choice but to “count” autism caused by the interaction between genes and environmental exposures as being caused by genes (p. 3).

The next generation of studies, attempting to address the broad spectrum of environmental exposures, genetic susceptibility factors, and the interplay between these, are currently under way, e.g. CHARGE study (Hertz-Picciotto et al., 2006) or EARLI study (Ball, 2009). The issue raised by Newschaffer in a statement above has important potential implications for theorising of the so-called ‘broader phenotype of autism’, discussed earlier in this chapter. It appears that in the absence of reliable information of environmental exposure, potential environmental contributions to the family history of the condition have not been considered, and problems in relatives were formulated as purely genetic.
Postnatal factors

Viral infections

The literature linking autism and postnatal viral infections in children is sparse. Several case studies described a sudden onset of autistic symptomatology following herpes simplex encephalitis infections (DeLong, Bean, & Brown, 1981; Gillberg, 1986; Gillberg, 1991). Deykin and MacMahon (1979) found significant association between mumps, chickenpox, fever of unknown origins, and ear infections and autism risk, although overall exposure rates were low, suggesting that these infections were not major contributors to autism etiology. A more recent population-based case-control study by Rosen, Yoshida, and Croen (2007) investigating various types of infections in the first two years of life of the children diagnosed with autism found no increase in the autism group as compared to control children.

Vaccinations

Vaccination as a possible environmental factor contributing to autism has generated much controversy over the last two decades. The debates have centred around two mechanisms in which vaccines were suggested to be causally implicated in autism (Boucher, 2009). The controversy surrounding the measles-mumps-rubella (MMR) vaccine started in 1998, with a small study by Andrew Wakefield and colleagues, published in Lancet, suggesting a connection between the use of the MMR vaccine and the onset of autism symptoms associated with chronic enterocolitis. The publication brought about significant public concern regarding the vaccine safety (Birmingham & Cimons, 1998), and years later, following an investigation by the U.K. General Medical Council’s Fitness to Practice Panel, The Lancet retracted this paper from the published record stating that several elements of it were incorrect ("Retraction - Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children," 2010). While the detailed review of Wakefield’s and his co-authors’ publications are beyond the scope of this chapter, the main idea of their hypothesis was that in susceptible children MMR vaccine might lead to a persistent measles virus infection and cause a chronic immune mediated pathology in the intestine. This would allow neurotoxic intestinal products to cross the blood-brain barrier and reach the developing brain, causing permanent damage (Halsey, Hyman, & the Conference Writing Panel, 2001). Wakefield also argued that the widespread use of MMR
immunisation was “a major determinant of the apparent (now substantiated) increase in rates of autism.” (Halsey, et al., 2001, p. e85)

The second hypothesised link between vaccines and autism implicated thimerosal, a preservative containing ethyl mercury (Doja & Roberts, 2006). Not unlike the MMR-autism issue, the thimerosal debate began with a publication of Bernard, Enayati, Redwood, Roger, and Binstock’s (2001) article hypothesising that autism was a novel form of mercury poisoning. The authors referred to the suggested similarity between traits and physiologic abnormalities of individuals with mercury poisoning and those with autism. They cited the findings of the 1999 US Food and Drug Administration’s (FDA) review that depending on the vaccine formulations used and the weight of the infant, some infants could have been exposed to cumulative levels of mercury within the first six months of life that exceeded the US Environmental Protection Agency’s guidelines for the safe intake of methylmercury. In 1999, the American Academy of Pediatrics, the Public Health Service, and the FDA recommended that vaccine manufacturers reduce or eliminate thimerosal in their vaccines (Newschaffer, et al., 2002).

The bulk of the evidence that has accumulated since 1999 suggests no causal relationship between the MMR vaccine and autism, and, similarly, thimerosal and autism (Doja & Roberts, 2006; Hornig et al., 2008; Parker, Schwartz, Todd, & Pickering, 2004; Rutter, 2005b; Uchiyama, Kurosawa, & Inaba, 2007), although, as Rutter (2005a) points out, “it is not possible to rule out the possibility that there may be occasional idiosyncratic responses” to MMR and thimerosal in individual children (p. 435). Despite the general consensus in scientific literature and statements and reviews by the American Academy of Pediatrics (AAP) (Halsey, et al., 2001), the World Health Organisation (WHO) (Global Advisory Committee on Vaccine Safety, 2003), and the US Institute of Medicine (IOM) (Institute of Medicine of the National Academies, 2004) that vaccines are not causally associated with autism, parents continue to experience doubts regarding the safety of vaccines (Doja & Roberts, 2006). Concerned parents have formed a number of advocacy groups, such as Generation Rescue (www.generationrescue.org), SafeMinds (www.safeminds.org), and Moms against Mercury (www.momsagainstmercury.org) (Doja & Roberts, 2006), devoted to the autism-vaccine hypothesis, while the vaccination rates have declined, particularly in the
United Kingdom (Burgess, Burgess, & Leask, 2006), and measles outbreaks have been registered (Jansen et al., 2003; Sugerman et al., 2010).

**Second causes of autism: Brain bases**

Due to the complexity and heterogeneity of symptom presentation in individuals with autism, there has been a considerable variation in neurological differences that have been observed and reported so far. A cohesive neurological mechanism that might explain the core features of autism has not yet been conceptualised (Bauman & Kemper, 2005a), “consistencies have been hard to come by” (Volker & Lopata, 2008, p. 260), and there are “huge gaps in current knowledge, not least concerning brain development” (Boucher, 2009, p. 132). Therefore, in this section I will briefly summarise the more consistently reported findings associated with brain bases, the pathology of the brain produced by the original or first causes of autism discussed above. For a detailed review please refer to Bauman and Kemper (2005b), and Poustka (2007).

**Abnormal brain size and brain growth trajectory**

Studies show that abnormal brain size (assessed using head circumference, structural magnetic resonance imaging (sMRI) and measured in post-mortem studies) is currently the most well established finding pertaining to brain anatomy of individuals with autism (Boucher, 2009). Children, who later develop autism, are born with a normal-size brain, however, subsequently tend to go through an accelerated head and brain growth period (by 6-14 months the brain size has been reported to be more than one standard deviation (84th percentile) above the mean for healthy infants), with the growth subsiding before the age of 24 months (Courchesne, Redcay, & Kennedy, 2004). Cerebral grey and white matter and cerebellar white matter are abnormally large in young children with autism, which could suggest abnormalities in the regulation of cell proliferation (both neuronal and glial), neuronal migration, or apoptosis (programmed cell death) (Courchesne et al., 2001; Schultz, 2001). The early period of accelerated growth is followed by an abnormally reduced rate of brain growth, and “sometime between 5 and 12 years of age the autistic brain is no longer significantly larger than normal” (Courchesne & Pierce, 2005; Courchesne, et al., 2004, p. 492). In typically developing children parts of the temporal and frontal lobes responsible for “higher order social and intellectual functions” increase in size by up to 20% between preschool years.
and adolescence (Boucher, 2009, p. 133). This hasn’t been observed in children with autism due to the atypical process of brain growth (Boucher, 2009).

**Abnormalities of specific brain structures**

Studies have reported multiple structural abnormalities at the level of brain structures as well as cell types and organisation (Boucher, 2009). Available data indicates a prenatal onset of at least some of the neuroanatomic irregularities found in the brains of individuals with autism (Bauman & Kemper, 2005a). The best established findings are associated with the areas of the brain stem and cerebellum (Boucher, 2009). Areas of the forebrain that have been reported to show abnormalities have included a number of structures that comprise a significant part of the limbic system (Bauman & Kemper, 2005a). The majority of studies of the amygdala and the hippocampus (key structures in the limbic system mediating social and emotional behaviour and memory and learning) have reported abnormalities in the overall size and at the cellular level (Boucher, 2009). Cerebral cortex malformations have been reported in some (but not all) studies (Boucher, 2009), and overall, “the presence, consistency, and significance of cerebral cortical abnormalities in the autistic brain remains uncertain” (Bauman & Kemper, 2005a, p. 184).

**Neurochemistry: Hyperserotonemia**

In their review of neurochemical research in autism Anderson and Hoshino (2005) emphasise “how few replicated differences have been found between autistic and normal subjects” (p. 464). The best documented biochemical marker of autism is elevated blood level of serotonin, an important neurotransmitter in the CNS involved in sleep, mood, body temperature, appetite, and hormone release (Anderson & Hoshino, 2005; Schultz, 2001). Serotonin also plays an important role in the development of brain cells, their connections and organisation of brain growth (Boucher, 2009). Neuroimaging data suggest that individuals with autism may have abnormal serotonin synthesis capacity, which could potentially contribute to altered brain development (e.g. Chandana et al., 2005). Other biochemical abnormalities have been reported to be associated with autism (Anderson & Hoshino, 2005), however the evidence has been less consistent.
Psychological models of autism: Early theories and dominant cognitive models

The third area of enquiry into the causes of autism focuses on atypical psychological function leading to the abnormalities of behaviour. This is conceptualised as being caused by the brain pathology, which was in turn produced by the original causes routed mainly in genetics with some biological environmental factors possibly contributing to the etiology. Historically, theories of autism have tended to mirror the “theoretical zeitgeist of their times”, being “barometers of psychological trends” from psychoanalytic theory, to behaviourism, and to cognitive formulations (Rajendran & Mitchell, 2007, p. 248). Although in his first description of autism, Kanner (1943) argued for its inborn nature, he later came to emphasise the emotional coldness and obsessive qualities of the parents, construing autism as a partly “innate”, partly psychogenic disorder due to “emotional refrigeration” inflicted by the parents (Eisenberg & Kanner, 1956; Kanner, 1949). Other writers, Bettelheim (1967) being most widely known due to his book “The empty fortress: Infantile autism and the birth of the self”, which was “heralded by many as a masterpiece in 1967” (Epstein, 2000a, p. 632), took Kanner’s “emotional refrigeration” argument much further, positing that autism was mainly caused by psychogenic factors (see Nadesan, 2005 and Volkmar, 2000 for a review). These ideas predominated until the late 1960s to early 1970 and were, as Epstein (2000b, p. 746) put it, “not the psychoanalytic tradition’s finest hour”.

The first attempt to conceptualise autism within the behavioural paradigm came in 1961 from Ferster (1985), who attributed the etiology of the disorder to inadequate reinforcement resulting from faulty parenting. When Ferster presented his ideas, unlike psychoanalysis, behaviourism was not the dominant, en vogue conceptual approach. This limited the impact of his arguments, and subsequently Ferster’s ideas did not have the widespread negative effects on parents as did the psychoanalytic theorising of the day (Schreibman, 2005a). Ferster’s focus on learning theory, however, contributed significantly to the later design and implementation of effective behavioural interventions, whose popularity increased with the application of Lovaas’s applied behavioural analysis (ABA) (Nadesan, 2005; Schreibman, 2005a). The latter, however, despite its popularity, “was discounted by many professional psychologists for its failure to explain the core autistic deficits” (Nadesan, 2005, p. 102). In fact, although the behaviourists did not endorse the parent-caused model of autism, they purposefully
de-emphasised the search for overarching “core” explanations, advocating for “applied and practical emphasis” of behavioural work (Lovaas, 1979, p. 318).

With the advent of the “Cognitive Era”\(^{20}\) in the 1970s came the need for cognitively-based formulations. Computer-inspired cognitive metaphors such as information processing have superseded the psychoanalytic understandings of autism “as an ego shipwrecked on the shores of object relations for lack of adequate mothering” (Nadesan, 2005, p. 6). In 1991, by which time cognitive psychology became the dominant non-biological approach to autism research and treatment (Nadesan, 2005), Frith (1991) asserted that “the cognitive explanation of autism provides the most complete understanding of the course of this disorder” (p. 16) and “may eventually allow us to bridge the vast gulf between brain abnormality and behaviour manifestations” (p. 17).

Three dominant theories attempting to account for the ‘core deficits’ in autism have emerged and consolidated since the early 1990s. These models were organised around the constructs of “theory of mind”, a cognitive drive for central coherence, and a group of cognitive skills broadly defined as “executive functions” (Prior & Ozonoff, 2007; Volkmar, et al., 2004). The most influential model in the social cognitive domain emerging in the 1980s–1990s was the “theory of mind” (ToM) hypothesis (Baron-Cohen, Leslie, & Frith, 1985), which explained social difficulties in autism by impaired capacity for attributing mental states to oneself and to others and to interpret behaviour in terms of mental states – the so called “mind blindness” (Baron-Cohen, 1995). In more general cognitive domain two main frameworks have been influential in guiding thinking about learning profiles of people with autism (Volkmar, et al., 2004). One of them was termed the “Weak Central Coherence” theory (WCC) (Frith, 1989; Frith & Happé, 1994). This model argues that the core psychological impairment in autism is the tendency to process information in a fragmented fashion (local processing) and lack of the “drive” for integration and achieving a higher-level meaning (global processing). The other model termed “Executive Dysfunction” hypothesis (ED) conceptualises autism as a disorder of impaired executive functions, “goal-directed, future-oriented cognitive abilities thought to be mediated by the frontal cortex” (Prior & Ozonoff, 2007, p. 102). Problems in this cognitive domain may result in “difficulties with change, reduced forward planning, and ineffective problem-solving skills that lack in coordinate

\(^{20}\) (Rajendran & Mitchell, 2007, p. 225)
reasoning and ongoing adjustment to feedback” (Volkmar, et al., 2004, p. 142). The three cognitive conceptualisations of autism have been critiqued for their lack of specificity to autism, explanatory power, conflictual experimental findings, and developmental modelling (creating a cohesive model of developmental psychopathology) (Volkmar, et al., 2004). More recently the focus of the studies have shifted to very early emerging social motivation and orientation skills (e.g. deficits in joint attention skills, imitation, and the lack of the infant’s drive for social engagement) (Volkmar, et al., 2004). Although there have been attempts to explain autism by linking specific psychological deficits to their brain correlates, not enough is yet known about the etiology of autism for clear-cut connections to be established across all the three levels of explanations, from the original or root causes up to brain bases, and thereon to psychological functioning and behaviour manifestations (Boucher, 2009).

Discourses of science and media

A recent study by Singh, Hallmayer, and Illes (2007) explored the trends in autism research and its coverage by the media by analysing three sources of data: government funding for research projects, peer-reviewed literature, and print press articles from top international media reporting on autism research during the period of 1994–2004. They found that brain and behaviour research received most funding (42% of the total), and was also the most prevalent theme in the peer-reviewed literature (41% of papers), however in print press this theme accounted for only 11% of articles. Genetics was the second most frequently identified category of funded research and peer-reviewed scientific publications (34%), but the genetic research reported in the media constituted only 7%. The study of environmental causes was clearly not the main focus of autism research, however, it was the focus of the media – newspaper reports on studies of the environmental causes of autism constituted 48% of all reviewed articles, whereas the environmental themes in funding and published research only constituted 7% and 13% respectively. Among the media articles focusing on environmental causality, 70% of the study sample was on the MMR vaccine, with 40% being on the controversial Wakefield’s 1998 study, now retracted by the Lancet. The authors report that for the most part, the tone was critical of the suggested link between MMR vaccine and autism. Another recent study (Matson & LoVullo, 2009) looked into a representative sample of published research on all the five pervasive developmental disorders (autistic disorder,
Asperger’s disorder, PDD-NOS, childhood disintegrative disorder, and Rett’s disorder) from the 1970s to 2008 and found that genetics was the top theme (129 out of 820 research articles sampled). The authors’ coding did not include environmental factors as a separate category, therefore it appears that in their sample environmental factors were clearly not the mostly frequent studied topic of the autism etiology.

**Concluding comments**

In this chapter I reviewed existing medico-scientific literature on the causes of autism, and organised my review around three levels of etiological explanations (the original causes, the “brain bases”, and atypical psychological function leading to behavioural abnormalities). I demonstrated that within current dominant knowledges of basic science and medicine, autism is constructed as a predominantly gene-induced brain-based disorder of abnormal cognitive functioning and behaviour.

Since the 1940s when the condition was first delineated, the ‘knowledge’ about the causes of autism has changed from psychogenic to mainly biogenetic attributions. The original causes of autism are now considered to be predominantly genetic, with some environmental contributions generally assigned the secondary role of “triggers”.

Although autism is portrayed within the dominant medico-scientific knowledges as a ‘highly heritable’ condition, the view of genetic etiology of autism does not appear to be unequivocally and incontestably ‘proven’. The results of twin studies imply a certain influence of environmental factors. The genes that may underly autism and the mode (or modes) of genetic ‘transmission’ of the condition are poorly understood, and the research in the field is complex, disjointed, with the abundance of inconsistent and contradictory ‘evidence’. Environmental factors in autism have been so far significantly under-funded and under-researched, although new generation large-scale studies aiming to investigate both genetic and environmental influences, and their interactions, are under way. At this stage, gene-environment interactions in autism remain unclear. In the absence of reliable information about environmental influences, autism caused by a combination of genetic susceptibility and environmental exposures is likely to be seen as caused by genes (Newschaffer, 2006). The efforts of modern science to explain personality and behaviour variation using genetic explanations (for example, in the case of the ‘broad autism phenotype’) can have pathologising implications for the relatives of people with autism construing broadly understood difference as genetic defects.
The current state of knowledge in the areas of inquiry focusing on the second and the third causes of autism (the “brain bases” and atypical psychological function) is also characterised by inconsistent findings and lack of clear explanations. Overall, the domains of knowledge and research concerned with all the three ‘levels’ of autism causation have yielded neither clarity nor a significant amount of “overlap and synergy” (Volkmar, et al., 2004, p. 144). As Belmonte et al. (2004) put it “like the individuals whom it seeks to understand, the field of autism research often falls victim to a sort of weak central coherence” (p. 658) and its current challenge is to organise a complex and often disjointed set of findings pertaining to all the three levels of causation into coherent explanatory models. The complexity of the state of knowledge regarding the causes of autism with its inconsistencies, lack of overlap between related areas of research and inherent uncertainty is likely to be puzzling for parents and professionals trying to apply this knowledge to a particular child. Whether parents familiarise themselves with the overall (multifaceted and unclear) picture by reading authoritative reviews and main texts on autism, research a specific area such as environmental factors in autism, or get exposed to information in a less systematic fashion (for example via e-mail updates about newly published autism-related research), accounting for what caused their child’s autism is likely to be a complex task of interpretation and meaning making. In the next chapter (Chapter 4), I will examine how parents drew on the “expert” explanations discussed in this chapter in their accounts of the causes of autism, and explore the ways they prioritised certain explanations over others to negotiate their identities as ‘good’ parents.
Chapter 4: 
Accounting for the Causes of Autism

...One of the first questions raised about any distress, and especially any distress that is perceived to be an illness, is: “What’s causing it?”. And “cause” is inextricably linked to responsibility and blame. It is noteworthy that the Greek root (aitia) for etiology (the study of causes) means not only “cause” but also “responsibility” and “blame” (Wynne, Shields, & Sirkin, 1992, p. 7)

I am just so glad that I really haven’t got a clue what caused it (…) so yeah, it’s still a mystery, and I am quite glad it will remain so for the rest of my life… at least we will see what happens with our grandchildren I guess… but no I would rather not know (Stephanie)

In the absence of an established cause, autism is sometimes depicted as a conundrum in need of understanding, explaining, and rationalising (Huws, Jones, & Ingledew, 2001).

This chapter explores how in the situation when the etiology of autism remains unclear, the causes of the disorder are portrayed by the parents of affected children. The analysis examines how parents draw on the current and past knowledges of causation of autism, discussed in the previous chapter (Chapter 3), and in the introduction to the thesis (Chapter 1). I discuss the causal explanations that were or were not given priority in parental accounts, and the personal meanings assigned to such explanations.

The shorthand of the unknown: Genetic susceptibility and environmental triggers

In the previous chapter, I discussed the current understandings of the causes of autism as portrayed by medico-scientific literature on the subject. I concluded that autism is generally depicted as a predominantly gene-induced disorder, with bioenvironmental factors being assigned the role of “triggers” of the condition in people described as “genetically susceptible”. I also hypothesised that the disjointed complexity of what currently constitutes “expert knowledge” of the causes of autism is likely to generate significant uncertainty in either lay or professional explanations of how this “knowledge” might apply in any specific “case” of autism. Parental talk on the causes of autism (which is the focus of my analysis in this chapter), was generated in response to my direct questioning. In my opening interview question, I asked parents to share
their current understandings of the causes of autism, the treatment options, and the prognosis for the future.

In line with the findings presented in the previous chapter and briefly summarised above, all 26 participants in this study emphasised that the exact causes of the disorder a) remained largely unknown, and b) that autism was heterogeneous in etiology and causes might differ between individuals.

_Graham:_ I’ve learned (…) that there’s all the different ways that it comes about and no one’s really prepared to say exactly how or why it happens

_Justin:_ (…) so the causes- I think that’s… well I mean they don’t know. I don’t think someone can put their finger on um you know what causes autism

_Julie:_ (…) my current understanding is that there’s probably, a range of causes and um you know many people with autism- the cause may be different for each individual… I mean my current understanding is that it’s not really known- that we don’t know but it’s likely to be a number of causes

The majority of participants (20 out of 26) came up with more than one possible causative factor for autism. The number of suggested causes ranged from 2 or 3, to more comprehensive “lists” of 10 to 15 possible causes. They varied greatly in specificity from very general (“genetic thing”, “environmental assaults”), to quite specific (“moulds, heavy metals, copper pipes, lead in paint, pesticides in soil”, “birth trauma, maternal vaccinations, maternal mercury in teeth”), and were mainly articulated in terms of the child’s biology (“genes”) and a broad variety of bioenvironmental factors contributing to the development of the disorder. In this chapter, I refer to these two main types of explanations, which broadly relate to what in the previous chapter was described as the “original” or the “root” causes of autism, as _genetic_ and _environmental_ discourses.

Most parents talked about a combination of genetic and environmental causative factors, and many of them used a particular verbal formula (genetic predisposition +
environmental factors), with minor differences in the actual verbal formulations, to introduce or sum up their talk about the causative factors. In some cases, they overtly referred to the current scientific (‘expert’) discourse as the source of their information. In other cases, parents’ stories were made more personal by their ‘taking ownership’ of the scientific discourse and using phrases like “I suspect”, “I think”, “my view”, or “my belief”.

Eric: (...) I think the current thinking on causes is that it’s a genetic um predisposition ah that’s sparked off by environmental insults

Anthony: (...) I think that the best that scientists can say is that it’s a combination of genetic predisposition and environmental factors (...)

Leanne: (...) I suspect it’s a genetic predisposition and I think that maybe some environmental factors can tip people who are predisposed to it over the edge

Julie: (...) my current understanding is that perhaps well there is probably a genetic an underlying genetic predisposition to autism and then some kind of environmental insult will cause the onset of the symptoms of autism

The dominant discourses of the causes of autism

Genetic discourse

The genetic discourse in parental accounts was concerned with constructing genetic factors as causally contributing (either singularly or in combination with other factors) to their child’s autism. In instances where a participant construed her/his own child’s genetic liability to autism as unclear or unknown, but endorsed the possibility of genetic liability to autism in general, I considered the genetic discourse to be present in their talk. I also considered genetic discourse to be present in two accounts where participants were either unwilling to discuss causation, or limited their talk on the subject to stating that “there was no conclusive cause” (Elaine), because both acknowledged their awareness of the risk of autism should they decide to have more
children. Almost all parents (24 out of 26) deployed genetic discourse in their accounts, however there was significant variation in the scope of discourse, from a mere mention of a possibility of genetic link in relation to other families (“I’d also sort of experienced um family members of people that I’d met who kind of seemed um odd as well so I kind of got that there was a genetic or I thought I assume there was a genetic link”, Graham), to an extensive talk about the meaning of “making an autistic child” (Lyn), which is discussed further in this chapter.

Environmental discourse

The environmental discourse was concerned with parental portrayals of a broad variety of environmental factors occurring during the pre- and postnatal periods as causally linked (either on their own or in combination with other factors), to autism in their child or other individuals. Again, if participants endorsed environmental causation for autism in general, but reported that for their own child the genetic factors were more likely to be causing the disorder (e.g. due to a history of autism spectrum disorders in families), I considered them to be using environmental (as well as genetic) discourse. Twenty-two parents deployed environmental discourse in their accounts. In a pattern similar to the use of genetic discourse described above, the scope of environmental explanations also ranged across participants from a brief acknowledgement of environmental factors as possible “triggers” (“there maybe certain environmental factors that actually trigger it”, Sabine) to detailed and extensive discussion of potential environmental contributors to the development of autism in the participant’s child (including obstetric complications, postnatal infections, vaccination, child’s medication, and a number of environmental toxins in the child’s living environment). Therefore, the genetic and the environmental discourses were used by parents in almost equal proportions, which was in contrast with the recent trends of medico-scientific explanations of autism as discussed in Chapter 3.

In scientific literature, autism is placed “among the most clearly genetically determined of all cognitive-developmental disorders” (Zhao, et al., 2007, p. 12831). It is frequently referred to as a disorder “with a strong genetic component” (Cook, 1998, p. 113) or “predominantly genetically determined” (Bailey, et al., 1995, p. 63). The evidence for such strong genetic component in the liability for autism is described as “compelling” by some authors (Rutter, et al., 1999, p. 25). Autism has also been referred to as a “neurogenetic disorder” (Bookheimer, 2008, p. 831) or a “neurogenetic disease” (Singh,
et al., 2007, p. 153). With the ‘expert’ discourse of causality being so strongly imbedded in genetics\textsuperscript{21}, there is a danger of laypeople’s construing or rather misconstruing autism as ‘purely’ genetic as a result, with the implications of total causality rather than general susceptibility or predisposition (see for example, Wynne (1983) for a discussion of misinterpretations of the genetic theories of schizophrenia). This was not, however, the case in this study, as the genetic discourse shared “dominance” with the environmental explanations, and in all but two parental accounts, where the genetic discourse was present, the genes were portrayed as either conferring susceptibility/vulnerability or as being just one of many candidate causal factors for autism.

\begin{quote}
John: \textit{(...) I think it is probably got some genetic predisposition or something um but then also it probably needs a few things to trigger it off as well}
\end{quote}

However, in line with Bumiller’s (2009) argument about “geneticization” of autism, one mother pointed out that many people (in her experience, mainly medical professionals), nevertheless disregarded environmental factors as important contributors to autism – the view she referred to as “old-fashioned”.

\begin{quote}
Anna: \textit{(...) I think people these days are much more flexible in their thinking because they- there’s so much information available these days that people can get to that conclusion [that autism is caused by a combination of genetic and environmental factors] rather than um autism is just some you know is purely genetic \textit{(...) but lots of people believe you know that the environment doesn’t make a foot of difference /mnmhm mnmhm/ absolutely no difference at all which I find pretty old fashioned actually quite- but that’s you know that’s what I find when I go to a doctor \textit{(...)}}}
\end{quote}

\textsuperscript{21} The phenomenon, which has been referred to as the “geneticization” of autism (see Bumiller, 2009).
Genetic discourse: Interrogating family history

Avdi, Griffin, and Brough (2000b) argued that biological causes could be favoured by parents – the construction of such causes as being beyond personal control engendered “a discursive shift in the location of blame following diagnosis” (Avdi, et al., 2000b, p. 249). According to Novas and Rose (2000), when an illness or a disorder is thought of as genetic, it becomes a family rather than an individual matter, and in order to locate the possible genetic contributions to the problem individuals often engage in interrogating their family history and constructing a “medico-genetic biographical narration” (p. 503). This process draws upon some basic knowledge of genetics including a general idea of the model of transmission of a particular “pathology”/disorder (Novas & Rose, 2000). In line with Novas and Rose’s argument about “genetic” conditions becoming “family matters”, participants in this study located their child’s disorder within the matrix of the family’s medico-genetic background. Therefore, although the genetic discourse placed autism outside parental control, the family (via the parents) were still construed as causally contributing, and as such at fault for passing on the ‘flawed’ genes. Whether the presence of the disorder in the family was ‘established’ (some family members were ‘officially’ diagnosed), or just suspected by participants, their own or their partners’ families often became the loci of the search for ‘evidence’ purporting to clarify the etiology of their child’s problem in genetic terms.

Gavin: (...) my wife’s family has quite a lot of autism in it um so there’s very strong genetic traits (...)

Anne: (...) in my family there’s no um autism in any other generation but in this generation there’s um a [relative] and then quite a few [other relatives] (...) and I’ve gone back and asked were there children that were put away (laughs) that nobody talked about (...)

Sam: (...) yeah well I mean you always think about you know could it be a hereditary thing you think of your families you know different people in the families how- what are they like I know there’s signs of autistic
traits or whatever within those families and those people you know you sort of think about that (…)

Christopher: (…) Stephanie [wife] was interrogating my family history

M.E.: Stephanie was interrogating your family history?

Christopher: [imitating Stephanie]: “Are you sure he [relative] wasn’t-”

Parents mostly constructed genetic factors as inherited, located within the family tree (as opposed to, say, de novo mutations).

Sarah: (…) from what I understand it’s a genetic- um there’s an inherited component of it (…) (emphasis added)

Stephen: (…) it’s in your genes so um that means that there’s um a gene that’s come from me my family whatever somewhere down the line that’s caused it doesn’t make me any happier (…)

Only one participant briefly remarked that the genetic liability may not necessarily be hereditary, however his main construction of genetic contributions was through interrogating the possibility of autism or some traits of autism in the family and/or in himself.

Peter: (…) the corollary of the whole genetic thing is that you start looking for people in your family who have it thinking about you know an uncle or a cousin um or yourself

As some of the examples above have already indicated, parents talked about the ‘evidence’ for familiar and presumably genetic etiology of autism in terms of either (a) the autism spectrum, including milder variants, such as Asperger’s disorder; (b) the “broad autism phenotype” (as discussed in Chapter 3); (c) a history of mental illness, such as bipolar disorder, depression, anxiety, or schizophrenia, or even (d) a broadly conceptualised “weakness in the genetic make-up” associated with some sort of physiological dysregulation. Surprisingly, parents expressed no hesitations in associating the presence of the history of mental illness in the family with the genetic
liability to autism. This was in contrast with the current ‘expert’ opinion, generally treating the evidence of whether the ‘genes for’ autism also confer susceptibility to such qualitatively different psychiatric disorders as inconclusive (see discussion in Chapter 3).

The current medico-scientific discourse of autism as a genetic condition describes a category of milder or incomplete manifestations of the disorder in the relatives of individuals with autism termed “broad autism phenotype” (or sometimes “broader” autism phenotype)\(^\text{22}\). Literature on the subject depicts the “abnormal” characteristics of people assigned to this category as “typically very subtle in expression” (Losh & Piven, 2007, p. 105), and describes the boundaries and components of the “broader phenotype” as still a subject of debate (Micali, et al., 2004). Nevertheless, the ‘existence’ of the category of people displaying some “subtly abnormal” (presumably autism-related and genetically based) characteristics is considered to be “established” in the field of science and medicine (Rutter, 2005a). The discursive theme of the ambiguous but abnormal “broader phenotype” impacted parental talk in this study, inviting parents to search the family history for any subtle differences of behaviour construed as abnormalities. The “signs of autistic traits” in family members were non-specifically, and somewhat dubiously defined as “odd”, “a bit weird”, “lacking in some ways in social skills” (emphasis added), “full of something”, or just “different”. Considering the obvious subjectivity of such constructions, and inevitable questions about the definition and boundaries of the concept of normalcy, there is a potential for the list of the family members ‘possessing’ such presumably genetically based characteristics to expand \textit{ad infinitum}, placing the child’s disorder firmly within the family medico-genetic matrix, and therefore strengthening the discourse of genetic causation. The embeddedness of autism within the discourse of genetic science constituted parental etiological narratives, whereby some probably not uncommon and overall unremarkable social behaviours of certain members of the family were construed as signs of genetically determined abnormalities and sometimes described in terms of diagnostic labels (e.g. “very Asperger’s”), while the contributions of socio-cultural factors to such behaviours were left unacknowledged.

\(^{22}\) See Chapter 3 for a discussion of “lesser variants”/ “broader phenotype” of autism.
Pauline: (...) with the history of all the mental illness in the family it’s like yeah this is our bag some people have heart disease some people have cancer ours is loopy people or something you know what I mean it’s the mental illnesses I mean you look through at the history and it’s there you know bipolar, depressions you know

Eric: (...) I can certainly see genetic links with various members of both sides of the family (...) there’s um there’s certainly um some lack of social skills in (short laugh) in certain members of the family um yeah I mean both me and Lyn can point to elderly relatives that um are just a bit weird um that you know were never diagnosed with anything it’s um I mean they’re not severe enough to not function in normal society

John: (...) on our both sides of our family um Pauline’s got bipolar and her mother’s full of something 23 I don’t know what and on my side my father is very um ... very Asperger’s I suppose um or we’re not a very close knit family I don’t know if he’s Asperger’s but he’s definitely not a social like person and very hard to get to know

Unsurprisingly, it was not only parents who drew on the genetic discourse of autism to ‘diagnose’ social characteristics and behaviours construed as “different”, difficult or “weird”. The two excerpts below represent a husband and wife’s constructions of the same event – the angry (“pissed off”) husband, leaving (“storming out of”) the paediatrician’s office with a distressed toddler following a “bluntly” presented diagnosis. The paediatrician then ‘diagnoses’ the husband with Asperger’s disorder based on this behaviour, which is constructed by the latter as “an accusation”.

Pauline: (...) I remember a lot of crying and screaming and Giles [child] banging on the door just wanting to get out and then John [husband] getting more and more agitated and then he um they finally left John and Giles and then the guy [paediatrician] saying to me and I said I said “are you sure it’s autism” and he goes “oh yes I diagnose one a

23 Later in the interview John states: “(...) her father’s just ah- he’s an alcoholic and the mother’s as nutty as they come (...)”.
John: (...) yeah he [paediatrician] said oh Giles’s a very interesting little character but he’s he is going to be on the autistic- he’s autistic and he’s going to be on the spectrum for the rest of his life I think those were his exact words yeah Giles’s a very interesting character... he’s autistic and he will be on an autism spectrum for the rest of his life (...) that was that blunt I got really pissed off with him and stormed out of the room I believe and then he accused me of being autistic in front of Pauline (emphasis added).

Such labelling, particularly coming from an “expert”, apart from being unprofessional, has a potential of adding to parental stress at the time of the diagnosis. The inference that a particular behaviour (in this case in the father) may be a manifestation of an underlying genetic cause similar to the one implicated in the son’s autism is not benign, but as I will demonstrate in the next section, is likely to engender feelings of responsibility, guilt, and self-blame.

**Genetic discourse: Negotiating responsibility, guilt, and blame**

Sarah: The genetic thing? But that’s not easy on parents (...) you know that whole pointing the blame at one side of the family or the other, well genetic causes don’t absolve the parents at all really, do they? (laughs)

Gray (2002) suggested that recognition of the genetic causation of autism (following a period of now discredited parent-blaming, and in particular, mother-blaming psychogenic attributions) might have contributed to a reduction of stigma in parents of children with autism, as the responsibility for a child’s condition shifted towards factors that were outside parental control. Wynne (1983) held a different view on the relationship between genetic causal attributions of an illness or a disorder, and parental responsibility, guilt, and self-blame. Discussing the issue in relation to schizophrenia, he stated that despite professionals’ assumptions that a genetic view of the disorder relieves the burden of self-blame, parents “blame themselves guiltily as the cause of their offspring’s illness” (p. 207). In a recent study by Dale, Jahoda, and Knott (2006),
the mothers of children with autism who blamed themselves for causing their child’s autism “understood the cause to be hereditary and felt to blame for the genetic links” (p. 471). Participants in the current study also portrayed possible genetic causation as parental “responsibility” or “parents’ fault”, and associated it with the feelings of guilt. Having a child with autism was constructed by some parents as a sign of their own genetic defect, a phenomenon that Novas and Rose (2000) referred to as a “spoliation of identity [in this case – parental identity] at the molecular level” (p. 498).

**Gavin:** (…) I would have said if it’s genetic then it’s completely the parents’ fault if they [the children]’d had a different father then they wouldn’t be autistic or if they had a different mother

**Vicki:** (…) if it’s genetics you still have guilt because it was your DNA you know that did- that caused it

**Lyn:** (…) and then you know there is the kind of well the genetic predisposition comes from my genes coming together with my husband’s genes and if we hadn’t come together then we wouldn’t have produced those children so you know there is a kind of a feeling of responsibility there as well not that I would change that but um I certainly don’t think that the fact that it’s genetic absolves me of responsibility

The discourse of parental responsibility for ‘making’ children with disabilities is prevalent in contemporary Western society (Avery, 1999; Landsman, 2009). Within the discourse of disability (Avdi, et al., 2000b), such children are constructed as “deviant” and are devalued as having “abnormal futurity”, that is their “anticipated value, well-being and productivity as adult citizens” are construed to be compromised (McKeever & Miller, 2004, p. 1182, see Chapter 5 for further, more in-depth discussion). Voysey (1972) describes “parental responsibility” as the degree to which parents are seen as “causing” the child’s disability either “genetically” (emphasis added) or “through negligence of their duties as parents” (p. 85).

Exploring the implications of the rise of molecular genetics for those at risk of developing Huntington’s disease and their relatives, Novas and Rose (2000) argue that
genetic identity (known genetic status of a person) “induces ‘genetic responsibility’” (p. 502), including decisions on how to conduct one’s life in relation to having children, getting married, or making health and career decisions. The authors construe “genetic responsibility” as one of the “contemporary norms of selfhood that stress autonomy, self-actualization, prudence, responsibility and choice” (p. 502), therefore firmly placing this concept within the dominant liberal-humanist discourse. Unlike Huntington’s disease (where the genetic mechanisms are generally considered to be well understood), what is currently ‘known’ about genetic contributions to autism is limited and inconclusive to say the least, which makes it impossible to even begin to speculate about the genetic identity and the issue of choice in autism. Nevertheless, societal constructions of ‘perfect’ (healthy, non-disabled) children as the “norm” (Bumiller, 2009; Landsman, 2009), together with the liberal-humanist discourse of broadly understood individual responsibility constitute parents as genetically responsible (due to their ‘faulty’ genes) for bearing children with disabilities. Avery (1999) argues that in contemporary Western culture, the ideologies in the areas of ‘perfect’ children and ‘good’ parents are fused, thus “societally induced shame” for producing less-than-perfect children distorts and devalues parental identities (in this instance – at the level of genetics), and renders the families as being “something less” (Landsman, 2009, p. 75). Using Goffman’s (1968) term ‘spoiled identity’, Avery, (herself a “parent of a young man who has disability”), states that “if identity is influenced by the forces of language, each conversation of ‘tragedy’ and each ‘victim’-ization of our children chips away at our own self-esteem: we have produced ‘damaged goods’ and must share in the ‘spoiled identity’ of our children (1999, p. 120, emphasis added).

While “making” an autistic child was often constructed as parental “failing”, several parents talked about having other non-autistic children in the family as proof of their ability to produce “normal” offspring, and not “failing” genetically, which attested to their own “normality” as parents:

*Stephanie:* (…) I know it has quite often popped up in families hasn’t it you get siblings as well but we were already quite confident that our little one didn’t have it so I sort of knew that we didn’t have the completely screwed up genes (emphasis added)
Vicki: (...) and then we’ve got another little boy that doesn’t have it it’s not you know not like we only make autistic children (laughs) so it- but it has been really really nice having a normal child (emphasis added)

And later: (...) I’m guessing he [child’s father] had the men’s guilt over it -as I do, and I guess maybe he feels like a failure yeah (emphasis added)

M.E.: men’s guilt- what’s that about?

Vicki: just that you know something that you- something in you in your system genes gave that to him and that it’s very hard to kind of um reconcile or live with

In McKeever and Miller’s (2004) study exploring mothers’ accounts of raising children with severe disabling conditions, several mothers reported that their non-disabled children “served to reassure themselves and others” of mother’s abilities to have and raise ‘normal’ offspring (p. 1182). Having ‘normal’ children was construed by these mothers as “important symbolic capital”, “a counterbalancing evidence of maternal social worth vis-à-vis social and cultural expectations of good mothering” (McKeever & Miller, 2004, p. 1182). Interestingly, a similar discursive theme was present in accounts of professionals in Gray’s (1997) study examining the social construction of normal family life among the parents of children with high functioning autism or Asperger’s syndrome. In the study, one of the participants (a staff-member at the local autism treatment centre), voiced that for a parent having non-autistic as well as autistic children was a confirmation “that you are normal and that you can produce normal children” (p. 1100), while only having a child with autism was defined as being “damaging for the ego” (p. 1100). Such talk, firmly embedded within the stigmatising discourse of disability, functions doubly both to devalue a child with autism by constructing him or her as a deviant “other” (Shakespeare, 1994), and to devalue the identity of parents who have ‘produced’ an ‘abnormal’ child (and are therefore themselves ‘abnormal’).

As the possibility of parental genetic contribution to the child’s autism was associated with culpability and feelings of guilt and failure, it was unsurprising, that as a topic of discussion between the family members, it was portrayed as socially inappropriate, equivalent to blaming, and if raised, defensive reactions were to be expected.
Vicki: (...) if I have other children [with a different partner] (...) what if they’re autistic then I will definitely know that it’s me not Simon [ex-husband] you know (laughs) do you know what I mean (…)

M.E.: did you ever kind of have a conversation about that

Vicki: no way (laughingly) no I mean like when I’m angry at him I might have a conversation with my family about it (laughs) sounds like a socially inappropriate thing to do (emphasis in the original)

Sarah: (...) Peter wonders if he is slightly Asperger’s (...) and he thinks he might have a [relative] who might have it but the family don’t really know (…) when we spoke to his mother (…) I thought his mother would be quite defensive about you know “no it’s nothing to do with Peter” (…)

In their accounts of the causes of autism, participants used a number of discursive strategies to resist the invitation to self-blame implicit in genetic discourse, and to reject the devalued identity of an “abnormal” and (genetically) culpable parent offered by it. One such strategy was to avoid talking about genetic links by constructing the causes of autism as inconclusive and unknown, and express satisfaction with the state of not knowing:

Elaine: (...) no nobody comes- or gives you a conclusive- (…) “we think this is the cause” yeah no so none of that (…) which I don’t think is necessarily bad because there is no conclusive um, conclusive cause of you know as far as I know

The second strategy used by participants was to counterbalance the discursive theme of parental genetic responsibility/“failure” by simultaneously deploying a theme denying the significance of genetic causation. Constructing the issue of genetic causation as unimportant and “non-relevant” helped parents to position themselves beyond the reach of blame. In the following two accounts by the same participant, having only autistic children was initially constructed as potentially equal to “failing” genetically, and later described as lacking importance (“what does it matter”) and “non-relevant”.

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Ian:  
(... we’ve got [more than one] healthy kids... maybe if you only had one child that was autistic maybe you could feel wow you know we’re genetic failures or something like that (...) (emphasis added)

And later:  
(... what does it matter either way even if it was genetic what else different could we have done if it wasn’t what else could we have done ah... you just you know I can’t- yeah just put “non relevant” (...)

The third strategy of resisting potentially uncomfortable or distressing talk about genes was to discursively prioritise environmental explanations. This way of de-emphasising genetic discourse was particularly noticeable in interviews with those participants who either had more than one child with an autism spectrum disorder, disclosed a family history of it (one or more relative), or both (eight participants in total). Somewhat counter-intuitively, in the accounts of all but one of them, having more than one child with autism or the history of the disorder in the family tree did not result in prioritising genetic over environmental factors. In fact, five out of these eight participants, having acknowledged the existence of a genetic link, sometimes in very broad terms (“genetic weakness”, “genetic susceptibility to something”), named environmental triggers as main causative factors, referring to the increase in the rates of autism to support their conclusions. In the excerpt below, the presence of autism spectrum disorders in Anna’s family history is constructed as non-inherited, only present in one (the child’s) generation, and resulting from an environmental trigger – “a reaction to something”. The genetic liability to autism is purposefully de-emphasised, as Anna repeatedly points out that neither her child nor other children in the family “were born that way”:

Anna:  
(...) I knew it wasn’t something he was born with I knew it was something that had happened to him (...) my understanding I guess as time has gone by is that he’s probably got a genetic susceptibility to something that the um the immunisation definitely tipped over the edge (...) there’s quite a few kids that are Asperger’s or autistic in our family but it’s only in that generation so to me- and they’re all about the same age so it’s more like an environmental- so it’s kind of yeah so just as a logical person I guess that’s what I look at (...) that’s how I see it and the same with um all the ones in the family that I know it was all a reaction to something not a um not a born that way (...) I
mean I’ve got [a large number of relatives] and not one of them has an issue it’s kind of like- and then the next generation there’s a whole heap have got issues so what you know you have to say well what is that? Is it because we’re susceptible to whatever’s happening at that time in the environment is it something they’re- some sort of new medication they’re all taking is it to do with immunisations to do with the food is it to do with- I don’t know all sorts of things that have changed in the population (emphasis added).

Predictably, as participants had to negotiate their identities as parents and resist the genetic discourse with its negative implications of responsibility and blame, some of their accounts appeared contradictory. Parents deployed competing discourses to account for the causes of the disorder and manage the feelings of responsibility and guilt. In the excerpt below, Liz begins by endorsing environmental causation, then talks hypothetically about a major emotional impact associated with genetically contributing to the child’s disorder, and finally acknowledges the family history and the presence of a “genetic factor”.

M.E.: Liz, have you ever thought about or has it ever interested you what could have possibly caused it in [child’s name]?

Liz: um I think initially you go through that a lot and of course was it the vaccine was it this was it that (...) to me I think it is an environmental thing it seems the most likely that it’s you know it doesn’t seem to be many other reasons why it’s increased so much over the past few years (emphasis added)

And later: (...) I feel like if I pass my genes on to him I’ll feel I think I’ll feel worse I don’t know yeah I’d feel like I shouldn’t have had children oh no I don’t but yeah I mean I do certainly believe it’s genetic it certainly runs in our family because I’ve got [Liz describes the family history of the disorder] so I certainly believe there’s a genetic factor

The fourth strategy, de-emphasising of the genetic discourse by normalising the ‘responsible’ genes, was used in the account of the only one participant, who reported a family history of autism and prioritised the genetic causation of the disorder (“I think to
be quite honest in our case that it is something in the family”, “in our case it’s – I mean there is definitely a genetic thing”, Sabine). In this mother’s talk “the genes for autism” are construed as very common, part of the genotype in the majority of population (“most people carry like the genes for autism”), and as such become far less ‘abnormal’. In addition to such normalisation of the genetic contribution to autism, Sabine actively resists pathologising implications of both the genetic discourse and the discourse of disability. She acknowledges the family history of autism, which she portrays as evidence of the genetic origins of her son’s condition, however she refuses to construct autism as a medico-genetic abnormality in need of remediation. Although Sabine emphasises that she is doing all possible to help the child “to be the best that he can be”, autism is not portrayed as something that can be cured or indeed requires a cure.

Sabine: (…) I don’t think it’ll kind of completely go away and because it’s like it’s kind of part of their genetic make up well at least in sort of in Harry’s case and- because if I would say that looking for a cure it’s like saying that all my [partner’s] family you know that there’s something you know wrong with them (laughs) it’s ah yeah so yeah so I’m quite- I’m not looking for a cure

It appears however, that Sabine has arrived at such a construction as a result of a search for and negotiation of meaning, having rejected blame or self-blame as a “non-productive” strategy. Shifting the discursive focus (in Sabine’s terms “changing your perception”) away from causation (in this case – genetic), with its potential for invalidation and generating blame, she affirms the child’s personhood (“he is who he is”). In Sabine’s talk, “autism” does not signify abnormality and negativity (it does not mean that there is “something wrong” with the person who has it), therefore the identity of an individual with this condition is not construed as compromised. The corollary of such a view of autism is that Sabine’s own identity as a mother is not devalued and her maternal social worth is affirmed.

Sabine: (…) we never said there was any one of us- our fault or you know- not blaming each other or anything (…) there’s no point in sort of saying well we did something or you did something or whatever you know it’s- we realised it’s not productive kind of so yeah (…) I don’t feel
like he’s you know something went wrong um and he’s the result of that kind of and I kind of feel like that’s how you can change your perception of him if you sort of look at it that way (…) he is who he is it’s kind of like yeah it’s really helped me to just accept him the way he is

Wynne et al. (1992) conceptualises illness as a “narrative placed in a biopsychosocial context” (p. 1). He argues that various family claims about the cause/causes of a family member’s illness, despite their potential diversity are “efforts at interpreting, and thereby coping with an inherently distressing and often mystifying experience” (p. 8). This framework of understanding causative explanations of illness as efforts to negotiate meaning is consistent with discursive patterns observed in parental talk in this study, whereby parents negotiated unspoiled subject positions for themselves and their children actively resisting invitation to self-blame inherent in genetic discourse.

**Environmental discourse: “It can be anything”**

Julie: (…) the concept of a genetic predisposition and an environmental insult- I suppose you are always going to be looking to what that environmental insult could have been (…) what Thomas may have come into contact with, or what event may have triggered the onset.

As discussed in Chapter 3, the current medico-scientific literature generally acknowledges that environmental factors can play a role in the etiology of autism, interacting with genetic propensity to contribute to the disorder. However, currently environmental links are significantly under-researched. The existing research is often inconclusive, the data are conflicting, the links between susceptibilities and triggers are poorly understood, and “no one agrees on what these [triggers] could be” (Sigman, Spence, & Wang, 2006, p. 342). Unsurprisingly, in parental accounts the potential environmental ‘culprits’ (triggers, insults) were talked about in very ambiguous and broad terms, e.g. “some sort of adverse event in their [children’s] lives” (Julie), or just “something” that “happened during the pregnancy or the birth” (Graham). Additionally, negotiating the factors that could potentially constitute the second part of the etiological dichotomy of autism (genetic susceptibility-environmental triggers) while the first part itself was often very ambiguously construed as some general weakness in the child’s
genetic make-up ("susceptibility to something"), led to very broad and equally ambiguous constructions of environmental links as potentially "anything", that can happen "anywhere", and "at any time".

*Pauline:* (...) well I think there’s a predisposition to a child um getting it like there may be genetic tendencies or some weakness in their whole make up and then there’s triggers that trigger it (...) so it’s compounded by- it can be anything (...) it’s individual for each person and you try and find out what it is for your child (emphasis added)

*Eric:* (...) the environmental insults I mean it’s just- we’ve got no idea you know that could have been anywhere at any time (emphasis added)

Consistent with the findings of previous studies exploring parental perceptions and beliefs about causes of autism (e.g. Harrington, Patrick, Edwards, & Brand, 2006; Huws, et al., 2001), participants in this study came up with a broad variety of environmental causal explanations including: environmental exposure to toxicants, immunisation, illness or injury (mother or child), pregnancy and delivery complications, antibiotics and other medication taken by the child, food allergies, and maternal diet (including alcohol and caffeine consumption). Apart from those candidate environmental factors that have been focus of the medico-scientific research (such as viral infections, vaccination, and perinatal and obstetric complications), parental accounts also included many additional factors of heterogenic nature. These factors, although not generally portrayed as ‘healthy’, are not currently linked in research literature with the increased risk for autism. They were, however, construed by the parents as harmful and potentially detrimental to the child’s normal functioning, and as such became valid candidates as environmental triggers of autism. These included for example: antibiotics and Losec (Omeprazole) taken by the child, having copper pipes and mould in the house, additives in food, or even seemingly insignificant or minor occurrences, such occasional consumption of fish and ham by the mother during pregnancy, or, in two unrelated accounts, a minor “bump” to the child’s head.

*Leanne:* (...) and around about that time I also pulled um you know the power cord off his monitor I was still using one plugged into the wall
through the side of the cot to shorten it or something and I flicked him in the head with it that also happened then- perhaps that caused it.

The accounts of some of the participants (four in total) who associated genetic vulnerability for autism with a (gene-based) physiological dysregulation (such as deficits in detoxification, immune abnormalities, disrupted gastrointestinal tract function) provided an explanatory model of how a wide range of environmental factors and exposures that do not generally pose significant health threat to the majority of the population, become “environmental assaults” and have a cumulative “poisonous” effect on a susceptible child.

Lyn: (...)

(...)

my understanding is that um autistic spectrum disorders are um caused by well there is a genetic predisposition towards them and my belief and I know that not everyone shares this but my belief is that in my children certainly they have been triggered by environmental assaults upon their bodies (...) if these children have this genetic problem then they are not able to screen out toxins as effectively as other children can … they’re um some people call it like a waste disposal unit you know they can’t they can’t get the waste out and so the waste the poisons- they can’t get the toxins out so the toxins build up and build up and then they have an overload and then things start to go horribly wrong um so that’s the that’s the theory. And when I look back and think about the things that my children were subjected to probably no more than other children of their age but I can see that they were subjected to you know lots of- well all the vaccinations um the all the um additives in food um things like the chemicals in sunblock (...) we plastered Dylan - when he was six months old we plastered him in sunblock because we were told to do that and now I see what chemicals are in the sunblock and it was in his skin and on his skin and I know the skin um is a great way to get chemicals into the body (...) so I know that he had a lot of exposure not necessarily any more than any other child his age but (...) probably more than I had as child when I was his age because there’s just more stuff around (...) and I believe that’s why we are seeing an epidemic of
Lyn’s account of the causes of autism is consistent with Lathe’s (2006) two hypotheses of the recent rise in the prevalence of the disorder. The first hypothesis, which Lathe (2006) calls a “trigger factor theory”, posits that a new widespread environmental factor, on a background of genetic challenge, triggers the development of autism. Infectious childhood vaccines in Lathe’s (2006) view are a plausible factor. However, since the causative link between vaccines and autism have not been established, he concludes that environmental toxicants are more likely candidates. The other hypothesis, which he calls a “combination theory”, suggests that “no single exposure produces autism, but a combination of exposures, including heavy metals, endocrine disruptors, and other chemical toxins, combined with biochemical insufficiencies (dietary deficiencies, occult genetic and metabolic deficits), converge to produce the disorder” (Lathe, 2006, p. 208). While the first theory was not represented in parental accounts in this study (none of the parents attributed the rise in prevalence to any one single factor such as vaccinations or an environmental pollutant), the construction of autism genesis as a combination of factors, of which Lyn’s account cited above is a perfect illustration, was present in one third of the interviews. In the majority of those constructions, however, the environmental factors converging to trigger the disorder in a susceptible child, were a) child specific, and b) not limited to toxic exposure, but included, for example, obstetric complications, maternal viral infections during pregnancy, or “wrong” medication prescribed to the child.

In Lyn’s account of autism causation cited above, she deploys environmental discourse portraying the development of autism in children (including her own) as a result of “environmental assaults on their bodies” (emphasis added). Rather than discussing passive exposure to waste and toxins, she describes children with autism as victims of harmful environmental institutional practices. She voices that they have been “subjected” to toxic agents and “poisoned”, and constructs the increase in prevalence of autism as “an epidemic”. Instead of approaching the issue of causation in the context of individual family, Lyn’s talk construes autism as a problem of generation exposed to

autism of autistic spectrum disorders in this generation (...) it’s my belief that children who display signs of autistic spectrum disorders are ill and basically have been poisoned (emphasis in the original)
unhealthy environment. She depicts herself and her husband as misinformed parents who have possibly (inadvertently) contributed to the overall exposure of their child to toxicants. However, Lyn actively resists blame, emphasising the impact of the authoritative knowledge of the day about healthy child-care practices (in this case – regular use of chemical sun protection for children) on her and her husband’s actions (“we plastered him in sunblock because we were told to do that”, emphasis added).

Environmental discourse: Mothers “under the microscope”

What parent doesn’t wonder if he or she did something to cause the autism (Grinker, 2007, p. 68)

Research on developmental disabilities including autism, as well as literature aimed at professionals and parents commonly talk about parental, and in particular, maternal guilt and self-blame for causing the child’s problem (Avdi, et al., 2000b; DeMyer, 1979; Heiman, 2002; Porter & McKenzie, 2000). Avdi et al. (2000b), for example, point out that it is common for parents, especially mothers, to link the etiology of autism with their behaviour or events during pregnancy and after birth. In doing so they often draw upon culturally available “early medical myths” (Hardwick, 1989). In this study, constructions of environmental links to autism as an accumulation of diverse factors that could potentially be detrimental for the child’s health and development were also associated in participants’ (predominantly mothers’) accounts with the feelings of guilt. Parents talked about responsibility for “making the condition come out” as a result of unintentionally “doing something wrong”. The development of autism (or at least the severity of autism) was portrayed as contingent upon the environmental insults in the child’s life. Similar to the mothers of disabled children interviewed by Landsman (2009), parents in this study often depicted their child’s autism as potentially avoidable and controllable through correct choices made during pregnancy and in early childhood. Preventing various environmental insults from occurring was linked in some accounts with the possibility that autism does not develop, “evolve”, or “get worse”.

24 In Hardwick’s (1989) article a “medical myth” is an erroneous belief regarding the etiology of the child’s medical, behavioural or mental health problem. For example, the child’s difficult behaviour may be attributed by the mother to an obstetric event that Hardwick describes as “common and usually benign” (e.g. the child was “blue at birth”, “needed resuscitating”, “unusual head shape at birth”). The mother then blames herself for causing “the defect” by, for instance, “not pushing hard enough during labour” (p. 9).
Graham:  (... if it’s your environment (...) you could have changed it you could have not had that beer or whatever while you were pregnant or something or you could have moved away from the power lines (...)

Eric:  (... the other big thing you go through is as parents is incredible guilt um you know you really feel like it’s got to be something we did wrong um and because nobody can tell you definitely yes or no then you’ve always got that in your mind um you know. And I guess that’s why the MMR’s particularly contentious because you know parents feel really bad about the fact that they may have made the- you know the condition come out

Pauline:  (... so if you remove those triggers like what they’re allergic to and um don’t immunise these children who are at risk you can probably help prevent it you know getting worse and evolving

Landsman (2009) argues that maternal behaviour around pregnancy is subject to scrutiny throughout the world as a causative factor of a child’s physical or cognitive impairment. She points out that in North American culture in particular reproduction “is saturated” in the discourse of maternal choice and control (p. 2). In the context of widespread biomedical information, promoting the link between healthy babies and normative (“healthy”) maternal behaviour and diet choices before, during, and after pregnancy, women are often held accountable for giving birth to a child with a disability (Landsman, 2009). Much like in Landsman’s (2009) study, the accounts of mothers in this research were imbedded in the discourse of maternal responsibility for the child’s healthy development and self-blame for “exposing” the child to all sorts of potentially harmful environmental factors. Since, as Pollitt (1998) points out, it is impossible to define the limits of what a pregnant woman must or must not do to ensure healthy development of the child, “what she should have known”, or at what point a trivial risk becomes significant” (p. 294), the potential for maternal culpability is vast.

25 Consider, for example, the recent March of Dimes’ video “Don’t U Dare” (http://www.marchofdimes.com/39679_27868.asp), where the main character, a young woman called Bella, who, it appears is not currently pregnant or planning to start a family, “gets busted” by the March of Dimes’ reality TV crew for “practicing some particularly unhealthy habits”, which can affect her reproductive health. The unhealthy habits include drinking coffee and eating doughnuts, and Bella is “caught” doing that by the “Don’t U Dare” camera.
The data in this study shows that even when the pregnancy and post-pregnancy environment (defined by maternal choices), was portrayed as perfect (“most healthy”, “wonderful healthy environment”) and no breaches or lapses were recalled, women still talked about guilt of exposing the child to some unknown environmental risk.

M.E.: have you ever been interested in what actually caused it in Jonathan?
Lora: very very interested yeah it’s it’s um… um it scares me because I fear that I may have done something that has caused it and how would you ever forgive yourself for that I suppose you’d have to because I hadn’t done it intentionally and um I was ever so cautious prior to pregnancy during pregnancy. I didn’t eat any- anything unhealthy I was incredibly vigilant he would have had the most healthy pregnancy one could have got almost really… and so I did my darnedest to help him at that stage and and yeah. All through his early couple of years I mean I did everything I could to to feed him healthily and to give him a wonderful healthy environment… um but there still remains a residue of guilt is there something I didn’t know that I exposed him to environmentally

Societal constructions of mothers as having primary responsibility for the foetus’s and child’s healthy development (Landsman, 2009), which enable women’s behaviours to become object of public (and family) scrutiny and potentially blame, were reflected in the accounts of two fathers, albeit in a very different way. One of them (John) acknowledged the public surveillance of maternal (but not paternal) behaviours, which he referred to as “being put under the microscope”, and assigning the blame for the child’s problems to the mother’s conduct.

John: she- I guess she blamed herself a lot never blamed me- she you know she said she painted the room she said she had a few wines, um through the pregnancy and stuff (…) and she would be under the microscope a lot more than I would be (…) people would point the finger at her and um and point her as an alcoholic and all that sort of stuff you know and “she’s a drinker and she’s this and the house
might be a mess and how do they survive” and you know you get put under the microscope (emphasis added)

The other one, Christopher, deploying the discourse of “maternal responsibility for control of foetal development” (Landsman, 2009, p. 21), held his wife responsible for not being “neurotic” enough regarding her diet during pregnancy, namely continuing drinking coffee. He also blamed himself for “not encouraging” her to adhere to a strict “healthy” diet while pregnant, portraying himself and his wife as lacking responsibility (being “cavalier”) as parents.

Anthony:  

(... I think we are probably a little bit cavalier as parents too um, ah when in the early stages of Elaine’s pregnancy um you know Elaine continued to drink coffee and things like that and I wondered you know obviously in hindsight (...) but if you had your time over again would you do something different yes you would probably I would probably have encouraged Elaine to drink less coffee drink less ah um in the very early stages in fact drink no coffee and you know be almost neurotic if you like about in some respects about it(...) (emphasis added)

Landsman (2009) argued that mothers’ narratives, in which they blame themselves for doing something wrong, albeit unintentionally, perpetuate the “dominant cultural belief that outcomes can be controlled through correct choices” (p. 32). In the current study, the discursive link between maternal behaviours around pregnancy and child’s development was so deeply embedded in the women’s accounts that they constructed searching for possible wrongdoings, self-blame, and feelings of guilt as a normal, “natural”, and common gender-specific response to the child’s disability. To minimise the discourse of self-blame, mothers’ accounts contained simultaneous counter-constructions of their own “guilty” reactions as unsubstantiated, irrational, and illogical, but maintained by the ambiguities and lack of knowledge about the “absolute” causes of autism. Ironically, the same discursive theme of maternal choices around pregnancy, in this case – responsible and “healthy” ones, was used to validate the “irrationality” of self-blame and guilt, therefore perpetuating the dominant discourse of maternal control and accountability for making the right choices.
Pauline: (...) you know you always think “oh you know did I do something to cause it” or you know you always look to blame you know yourself was it because I had fish you know I ate fish I ate ham and I did I didn’t have completely alcohol free pregnancy I had the odd glass of wine but I was very careful and I rested a lot and I tried to eat a lot and no it wasn’t my fault but you know I think it’s a natural thing to feel you rake everything over in your mind

Leanne: I feel very guilty that I um well I have at times felt guilty that he is autistic because you know maybe it was those one or two drinks that I had when I was pregnant ah maybe it was you know maybe I didn’t push my obstetrician hard enough um to perform a caesarean and he let me go through 36 hours of labour um with the foetal monitor on so there was absolutely nothing wrong during labour really except that it took a long time um...so I can be quite rational about that I know it wasn’t that couple of drinks I know you know (...) it would be quite good if they would say okay the absolute cause of autism is this and you couldn’t possibly know that- you couldn’t possibly prevent that from happening then perhaps I wouldn’t feel guilty about it

Julie: I’m sure I’m not the only mother that’s gone through the phase of wondering what we did wrong during our pregnancies or what we did wrong um in the early stages of our parenting (laughs) to to cause this (...) that thought still pops into your head every now and again as a mother and there’s times when (...) I have to make a conscious effort to push these thoughts aside that it’s not my fault that it’s nothing I did that you know I’ve yeah and it’s just maybe that’s something that will always possibly be there I don’t know it’s I mean I know logic- on a logical level that it’s not my fault and it’s nothing I did but every so often this little yeah this little thought comes in
It is noteworthy, that compared to an early (1979) study by DeMyer, where 66% of mothers of children with autism reported feeling guilty “about something [they] had or had not done” (p. 151), which could have contributed to the child’s disorder, in more recent studies, including the current one, there has been a clear discursive change in the nature of the reported “wrongdoings”, reflecting a shift in both “expert” and lay discourses of autism. Women in DeMyer’s study, published during the early days of biological explanations of autism, when psychogenic causative theories were still very much alive\textsuperscript{26}, blamed themselves for contributing to autism psychologically (for example, through failure to feel close to a child). In the current study, maternal self-blame was predominantly concerned with biological environmental factors, construed as detrimental for the child development, as discussed above. Only one mother talked about a psychogenic causative factor as potentially contributing to her son’s autism (see the following section for discussion).

“The lingering agony of “refrigerator mother””\textsuperscript{27}

Despite the apparent dominance of bio-genetic discourses of autism, Grinker (2007) argues that psychoanalytic model of autism left a legacy that is manifest in the “discomfort and guilt” parents of children with autism continue to feel (p. 83). The results of this study indicate that, although scientifically discredited, the historical mother-blaming discourse of autism causality has not completely disappeared from lay accounts. Although many participants in this study briefly acknowledged their familiarity with “the refrigerator mothers myth”, two mothers talked about their personal experiences with the lack of love ‘model’ of autism. For one of them, Leanne, “not bonding well enough” with the child was just one of the “items” on her list of possible breaches of perfect maternal conduct (alongside an occasional glass of wine during pregnancy or not insisting on a caesarean and going through a long labour), all of them linked with self-blame. The fact that in the past the “refrigerator mother” model of autism was validated by the authority of dominant medico-scientific knowledge (and practice) appeared to be enough for Leanne not to dismiss it completely as erroneous, but to question the quality of her mothering instead.

\textsuperscript{26} In 1974, for example, Tinbergen still argues that “many autists are potentially normal children, whose affiliation and subsequent socialization processes have gone wrong one way or another” and “this can only be traced back to something in the early environment – on occasion a frightening accident, but most often something in the behaviour of the parents, in particular – the mothers” (p. 22).

\textsuperscript{27} Nadesan (2005, p. 22)
Leanne: Yes well I blame myself for that [refrigerator mothering] too because I was the one who stayed at home with him for the first twelve months so maybe I did not bond with him well enough

M.E.: Where did you get that from-this kind of- did you read about it?

Leanne: Yeah I did read about it and that we moved on from that you know we no longer think that that is the case but still at some stage they did think that was the case and maybe there is something to it (...) maybe I wasn’t doing a very good job in those first very formative few months

The second mother, Pauline, portrayed the “refrigerator mother” discourse as still being present in the society, and talked about the emotional impact it had on her, including low mood and lack of confidence.

Pauline: I had a neighbour come knocking on the door (...) and she gave me this book and she was a [staff member at a higher educational institution] and I read this book and it was damming of the parents you know all this the parents fault and problem and everything else (...) it was about this um refrigerator mother syndrome and you know it was um the parents all the parents it was a psychological problem and all the parents were it was all it was just totally nuts. (...) I used to get really depressed about all of this and I used to get- and I felt lack of confidence and I did I felt awful I felt you know people think this of me you know they could potentially think this of me and it used to make me feel awful you know I thought God that’s so not right you know what I mean God almighty (emphasis in the original)

While Leanne talks about her acceptance (albeit tentative) of the mother-blaming discourse of psychogenic causation of autism and blames herself for “not doing a very good [mothering] job” in the first “formative” months of the child’s life, Pauline chooses to actively resist blame, asserting her identity as a good mother. In her account, she describes how she returned the book, declaring that it was “totally incorrect” and “not even near the truth”, and suggested that her neighbour familiarised herself with the current (correct) biological explanations of autism instead.
Unwanted answers: The benefit of not knowing

Stephen: nah can’t say that I basically care what causes it (…) it’s not that I don’t care about the problem for myself and indeed for other people but it’s just yeah not of interest to me as to what caused it

Vicki: (…) I really don’t want to know the answer to that

As discussed above, the parent-blaming implications of both genetic and environmental constructions of the causes of autism in parental accounts were frequently associated with a “negative emotional response” – the feelings of guilt, self-blame, and failure. In their accounts, parents used a number of strategies to manage their identities and negotiate blame. They prioritised one discourse over the other, deployed contradictory statements to negotiate meaning and position themselves beyond the reach of blame, or avoided the topic of causation altogether (for example, by constructing causes as “unknown” without further elaboration). Some parents accepted the invitation to self-blame inherent in the discourses of autism causation, others – actively resisted it, refusing the subject position of a “bad parent” responsible for the child’s problems.

Many parents in this study portrayed thinking about the causes of their child’s autism as a stressful and worrying activity, an unhelpful and pointless “dwelling on the past”, which could potentially generate more guilt. Therefore, purposeful avoidance of searching for answers, which could result in “knowing” the causes and generate self-blame, became a frequently reported strategy to deal with an emotionally difficult topic, a way of self-care and saving emotional and mental energy to invest into childcare and remediation. Declaring the topic of causation to be “of no interest” served the purpose of reinforcing participants’ intention to avoid the stress associated with its exploration and to guard against “knowing too much”. Reframing the development of the disorder as “an accident”, “a bad luck” or even “a statistic” that “has to happen” was reported by some of the participants to be another helpful way of stopping themselves from engaging with the emotive topic.

Christopher: I’m not interested whatsoever in the cause because that’s how it is really (…) maybe it helps me dealing with things better it’s almost like

(Heiman, 2002, p. 163)
the diagnosis itself is such a big thing to take on that I haven’t got
time to invest in all this worrying about what caused it you know
(emphasis added)

Sarah: I didn’t know that we could gain much by trying to find out exactly
apart from knowing vaguely (…) I don’t know what we can gain by
knowing too much about it (…) we can’t do anything about it um yeah
(emphasis added)

Vicki: you know stuff just happens in this world and I don’t really need to
know why I don’t personally need to know why it’s actually not
probably very helpful with my life um /M.E.: stressful/] yeah (…) and
you know you can point the finger at all you like but at the end of the
day it’s not gonna change Tyler it’s not gonna um it’s just going to
probably bring more guilt onto me which I don’t need um so I really
couldn’t care why to be honest I don’t I don’t even go there in my
mind cause it’s just yeah- I try and cut myself a little slack in that area
(laughs) and just say it was just- it was an accident like you know
that’s how I feel about it (emphasis added)

Pauline: [a relative] was good about it I remember him once saying to me (…)
it’s just like bad luck he said it’s a statistic…so many people will get
this so many people will get that because that’s statistically what has
to happen you know… and I thought that’s so true

It is noteworthy that the constructions discussed above co-existed in the accounts of two
participants (Vicki and Pauline) with a well-articulated causative model of their child’s
autism. Vicki portrayed the causes as genetic (inherited), while Pauline associated her
son’s problems as resulting from a broadly described genetic susceptibility triggered by
a “snowball” of environmental insults. Both mothers talked about feelings of guilt and
self-blame for being in some way “responsible” for the child’s disorder and described
their way of managing these negative emotions via refusing to engage causative
discourses (either genetic or environmental) and construing the child’s autism as an
“accident” or a “statistic”.

85
Concluding comments

As discussed in Chapter 3, the ‘expert’ body of knowledge of funded research and peer-reviewed scientific publications portrays the causes of autism as predominantly genetic, with environmental factors (most commonly vaccines) being the domain of print media. Some authors argue that the genetic view of autism has “taken hold” in both professional and public circles (Bumiller, 2009, p. 878), narrowing “expert” and lay perspectives, and distracting attention from the multiplicity of non-genetic factors behind the disorder. Researchers have also suggested that parents of children with autism may favour the genetic discourse of causation as it enabled the responsibility for autism to be shifted “away from their [parents’] actions and toward factors that are not under their control” (Gray, 2002, p. 746, see also Avdi et al., 2000). The data in this study, however, show that the parents neither over-emphasise the genetic discourse in a reductionistic manner at the expense of the environmental explanations, nor do they favour it. The genetic and the environmental discourses of causation were present in parental account in almost equal proportions. With the genes portrayed as conveying broad susceptibility, rather than total causality, the environmental factors took on the role of triggers or “insults” necessary for the disorder to develop. Nadesan (2005) describes such constructions as being “fundamentally systemic” since “the generic susceptibility alone is not seen as the sole source of autistic symptoms” (p. 168). Far from being responsibility-free, genetic discourse of causation was frequently associated in parental accounts with guilt and self-blame: the genetic mode of transmission of autism was portrayed almost exclusively as hereditary, and passing on to the child one’s own genes, construed as faulty, was in many cases synonymous to “failing” as a parent.

The construction of genetic link as a propensity for some sort of physiological dysregulation, given that environmental risk factors for autism have so far been significantly under-researched, creates the potential for the list of candidate environmental culprits to become almost endless (Nadesan, 2005). Multiple candidate factors (on their own or in combination with other factors) were construed in this study as having the potential to bring about or worsen the symptoms of autism in the child who was depicted as inherently vulnerable. In the words of the participants the environmental trigger “can be anything, anywhere, at any time”. Dominant discourses of procreation and mothering in the Western society link the child’s disability to
maternal behaviour and conscious choices made around pregnancy, assigning full responsibility to the mothers should things with the child go wrong (Landsman, 2009). This was reflected in parents’, in particular – in mothers’ constructions of their responsibility and guilt for either exposing the child to or not protecting him from environmental risks of biological nature (e.g. maternal “unhealthy” diet choices, maternal viral infections, environmental toxicants in the child’s environment etc.). Although many years have passed since the “psychiatric misadventure” (Folstein, 2008a, p. 173) in the history of autism, when mothers where blamed for causing the disorder in their offspring through emotionally-distant child-rearing style, the data in this study show, that even today the discourse is still present in maternal accounts, albeit infrequently. Landsman (2009) points out that maternal responsibility for disability, including autism, “has not abated since that time but rather has been expanded to, and now focused upon, the gestational period” (p. 21). Based on the current study, maternal responsibility for autism incorporated psychological, genetic and bio-environmental factors: apart from issues of bonding and child-rearing style, mother-blame expanded to incorporate responsibility for failing to provide “perfect” pre-peri- and postnatal physical environment, and passing on faulty genes (the latter responsibility being shared with the child’s biological father and extended family). Parents used various strategies to actively resist discursively imposed responsibility and blame and negotiate their identities as good parents. Nevertheless, as the dominant genetic and environmental discourses of causation assign responsibility for the child’s autism to the parents, it is not surprising that parents managed the burden of such responsibility and the feelings of guilt and self-blame by avoiding “knowing too much” about causal pathways, and discursively prioritising remediation over causal explanations.

I have discussed how parents of children with autism accounted for the causes of this condition drawing on the current and past medico-scientific knowledges of autism etiology. I have argued that both the genetic and the environmental discourses of autism relegated parents to devalued subject positions that conferred responsibility and blame constructing parents as culpable for ‘producing’ less-than-perfect children. In the following chapter, Chapter 5, I will build on the analyses presented here to explore the issue of stigma in autism. I will also demonstrate how discourses of disability, “perfect children”, and parental responsibility for childbearing and childrearing work together to create stigmatised subject positions for parents.
Chapter 5:  
“The Differences that Matter in People’s Lives”: Parents of Children with Autism Negotiating Stigma

… The role of social stigmatization for both parents and children with autism is often represented as the most painful aspect of the disorder…. Family members of people with autism do experience considerable social stress and emotional exhaustion. Thus, the differences that are organised and labelled by the idea of autism are differences that matter in people’s lives (Nadesan, 2005, pp. 196, 210, emphasis in the original)

(…) you want to say “but it’s autism…but of course you don’t want to do that because that’s going to single him out…make it even harder for him to play with other kids. So you know… it- there’s always situations like that where the stigma is attached (Eric)

Introduction (a “writing story”)

My interest was first drawn to the exploration of the concept of stigma in relation to autism during the time of my work as an ABA therapist prior to starting my training as a clinical psychologist. The job involved spending lengthy periods of time (from two to three hours at a time several times a week) working with children with autism and their families both in their homes and in various community settings in Auckland. I couldn’t help but notice that for many parents taking their children out to do different things in the community (e.g. going to the zoo, local park, supermarket, doctor’s surgery, visiting extended family and friends) was a major source of stress often resulting in a variety of negative emotions. It appeared that the increased amount of stress was not solely due to these activities being associated with a higher level of the “routine hassles” of caring for a child “whose disability creates disruptive behaviours and/or needs for assistance with activities of daily living” (Green, 2003, p. 1362). The typical “routine hassles”, such as the (often complex) logistics of the trip, although undeniably a significant source of strain, were mostly anticipated and prepared for. In many cases the child’s behaviours in social situations, albeit unusual, such as continuous humming or a singular fascination with a ceiling fan in a museum, could hardly be considered ‘disruptive’. For younger children even some of the ‘disruptive’ behaviours such as a tantrum or hitting
another child in the playground were developmentally not ‘abnormal’. Nevertheless parents often appeared anxious and reluctant to take the child out in public, expected to become the focus of public scrutiny and criticism, even when among friends and family members, and described the general public in ways that portrayed people as hostile (“rude”, “staring”, “disapproving”, “judging”). They talked about feeling “uneasy”, “embarrassed”, and “awkward”, when the child’s behaviours, even mildly different from the taken-for-granted ‘norm’ could be observed by others, but also when others became aware of the child’s diagnosis. On more than one occasion I saw mothers in tears and fathers visibly upset following a public outing with a child. The following excerpt from the current study, a mother’s portrayal of her experience of “being in public places”, tells a story very similar to the ones that I had heard from parents time and time again.

Julie: I never could have anticipated (...) the stresses around that - being in public places and and and comments and looks and disapproving glances and all that sort of stuff from members of the public (...) so that was- it caused a huge amount of stress and inevitably I would just come home a complete mess just yeah stressed and in tears and yeah so (laughs) it has been very very stressful (emphasis in the original)

The disclosure of the child’s diagnosis (when, how, and to whom) was an emotive and at times hotly debated topic. For some parents, it was associated with a considerable degree of reluctance and unease about using the diagnostic label, sometimes even with friends or extended family members.

The experiences described above, particularly the anxiety about becoming a focus of negative social judgement, rejection, and feelings of embarrassment experienced by parents genuinely concerned and at the same time puzzled me. On numerous occasions when I worked with the children in a variety of community settings I could not recall ever feeling embarrassed, even in those situations when a child happened to become the centre of public attention as a result of his/her unusual ways of interaction or non-typical behaviours. The looks from the members of the public the two of us attracted did not feel anything like “overtly hostile staring” (Gray, 2002, p. 741), rather I
interpreted them as inquiring glances of people trying to understand what was going on. Although I was aware of the societal discourse of stigma associated with being a parent of a child with disability, my own ‘safe’ identity as a mother formed through my non-disabled son shielded me from its negative impact and prevented me from understanding the impact of this discourse on parents of children with autism. The reason why I did not feel embarrassed and anxious about the negative reactions of others was because the child, displaying all these unusual behaviours, was with me but not of me\(^{29}\) – I was not the child’s mother.

**Theoretical overview**

This chapter examines parental talk of stigma being associated with having a child with autism. Since Goffman’s (1968) highly influential essay *Stigma: Notes on the Management of Spoiled Identity*, the construct of stigma has generated a wealth of theoretical and empirical research theorising its sources, nature, and consequences. As Yang, Cho, and Kleinman (2008) observe, the concept of stigma has not been “confined to a strict definition” (p. 219), but rather has been understood through the variable formulations of a number of leading theorists. Although most formulations of stigma share common features, they also reflect various disciplinary perspectives (e.g., sociology, social psychology, evolutionary psychology, anthropology) and the theoretical orientations of the authors (Yang, et al., 2008). A comprehensive review of the various existing definitions of stigma is outside the scope of this chapter. However, in order to introduce the formulation of stigma used in this research, I will briefly discuss the changes in stigma theorising in terms of its ‘location’, from “a construct largely grounded in the individual to one rooted in social space” (Yang et al., 2007, pp. 1524-1525).

Goffman (1968) in his classic sociological essay defines stigma as “an attribute that is deeply discrediting” (p. 13). Although he refers to such attribute as something that a person “possesses”, he also emphasises that stigma belongs within a “language of relationships” (p. 13, emphasis added) – specifically, that it is “a special kind of

\(^{29}\)Kenneth Burke writes: “The offspring is substantially one with the parent (…) and its status of offspring of this parent rather than that keeps it consubstantial with the familial source” (1962, p. 405, emphasis in the original). “(…) The child is at once outside them [the parents] and of them” (1973, p. 45). Quoting the latter statement, Avery (1999) argues that “whereas most parents take personal gratification in compliments of their children (…) parents of children with disabilities may take personal blame for their less-than-perfect ‘production’ ” (pp. 116-117).
relationship between attribute and stereotype” (p. 14). More importantly for the purposes of the current study, he posits that stigma constitutes a discrepancy between “a virtual social identity” (societally defined characteristics “felt to be ordinary and natural” for members of certain social categories) and “actual social identity” (the attributes a person “could in fact be proved to possess”) (pp. 11-12). Such discrepancy “when known about or apparent”, “spoils” the individual’s social identity (p. 31). From this perspective, for instance, a middle-class mother of three, who for the members of her social circle and her wider community epitomises ‘perfect’ (caring, devoted, selfless, and responsible) motherhood would likely be stigmatised if it became known that in her late teens she gave birth to a child whom she adopted out and have never seen since. Goffman (1968) also introduces the concept of “courtesy stigma”, arguing that stigma tends to “spread from the stigmatised individual to his close connections” (p. 43), including the family members. This term has since been frequently used in stigma research, mainly in relation to parents and other family members, to define the stigma of affiliation with a stigmatised other (e.g. Albrecht, Walker, & Levy, 1982; Birenbaum, 1970, 1992; Koro-Ljungberg & Bussing, 2009).

Another influential formulation defines stigma as arising when “individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context” (Crocker, Major, & Steele, 1998, p. 505). In this social psychological formulation Crocker et al. (1998) incorporate and emphasise the social context of “whether and how a stigmatized attribute devalues an individual” (Yang, et al., 2008, pp. 219-220). Since the publication of Goffman’s (1968) study, there has been a rapid growth of research on stigma applied to a broad array of circumstances, including leprosy, cancer, mental illness, physical disability, being a lesbian mother etc. (Link & Phelan, 2001). This body of work later received criticism for some “serious conceptual limitations” (Parker & Aggleton, 2003, p. 15).

Link and Phelan (2001) pointed out the variability and vagueness of the definition of stigma, calling it “a curious feature” of literature on stigma (p. 364). They noted that researchers tended to either completely omit explicit definitions of stigma in their studies, use a dictionary definition (such as “a mark of disgrace”), or use a related aspect of stigma (such as negative stereotyping or rejection) to introduce the concept. Parker and Aggleton (2003) drew attention to an individualistic emphasis in many of the published stigma studies, which they explained by the strong social-cognitive focus.
adopted in stigma research. Many studies focused on people’s perceptions, the consequences of these perceptions for micro-level personal interactions, and on stereotyping, while paying less attention to the structural conditions and power relations in the society. Stigmas, therefore, came to be seen as something in the stigmatised individual rather than a designation or tag that others attached to the individual (Fine & Asch, 1988; Link & Phelan, 2001). As Oliver (1990) put it, discussing stigma studies of disability:

“Stigma is still reduced to individual adaptation…. The idea that individuals might confront, reject, or ignore, as a deliberate strategy, their stigmas rather than cope with them, is not even considered. Stigma is all embracing but still an individual problem” (p. 67, emphasis added).

For the purposes of this research, discussed in Chapter 1, Oliver’s (1990) critique is particularly important as it emphasises the need to depart from the pathologising “stigma vs coping/individual adaptation” model, locating stigma within the individual. Importantly, Oliver (1990) affirms the role of individuals in actively managing (“confronting”, “rejecting”, or “ignoring”) stigmas that exist in the domain of the social to negotiate their subjectivities.

Addressing the issues raised in these critiques, Link and Phelan (2001) developed a sociological definition of stigma as a broad umbrella concept, linking six interrelated components. The first four components – labelling human difference, stereotyping, cognitive separation of labelled individuals from ‘normal people’, and emotional reactions engendered by stigma – relate to social processes in the socio-cultural environment “whose effects can be observed within the individual” (Yang, et al., 2007, p. 1525). Yet the fifth and the sixth components – status loss and discrimination within the context of power differential – emphasise institutional practices and power relations in the society. Yang et al. (2007) built on this work by adding the concept of “moral experience” to stigma theory. Defining moral experience as “what is most at stake for actors in a local social world”31, the authors hypothesise that “stigma exerts its core effects by threatening the loss or diminution” of what really matters for the sufferers in

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30 The latter was added in a later publication (Link, Yang, Phelan, & Collins, 2004) and included the emotional responses and reactions of both the stigmatisers and the stigmatised.

31 In Yang et al.’s (2007) formulation “a local world” represents “a circumscribed domain within which daily life takes place”, e.g. a social network, a neighborhood, a work environment, an interest group etc.
their daily life, such as relationships, status, money, life opportunities, or a job (p. 1524).

As mentioned above, stigma is “a vibrant topic” in research literature addressing a broad variety of human characteristics from being a welfare recipient to racial and ethnic differences (Hinshaw, 2006, p. 843). Based on the search of the titles of journal articles indexed in Psycinfo every five years from 1955 to 2005, Phelan, Link, and Dovidio (2008) found that the overwhelming proportion of articles on stigma (92%) dealt with illness, disability and “behavioural and identity deviance”\(^\text{32}\). Research on stigma that focused on families of children with disabilities has been less common, although there exist a small body of research exploring this topic (e.g. Baxter, 1989; Birenbaum, 1970, 1992; Green, 2003; Green, Davis, Karshmer, Marsh, & Straight, 2005; Voysey, 1972). ‘The stigma of autism’ and its negative impact on the parents is frequently mentioned in popular and professional discourse, such as in the published parental narratives or various guides for parents and professionals (Boucher, 2009; Dillon, 1995; Grinker, 2007; Ives & Munro, 2002; Ozonoff, Rogers, & Hendren, 2003). Studies on autism report that professionals involved in the diagnostic process consider the diagnosis to be stigmatising (Nissenbaum, Tollefson, & Reese, 2002) and in some cases, because of that, and in anticipation of parents’ negative reactions, they are “afraid to bring up the word” (Kennedy, Regehr, Rosenfield, Roberts, & Lingard, 2004, p. 391). The forthcoming study by Bernier, Mao, and Yen (in press) encourages clinicians to consider the stigma associated with autism “at the societal and cultural levels” and be aware “of their own cultural biases on how autism is characterized and treated” (p. 9).

Despite this, the research on stigma as applied to autism is very limited. At this point of time, there have been only four studies focussing specifically on this issue (Farrugia, 2009; Gray, 1993a, 2002; Mak & Kwok, 2010). Some studies (e.g. Avdi, et al., 2000b) discussed the issue of stigma in autism as part of a wider topic (in this case – parents constructions of the ‘problem’ during assessment and diagnosis of their child). Gray’s (1993b, 2002) and Mak and Kwok’s (2010) research was conducted from a positivist perspective. Despite some references to the wider social context, the focus of these studies are mainly individualistic, that is stigma is seen as located \textit{within the individual} (see discussion at the beginning of this chapter) as something that an individual \textit{has}

\(^{32}\) The authors explain that they use “deviance” not as a pejorative term, but in the traditional sociological sense of deviation from societal norms.
(and the researcher purports to uncover\textsuperscript{33} and needs to cope with. Mak and Kwok’s (2010) study, for example, is entitled “Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong” (emphasis added). The studies by Farrugia (2009) and Avdi et al. (2000b) used a social constructionist approach, which allowed them to view stigma not as an attribute of an individual but as a social construct created by the dominant societal discourses of deviance and disability, and therefore to avoid pathologising implications of the positivist framework. In the section below I will discuss some of the relevant findings of the research on stigma in autism in more detail.

Gray’s (1993a, 2002) qualitative analyses of the interviews with parents of children with autism (including “high-functioning” autism) showed that the majority of parents “perceived themselves to be stigmatised by their child’s disorder” (Gray, 1993b, p. 102). He concluded that autism had “uniquely stigmatising aspects” due to a discrepancy between the children’s normal physical appearance and their highly disruptive (“antisocial”) behaviours in the context of the lack of public knowledge about this condition (p. 102). In his 2002 study, Gray used Scambler and Hopkins’ (1986) typology of felt versus enacted stigma to analyse parental experiences of ‘courtesy stigma’. Scambler and Hopkins (1986) in their study of stigma in epilepsy define enacted stigma as “instances of discrimination” against individuals “on the grounds of their perceived unacceptability or inferiority” (p. 33). They consider felt stigma to be a more complex phenomenon, referring mainly to the fear of enacted stigma, but also encompassing a feeling of shame associated with having a stigmatised condition\textsuperscript{34}. The felt versus enacted stigma typology has since been frequently used in research on stigma in relation to a broad variety of human characteristics (Jacoby, 1994; Lekas, Siegel, & Schrimshaw, 2006; Saewyc, Poon, Homma, & Skay, 2008).

Gray (2002) discusses ‘courtesy stigma’ in terms of the “success or failure of the individual in maintaining a ‘normal identity’” (p. 737, emphasis added). He posits that enacted stigma indicates that “the individual with the courtesy stigma has failed to achieve a normal appearing round of life”, while the experience of felt stigma signals

\textsuperscript{33} Note, for example, the title of an Honours thesis – “Uncovering the Stigma in Parents of Children with Autism” (Wnoroski, 2008).

\textsuperscript{34} Scambler and Hopkins (1986) posit, for example, that in their study “respondents felt ashamed fundamentally because they interpreted being epileptic as an infringement against what Goffman (1968, p. 152) has called “norms of identity or being”.

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“an individual’s fear of [such] failing” (p. 737, emphasis added). Gray (2002) found that a large majority of parents reported both types of stigma, with the parents of children who displayed more aggressive behaviours being more likely to feel stigmatised. He described three forms of enacted stigma experienced by parents: avoidance by others, overtly hostile staring, and rude comments. Felt stigma, which was found to be more commonly experienced than the enacted stigma, was strongly associated with parents ‘imagining’ that others were critical of their child-raising abilities and were not accepting of them, and commonly manifested itself as the feeling of embarrassment. Notably, Gray (1993b, 2002) found that: (a) stigmatisation, albeit widespread, was not universal and that some parents “denied being stigmatised by their child’s autism” (1993b, p. 114), (b) mothers reported feeling more stigma than the fathers, and (c) that the conceptual distinction between felt and enacted stigma might need to be reconsidered as parents often conflated the two types, and “had trouble distinguishing between the two without being prompted by the interviewer” (2002, emphasis added). The latter point is particularly significant as it raises an important question in relation to Scambler and Hopkins (1986) dichotomy. Although Scambler and Hopkins (1986) define felt stigma as an individual internal experience (“an internalised sense of shame” (Scambler, 2008, p. 209)), and enacted stigma as instances or acts of overt stigmatisation/discrimination (by others), what is at the core of both definitions (and what constitutes the focus of research in the area) is the experience of a stigmatised individual. For example, what Gray’s (2002) study discusses in relation to enacted stigma are parents’ experiences of being stared at, avoided, and receiving comments about their child’s behaviour. It is also questionable that enacted stigma can be conceived of as ‘existing’ separately from the felt one, namely research participants would likely not describe a certain behaviour of others as stigmatisation or discrimination had they not felt that they were being stigmatised. Even those researchers who claim that the Scambler and Hopkins’s dichotomy is valid recognise that in their participants’ reports “felt stigma….preceeded….. episodes of enacted stigma” (Jacoby, 1994, p. 207).

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35 Gray hypothesised that this could be explained by “a link between perceived responsibility and perceived stigma” (1993b, p. 115) and that mothers, who were usually considered to be the parent with the highest degree of responsibility for the child, often experienced guilt for the child’s disability (2002, p. 744).
Using a social constructionist approach to analyse the talk of three sets of parents whose children were diagnosed with autism, Avdi et al. (2000b) associated stigma with the discourse of disability, which positioned the disabled child as a different and/or deviant ‘other’. They found that the parents in their study drew on this discourse in their considerations of managing the child’s stigmatised identity. The latter was construed in Goffman’s (1968) terms as “possibly spreading to the whole family as a ‘courtesy stigma’” with the likelihood that the parents might experience “rejection, avoidance or ridicule” (Avdi, et al., 2000b, p. 250). In another recent exploration focused specifically on stigma constructions by parents of children with autism, Farrugia (2009) attempts to “reconstruct the meaning of stigma” in an effort to move beyond the individualistic and micro-social emphasis of previous (positivist) stigma concepts (p. 1014). He bases his paper on the premise that “stigmatisation concerns identity construction in the context of social control” (p. 1014), considering ‘the norm’ (the unspoilt subject position) as well as ‘the abnormal’ (the spoiled subject position) to be produced by the dominant societal discourses. Unlike Gray (2002), whose definition of ‘courtesy stigma’ cited above, places at its core individual’s failures to appear ‘normal’, Farrugia’s (2009) study conceptualises stigma as socially produced. Rather than talking about strategies of coping with stigma, which implicitly reinforces the view of stigma as a ‘fact of life’, an unavoidable ‘reality’ whose ‘existence’ must be accepted and ‘coped with’, Farrugia (2009) focuses his analysis on ways of resistance to stigma which are performative and discursive. Within this framework, and using the Scambler and Hopkins’ (1986) typology of felt and enacted stigma, he defines felt stigma as “the experience and articulation of a subject position discursively constructed as ontologically inferior (in Goffman’s terms, “spoiled”)” and enacted stigma as “an overt political/discursive act of power for the purposes of social control which attempts to position the stigmatised as spoiled” (pp. 1014-1015). Somewhat surprisingly, although all the parents in Farrugia’s (2009) sample reported experiencing enacted stigma (construed as changes in the parents social circle, such as loss of friendships, “looks” or “glares”, and unsolicited advice about parenting by the members of the general public in response to the child’s disruptive behaviours), the author argues that felt stigma in his sample was “extremely rare”. Many parents “resisted felt stigma”, using certain discursive strategies (in this case – deploying medical discourses of autism as an illness), and claimed an unspoiled subject position. Farrugia (2009) concluded that such a position cannot be described as
stigmatised. Put simply, he argued that where “felt stigma remained successfully resisted” by parents, it was not present at all (p. 1024).

In the section above, I have provided a brief theoretical overview of stigma research and discussed several influential formulations of stigma by a number of leading theorists. I traced the development of stigma theorising in terms of its “location”, from an attribute that a person “possesses” to a discursively produced subject position. I have reviewed the available literature on stigma in relation to parents of children with autism, highlighting the limitations of a positivist paradigm within which much of the research has been conducted. I have emphasised the pathologising implications of conceptualising stigma as something ‘real’ that an individual ‘has’. In particular, I have pointed out that such understandings construe the experience of stigma as being dependant on the ‘success’ or ‘failure’ of a person not to ‘reveal’ his or her ‘true’ (‘spoiled’) identity, therefore implicitly blaming the victim of stigmatisation for being and/or feeling stigmatised. I have also discussed the studies that counter individualistic focus of positivist research on stigma by approaching the issue from a social constructionist perspective. My work that is presented in this chapter takes off from this research.

**Methodological and analytic points. Definition of stigma**

The analyses of parental talk in this chapter are aimed at addressing the general lack of research on stigma as applied to being a parent of a child with autism. My main analytical focus is to make explicit the processes by which parents “come to describe, explain, or otherwise account for” their experiences and meanings of stigma (Gergen, 2003, p. 15) with the intention to “de-inevitabilise” a number of taken-for-granted assumptions commonly present in positivist research and professional literature. Importantly, I will argue that ‘courtesy stigma’ does not inhere within parents of children with disability in coping with which they either succeed or fail (see discussion above).

Professional and research literature on parents of children with disabilities as well as literature conveying ‘expert’ knowledge for lay audiences often construct parental feelings of guilt and self-blame for the child’s problems as “natural and normal”

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36 (Hacking, 1997, p. 2)
("Autism spectrum disorders: Factsheet," 2008, emphasis added). Waechter (1970), for example, states that “all parents are deeply concerned when their child varies significantly from the normal” (p. 202), which results in the feelings of shock, shame, embarrassment, guilt, and personal failure. The author then recommends that a nurse helps a mother to understand that her feelings are “natural” (p. 209). In this chapter I set out to demonstrate that for parents to feel guilty and blame themselves for the child’s disorder is neither “natural and normal” nor is it “irrational”37, but that these feelings are socially induced and rooted in societal discursive practices of the day.

Building on my analyses in Chapter 4, in this chapter I will also argue that biomedical attribution of the etiology of autism does not necessarily mean that “parents stand absolved of parental failure” (Nadesan, 2005, p. 197). Additionally I will demonstrate that contrary to the popular constructions of support groups for parents of children with disabilities, including autism, as “a setting in which they felt relaxed and ‘normal’, as opposed to feeling isolated from society and stigmatized” (Solomon, Pistrang, & Barker, 2001, p. 124), attending a support group does not always reduce parental stress, isolation and feeling of stigma.

In my exploration of stigma I use a discourse-analytic approach informed by social constructionism as outlined in detail in Chapters 1 and 2. In terms of this approach, in my analysis of parental talk I am not searching for ‘true’ fixed meanings (Nichols & Foster, 2005), but focusing instead “on the linguistic and social construction of reality, on interpretation and negotiation of the meaning of the lived world” (Kvale, 1992, p. 35).

Taking into account the critiques of the individualistic focus of stigma research discussed above, I consider a constructionist perspective, which views meanings, experiences and identities as socially produced, and which takes an anti-essentialist stance that “there are no ‘essences’ inside things or people that make them what they are” (Burr, 1995, p. 5) particularly suitable for the study of stigma. In this chapter I use the form of discourse analysis proposed by Wetherell (1998; see also Wetherell & Edley, 1999) which combines “the emphasis on the action orientation of people’s talk”

37 From psychoanalytic perspective, Simpson (2005), asserts that parental reactions to the child’s learning disability, such as “painful sense of guilt” or the expectations of being blamed by others are “a defense against a more fundamental and irrational feeling that they have caused the disorder” (p. 105, emphasis added).
(Wetherell & Edley, 1999, p. 338) and “the rhetorical strategies used to make and counter claims” (Lafrance & Stoppard, 2006, p. 129) with the attention to macro-level discourses\(^{38}\) available in a particular cultural context, discourses “which have a history and which imbricate power relations” (Wetherell & Edley, 1999, p. 338).

For the purposes of the current exploration and addressing previous critiques of stigma research calling for clarity of the definition of the term (Link & Phelan, 2001) I define stigma as a subject position socially constructed as being outside of or in opposition to the existing dominant (normative and culturally valued) discourses of identity and experienced as adverse. Using Weedon’s (1997) conceptualisation of discourses as patterns of meaning that “constitute the ‘nature’ of the body, unconscious and conscious mind and emotional life of the subjects which they seek to govern” (p. 108), I emphasise the lived-in moral-emotional dimension of stigma (Link, et al., 2004; Yang, et al., 2007), whereby it affects people’s daily existence in their local social world, threatens their valued social identities (such as an identity of a responsible, competent and caring, and therefore ‘good’ parent), and is experienced as a range of negative emotions including embarrassment, shame, fear and anger. Therefore, as indicated by the first epigraph to this chapter, it focuses on the social construction of differences that really matter in people’s lives. Finally, in line with Gray’s (2002) findings that parents did not differentiate between the concepts of felt and enacted stigma, experiencing them as “varying manifestation of the same negative experience” (pp. 747-748), I do not consider the two notions as being conceptually distinct. In my approach to stigma it is conceptualised as always enacted through the constitutive power of the dominant discourses constructing individuals as devalued ‘others’, and felt as a result. Whether or not the ‘overt acts’ of stigmatisation take place, and what exactly gets constructed as instances of overt stigmatisation is in essence secondary to the idea that stigma is (first and foremost) enacted through the power of discourse. Unlike Farrugia (2009) who regarded felt stigma and parents’ resistance to it mutually exclusive, I propose that the former is the necessary precursor to the latter; put simply in order to resist something one first needs to experience its (adverse and morally important) effects. To differentiate between the stigma of the diagnosis of autism (and the identity of a child labelled autistic) and the stigma of “bearing and raising” (McKeever & Miller, 2004, p.

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\(^{38}\) The term used by Yardley (1997a).
such a child, embedded in the rhetoric of parental responsibility, I will refer to the latter using Goffman’s (1968) term ‘courtesy stigma’.

“Un-cool condition”: Parental constructions of the stigma of an autism diagnosis

Autism. It conjures up images of a solitary, mute, rocking child. (Overton, 2000, p. 221)

It’s not one of the coolest things to have anyway (laughs). If you had to be struck down with something I’d rather it not be autism (Lora)

Avdi et al. (2000b) report that parents in their study drew on the discourse of disability in their talk about the diagnosis of autism and their child’s “differentness”. Quoting Shakespeare (1994) the authors describe the discourse of disability as locating “the disabled child as ‘other’ and raising issues of deviance, differentness, and stigma” (p. 250). They argue that following the diagnosis of autism the child can “no longer be constructed as ‘normal’ as the two categories have mutually exclusive membership” (p. 250). Landsman (2005) also highlights the mutual exclusivity of the normalcy-disability binary with the diagnosis signifying the discursive re-assignment of a child from the former category to the latter. In their talk about autism and its public image, the parents in this study also deployed the negative discourse of disability, which associated it with abnormality, “deviance, damage, and dependence” (Corker, 1998, p. 221) and reflected negative stereotypes that devalued, stigmatised, and marginalised individuals with disabilities

39 Within disability studies this discourse is often associated with the widely criticised individual or medical model, which “highlights pathology and deficit within the individual, with little attention to the role of environment” (Prilleltensky, 2009, p. 265)40. Writing more than 15 years ago and based on Australian data, Gray (1993b) argued that autism had “uniquely stigmatising aspects” which could partly be attributed to the lack of public awareness and understanding of the disorder (p. 102). Parental accounts in this study still constructed

39 See also Marks (1999), who cites the definition of disability by the World Health Organization as “any restriction or lack – resulting from an impairment – of ability to perform an activity in the manner or within the range considered normal for a human being” (p. 53, emphasis added)
40 Conversely, the social model locates disability not within the individual, but “in an excluding and oppressive social environment” that fails to accommodate human difference (Marks, 1999, p. 79). See Marks (1999) and Prilleltensky (2009) for the discussion and critique of both models.
autism as a poorly understood condition about which general public (including parents themselves prior to and at the time of the diagnosis) had very limited knowledge. As a shorthand for the public (and their own pre-‘expert’) view of the diagnosis of autism, parents used two images. The first one (further referred to as ‘the child in the corner’) represented a child who is emotionally disengaged, unaffectionate, non-verbal, intellectually impaired, and engaging in repetitive or self-injuring behaviours, which some parents referred to as the “classic” image of autism. The second image (“Rain Man”, (Levinson, 1988)) indexed a Dustin Hoffman’s characterisation of a person with autism, portrayed in the film as significantly disabled despite the “spectacularized” savant-skills, incapable of leading independent life in the society, and belonging in an institution⁴¹. Parents frequently emphasised that before autism became “part of their lives”, their view of autism had been informed by the same two main images⁴².

Lyn: (...) the only thing I knew about autism was when I was quite young I think I was a teenager I read a book about a girl with autism and it was classic you know kind of rocking in the chair not speaking- and that’s what I thought autism was… that’s all I knew yeah I had no other information (...) the only things I knew about autism was the book I had read oh and Rain Man so that kind of very stereotypical sort of severe autism (emphasis in the original)

Despite being portrayed as negative and stereotypical, ‘the child in the corner’ image of autism was not necessarily rejected as false or inaccurate. For example, in the excerpt below, Gavin, who initially described the image of autism as “someone rocking in the corner watching something spin”, also points out that this was a fairly accurate depiction of his own son’s pre-treatment presentation.

⁴¹See Baker (2008) for a detailed discussion of the definitional power and the discursive impact of the portrayals of autism in feature films, particularly the “spectacularization” of the disorder locating the value of the characters with autism in their savant abilities, and rendering all their other characteristics as worthless and burdensome. Baker (2008) refers to spectacularization as the “most troubling feature” of the film representation of autism, as it constructs the majority of the individuals with autism who have no savant skills as “savant-deficient”, and thus “lacking the key redeeming feature of cinematic autism” (p. 236).

⁴²See also, Singer (1999) who also states that “autism is associated in the public mind with images of rocking, emotionally cut-off, intellectually impaired children and ‘Rainman’-like savants” (p. 63).
Gavin: (...) autism is a lot in TV programmes and stuff now but it’s you know you’d generally see a more severe cases because it makes more interesting TV so- but I mean Ethan might have been like that if we’d never done anything because that’s what he did all day...he didn’t- he’d watch things turn and he would rub his head against the ground that’s what he did all day so you know I’m glad we still don’t have that child

Contesting the constructions of medicine and “medical language of disease and treatment” as objective and value-free, Conrad and Schneider (1992) argue that “to call something a disease is to deem it undesirable” (p. 249). As in Gray’s (1993b) study, insufficient public knowledge (in combination with negative cultural representations, such as ‘the child in the corner’ or the Rain Man images) was portrayed as contributing to the emotionally negative (“scary”) societal view of the diagnosis.

Liz: (...) the word autism was so scary. I think before you know- I mean it’s scary when you know what it is... I think it’s even scarier when you don’t know

Parents in this study emphasised the non-neutrality of diagnostic labels. They frequently spontaneously engaged in comparisons of autism with various other diagnostic labels such as diabetes, cancer or Asperger’s disorder, creating taxonomies based on the social and emotional connotations these labels were presumed to carry. To highlight the negative cultural meaning of autism, some of these diagnoses were portrayed as being far more “socially acceptable” and lacking negative discursive implications. In the first excerpt below, Peter talks about dyslexia and diabetes as being emotionally neutral, and Asperger’s disorder as connoting exceptional intellectual abilities (“genius”) unlike autism, which has powerful negative connotations. In the second excerpt, Lora unfavourably compares autism with cancer. She construes cancer as a familiar, “sociable” disease, which engenders empathy, compassion and charity as opposed to autism, an “un-cool” and “almost socially unacceptable condition” (“weird”, “unpredictable”, “disruptive”), incongruent with societal expectations of normalcy and therefore inducing negative emotions in others, in this case – fear. Significantly, Lora
describes fear as “being attached” to the diagnosis of autism emphasising that the diagnostic label is inseparable from negative connotations.

Peter: *I think it’s a word that immediately conjures up negative connotations for people with autism. If you said to me “she has dyslexia” it doesn’t… if you said “she has diabetes” it wouldn’t (…) it’s just certain things- you get immediate emotional response to something and it’s like that- getting immediately negative image. It’s based on-sure it’s based on the Rain Man but you know but the first thing- I think of someone with autism as someone who wants to bang their head against the wall. I don’t know where that came from um and when you think of people with Asperger’s you think of sort of a genius. And they’re just completely emotional kind of you know subjective responses I’ve got from somewhere… but I think for autism most people have that kind of response to it and that’s kind of the hardest thing about the diagnosis*

Lora: *(…) autism’s a big heavy label that will be very hard to shake (…)*

M.E.: would you say it’s a negative label?

Lora: *it’s definitely a negative label. Before I’d speculated that he would-you know he might be autistic I would have thought of autism as an un-cool condition to have. I mean if you have cancer- if a child has cancer in a very crude way it’s kind of a cool disease to have because people understand it they feel very compassionate they give lots of money to it…they’ll buy you a bandana if you’re raising money for teens with cancer. It’s a sociable thing to have because we all know somebody who’s had cancer and “hey let me give you a hug”- with autism there’s a fear attached to it that this kid is a little weird um likely to be um unpredictable maybe disruptive um ah yeah and it’s almost socially unacceptable condition to have at least that’s the way I viewed it before I considered it part of my life. And I think it’s still the same I still probably feel it’s the same it’s not really socially acceptable is it? Not that diseases or conditions or whatever should
necessarily be I suppose but um it’s not one of the coolest things to have anyway (laughs) if you had to be struck down with something I’d rather it not be autism.

Thus for the parents in this study the diagnostic label of autism was firmly embedded within the discourse of disability with its negative social and emotional connotations, with the diagnosis itself acting as a designator of the child’s “acquisition” of a new devalued identity, or, in Avery’s (1999) terms his or her “deteriorization” from the land of normality. Many parents described the diagnostic label as “limiting”, “boxing the child in”, construing him or her as “a curiosity”, and diminishing the child personhood and individuality. The descriptions of the emotional distress (shock, fear, withdrawal) associated with receiving the diagnostic label in the accounts of some parents were explicitly attributed to the concept of stigma, which many parents brought up spontaneously. (Those parents who did not spontaneously raise the issue of stigma themselves were later asked to share their thoughts on the subject).

Pauline: I knew nothing all I knew was firstly that it was something to be feared (...) that’s all I knew and I was just freaked to the backs…that’s all I knew about it (...) I basically just ended up a nervous wreck and just not coping at all like I say I just kept going sort of I withdrew a lot as well (...) it was like death you know but worse because you were living it. It was almost like an nightmare and you didn’t wake up from it (...) it was just hugely stressful

M.E.: if you look back now what do you think was- what do you think was the most stressful part of it? Because you said it was like a death but worse- what was what was so frightening about it?

Pauline: oh just like … the fear of- my God you know how do you- just the unknown (...) just a huge fear thing and um anything you read or looked up and it all looked so grim you know and I think it was just um yeah the fear of it the stigma of it (emphasis in the original)

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43 Compare with Avdi’s (2005) discussion of a child’s psychiatric diagnosis as a constraining, pathologising, disempowering, and objectifying subject position, which has negative implications for the child’s parents evoking the notions of “parental failure, fault and pathology” (p. 497).
Theorising parental experience of “the label” of autism, Nadesan (2005) suggests that this needs to be considered in relation to the dominant discourses of “the value” of children in the western society in late-twentieth and early-twenty-first century. She argues that children may be valued in relations to: (a) their sentimentality, since in the early twentieth century the role of children as a physical labourers was supplemented by the view of childhood as a special period of life, and (b) future economic potential, the latter necessitating the acquisition of skills to participate in the knowledge-based economy. Therefore in Nadesan’s (2005) view, the children diagnosed with autism are experienced as devalued firstly because the diagnostic criteria construe the child as “lacking social or emotional reciprocity”\(^\text{44}\) (the foundation for “sentimental value”), and secondly because the children often show “abnormalities in the development of cognitive skills”\(^\text{45}\) and may qualify for a diagnosis of mental retardation, losing “value” in terms of economic potential. Similarly, in the current study, parents’ talk about the stigmatising nature of the diagnosis, centered around three ‘attributes’ occurring in both the medical and the popular discourses of autism: cognitive deficits/mental retardation\(^\text{46}\), social unresponsiveness, and violation of normative expectations of social interaction (the latter two, as illustrated above, described as “socially unacceptable”, “weird”, “unpredictable” and “disruptive” features of the disorder).

Sarah: (…) when you say autism it’s a retarded person that’s someone who’s completely in their shell

Sam: (…) I think it’s that sort of mental- something wrong (…) if it’s a physical disability maybe people are a little bit more accepting of it (…) but “oh that little boy he’s mentally” you know “handicapped”- (…) I suppose a bit more of a stigma

Christopher: (…) just the um oh the seclusion the isolation of you know they can’t lead a normal life they have to be in homes and that kind of thing you

\(^\text{44}\) (American Psychiatric Association, 2000, p. 75)
\(^\text{45}\) (American Psychiatric Association, 2000, p. 71)
\(^\text{46}\) See also Prussing, Sobo, Walker, & Kurtin (2005) who found that parents of children with Down syndrome reported the “sense of stigmatization, particularly regarding the associated probability of mental retardation” (p. 592). Landsman (2009) also notes that mental retardation may occupy the lowest position in the “pecking order” of disabilities in American culture.
know if you’re autistic you obviously- like an integration you can’t integrate

Ian: (...) it’s a scary thing when you see ah stimming [self-stimulatory] behaviour (...) the average person is very scared of stimming the stimming behaviour is a scary thing

M.E.: what do you think is scary about it?

Ian: the unpredictability of it and the not knowing of it. They don’t know and they’ve got no idea how to predict what’s going to happen

All these characteristics were regarded as decreasing children’s integration within society and negatively affecting their “futurity” – their “anticipated value, well-being and productivity as adult citizens” (McKeever & Miller, 2004, p. 1182), which was reflected in parental talk. In the excerpt below, for example, Stephen engages in an exploration of his emotional response to the child’s diagnosis and his felt need to explain the child’s differentness to others. He purposefully resists the word “embarrassment” due to its negative connotation, and uses the word “weird” to convey the novelty of and uncertainty about his feeling of apprehension, unease and protectiveness (“defensiveness”) about the child’s future.

Stephen: (...) it is a funny- it is funny kind of feeling (...) ah it’s not embarrassing it’s just yeah weird /M.E.: weird/ yeah /M.E.: in what way? / ah ... oh ... ah [speaks very quietly as if to himself] why is it weird- no cause I am not embarrassed about that you know I’m totally you know he’s the best kid you can ever get cause it’s like this is how much he means to me kind of thing and um so I am not embarrassed about him but I just feel for him for his future and what um problems he’ll come up against and stuff (...) you just kind of feel defensive for him (…)

Although, like Stephen, many parents talked about their fears and concerns in relation to the child’s future, the emotional impact of the stigmatising diagnostic label was mostly described as being felt in parents’ current day-to-day life in their local social world, for
example in communications with other family members, friends, acquaintances, work colleagues, at a local playground, at coffee group meetings etc.

In the excerpt below, Stephanie portrays the diagnosis as transferring both her son and herself into the category of the “weird” that “normal” others are likely to avoid and reject. As the disability discourse that Stephanie draws on places her in a powerless position, she negotiates this by indicating that she has managed to overcome at least some of its effects (stopped “hiding”, disclosed the child’s diagnosis to people in her immediate social environment). Stating that some of her fears of overt rejection of herself and the child by others (“my paranoia”) may have been exaggerated, she nevertheless asserts the power of the disability discourse and the validity of her experience through juxtaposition of the polite convention (“people want to be really nice if they can”) and the “hegemonic norms of embodiment”\(^{47}\) (“they are just probably really glad it’s not them”).

*Stephanie:* (…) it took me a while to tell people at play group and the coffee group and stuff and my neighbours (…) I just hid a little bit…for a wee while… not too much but just- You know... people are really nice but it’s... you know- You just don’t know that well with people you don’t know so well um. And sort of feel like perhaps um… you know that maybe they won’t want their child playing with [my son] (…) maybe they just think you are a bit weird or something or he’s a bit weird or you know and they don’t necessarily want you to- I kind of think it’s me kind of projecting all my paranoia onto people… because actually you know everybody’s been absolutely awesome about it (…). People actually generally want to be really nice if they can you know they are just probably just really glad it’s not them (laughs) (emphasis in the original)

In the two excerpts below parents deploy the disability discourse to illustrate the responses of the family to the child’s stigmatising condition. The diagnosis was depicted as engendering embarrassment and fear in extended family members, which

\(^{47}\) (Rocque, 2010, p. 486)
led to resentment and bitterness in the child’s parents, and subsequent distancing and weakening of family ties.

Anna: We don’t talk about it ‘cause they’re very- [whispers, imitating family members] “we don’t talk about things like that it’s not nice”

John: (...) they [extended family] have kept their distance um very much from him ay especially in the earlier earlier… earlier times so yeah

M.E.: why- why do you think?

John: [sarcastically] scared of him /M.E.: scared of him/ yeah

Perpetuating Stigma? Using the discourse of disability to “normalise” the child

Prussing et al. (2005) found that parents of children with Down syndrome sometimes strategically positioned their children in relation to other children with the same disorder in order to manage their identities and create a more favourable subject positions for them. Avdi et al. (2000b) observed that parents of children with autism talked about other children (in special education settings) as “more disabled, stigmatized and damaged than their own child”, posing a risk of their child falling to other children’s (more severe) level of impairment (p. 251). The interview accounts in this study also showed that in order to create a better identity for their child, parents frequently negotiated it using the same readily available devaluing constructions of disability (whose impact they themselves had experienced as stigmatising) in relation to “other” children. Similar to Avdi et al.’s (2000b) study, these constructions occurred in the talk concerning special educational settings, a symbol of segregation and otherness, likely to increase the visibility of stigma. However, unlike the parents interviewed by Avdi et al. (2000b), whose devaluing constructions were “concealed and disowned” (p. 251), many participants in this study unequivocally portrayed the prospect of their child attending a special school and finding him or herself among other disabled children as “terribly disturbing”, re-inscribing the child as “a complete freak”, and even morally wrong (“unfair to”, “undeserved” by the child). Parents argued that since their children live “in the world with typically developing people” it’s best for them to “mix with” or

48 As Giles was diagnosed at two-and-a-half years of age, John is talking about the extended family being “scared” of a very young child.
“be around” the dominant group with allowances made to accommodate the disabilities (“my children need to mix with neurotypical children but they just need to have more allowances made for them”, Lyn). In order to create better identities for their children and protect them from the stigmatising discourse of disability, parents consistently distanced their children from the devalued group, constructing “other” disabled children in special settings as being “far more” severely affected than their own child (consider one father’s depiction of a local special school as a “really special needs school for the very severe”, Eric, emphasis in the original). In the excerpt below, John, who on many occasions throughout the interview describes his son as “autistic”, normalises the child’s identity by defining him as “a normal kid” as opposed to “intellectually handicapped people”, therefore disassociating him with what he construes to be a group of more stigmatising disabilities.

John: (...) he’s not low functioning and he’s not- doesn’t deserve to be in a group of with intellectually handicapped people with you know cerebral palsy and stuff like that he doesn’t you know- would you put a normal kid in with a group of cerebral palsy and Down Syndromes and stuff like that? I mean that’s the bit that will really stink if it comes to that

On the ‘production’ of ‘less-than-perfect’ children, parental competency, and “not doing enough” for your child: ‘Courtesy stigma’ and the discourse of parental responsibility

In their recent explorations Rothschild (2005) and Landsman (2009) demonstrate how the discourse of human perfectibility and “perfect” babies permeates contemporary Western society. Discursive reminders (both verbal and symbolic) of “unmarked-beautiful-healthy-intelligent-‘regular’ children” have become ubiquitous in contemporary Western culture (Avery, 1999, p. 117). Landsman (2009) argues that the notions of ‘normal’ and ‘perfect’ are currently conflated in both the lay and medical discourses of procreation and parenting, with the creation of perfect children becoming “the imperative of the attainable norm” (p. 73)\(^\text{49}\). As “self-regulating and responsible citizens of the neoliberal state” (Nadesan, 2008, p. 132), societal discourses inscribe

\(^\text{49}\) Consider the description of a child with autism in the earlier study by DeMyer (1979) as “a child that failed”; having such a child was portrayed as “a serious assault” to a mother’s self-esteem.
parents as fully responsible for the ‘production’ and rearing of their offspring. McKeever and Miller (2004), who describe mothers as the parent having the highest degree of responsibility for their children’s health and wellbeing, state that they “share in the stigma and marginalization of atypically developing offspring” (p. 1182).

Parental constructions of ‘courtesy stigma’ in this study centred around three main discursive themes that will be discussed below: 1) ‘production’ of ‘less-than-perfect’ children, 2) parental competency, and 3) “not doing enough” for the child. The first discursive theme, ‘production’ of ‘less-than-perfect’ children, was concerned with parental responsibility for bearing a child with autism, a stigmatised “identity of being” (Goffman, 1968, p. 152). I explored this theme in detail in Chapter 4, where I argued that parents portrayed themselves as holding responsibility for both genetic and environmental contributions to the child’s condition. This negatively affected their identities as ‘good parents’ and was associated with the feelings of guilt and self-blame. Parental responsibility for ‘causing’ the child’s disorder relates to the aspect of autism-related stigma, which Scambler (1984) termed “ontological”, emphasising that the only “offence” of an ontologically different individual, who is societally “judged as an essentially ‘imperfect being’”, is that he or she does not conform to a class of societal norms “pertaining to how people should be rather than how they should act” (1984, p. 208).

The second discursive theme constituting ‘courtesy stigma’, for which I use a shorthand parental competency, was concerned with the responsibility for ‘parenting’ as opposed to ‘being a parent’. This theme was represented in the talk about parental responsibility for the child’s compliance with the societal norms of behaviour and for how the children act in public as opposed to how they should be. It involved the notions of raising, handling, and controlling children (Suissa, 2006) and used the language of parenting competencies, behavioural norms, skills, techniques and parenting courses (Smeyers, 2010). The theme of guilt, self-blame, inadequacy, and stigma in relation to parenting a child with disability has been previously discussed in literature mainly in relation to mothers and mothering. For example, Gray (1993b, 2002) suggests that mothers may experience more stigma as they have the primary responsibility for caring

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50 Voysey (1972) defines this type of responsibility as “the degree to which parents or others define the parents as “responsible” for the child’s disability, i.e. whether they have “caused” it either genetically or through negligence of their duties as parents” (p. 85).
for the child and public presentation of the family. Interview accounts in this study indicate that such parenting-related stigma experiences were situationally bound rather than gender-specific: fathers and even a step-father reported experiences similar to those of mothers in the course of their public appearances with the child as a family or as the parent-in-charge. Negotiating public encounters (or managing, negotiating, and resisting stigma) is a common topic in most stigma research (e.g. Birenbaum, 1970; Farrugia, 2009; Gray, 2002; Green, 2003; Rocque, 2010; Voysey, 1972). Voysey (1972) points out the significance and problematic nature of such negotiations arguing that it is in public encounters that parents’ competence is assessed and “most threatened” (p. 81). As children with autism can display highly unusual behaviours and be construed as violating “some of the most basic rules of societal interaction” (Gray, 1993b, p. 111), parents’ identities are threatened and negotiated on a regular basis and within their local social world (at the supermarket, playground, at school events or social gatherings involving friends and family). Due to the strong moral-emotional component of this type of ‘courtesy stigma’ the descriptions of stigma and its negotiation in public encounters were abundant in parental talk.

_Lyn:_ (... hugely stressful um dealing with embarrassment and humiliation in social situations (...) Dylan is very disruptive and it’s not fair for the other children and so you know there is that stigma for me as well I know that every- I have other parents come and tell me what Dylan’s been doing at school (cries)(emphasis in the original)

_Eric:_ (... other parents’ and other people’s opinions um are offered quite freely um and I know it does have an effect it doesn’t matter you know how tough you are and how much you you shrug it off and say you know “I’m not concerned by what people think” um you just are you know you can’t you can’t get round it um- I mean it shows up in so many areas like you go to you go to a café and the kids will only eat you know really restricted range of things um you know Ethan will request weird stuff (...) so you can tell straight away that those people are looking at you as if you’re some kind of over indulgent terrible parent that should have better control over your kids (...) you feel all the time that people are looking at you and thinking “your kids are a
Parents talked about two main ways of negotiating stigma in public encounters: avoidance of some or most social situations where they and their children can become objects of public scrutiny and criticism, and discursive management of the child’s and their own identity. As I have mentioned earlier in this chapter, from a constructionist discourse analytic perspective I do not make a distinction between enacted and felt stigma. As Singh (2004) points out drawing on Foucault’s (1975) concept of community surveillance systems, where each individual is both the subject and the object of the disciplinary gaze, which is also internalised, it does not matter whether parents are actually ‘experiencing’ stigma or ‘imagining’ it. What matters is that even parental ‘imagination’ (or “paranoia” and “sensitivity”, the words used by the participants in this study) reflects the internalisation of the disciplinary gaze of the dominant stigmatising discourses of parenting.

In the two excerpts below, June and Leanne talk about avoidance of social situations as a means of managing ‘courtesy stigma’. Leanne recalls negative comments from members of the public in response to her son’s aggressive behaviours. June does not mention any specific instances of overt stigmatisation apart from “sideway looks” from other parents at the kindergarten, however, she constructs an imaginary dialogue with a judgemental accusing other in which she locates herself as the main object of stigma, a “slack parent”. Both mothers experience the powerful distressing and isolating effects of their identities being compromised as they are positioned (by others and by themselves) to bear responsibility for the child’s ‘transgressions’ and their own failure to control the child as ‘good’ (competent and responsible) mothers are expected to do.

**June:** um I’m more reclusive now than I ever have been before in my life um typical scenario um yeah I’ve turned into a hermit
M.E.: and that’s because of? Just kind of too much and not any energy to- or-

June: um probably because I can’t deal with it (upset, fighting tears) /M.E.: yeah/ I don’t want to have to deal with the outside world um... don’t get me wrong I really like people and I like interacting and I used to be your slash party hearty girl and everybody knew my name and that’s all changed since having children um as you do you grow up and you um you do change ... you know but it really didn’t start getting bad until Brian was probably at kindy ah and you would see other parents looking at you sideways and um... (fighting tears) that’s probably where it starts too (...)

M.E.: (...) is it more about the child or more about you

June: you being a slack parent - absolutely you know “why would you let your kid run around with no clothes on in the middle of winter you idiot they’ll catch a cold” “why is he running under the sprinkler” um “sorry it’s out of my control he took his clothes off”

Leanne: Um it’s very frustrating it’s very um socially isolating I think ah ... there is a number of reasons why it’s socially isolating first of all we are both very tired (...) all the time so it’s hard to (...) organise much of a social life um- when Jonathan was younger and his behaviour was worse he was very aggressive so it was very difficult to take him amongst other people’s children um he would scream the supermarket down so we wouldn’t take him shopping um... he would lash out at people he would pinch bite hit um scream people would say things like can’t you control that child (...) people are cruel ... so you end up staying home (crying)

Discussing the performative, action-oriented role of language in relation to disability and the labelling of difference, Marks (1999) argues that in real life “labels tend to be used strategically to achieve particular contextually bounded outcomes”, and that categorisations are not fixed, but fluid, shifting “according to the pragmatic needs of the
In their talk, parents described a number of strategies used to manage/resist stigma by discursively negotiating the child’s and their own identity. Although in my analyses I do make a conceptual distinction between stigma associated with the child’s and the parental ‘spoiled’ identities, it is important to point out that some strategies used by the parents were aimed to negotiate both. For example, a mother portraying her son as having “language processing issues” in a situation where he is not communicating ‘normally’ with others may position her as not responsible for her child breaching a social norm. At the same time such portrayal construes the child as having a ‘condition’ rather than being naughty, without evoking the stigma of the autism diagnosis. There were very few parents in this study who reported that they were always open about the child’s diagnosis, and felt no hesitation or concerns talking to others about it. All of them indicated that their situation was not typical, and might have to change (in the example below – when the child starts school, as the diagnostic label will position him unfavourably in a setting where the discourse of hegemonic developmental normalcy is structurally embedded).

Anthony: we know through our respective careers um of other people who have autistic children but they’re not people who talk about it and we never talk about it… but we are open about it … it has I hate to say it has- I had wondered whether or not there comes a point in time when you need to shut up about it ah and that’s when he goes to school but um you know at the moment I’m comfortable with being perfectly open about it (emphasis in the original)

The majority of parents used a combination of discursive strategies to negotiate stigma in their day-to-day life, the choice largely dictated by the pragmatics of the social context. With those people who occupied important and stable roles in the social world of the family, such as other family members, close friends and professionals involved in the child care and education (for example, kindergarten or school teachers, regular babysitters, or sport coaches) parents’ typical strategy was to share the child’s diagnosis and counter the stigma by educating others about it. As Rocque (2010) points out “explaining children to others” (p. 489) increases the possibility that their differences will be better understood, their personhood – respected, and, as a result that they will be better accommodated and socially included by others. This strategy involved verbal
explanations by the parents, supplying others with a variety of educational resources (books, websites, videos, articles) and even, in one instance, organising special training for the teachers and teacher aides. Silverman and Brosco (2007) emphasise the important historical role of parents of children with autism as advocates for their children. They describe parental activism in challenging stigmatising psychogenic explanations of the causes of autism, promoting treatment, funding research, facilitating education of the educators, changing society’s views toward children with autism, and ensuring that children have “full access to work, schools, and recreational activities” (p. 396). In the second excerpt below, Anna talks about taking an activist stance as a strategy to resist stigma. She describes facilitating organised training for educational professionals in schools through Autism New Zealand to help school staff to better understand autism and provide appropriate support and education for her son and other children with this condition.

Lyn: (...) if (...) we go to the same place week after week you know I’ve told other parents and I I’ve told the teacher that- it’s all right to tell the parents because obviously you know they are going to see behaviours week after week (...). I think it’s fair that they should know so that they can um you know understand what’s going on and make allowances um but I think you know in a shopping centre or whatever- no

Anna: (...) he’s at mainstream school um all the training through GSE\(^51\) for teacher aides or teachers (...) was so old fashioned autism it was just like- they’d come back from a day’s training and (...) they’d be “oh there’s no hope” (laughs) and it’s like “this poor kid nothing’s gonna ever-“ and then they’d be “oh he’s in the wrong place he should be in a special school cause there’s nothing we can do to help him” so we set up (...) through Autism New Zealand (...) a whole series of seminars where teachers can go and be trained by professionals who are actually providing hands on therapy to children with autism so it’s very positive (emphasis in the original)

\(^{51}\) Group Special Education, a department within the Ministry of Education.
In the context of more casual public encounters within the family’s local social world (e.g. at a supermarket, restaurant, playground, or sports training) parents described using three main strategies to negotiate stigma in public situations: using the diagnostic label of autism as a “medical disclaimer”, avoiding the use of the diagnostic label altogether, and using a more “benign”, less stigmatising descriptor as a substitute for the negatively loaded label of autism.

The term “medical disclaimer” belongs to Schneider and Conrad (1980), who suggested that by “bringing a blameless, beyond-my-control medical interpretation” to discrediting (or potentially discrediting) events people “intended to influence others’ reactions” and “reduce the risk that more morally disreputable interpretations might be applied by naïve others” (p. 41). Parents talked about using this strategy in the social situations where atypical behaviours, constructing the child as “weird”, “naughty”, or “spoilt” and themselves as “bad”, “slack”, and “out-of-control” parents were either occurring or likely to occur (the typical example of the latter was a birthday party/play date involving typically developing peers). However, unlike the participants in Farrugia’s (2009) research, parents in this study did not suggest that deploying medical discourse of autism-as-illness was fully de-stigmatising. In their talk, parents did not construe medical discourse as conferring an unspoiled identity either for themselves as parents or for their children (see the above discussion of autism as an “un-cool condition”). Although some researchers argue that there is a greater social acceptability for a child to have a ‘condition’ rather than wilfully misbehaving (Tait, 2001), interview accounts in this study suggest that the label of autism is generally seen as too negative for it to necessarily be the case, with the use of the term being associated for many parents with psychological distress. Therefore, based on the multitude of pragmatic situational factors, parents made a choice between the two ‘evils’ – using the stigmatising “medical disclaimer” or avoiding the use of a diagnostic label altogether and therefore risking to be positioned by the public as ‘bad’ parents of an ill-behaved child.

**Leanne:** I couldn’t for the first three years I couldn’t say the word autism so if somebody said something to me in the shops about couldn’t I get my child to behave or make some reference to the fact that he was screaming or anything like that I would just burst into tears um or
remove myself from the situation somehow you know just leave the basket of groceries and go

**Sarah:** I mean it is a medical condition but I just think that like we talked about there is a stigma there can be a stigma and I don’t want parents to think they understand Sophie and autism and her being a curiosity “oh there’s the autistic child”

**Lora:** at this stage I have- we have decided not to do that [disclose the diagnosis] we are telling people that are dealing with him day-to-day like his kindy teachers (...) and our very close friends (...) we've decided that for the time being we are not going to tell the community at large because we don’t want him to be boxed in and and and wearing that label (...) and it feels like a very private matter (...) I’m nervous about how I’m perceived (...) if we don’t tell them. People will be thinking because his behaviour is quirky sometimes why doesn’t she rein him in and control that particular behaviour it’s not normal (...) we we have been desperately in love with him since the day he was born we want other people to see that um his warmth his um exuberance and yeah ah his beautiful character and not not see first a very limiting label and their own possibly skewed opinion of what that might be

Several participants linked their choice of avoiding the use of medical discourse to negotiate stigma with the societal constructions of autism (or at least atypical behaviours associated with it) as caused by bad parenting. Therefore, whether parents used the label of autism, with its pathologising connotations, or avoided it altogether, they were equally at risk of being assigned a negative identity label of a ‘bad’ parent, which rendered the “medical disclaimer” pointless and resulted in the anger and bitterness present in some of the accounts.

**Julie:** (...) it makes me angry that people feel that they have got the right to be judgmental when they have absolutely no idea of the circumstances or whatever but um, yeah there there are times that I have said you
know he is having difficulty coping because he he has autism so you know um-

M.E.: And how people would normally respond when you say that?

Julie: Oh there’s such a range of different ways I had one woman tell me once in The Warehouse\textsuperscript{52} that she knew a child with autism and he didn’t act like that so implying um it was just my bad parenting (laughs)

Vicki: I mean you get all the stares at the mall when your child’s having-he’s humming or he’s in a little trancey thing that he does um. I’ve had people say to me things like when he got diagnosed someone said to me well now you know what it is you can start disciplining him more (laughs)(…) you try and justify yourself to the world you will do that for the rest of your life

To prevent being constructed by others as ‘bad’ (irresponsible, out-of-control) parents and avoid the stigma associated with the diagnosis of autism, parents sometimes used a more ‘benign’, less stigmatising “medical disclaimer” for the child’s behaviour, such as “Aspergers’s”, “slightly deaf”, “language processing issues”. One father described his tactic of saying the word “autism”, while immediately adding a reassuring statement that the child’s differences are “OK”.

Sarah: we prefer to call it Asperger’s to other people (…) because I think Peter feels like if you say Asperger’s people think it’s a savant it’s kind of a slightly quirky incredibly talented person

Anna: (…) I don’t say autism see I- I have- I confuse people I’d rather say my-“oh my child has language processing issues” /M.E.: right/ so could you speak slowly to him

Ian: if he’s playing on the slides with the others kids “hey guys Jack’s autistic it’s a little different but he’s okay” it’s you know I don’t want

\textsuperscript{52} The name of a large department store.
to make a big scene as in “look after my child” but I I personally think a little bit of awareness um just makes- calms everyone down so that you just ah just pre-empt people going gosh that’s a little bit strange behaviour

Whether parents chose more or less activist strategies to negotiate stigma (and most of the participants reported using a combination of both), all of these strategies are in fact pragmatic and situation-specific responses to devalued and stigmatised subject positions created by the societal discourses of disability, ‘perfect children’, and parental responsibility – (consider, for example, two excerpts from Anna’s talk used above, where she negotiates stigma at her son’s school through education and activism, organising training for the staff, while mobilising a less stigmatising “medical disclaimer” of “language processing issues” in her day-to-day casual encounters.) As previous research has pointed out, the attempts to ‘hide’ disability or make sure that the child looks as ‘normal’ as possible (e.g. Amundson, 2000; Landsman, 2009), as well as the strategies focusing on education and activism (e.g. Green, 2003; Rocque, 2010) need to be understood in the context of parents experiencing, strategically assessing, and acting upon the stigma and discrimination “they know confronts those with impairments” (Landsman, 2009, p. 190). However, the very need to act, to resist, can be experienced by parents as disempowering 53. It was therefore unsurprising that during the interviews some parents, mainly fathers, directly resisted the powerlessness associated with the stigmatised subject position allocated to them by the dominant discourses discussed above. They refused to take up such positions by constructing themselves as less concerned with public opinions than “other people” (or “other parents”), and therefore personally unaffected by stigma. One might speculate, however, that at least for some parents this way of resisting stigma might be ‘prompted’ by certain contextual factors, such as the severity of their child’s condition and/or the extent and frequency of the parent’s contact with general public that involves the child. For example, positioning oneself as unaffected by public opinion would likely be easier for a parent whose child has mild autism with no significant behavioural concerns, and

53 Compare with Green’s (2003) observation that the mothers in her study who found “meaningful, positive ways of coping” with stigmatisation felt “burdened by the constant need to exercise these coping strategies” (p. 1367, emphasis added).
who is rarely involved with child-related daily activities outside the home (and therefore has limited exposure to public opinions).

Gavin: oh I’m sure it bothers other people but I’m not really that fussed about stuff like that I’m yeah when it comes to other people’s opinions and stuff I’m not really no yeah it doesn’t bother me very much I’m pretty oblivious to that sort of stuff and that’s part of my autism if you like (laughs) I have very little um I have some regard for what other people think but only as far as it doesn’t inconvenience me too much

M.E.: What impact do you think those various understandings of autism (...) the ones that we’ve discussed have- /Christopher: on parents? / yeah

Christopher: Um me personally? No effect whatsoever because … because yeah it’s probably just a- I’m not really interested … in other people’s opinion

The third discursive theme that emerged from the data constituted ‘courtesy stigma’ as a consequence of parents “not doing enough” to help the child. Both mothers’ and fathers’ talk on the child rearing was strongly embedded within the liberal humanist discourse that asserts every child’s entitlement to reach his or her fullest personal potential (Prussing, et al., 2005). The constructions of positive parental identities within this discourse are linked to the overall responsibility for the child’s progress and fulfilment, and, in case of illness or disability – his or her optimal treatment. Several parental accounts included the rhetoric of “dreaming big dreams” and making “miracles” happen for their child through hard work and dedication to the chosen course, using stories of success and “miracle achievements” of other parents and children as motivators.

Lora: (...) some of them [children with autism] even go to mainstream school some of them even live independently um dream big dreams for your child because ultimately you project them into the world and he will stand on your shoulders (emphasis added)
Ian: 

(...) we’re pretty much into you know you decide with your mind what you want to achieve and then you go out and you get it (...) the worst case scenario um...you know I had to make money so you know he can stay with us you know we can have someone to to come and live here and look after him you know he won't go into a home that won’t happen (...) but then we start looking for people that have that have had success and that’s um so then you start you know there’s lots of stories (...) and then you say okay there is people that have- some people call it miracle achievements (...) so I you know I personally think that you have the right to claim the miracle if you go do the work and do the searching (...) and it could be that he could go to school and know how to go to classes and sit down properly and then you know it could be that he is able to get a job and the ultimate would be that you know he finishes and can find love and get married and so the miracle could happen in different gradients (emphasis added)

Analysing the talk on parenting in popular literature and culture, Suissa (2006) argues that parenting has become primarily associated with performing tasks or “doing things” for the children (as opposed to “being with them”), and that parents are discursively encouraged to see themselves in a functional role. In the area of autism, the dominant narrative of a parent is one of a fighter, a “hero” (Fleischmann, 2005) tirelessly battling autism to help the child. Parents and advocacy groups have historically played a very active role as proponents and sponsors of research and intervention (see Silverman and Brosco’s (2007) exploration of the parents’ impressive contribution to autism research and treatment over the last fifty years). Fleischmann’s (2005) study of web-based narratives found parents portraying themselves as actively engaged in “doing things” for their children in the form of organising and facilitating of multiple interventions and stimulating activities. With the dominant liberal-humanist rhetoric of the child’s right to reaching his or her full potential and abundant stories of highly involved and active parents as role-models, it was unsurprising that some mothers in this study described ways in which their identities as ‘good mothers’ were compromised as a result of “not doing enough” for their children.
Leanne: Well I do I compare myself very unfavourably to other parents of autistic children as well and I’ve always done that because they do so much more for their kids than I do

M.E.: What do you think is… um most stressful about it I’m not asking easy questions am I

Lyn: Well um…for me a huge stress is (sighs) worrying all the time about not doing enough for them um you know kind of um getting them as much help as they can as as early as possible um you know um (sighs) following through on sort of behavioural programmes and you know following through on diet and um um you know um vitamin and mineral therapies and following through on exercises and you know just kind of um doing all that stuff um sorry I’ve forgotten the question again (laughs)

M.E.: What is the most stressful?

Lyn: The most stressful so for me that’s hugely stressful um being a good enough mother to do all those (cries, emphasis in the original)

The constructions of stigma as “not doing enough” for the child mainly occurred in the talk about associations of parents, such as community and online support groups. Within some of these groups and associations high parental involvement with various interventions became the new ‘norm’, with stigmatising consequences for those who were construed (or construed themselves) as doing “nothing”, or “not enough”. Such constructions of support groups deployed the rhetoric of ‘othering’, excluding, and, in one participant’s account – competitiveness, rather than support, with the child’s progress depicted as a measure of parental performance.

Gavin: yeah well I guess in the world of autism if you are not doing anything shove you (laughs) we don’t want to know you so they probably don’t want to enter that world (...) I went to a support group meeting with it was with the Asperger’s support group (...) I was stunned that they didn’t do anything you know because I was so used to meeting parents that did everything (laughs) and then these people didn’t do anything I
thought why aren’t you doing anything that’s a bit weird (emphasis in the original)

John: (...) with some other mothers in what they call internet groups and on the phone and stuff like that it’s very it’s it’s a sick thing but it’s also very competitive “how’s your boy doing mine’s doing better than yours mine can go to the toilet mine can say ten words now mine-“ you know

In the two excerpts below, Liz and Sabine construct their involvement with the local support groups (and in Liz’s talk – with the wider autism community which she refers to as “the world of autism”) as “stressful” and “divisive”. Ironically, the selfless determination and efforts of other parents in Sabine’s account, whose level of involvement she finds she is unable to match, create a normative discursive landscape within which she eventually locates herself as an exhausted and stressed ‘other’, construing her own maternal identity as compromised. Sabine manages the stigma and the distressing emotions associated with it by withdrawing from the group, while Liz in the second excerpt utilises information control, limiting the amount of disclosure, and hence – stigma.

Sabine: at first you kind of you have a bit of a yeah you know shock realising that your child has autism and all the things that go along with that but then the second stress which I found really hard is that you know “am I doing enough for my child?” there’s all these things out here I should be doing even more because I mean I know other parents have sold houses to pay for therapies and things and who had a mother come in and look after their baby while they dedicate their time to the older child with autism… and and you know and in the end actually I- I I was quite involved with everybody but then I actually had to pull back because I was starting to feel so bad because I felt like I wasn’t doing enough (sighs) sometimes you think it should be like supportive with other parents… but actually I found in the end it was getting a bit stressful. I was just literally so exhausted and I was getting even more exhausted getting stressed from feeling I wasn’t
doing everything that could be done /M.E.: that other parents did?/ yeah yeah so so it sounds weird but actually (laughs) support groups can be stressful too

Liz: (...) [about support groups] in a way it’s really divisive I mean I’ve found parents quite um funny about what intervention you do I found that quite hard actually where people have told me off for not doing ABA (…)

M.E.: it doesn’t sound like a lot of support

Liz: no…you just feel like well I’ll just sit there and say nothing because I’ll just get told off again (laughs) (...)I find that a lot in autism- in the world of autism because it’s so emotional it’s your child you’re talking about

Finally, it is important to consider parental talk about “not doing enough” for their child within the context of the New Zealand institutional practices in the area of autism remediation. The current focus of such practices (in particular – special education) is on “participation and development, rather than treatment or ‘fixing’ the child”(Ministries of Health and Education, 2008, p. 21), and at this stage there are no publicly-funded, autism-specific behavioural services in New Zealand (Ministries of Health and Education, 2008). A recent report prepared for the Ministry of Education concluded that there were some good privately provided programmes for children with autism in New Zealand, but that the cost of these programmes was high (Godfrey, Moore, Fletcher-Flinn, & Anderson, 2002). In the absence of publicly funded interventions, many lower- and even middle-income parents experiencing the moral imperative to “give their children a life” (see Lora’s account below) may experience the stigma of not doing enough for their children, and feel compelled to fund the interventions privately (“make it happen”) at a significant financial and emotional cost to the family.

Lora: (...) it was just the Listener [New Zealand weekly magazine] article was saying forty to sixty thousand [New Zealand dollars a year] and somebody else (...) was quoted seventy thousand for forty hours [of ABA a week, one-year estimate] (...) that’s absolutely crippling for any
family I mean unless you’re you know in the top two percent of the population economically that’s crippling (…) families have to not only deal with the um the very emotionally taxing physically taxing job of raising an autistic child they also are financially taxed to an excessive degree. Would a parent do it? I think most people would you know because how can you measure the value of that to a child giving them a life versus you know- and then to scrimp and save and change your lifestyle and everything to afford that you would you would you’d make it happen I suppose but it has to be understood that that comes at enormous cost to a family and especially at a time when they need as much security and normality safety and actually pleasure as well to survive this

Concluding comments

In this chapter I explored the issue of stigma in relation to being a parent of a child with autism. I built on the analysis in the previous chapter (Chapter 4), which focused on the current discourses of autism causation and discussed parent blaming and stigmatising attributions inherent within these discourses. I began this chapter with a brief overview of theoretical and empirical research on stigma and stigmatisation. To introduce my own formulation of stigma used in this research, I addressed the changes in stigma theorising in terms of stigma ‘location’, from an ‘attribute’ that a person ‘possesses’ to a construct grounded in socio-cultural space. I provided a summary of the few available studies focussing on stigma as related to parents of children with autism and discussed methodological limitations of the positivist paradigm for looking at this issue. Namely, I argued that despite some references to the wider social context, the focus of studies conducted within a positivist framework was mainly individualistic with stigma being regarded as something that an individual has and needs to cope with. I emphasised the pathologising implications of such individualistic emphasis of stigma theorising. In particular, I argued that the corollary was that a person’s experiences of stigma came to be understood by some researchers as related to this person’s ‘success’ or ‘failure’ to cope with it by trying to maintain ‘normal’ identity. I also argued that focussing on individual coping indirectly construed stigma as a given, a naturally occurring ‘fact of life’, de-emphasising and making less ‘visible’ its socio-cultural origins.
Conceptually and methodologically, my exploration of stigma presented in this chapter built on the work by Avdi (2000b) and Farrugia (2009) whose research countered the limitations of the positivist theorising by approaching the issue of stigma in autism from a social constructionist perspective. For the purposes of this study, I defined stigma as a subject position socially constructed as being outside of or in opposition to the existing valued discourses of identity, which is experienced as adverse. In my conceptualisation of stigma and in the analysis presented in this chapter, I emphasised the lived-in moral-emotional dimension of stigma. I described the ways stigma affected parents’ daily existence in their local social world threatening their identities as ‘good parents’ and drew the reader’s attention to the emotional distress it engendered.

My analysis of interview accounts showed that parents drew on the pathologising discourse of disability, which constituted a disabled child as a ‘deviant other’, to construct the diagnostic label of autism as infused with negative social, cultural, and emotional connotations. In order to create better social identities for their children, some parents used a strategy of discursively ‘normalising’ their children. They portrayed their own children with autism as less severely affected by their condition than other children with disabilities and emphasised their belonging within “the world of typically developing people” – similar findings have been reported by Prussing et al. (2005) and Avdi et al. (2000b). In doing so, parents drew on the same readily available devaluing discourse of disability (whose impact they themselves had experienced as stigmatising) in relation to ‘other’ disabled children – the finding that highlights the pervasive nature of this dominant discourse.

In this chapter I demonstrated how discourses of disability, ‘perfect children’, and parental responsibility for bearing and raising ‘normal’ offspring converged to create devalued and stigmatised subject positions for parents. My analysis of parental talk yielded three discursive themes constituting ‘courtesy stigma’: parental responsibility for the ‘production’ of a ‘less-than-perfect-child’, parental responsibility for the child’s compliance with the societal norms of behaviour (I called this theme “parental competency”), and “not doing enough” for the child.

Approaching the issue of stigma in relation to parents of children with autism from a social constructionist perspective allowed me to avoid the pathologising essentialist stance and individualist focus of previous stigma research and to make explicit the
socially produced nature of stigma. Using a form of discourse analysis that combined the focus on people’s talk with the attention to macro-level societal discourses my analysis demonstrated how parents resisted and actively negotiated subject positions constructed by discourses of disability, “perfect children”, and parental responsibility for childbearing and childrearing.
Chapter 6: “It’s Autism, Off You Go”: Parents’ Experiences of the Diagnostic Process

…It became clear to us that the memory of the interview with the doctor over the initial diagnosis lived on, in some cases for years, with a vivid and almost disconcerting immediacy. Some parents were still feeling the impact, remembering details of words, movement, expression, and attitude, the manner and style of delivery, the information given or apparently withheld and by whom and to whom it was given, and in what place. (Woolley, Stein, Forrest, & Baum, p. 285)

…it seems to me to be kind of a bit negligent (…) to diagnose somebody and not be able to tell you what you should do about it (…) it seemed to me to be a real failure of - as a parent to do nothing about it when you can do things about it (…) just to think - you know you covered all the options for your child (…) I think her quality of life, you know, that should be paramount… (Peter)

When a diagnosis is discussed, care is needed to think, with the family and other professionals involved what role this diagnosis might serve. (Reid, 1999, p. 64)

The idea of this chapter has come from my concerns about certain shortfalls in the process of diagnostic interviews, during which parents are presented with the “official” diagnosis of their child’s autism by an ‘expert’ or a group of ‘experts’ (e.g. a developmental paediatrician, a psychologist, or a multidisciplinary team of clinicians). These concerns were based on a study of the literature on the subject and anecdotal evidence that I had gained in the process of my own professional contact with parents of children with autism. The existing literature focusing on the impact of the diagnosis of autism and other developmental disabilities on parents, frequently portrays the diagnosis as a “crisis”, possibly parents’ “most difficult and shocking experience” (Heiman, 2002, p. 160). Receiving the diagnosis has been described as both a relief in terms of achieving clarity and having questions answered, and a traumatic and distressing event (Avdi, et al., 2000b; Heiman, 2002; Midence & O'Neill, 1999; Nissenbaum, et al., 2002; Siegel, 1997; Sullivan, 1997; Whitaker, 2002). These studies, which included both parental and professional perspectives, described parents experiencing such negative
emotions as shock, fear, self-blame, guilt, despair, hopelessness, anger, confusion, isolation, uncertainty, devastation, helplessness, loss, sorrow, and grief. References are also made to the phases of grief as identified in the bereavement literature and to “chronic sorrow”, a concept introduced by Olshansky (1962), suggesting that parents can never fully resolve the grief following the birth of a disabled child (Siegel, 1997). Some studies discuss parents’ emotional responses to the diagnosis per se, and reflect on parental “coping with the diagnosis” without focusing enquiry on the process of the diagnostic encounter (e.g. Fleischmann, 2005; Schall, 2000; Siegel, 1997).

Alternatively, authors briefly reflect on some negative experiences parents have en route to obtaining the diagnosis, such as incorrect diagnosis or clinicians negating parental concerns (Midence & O’Neill, 1999). Other studies (e.g. Mansell & Morris, 2004), which assessed parents’ reactions “to the diagnosis”, do not always, in part due to their format\(^\text{\textsuperscript{54}}\), differentiate between the diagnostic event itself (the reality of the child receiving a diagnosis), and the process of the clinical assessment and diagnostic disclosure, which makes it impossible to theorise whether parental responses, e.g. “shock, anger, hopelessness, denial, and confusion” (Mansell & Morris, 2004, p. 402) could also reflect the process-related stress of the diagnostic encounter. Exploring parents’ “reactions to” and “coping with” the diagnosis without considering process-related factors has the potential of construing the diagnosis as an objective fact, which is “discovered” when the symptoms and signs have been “sorted out and deciphered” by the clinician (Malterud, 1999, p. 275) and then “expertly” communicated to the parents. Leaving the context of the diagnostic encounter outside the focus of enquiry and focussing solely on parental stress and adaptation has another important and potentially harmful implication. It may create a false impression of a direct association between parents’ negative emotions (as described above) and their unsuccessful (‘maladaptive’, ‘dysfunctional’) coping practices, and therefore implicitly blame parents for their own distress.

There is little doubt that the diagnosis of autism in itself can be a major source of distress for parents. As Harris and Powers (1984) put it “few of us are heroic when confronted by such painful problems in life” (p. 216). However, research shows that the way in which the diagnostic encounter is conducted and how the diagnostic information is conveyed, can have a significant long-term impact on parents, their levels of stress,

\(^{54}\) In the case of Mansell and Morris’s (2004) study – a questionnaire-based postal survey.
their ways of dealing with the child’s problems, and can affect their views of the professionals involved and of the services provided (Howlin & Moore, 1997). Cunningham (1994) argues that the grief parents are reported to experience following a disclosure of a diagnosis cannot be solely attributed to the bad news itself, but is a consequence of the less-than-perfect diagnostic process.

Surveys of parents (Goin-Kochel, Mackintosh, & Myers, 2006; Howlin & Moore, 1997; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010)\textsuperscript{55} show that the level of dissatisfaction with the diagnostic process is high: 49% in Howlin and Moore’s study, 40.1% in Goin-Kochel and colleagues study, and at least 49% in Keenan and colleagues (2010) study. The latter study found that 49% of parents were dissatisfied with the information received during diagnosis and did not think that the process was conducted “in a timely and professional manner” (Keenan, et al., 2010, p. 393). In the same study, 70% of parents reported dissatisfaction with the advice regarding financial entitlements. Howlin and Moore (1997) also found that a significant proportion of their participants (34.8 %), were considerably dissatisfied with the help received following a diagnosis.

There is a wide range of literature on the process of communicating children’s diagnoses of illnesses and disabilities other than autism to families. Research has been conducted with parents whose children were diagnosed with Down syndrome (Cunningham, Morgan, & McGucken, 1984; Gath, 1985), severe mental handicap (Quine & Pahl, 1987), and a variety of other, sometimes multiple, serious, chronic, or even life-threatening conditions, such as cerebral palsy, acute lymphocytic leukaemia, cleft palate, blindness, mental retardation, and brain damage post meningitis or cerebral anoxia (Cottrell & Summers, 1990; Leff & Walizer, 1992; Myers, 1983; Woolley, et al., 1989). These studies conclude that dissatisfaction with diagnosis is not inevitable and that parents are “abundantly wise” (Leff & Walizer, 1992, p. 147) about how the process of the diagnostic encounter needs to be handled and what features of the interview were helpful at the time and after the diagnosis. Parents also identified the features of the diagnostic interview which they found unhelpful or distressing, and the memory of which persisted long after the diagnostic encounter. In some studies (Kearney & Griffin, 2001), parents also clearly differentiated between the unavoidable

\textsuperscript{55}Goin-Kohel and colleagues (2006) study was web-based and included 494 participants from five countries, with the majority (76.3%) coming from the U.S. Howlin and Moore (1997) surveyed 1295 parents, members of autistic societies in the U.K. Keenan et al. (2010) surveyed 95 parents in Northern Ireland and the Republic of Ireland.
(“existential”) pain and grief associated with the reality of the child’s condition (in Kearney and Griffin’s study – a developmental disability), and the avoidable pain that derived from the “overwhelming picture of negativity” (p. 586) and no-hope messages received from others, including professionals. McLaughlin (2005) describes the initial diagnostic interview and the discussion of the diagnosis with parents as fundamentally important, as inadequate communication during initial diagnostic encounters “can leave a legacy of mistrust and anger that influences future relationships between parents and the range of health and social care professionals they come in contact with” (p. 285).

Literature using qualitative methods of enquiry into the process of an autism diagnosis and giving voice to parents is still limited (Kerrell, 2001; Nissenbaum, et al., 2002; O’Brien & Daggett, 2006), with some studies providing evaluations of specific diagnostic services (Kerrell, 2001). Both the survey-based and the in-depth qualitative studies have provided valuable recommendations as to how to improve the process of the diagnostic encounter. They have also shown that professionals can significantly impact parents’ experiences of the diagnostic encounter. The ‘experts’ involved in the diagnosis can either ensure that parents feel “supported, respected and informed, or conversely, they can leave parents feeling confused, angry, distressed, and humiliated” (Brogan & Knussen, 2003, pp. 44-45).

In her (2004) research on the Māori perspectives of autism, Bevan-Brown (2004) conducted interviews with seventeen 17 Māori families of children with autism. Amongst other topics, parents shared their experiences of the diagnosis, which “varied from no help and information at all to informative explanations and support” received by some families (p. xi). Many families reported delays in diagnosis voicing that they felt “unbelieved, unlistened to, and unsupported”. Some families described “periods of depression, confusion, sleeplessness and anxiety”(p. 5) as they were waiting to find out what was wrong with their child and to have some professional assistance and guidance. Apart from this research with Maori families, there have been as yet no studies conducted in New Zealand, which explore parents’ experiences of receiving a diagnosis of autism. The analyses and recommendations in this chapter are aimed to address this gap.

The analysis of parental accounts in this chapter is informed by a critical realist position (e.g. Sims-Schouten, et al., 2007; see also Ussher, 2000), an epistemological framework
that “affirms the existence of reality, both physical and environmental” (Ussher, 2000, p. 221), validates individual experiences and the production of meaning associated with these experiences, while recognising that the experiencing and the meaning-making take place within the broader socio-cultural context, and are mediated by it (Braun & Clarke, 2006). Within this chapter, such an approach to parents’ talk about their subjective experiences of diagnostic interviews (and their suggestions on how the process can be improved) enables me to conceptualise their accounts as descriptions of real events and experiences influenced by the current historical, cultural, and political milieu within which they are produced (Burns, 2004). Following Willig (1998), in my approach to parental accounts I differentiate between ‘reality’ and ‘truth’. While I treat participants’ stories as ‘real’ phenomena, I make no claims as to their truthfulness. For example, the mother’s belief that during the assessment interview the rationale behind the clinician’s background questions was to establish whether the parents were “meth dealers” or “slack arse parents” (Helen), may not be true, however the resulting negative experience of “feeling intimidated” and being treated “unfairly” and “inappropriately” is quite real. In the interviews I asked the parents broadly-formulated questions about their experiences of the diagnostic encounter, seeking to elicit the stories in their entirety rather than asking more specific questions about the positive and/or negative experiences during the diagnosis. Despite this approach, I found that parents talked mostly of their negative or unhelpful experiences during diagnosis, and made suggestions of how this could be improved, and that the reports of positive experiences were rare. This determined the focus of my analysis and the structure of this chapter, which begins with a description and examination of the only entirely positive account of a diagnostic process found in the data. This mini-case study of the mother’s subjective experience introduces the second part of this chapter, where I present the accounts of negative experiences and areas in need of improvement, having organised them into themes or discrete topics. I provide an accompanying narrative on the meaning of such experiences in relation to parental identities and practices. In making parental critiques the main focus of the chapter, I am by no means suggesting that diagnostic encounters are mostly experienced by parents of children with autism as negative or unhelpful, and that parents are rarely satisfied with the process. I hope however, that the analyses presented in this chapter may contribute to clinicians’ better understanding of parents’ needs during the diagnostic process, the subjective meanings they attach to them, and therefore contribute to the improvement of the services provided.
Diagnosis as a “working tool”: Anna’s story of positive (vs negative) diagnostic experiences

The diagnosis is not the end of a process but the beginning (O’Brien & Daggett, 2006, p. 115)

In the two extracts presented below, Anna, the mother of an 11 year old boy with autism, describes her experience of three diagnostic encounters. The child was initially assessed and diagnosed at the age of two-and-a-half years in Australia by a clinical psychologist (referred to in the extract as Dr X), then by a developmental paediatrician in New Zealand, and later, when the family moved to Australia, the child was assessed again and the diagnosis was confirmed by a multidisciplinary team of professionals. In her narrative, Anna compares two positive experiences (diagnostic encounters with Dr X and a multidisciplinary team in Australia), with the one that Anna describes as a “complete waste of time”. The latter took place in New Zealand, when the child was diagnosed by a developmental paediatrician. Although the extract is lengthy, I have chosen to present it here almost in its entirety with only minor abbreviations as a clear and powerful portrayal of helpful (vs unhelpful) diagnostic processes.

M.E.: And when- like if you think back to actually when you saw the doctor /Anna: yeah/ it was [Dr X] the first one, right, who diagnosed him? /Anna: yeah/ do you remember the whole process of it?

Anna: Ah well he was really good because we- ah he- like from me ringing him to when we got an appointment was within about two weeks (...) so he put us up on the list so we flew over there and he interviewed him [Jack, the child] for about two hours which was really good he let me tape it so we had that when we got home… and he was just very good at explaining the um what- why somebody would meet the criteria for autism and also what Jack’s specific issues were and then he recommended what we needed to do with him which was ah really good like who we needed to include and what we needed to do for a

56 Anna had in fact one more professional contact with a clinical psychologist in New Zealand at the time when she first became concerned about her son’s development. This encounter did not result in a diagnosis. Her account of this (negative) experience is presented in the second part of this chapter.
treatment plan so that was really good and when we came back to New Zealand we finally got an appointment with the paediatrician. That was a complete waste of time because that was more or less saying- ah it didn’t give us any information on autism and it was more or less her- we sat in her office for half an hour the child did absolutely nothing and she more-or-less said well are you- ah he is severely autistic- you are aware of that and ah that was kind of it and I felt because she was a paediatrician ah ah my experience with paediatricians is that they are not the right people to be diagnosing- it’s kind of more of a - because it’s obvious what’s wrong. But what’s not obvious or it would appear it anyway to me was what the treatment was going to be or where he fitted specifically on child development um and I didn’t know about child development at that stage so it was kind of like- saying he is autistic but they’re not giving you any tools to understand child development or what his- what why he was autistic or where he was on the communication and social scale and behaviours and all that sort of thing so yeah so none- from New Zealand we really didn’t get anything of value. We did from Aussie [later on when the child was older] (…) we had had a really comprehensive diagnosis ‘cause he’d changed of course. That was nearly two- two years later and so there we had to spend- I think we spent six hours with the psychologist or psychiatrist who did lots of different IQ tests visual ones and ones that he could do- till he found that exactly cognitively what- and we spent about six hours with a speech pathologist over time. And as well hers was really valuable because it showed us what he could and what he couldn’t do um and then the paediatrician just signed it off so that was really valuable because then I had all these pages of stuff we could then take to providers and- and what I knew then what he could and what he couldn’t do and knew what he should be doing and so that was- sort of like it educated me which was really important. So then when I went to the speech pathologist or I went to [name of an organisation - a private provider] or whoever became our provider we knew exactly what we were looking for so we were actually putting a program
together as opposed to “here’s my autistic kid” ’cause they’re all so different … yeah. (…) A diagnosis in my view is something that needs to be comprehensive so it’s a working tool rather than a- ’cause a label “autism” doesn’t mean anything to anybody. So that was kind of like a well yes he’s autistic. I mean I wasn’t interested in whether he was autistic or not I was more interested in finding out you know why his development has stopped or what we needed to do to get his development going again (…)

(...) I was just asking him [Dr X] what um how bad is he [child] how bad is he on the autism scale and what can and what can’t he do compared to a another a typical child of his age and he was really good he explained you know these are all the things that make somebody autistic (…) in normal language (…) so I could understand it really easily it was really obvious to me how many gaps he actually had whereas before I knew there were things wrong but I didn’t quite know how severe he was (…). So yeah I just found it really easy to understand his way and he is quite funny he is quite personable with all those things he is definitely not a he doesn’t come across as a “I’m the doctor you’re the … whatever” (…) he just said to us you need to go and work with this child. He didn’t… he didn’t he definitely didn’t recommend any sort of a therapy but he said you need to keep the child interacting and engaged for you know minimum 40 hours a week like his waking hours whatever you’re doing is keep him with people interacting doing things (…) whereas when the paediatrician in New Zealand I mean really says nothing so it wasn’t you know it was more based around (…) here’s your disability allowance and here’s your- you can probably get some funding through health and you can probably get some funding through um education but it was more based on “here’s the system” not what you need for the- I wasn’t interested in that I was interested in what we needed to do for him [the child](…) I don’t just see the point in going to see anybody unless there’s- it’s focused on what we’re doing yeah whereas here it was more like you’re going to get this, this, whatever it is this kind of
confirmation that this is what it is and then you go “and?” (laughs) and there’s no and afterwards (emphasis in the original).

As for many other parents in this study, the diagnosis of autism did not come as a surprise for Anna, as the word “autism” had come up during her earlier communications with the preschool and the Group Special Education staff who had concerns about Jack’s development. Following this, Anna contacted Autism New Zealand, ordered a number of videos on autism, and after watching these “self-diagnosed” Jack prior to receiving an official (‘expert’) diagnosis. She had also organised some behavioural intervention for Jack privately (based on the discrete trial training method) as after doing some research, she came to the conclusion that without treatment her son’s prognosis would be poor and he would not be able to live independently as an adult. What Anna finds positive and valuable in a diagnostic encounter is not just obtaining the definitive diagnostic label, but gaining an understanding of what is wrong with her child in particular, why he meets the criteria for autism, and what Jack’s specific strengths and weaknesses are compared to his typically developing peers. For Anna, the question is not whether to treat or not to treat her son, but how to treat him best. Her goal (or “destination” as Siegel (2008) puts it), is the optimal individualised treatment plan for Jack, and her expectation of the diagnostic assessment is that it provides the “map” (Siegel, 2008) to reach this destination – the child-specific information that would help the family to plan Jack’s treatment. From this standpoint, Anna describes an assessment by a multidisciplinary team of professionals as the most valuable diagnostic experience since the data obtained as the result could be used as “a working tool” to inform future intervention. Predictably, the thorough comprehensive way in which the assessment is done (professionals spending many hours with the child) adds value to the diagnosis. Conversely, Anna’s second diagnostic encounter, where the clinician appears to take a ‘look and diagnose’ approach that does not involve a thorough assessment and confirms the diagnosis without addressing child-specific issues and needs, is described as “a waste of time”. Focusing on potential sources of available public funding in the absence of a discussion about a treatment plan for Jack is portrayed by Anna as prioritising “the system over” the child’s needs, and as such lacking in value.
As McLaughlin (2005) points out, a diagnostic encounter does not take place in a social vacuum. Both parties (parents and clinicians), bring with them current discourses of disability (in this case – autism), that have an impact on the way a diagnosis is framed and discussed. Over the last 20 years, the ideology and practice of helping professions have in general, moved towards a partnership model emphasising “respectful collaboration between professionals and their clients” (Avdi, et al., 2000a, p. 327). In the area of child health, a concept of family-centred care emphasised the need for professionals to work in partnership with the family, recognising the parents’ central role in providing health-care, and making important choices and decisions related to the child’s wellbeing, education and treatment (American Academy of Pediatrics. Committee on Hospital Care, 2003; Seligman & Darling, 2007).

In the area of autism, parents have become recognised as key players in the effective treatment of their children and experts on their own child’s development. The creators of almost all of the currently used behavioural programs emphasise the centrality of parents’ participation (Marcus, Kunce, & Schopler, 1997; Silverman & Brosco, 2007). Parents of children with autism, particularly in the United States, have also historically played a very active part as proponents of both research and interventions via providing significant research funding, suggesting new avenues for research, building clinical research networks, and popularising empirically based therapies such as the Lovaas method, which became increasingly popular due to the activism of parents seeking to obtain the best treatment for their children57 (Silverman & Brosco, 2007). With the increased availability of behavioural and educational interventions, early “aggressive” treatment for autism has become more desirable to parents as opposed to “social policies focused on accommodation and acceptance” (Silverman, 2008).

In line with what Landsman (2003) described as “the heroic discourse of progress and rehabilitation” (see also Fleischmann, 2005), in which the effects of the disability can and should be overcome, parents construe themselves as being responsible for the child’s progress and outcome (O’Brien & Daggett, 2006). They portray the diagnosis as the starting point for treatment and a “ticket for access to services” (Avdi, et al., 2000b, p. 248). Consistent with this parental role, recent literature for parents provides

57 According to Silverman and Brosco (2007), for example, Bernard Rimland and other parents founded the National Society for Autistic Children (later the Autism Society of America) in 1965 in part to promote a then-new intervention, applied behavior analysis (the Lovaas technique). This was well before Lovaas published the results of a controlled trial based on his method (Lovaas, 1987).
information and advice on how to target the treatments that match their child’s needs, evaluate his or her strengths and weaknesses, form effective relationships with professionals, and deal with legal issues (Siegel, 2008). At the same time, literature aimed at professional audiences provides guidance on how to best understand and meet families’ needs by providing the child with optimal assessment and interventions (O’Brien & Daggett, 2006). The role of professionals is seen as “educated partners with families” determining which intervention/s would lead to the best outcome for the child (Kelly, Kemper, & Rosen, 2007, p. 416), whereas parents are described as “experts …. in need of expert input” (Avdi, et al., 2000b, p. 331). In her narrative, Anna positions herself as a party responsible for her son’s treatment and overall developmental progress, and from this position values the input of an expert (group of experts), who provides her with what she needs – the “education” on how to best help her child. She also values when the expertise is shared in a way that facilitates the educating process (clear explanations, lay-friendly language, permission to videotape the session for future references), and affirms her position as an equal partner (friendly, personable manner, not “I am the doctor, you are the … whatever”). The latter in Billig et al.’s (1988) terms, is an important part of professional expertise – the ability of an expert to balance the claims of equality and authority in an “authoritatively friendly manner”, without appearing domineering in one’s expertise or, conversely, allowing friendliness to outweigh professionalism (p. 77).

**Negative experiences of the diagnostic process: What parents want changed**

In this section of the chapter I focus on parental accounts of their negative experiences of diagnostic encounters and their suggestions of how the diagnostic process can be improved. Apart from Jack, whose diagnostic encounters were described in the previous section of the chapter, all the other children in this study were diagnosed by one clinician rather than a multidisciplinary team of professionals, either a developmental paediatrician or a psychologist. Occasionally, for a variety of reasons, including parental dissatisfaction with the original diagnosis, seeking a second opinion, or the family relocating to a different city/country, more than one clinician was involved in the process at different points in time. Diagnoses were obtained from clinicians in both public and private practices. Diagnosing clinicians rarely made referrals for further, more comprehensive assessment of the child.
Some of the topics presented below were introduced in the preceding section of the chapter discussing Anna’s story of her positive (vs negative) experiences of diagnosis. The experiences of parents analysed in this section can be easily summed up by the words of one of the mothers, describing the essence of her diagnostic encounter: “…It’s like ‘yeah it’s autism, off you go’” (Pauline). I organised parents’ accounts of their negative experiences of the diagnosis into the following themes: “look and diagnose” approach, “it’s not about me”, “go home and do your best”, lack of hope and bleak forecasts, and low expectations.

“Look and diagnose” approach

Some parents talked about the lack of a thorough assessment and a cursory “look and diagnose” examination of the child. Such an approach to assessment and diagnosis did not provide them with any information about the child’s specific problems, or the individual pattern of his or her strengths and weaknesses.

Sarah: [Clinician Y] was very um he was just observing her for 15 minutes there he wasn’t asking us much about her at all or interacting with her much at all

Gavin: Oh it was pretty amusing (…) we’d been in the waiting room for about 20 minutes um before we got in and the guy basically opened the door and Ethan went in and started playing with some toys and the paediatrician said “hello Ethan” and he just played (laughs) he just basically completely ignored the paediatrician and the guy said “he’s autistic” that was it (laughs)

The issue of brief assessments has been previously reported to lead to parental dissatisfaction with service provisions. In Kerrell’s (2001) study, parents of children with autism expressed doubts that the interviewer could obtain a good understanding of the child’s abilities in a short period of time. Siegel (2008), in the section of her book entitled “What if Your Child’s Assessment Doesn’t Include Much Interview or Observation?”, describes the “look and diagnose” approaches as outdated and not helpful to parents in their goal of establishing a treatment plan for the child:

58 The term used by Siegel (2008).
In the olden days, it was acceptable for a doctor to give a diagnosis after fifteen minutes of a little kid running around his office while he chatted with parents. Today it is certainly not … I’d also be concerned that a doctor who conducts cursory diagnostic exams will have a cursory understanding of treatment alternatives – and choosing among those treatments is the ultimate goal of any diagnostic assessment. (p. 41)

Unsurprisingly, in all the cases in this study where the child received such cursory diagnostic exam, treatment options were not discussed with the parents. New Zealand Autism Spectrum Disorder Guideline (2008) recommends that following assessment an individual formulation is developed detailing the person’s strengths and weaknesses, developmental course, ASD symptoms, and recommendations for the future. This was not the case in the excerpts above, and the parents are clearly disappointed, talking about the clinician’s lack of attention to the child, apparent indifference and lack of motivation (or possibly lack of skill and knowledge) to do a more thorough diagnostic examination, and unwillingness to include parents (as experts on their child) in the process. However, in both instances in the interview, parents refrain from overtly criticising ‘the expert’ and expressing their disappointment, and do so indirectly. In the second excerpt, for example, Gavin uses irony by calling a clearly inadequate diagnostic encounter “amusing”, and laughs while describing it, which can be seen as a way of masking disappointment and bitterness. As a father, Gavin is not receiving an adequate ‘expert’ input and notably refers to the diagnosing paediatrician as “the guy”, therefore denying him the status of an ‘expert’ – a strategy used by other parents in this study to express their disappointment with a professional.

“It’s not about me” (Anna)

Two mothers in this study described their experiences of an assessment by psychologists (in private practice), which they both found unsatisfactory and distressing. In both cases, the mothers reported that they (and not their children), became the focus of the assessment. In the case of Anna, this was her first diagnostic encounter with ‘an expert’, however prior to that she had a clear idea that her child had autism, and was expecting to receive clarification about the child’s pattern of strengths and weaknesses (“how he is autistic”) and recommendations regarding interventions. In the case of June, the child had just been given a diagnosis of “autistic tendencies” by a
paediatrician in private practice, who himself did not provide the family with adequate information about the diagnosis, and referred them to a psychologist for further input (“oh your kid’s got some autistic tendencies have a nice day and we’ll see you later you go and see these people [psychologists] and they’ll explain it to you more fully than I can”). In both cases, mothers portray the clinicians’ questions related to the parents’ background and the current family functioning (a standard part of a psychological assessment, see Carr, 2003), as “inappropriate” and “totally off”. Focusing assessment on the parents and their background rather than the child\textsuperscript{59}, and in the case of Anna, on aspects of family functioning (marriage, absent husband/father) creates a very strong emotional response of feeling “disgusted”, “intimidated”, “furious”, “wild” and upset (“bawling most of the way through”).

Anna: (...) I’d called this guy [psychologist] in to see and he came in home and (...) Jack was running round and round the room doing all this-by that stage I knew all the autistic signs cause I’d seen them on the video (...) and the guy sat there and asked me questions about my marriage and about totally nothing to do with the subject and gave an opinion about um how we needed to have more stable life blah de blah de blah this went on and on and on I felt wild but I just took his cup of coffee off him and asked him to leave my house because he was totally focused on the family and not on the child and I was really disgusted (...)  

M.E.: if that’s not terribly uncomfortable Anna can you tell me a little bit more about things that he asked you? 

Anna: well he asked me like for him he was he had all these prejudices which I could see straight away which people do and continue to have like he said “oh well where’s your husband?” (...) what I was asking the guy to come and do was to look at Jack and tell me you know what do you see you know how how- he’s autistic tell me how he’s autistic what we can do (...) but he focused on as far as I was concerned he focused on all the wrong things like he focused on the fact that um that

\textsuperscript{59} It is possible that in both interviews parents were also asked questions about the child’s development, however, neither of the mothers reported that this was the case, and both of them construed the assessment as (“inappropriately”) focusing on the parents rather than the child.
my husband was overseas (...) the guy’s sitting there with his little pad doing inter- you know like a- like here we are I’m doing this interview with you and it’s like everything’s inside me screaming “it’s not about me” so it was totally off (emphasis in the original)

M.E.: and why did he ask you what was his rationale for asking you where your husband was- what was he sort of what did he have in mind?

Anna: I had no idea but I can- I thought it was kind of like the um you know like people um I guess think that if you change all these other things somehow the autism will change (...) it was very disguised sort of you know parental um the way you are doing the family thing is not right... so that was kind of that was an awful experience

June: (...) it was hugely inappropriate the whole thing

M.E.: can you tell me about it?

June: it was um you know “oh what’s your background and oh you are an only child” I mean just the entire thing was more about us as being slack arse parents is what we thought- (...) and it was very- quite intimidating

M.E.: so she [psychologist] asked you about your childhood /June: yep/ and background and-

June: yep (...) almost analysing us to see whether we were the meth dealers or who we were where we fitted in society in the world basically. In a nutshell um and it wasn’t appropriate at all and yeah it wasn’t fair and we should never have been sent there in the first place we just needed information (...) but yeah um as I said my husband was furious because it had completely wasted his time for xyz hours um I yeah ended up bawling most of the way through it was just the pits

As mentioned above, a developmental and family history and routine child and family evaluation are standard parts of a psychological assessment, and are recommended for interviews with parents of children with autism (Carr, 2003). It is extremely important
however, that prior to the assessment the clinician and the clients (in this case – the parents), clarify their expectations of the assessment, and it is explained to the parents what the assessment involves, a rationale for it is given, and that they agree to continue with the assessment. Forming a “collaborative partnership” (Carr, 2003, p. 113) with the parents is key to a successful assessment and treatment planning for the child. This clearly did not happen in either of the interviews above, and both families had expectations from the assessment that were different from those of the psychologists, and felt extremely dissatisfied as a result. Considering that the early ‘expert’ discourses of the causes of autism, and the resulting “treatments”, aptly described by Folstein (2008b) as “one psychiatric misadventure after another” portrayed parents as causing or at least contributing to their child’s disorder, it is not surprising that parents can be very sensitive about the motives of the interviewer “focusing” on them, an approach which in Anna’s case is portrayed as “prejudiced”. These early discourses of autism left a legacy that is evident in the discomfort parents still feel when “presenting …. children with autism to the world” (Grinker, 2007, p. 83). “Focus” on parents during assessment (particularly if it is poorly explained and inadequately justified) also changes the positioning of a parent in a parent-professional dyad from a “co-expert”, overall responsible for the child’s progress, but in need of professional expertise to achieve the optimal result, to an object of assessment, which is incompatible with the former role. In both cases described here, the mothers resolved this tension by asserting their role as an expert on their children and taking action. Anna “fired” the professional she was dissatisfied with on the spot, while June did return to see the same psychologist, but stipulated before the session that she only required advice on behaviour management for a specific problem the child had. She was very happy with the recommendations, which worked for the child.

“Go home and do your best” (Julie)

Most parents in this study talked about a lack of information about autism they received at the time of diagnosis, and the need to do extensive research themselves to find answers to their many questions without any professional guidance, at the time when they were feeling emotionally vulnerable following the shock of receiving a diagnosis of a developmental disorder for their child.
Peter: I just remember it being- I don’t remember it taking a long time and being told a lot not what you’d expect and then we went away and started looking things up that night and geared ourselves

Eric: basically you get your diagnosis and you are told to go away and get on with it um as you can tell I’m quite bitter about that um you get more information if you keep going back to them and keep fighting and you keep asking for more um but it’s very hard work

Lora: (...) I’ve been very very disappointed with the quality of information that I’ve received from anywhere (...) I don’t think he [diagnosing paediatrician] really sat down through the appointment and said “autism is this” and here is a pamphlet saying this is what autism is that would be very helpful I’m a little bit startled at the lack of professionalism I’ve seen on so many levels I have to say we should have left the paediatrician with a sheet saying your diagnosis um is this, this is what it is in a nutshell so that you can go and then express that to your family close friends whoever you want to speak to and you can go and hold each other after the appointment and you know husband wife and say hey lets have a look at this together this is what we are dealing with now rather than having to go and sit on the Internet and you know go through many poor sites to find a good one and that sort of thing wade through things for hours and hours trying to make sense of it all (...) I mean this is like a one page thing it doesn’t have to be it’s not hard work for them they photocopy it and here is a support group here is an information line or a information website or something like that why can they not do that? I mean they’ve just dropped a bombshell on a family completely altered their um their their trajectory through the world they are now heading in a completely different direction with their family this will impact them for a life time give them a few life lines just answer a few questions and there should be that kind of professionalism
In her account, Lora, like many other parents in this study, also raised a common issue of the lack of written information (for example, pamphlets explaining what autism is, reliable and informative websites on autism, contact details of support groups), for parents to take home from the diagnostic appointment. The importance of giving parents written information at the time of the diagnosis have been emphasised by O’Brien and Daggett (2006), who argue that verbal communication between parents and professionals that is not also provided in written form was of questionable value as the shock and dismay of hearing the diagnosis (which Lora describes as “dropping a bombshell on a family” that “completely alters their trajectory through the world”), was likely to impact parents’ ability to absorb and remember any other information that was given to them. In the accounts of parents in this study, lack of helpful information at the time of diagnosis also acquired a somewhat symbolic meaning of lack of caring and support on behalf of the professional. Parents talked about feeling unsupported after initially receiving just the diagnostic label and having to do their own research on autism (“she [developmental paediatrician] just said oh yeah that’s autism and you know go away and read about it (…) so yeah I remember like both of us me and Lyn just feeling like you know just totally um totally alone” (Eric), and emphasised the importance of being able “just to feel like someone is providing it [information] for you” (Liz, emphasis in the original).

A typical diagnostic encounter described by the parents in this study took place over one session which was dedicated to the assessment of the child, and finished with the clinician presenting the parents with the diagnosis at the end of the session. This was normally followed by filling out a form for a small disability allowance for the child, a referral to a local disability support service for a needs assessment, and a suggestion that the family contact the local branch of Autism New Zealand.

Lora: (...) we had more than an hour allotment um at the end of that time of his observation and questions he said “well this is what you know where he’s at he has autism spectrum disorder I’d say he’s mild to moderate” his written report came back as mild um and then he said “oh you know you qualify for a child disability allowance you I will refer you to [name of an organisation that facilitates disability
support services] and you know you should ring Autism New Zealand thanks bye” (laughs).

Some parents reported not receiving even this bare minimum of information and assistance at the time of diagnosis from their diagnosing clinician. Similar findings were reported by Howlin and Moore (1997) where for many families in the U.K. “even basic information was often lacking” (p. 160). A number of parents left the appointment without a clear understanding of the nature of the diagnosis.

Sarah:  (...) anyway he [diagnosing paediatrician] didn’t give us any information to take away with us we had to find the Autism New Zealand website and I wish he could have- if he’d done one thing he could have given us that website (...) I went to my GP following the diagnosis for something else and she was the one that told me about the Child Disability Allowance, Dr X hadn’t told me about so she signed me up for that straight away which was great um someone else told me about the [name of an organisation that facilitates disability support services]- oh the [name of a support group] told me about that which- so we get some help with evening and respite carer support hours so yeah Dr X didn’t tell us about that either

John:  (...) I didn’t really know what it [autism] meant but I just didn’t like the sound of it, it just sounded like um… sounded very bad and that happened on a Friday we went down to the beach and it was pretty rough but um you know… we- I really didn’t understand what it was and all I knew was that it was bad and that he wouldn’t talk

M.E.: Did he [developmental paediatrician] try to explain what it was or did he kind of suggest /I- no no/ any treatments?

John: No he didn’t explain what it was he assumed that we knew and… um- that’s the way I interpreted it… and… he gave us a couple of phone numbers and filled out a bit of paperwork so we got the [disability] allowance or whatever it is from the government… and basically that was it.
One couple reported that when the wife contacted the paediatrician the day after the diagnostic interview to ask where they could find some information on autism, she was told to look on the Internet.

Sarah: (...) we were in such shock as we left (...) I rang him the next day and I said look where do we go for information (laughs) “just look on the net” (laughs)(emphasis in the original)

Peter: (...) he was quite blasé and he said just go on the Internet and I thought that to me was pretty negligent because there’s so much on the Internet all shades of information (...) there’s probably a lot of people who get a diagnosis like that and don’t get any help and don’t know where to start

It appears that in this particular case the clinician sees his role only in diagnosing the child and is overtly disinterested in consulting the parents on what to do next – not only do the parents leave without any suggestions regarding the treatment plan, but the doctor appears to be unwilling in educating them about autism or directing them towards some reliable sources of information, therefore leaving the parents at a very vulnerable time immediately post-diagnosis to search the Internet looking for answers. As the doctor is not assisting the parents in making an informed choice about the treatment options for their child, and “referring” them to the Internet instead, his ‘expert’ status in the eyes of the parents is compromised, and he is portrayed as being “blasé” and “negligent”.

Many parents in this study talked about the immediate emotional effect of being given the diagnosis of autism for their child. They described it as “a bombshell”, “a huge blow” associated with feeling “hurt”, “upset”, “devastated”, “numb”, “angry”, and “overwhelmingly sad”. In the excerpts below, Pauline and Sarah describe their experiences immediately after receiving a diagnosis of autism for their children:

Pauline: (...) we went away and we were so hurt and upset and sad and everything- (...) it was like horrible I mean we just sat around crying the whole time it was awful yeah it was horrible (...) (emphasis in the original)
Sarah: (...) I’d remember what’s happened and I’d just have this huge sinking feeling you know it’s just like- (cries) like the world’s ended … I just guess it was shock you know (…) 

“Shock” was the word most frequently used by the parents in this study to describe the immediate aftermath of a diagnostic disclosure. One of the mothers also referred to it as a “dazed phase”. Literature based on interviews with parents of children with autism and other serious disabilities (Cottrell & Summers, 1990; Nissenbaum, et al., 2002; O’Brien & Daggett, 2006), talks about the shock and dismay experienced by parents at the time of the diagnosis, pointing out that this may affect their ability to absorb and retain information given during the diagnostic encounter. O’Brien and Daggett (2006) recommend to clinicians that parents get sufficient time to have their “most important questions” answered and “do not feel rushed” (p.124). In this study however, many parents reported that having received inadequate information at the time of diagnosis and sometimes having “no idea what autistic spectrum disorder was”, they nevertheless did not ask questions (even when invited to do so by the diagnosing clinician) due to the overwhelming state of shock.

M.E.: Did you ask him [diagnosing paediatrician] questions?

Pauline: no I was in shock I was like “oh blow me away” and all I could think of was “I’ve got this- right okay right okay” and I was- just blew my mind

Vicki: (...) I was in such a shock that I didn’t really- I couldn’t think of anything to ask

Despite recommendations in the existing literature on diagnostic disclosure (e.g. Cottrell & Summers, 1990; Nissenbaum, et al., 2002; O’Brien & Daggett, 2006) about the importance of providing follow-up soon after the initial appointment to ensure that parents have time to consider the diagnosis and have their questions answered, this was not the case with the participants in this study. Acknowledging both the necessity for the parents to get over the initial state of shock following the diagnostic disclosure, as well as the time-limited nature of a diagnostic encounter, many participants talked about
the importance of a follow up appointment and expressed disappointment that they were not offered one.

Paul: [what needs to happen is] a follow up type of meeting to explain such things you know to say oh “here’s a diagnosis I’ve got another patient but what I want to do is book you in dah dah dah another week. I’d like talk to you about some treatments” you know or “give you some” you know “genuinely- genuine um information wisdom about what to do” just disappointed at- that that didn’t happen (...) (emphasis in the original)

The majority of parents in this study reported that during the diagnostic encounter, they received inadequate information regarding child-specific treatment strategies. The issue of treatment options were either not discussed with the parents at all, or at best, the names of some treatment providers were given as a list of options for the parents to explore on their own, without any child-specific recommendations being made. Many parents talked with bitterness about professionals “not believing in”, “being closed to”, or “making no commitment” to treatments for autism, leaving parents with no direction, guidance, or any specific advice regarding for example, the ways to address some of the child’s most challenging behaviours.

Julie: I don’t remember leaving with any idea of what the treatment might be either and I felt very lost by that I felt absolutely shattered by that because I felt more or less that- I suppose the essence of the absence of a treatment plan leaving with the absence of a treatment plan in place felt to me like well there isn’t one really so you know go home and do your best that’s how I felt at the time (emphasis added)

Eric: Oh I think I think she [developmental paediatrician] might have mentioned Autism New Zealand um but not much else. Um I don’t ever remember being told there were treatments um you know I think I mean we’ve been back to see [Service X, public healthcare provider] on quite a regular basis since then and um and they still don’t think there’s any treatments, they don’t even think ABA is mainstream
therapy um even though it’s had huge success, um they’re certainly against biomedical intervention, um the [Service X’s] line at the moment is basically just put up with it um you know they monitor it and they’re very nice and they’re caring and they’re friendly but they don’t do anything. Um so yeah it was um obviously we were very shocked and really had no idea where to go from there

Elaine: Dr. A [developmental paediatrician] gave us the different options available like go to Autism New Zealand and talk to the EarlyBird Program\textsuperscript{60} um contact [Service Y]\textsuperscript{61} um he gave us like about five different people to contact but didn’t delve into what they all provided didn’t go through any huge explanation he just said “here’s my list, these are the people you can contact” um, “[Service Z]”\textsuperscript{62} he said but he said “they are private they cost a lot of money”, and that was basically all the information he gave us and then sent me on my way

Nissenbaum et al. (2002), who interviewed professionals as well as parents in the U.S. regarding their experiences of sharing the diagnosis of autism with the families, found that although professionals (in their sample – non-medical, such as psychologists or occupational therapists) were concerned about how the families will access services in the community, they typically did not suggest specific interventions, and only one professional out of eleven indicated that she discusses various treatment options. O’Brien and Daggett (2006) hypothesise that some professionals may consider that it is not their responsibility to link families with treatment providers in the community, or may not want to recommend “specific agencies or intervention models over others” (p.125). However, the parents in both Nissenbaum et al.’s (2002) study and in O’Brien and Daggett’s (2006) research voiced their preference for receiving specific information about treatment options for the child to give them a sense of direction and assist with accessing services. They attributed the lack of such recommendations to professionals’ “concern for legal issues”, “lack of knowledge” (Nissenbaum, et al., 2002, p. 36), and

\textsuperscript{60} The EarlyBird program is a 12 week psycho-educational early intervention program for parents of preschool children with autism jointly funded by the Ministry of Education and the Ministry of Health, and is provided through Autism New Zealand.

\textsuperscript{61} This service provides therapy for children with Asperger’s Syndrome, social skills groups and Relationship Development Intervention (RDI) programs.

\textsuperscript{62} This service provides interventions based on the principles of Applied Behaviour Analysis (ABA).
“lack of caring on professionals’ part” (O’Brien & Daggett, 2006, p. 125). As I argued in the first section of this chapter, parents in this study position themselves as having the overall responsibility for their child development and progress, and for doing everything possible to meet the child’s developmental needs. The diagnosis of autism makes the process of meeting the child’s needs more complex and challenging. As Lora put it in the excerpt below “it takes nurture to a whole new level” – that of providing the child with professional help – the optimal interventions for his or her condition.

Lora: (…) it’s such a pleasure to care for and provide for and love and nurture your children and so this [the diagnosis of autism] takes nurture to a whole new level because suddenly my child has needs that I was unaware of that I was unprepared for- and it is my duty my responsibility and my joy to step up and meet those needs (…). Now there are many different layers to his development that need my attention and the attention of professionals, it’s my responsibility to get him the professional help that he needs um and it’s my responsibility to get him the parental help that he needs

The child’s quality of life is portrayed by participants as “paramount” (see the second quotation at the beginning of this chapter). Therefore getting the child the professional help in the form of interventions that have the potential to improve his or her quality of life becomes a “duty”, a “responsibility”, and part of good parenting (“if her quality of life can be improved by different therapies we’re doing then we should do it”, Peter). Conversely, not providing any interventions for the child is portrayed as incompatible with good parenting (“a real failure as a parent to do nothing about it [child’s autism]”). In such a context where positive parental identities and practices are linked with organising treatments to improve the child’s quality of life, the diagnosis is expected to be, as Anna put it in the first section of this chapter, “a working tool”, and the value of professional expertise becomes contingent upon the perceived quality of “expert” advice regarding child-specific treatment options. In this study, when such “expert” input was reported as lacking, parents’ expectations of the professionals’ role were not met (see Huws, et al., 2001, for similar findings), and they frequently responded with disappointment, scepticism, or even harsh criticism of the diagnosing clinician. Avdi et al. (2000a) reported that professionals were constructed by parents as possessing “some
deeper knowledge and understanding” about the child’s condition and, because of that had “the right and responsibility to regulate” what information was disclosed to the parents and how it was done (p. 331). This was not the case in the current study, where similar to the participants in Nissenabum et al.’s (2002) and O’Brien and Daggett’s (2006) studies, parents construed the lack of advice and guidance as either lack of “expert” knowledge on the subject, or lack of effort, care and support (“negligent”, “can’t be bothered”).

Liz: when the paediatrician said to me that you know “he’s happy perhaps you should just leave him like that” (laughs) um that’s you know not-don’t do anything- I think that really stuck to me because I just thought you know if you read the research on outcomes for autistic people it’s not very pretty (…) I think you know a lot of the paediatricians here are a long way behind the research on what autism is and you know how it develops and things like that

Peter: (…) it shouldn’t be the parents’ decision really well it should be their decision but it shouldn’t be entirely up to the parents to decide which therapy or which course of action to take. I don’t think- it doesn’t seem right to me I mean with all the choices you can have you know and there’s no-one to tell you “yes you should do this or that” ABA or RDI it seems to me to be kind of a bit negligent (…) to diagnose somebody and not be able to tell you what you should do about it

Stephen: (…) treatment plans? not a lot no not really, um Lora [wife] has been doing all the hard work as far as I’m concerned with- um where we’re at it’s all down to what Lora’s done /M.E.: okay/ and ah yeah she’s found out you know some good stuff and some good people and some great programmes and things that have really got us on our way but um did they come from that guy? Nah nah no it didn’t not in my mind (…) I didn’t really get much of a direction. I thought well that’s a bit piss-poor quite frankly um for that kind of you know professionalism (…) a guy you pay $300 bucks an hour can’t actually be bothered to tell you “oh to go and do this and go and do that cause you need to
A recent qualitative study conducted in New Zealand about the experiences of diagnosis for Alzheimer’s disease reported that the high cost of private consultation was likely to be associated with higher client’s expectations of the quality of the service provided (Fabian, 2007). Although many children in this study were diagnosed by clinicians in private practice, only one father (Stephen in the excerpt above), commented on the high consultation fee as a factor contributing to his overall dissatisfaction with the diagnostic experience.

O’Brien and Daggett (2006) recommend that parents leave the diagnostic encounter with sufficient information and recommendations to enable them “to do something to begin the process of obtaining intervention services that address their child’s needs that very day if they so desire” (p. 125, emphasis in the original). Parents in this study often expressed their desperate desire to commence interventions immediately post-diagnosis to help the child. Accepting that not all of their questions about the child diagnosis and treatment can be answered within the time-frame of the first diagnostic encounter, they talked about the importance for the professionals to at least start the discussion, and provide the parents with some information and guidance about what to do next, rather than leaving them to do their own research.

Sarah: (...) I felt like I needed to know what to do, I desperately wanted to know what to do to make it better to to start doing something and yeah to understand what what we needed to do

Liz: it is hard- it’s hard to give the information because there’s so much and it’s all so different but um just getting something, just getting a starting point for people that um yeah and not- and just to feel like someone is providing it for you because it was really tiring to find out about all the different things to start with, I mean I did it all by myself for ages before I joined support groups and stuff and actually realised that somebody else had already researched this
Parental “desperate” desire to start treatments immediately after the diagnosis is best understood in the context of the discourse of the early intensive intervention, which over the last two decades has become quite prominent in autism literature, including research, professional literature, and published accounts of autism by parents. A comprehensive report based on the review of 10 early-intervention programs in the U.S. (National Research Council, 2001) concludes that:

… the available research strongly suggests that a substantial subset of children with autistic spectrum disorders are able to make marked progress during the period that they receive intensive early intervention, and nearly all children with autistic spectrum disorders appear to show some benefit (p. 166).

All 10 programs reviewed in this report emphasise the importance of commencing a treatment program “when children are at the earliest possible ages” (p.151). In a recent randomised controlled trial funded by the National Institute of Mental Health, Dawson and her colleagues demonstrated for the first time the efficacy of an early intensive behavioural intervention designed for toddlers with ASD as young as 12 months of age (Dawson, et al., 2010). After two years of treatment, the children who received this intervention showed significant improvements in cognitive abilities, adaptive behaviour, and diagnostic status compared with the children who received community intervention. In an earlier article, Dawson argues that “prevention of ASD is plausible” (Dawson, 2008, p. 775) if infants at risk of developing autism are detected before the full syndrome is present. She posits that due to the early brain plasticity, “early interventions aimed at stimulating young infants and toddlers at risk for ASD can substantially change the course of both behavioural and brain development”. Overall, research indicates that although individuals of all ages may benefit from autism-specific interventions, children who begin intensive treatment before age 4 tend to make better progress (Harris & Handleman, 2000; Rogers, 1996). Harris and Handleman (2000) argue that for their program “age at time of admission is a crucial factor in outcome”

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63 For example, the intervention and findings reported by Lovaas (1987) were popularised in a book entitled “Let Me Hear Your Voice: A Family’s Triumph Over Autism”, written by a mother of two children with autism (Maurice, 1993). The book describes the experience of the author and her own children and their “recovery” from autism as a result of early intensive behavioral intervention based on Lovaas method.

64 Ciaramello et al. (1995) describes the phenomenon of plasticity of the developing brain as its “amazing ability to adapt to changes in its environment and to fine-tune its connections during development” (p. 120).
Recently published New Zealand Autism Spectrum Disorder Guideline (Ministries of Health and Education, 2008) identifies “making the earliest possible start to intervention” as one of the characteristics of quality intervention programs and recommends that parents are able to access early intervention services as soon as significant developmental problems are recognised, even prior to the full completion of the diagnostic process (p. 91). It was therefore unsurprising that parents in this study were concerned about starting interventions as soon as possible to avoid “wasting precious learning time” and to increase the child’s opportunity for learning.

Pauline: (…) I can only rest if I know my child is being taken care of plus he was learning because I couldn’t waste a moment of precious learning time (laughs) you felt like you were running against time you had to get as much as you possibly could get into this child as fast and as early on as possible cause everything you read indicates that the sooner and earlier you do it and the brain has a certain time frame so you really felt like you had to go all out in a certain time frame

For those parents whose children were diagnosed early, additional factors contributing to their desire to start interventions urgently was to improve the child’s condition, particularly if the symptoms were mild so that the problems were less “noticeable” by the time the child reaches school age, and to increase the child’s chances of attending a mainstream school (as opposed to a special school), with minimal amount of assistance such as input from a teacher aide (The topic of social stigma attached to the diagnosis of autism has been discussed in detail in Chapter 5 of this thesis.). In the first excerpt below, Stephanie, whose child was diagnosed when he was less than 3 years of age talks about her initial desire to organise treatment for the child (“fix him up”), in hope that by the time he reaches school age there would be no need for the diagnosis (“he will be all right”). In the second excerpt below, Lora, whose child was also diagnosed before the age of three and only three weeks before the interview took place, construes the possibility of her child going to a special school as “devastating” for herself and stigmatising for him. She is determined to organise therapy for him for the next two years to increase his chances at attending mainstream school, hopefully without a teacher aide. Notably, one of the earliest and possibly best-known studies of early intensive behavioural intervention for children with autism (Lovaas, 1987) argued that
educational placement within a mainstream school was a “particularly valuable measure of progress”, being sensitive to educational achievements and social and emotional functioning. “Successfully passing through normal first grade in a public school” (p. 6) together with improved IQ scores were the main indicators of the treatment success, and the terms “normal functioning” and even “recovered” were used to describe these children.

Stephanie: yeah well I thought well if he is really mild perhaps we can avoid just giving him that label and um perhaps we will just fix him up and he will be alright before anybody ever needs to know kind of that’s part of my process I think but it didn’t last very long because I knew it was just going to be too difficult but there was a certain point where I yeah a stage of thinking that the label would actually be a bad thing for him (emphasis added)

M.E.: Lora, what are your views on schooling I know there is a couple of years ahead um but what do you think - mainstream or special school?

Lora: mainstream absolutely yeah I I would be quite devastated if he went to a special school um I I think at this stage he could at this stage he could function in a mainstream school, if I project forward with a couple of years say with a couple of years therapy um hopefully without a teacher aide but if necessary we’d fund the teacher aide or I would be a teacher aide or something if he needed to yeah I’d find out a way of making it work I think yeah mmm I find it terribly disturbing to think of him going to special school that would be a heavy label /M.E.: why?/ well because I I think um firstly and foremostly your self-perception um, he would- if he didn’t understand then he would understand later in life that he went to a special school and he’d be thinking “I’m really different I’m odd” I I you know how some people well everybody feels a little bit like an outcast at times like they are not part of the group and that’s good fuel for thinking that “yes I am different I’m stupid” you know um so that I wouldn’t want to um fuel that at all
Parents in this study on several occasions talked positively about receiving valuable advice on various techniques or specific focused interventions for the child, such as prompting, reinforcement of the desirable behaviours, stimulus control (e.g. for sleep problems), or using visual schedules to facilitate successful transitioning between activities. Such advice was gained from a variety of sources including literature, other parents, EarlyBird trainers, or therapists working with the child as part of an ABA-based comprehensive treatment program. However, when one of the families was recommended a focused intervention at the time of diagnosis instead of a comprehensive treatment model, this was construed by the mother as the clinician’s low expectations and lack of optimism about the child’s ability to make significant progress.

M.E.: was there any talk at that point of time about um- did he [developmental paediatrician who diagnosed the child] comment on what he thought was um a better treatment option for Giles?

Pauline: no /M.E.: no? / he made no commitment to anything, he liked this woman [name] who ran [a non profit organisation and parents support group promoting an intervention called “photographic learning and communication strategies”] um she was a parent and everything and he probably liked her because she did nothing biomedical and did nothing else, all she did was visuals and he thought she had a good grip on things /M.E.: and visuals- what-/ just photographic visuals to um help explain to the child what’s going on so that was the extent of what he thought the child needed

On the lack of hope and bleak forecasts

Many parents cried when discussing the need for hope (Nissenbaum, et al., 2002, p. 36)

Hope is not denial of the child’s difficulties….For parents, hope embodies the belief, the conviction that their love, care, and hard work will help, will help build the best possible life for their child in need….Professionals who nurture hope leave parents with a lifeline. (Leff & Walizer, 1992, p. 166)

Previous studies conducted with parents of children with disabilities (including autism), have consistently emphasised the importance of giving hope to parents at the time of the
diagnosis (Cottrell & Summers, 1990; Fleischmann, 2005; Kearney & Griffin, 2001; Leff & Walizer, 1992; Mansell & Morris, 2004; Nissenbaum, et al., 2002). Parents in these studies voiced that although they were by no means expecting the clinicians to raise false hopes of cure for their children, “providing too bleak a prognosis” (Mansell & Morris, 2004, p. 396) was most unhelpful. Hope, which Kearney and Griffin (2001) define as “a belief in possibilities”\(^{65}\) (p.587), was portrayed as “an absolute necessity” (Leff & Walizer, 1992, p. 166), without which parents were likely to despair and lose motivation “in the tireless attempts necessary to propel their children with autism forward” (Fleischmann, 2005, p. 310). Parents of children with autism in Nissenbaum et al.’s (2002) study suggested that clinicians can provide hope by “being positive, describing the child’s potential for improvement, discussing the positive effect of early intervention, and providing examples of success stories” (p. 36).

Parents in this study frequently talked about the utmost importance of being given hope and motivation at the time when the diagnosis was first presented to the family and the negative impact of being presented with the worst case scenario prognosis (“the doom and gloom”). Recognising both the pervasive nature of autism and the overall uncertainty of the prognosis, none of the parents talked about hopes and expectations that within the current clinical discourse on autism would be considered unrealistic (e.g. hopes for complete recovery or a quick cure for autism). Autism was typically construed as “treatable, but not curable”\(^{66}\). Like van Manen’s “belief in possibilities” (emphasis added), parental portrayals of “hope” in this study were associated with “motivation”, “progress”, and giving their child an opportunity to live “a more fulfilling life” and “happiness” in the future.

Vicki: when he was diagnosed the paediatrician said that he may never speak and that he may never reciprocate love and I was just sort of sitting there thinking “what’s autism”? (laughs) I had no idea (...) I was just in shock really for weeks until I could bring myself to kind of...

\(^{65}\) van Manen (2006) explores the meaning of hope for children in official pedagogic discourse. He argues that hope itself gets purged from the professional “pedagogic hope” expressed through the language of aims, objectives, expectations, and intended learning outcomes, which he refers to as “the language of ‘hopeless hope’”. He compares professional hope with parental hope, the belief in possibilities that “lie outside the direct or indirect field of vision of the expectations” (p. 123).

\(^{66}\) Compare the following observation by Reid (1999): “parents report being advised that, because autism is organic, it cannot be treated. Here there seems to be a confusion between treatment and cure. Doctors do not refuse treatment to people with incurable physical illness if it may alleviate some aspects of their condition, or, at the very least, improve the quality of their lives” (p. 65)
find out about it because it was all too much um and so I yeah. I mean Tyler has improved so I know there’s hope (…) I believe he will um improve in his communication I mean I know he’ll always have autism um but hopefully as he gets older he will be able to communicate better and be happy… that’s all I want

Lora: (...) the most important thing I think that should happen is following a diagnosis within 24 or 48 hours probably you need to be able to speak to a support person and have your questions answered and also have a little hope be offered, a little hope. Um I was fortunate to know somebody whose child had been through the ABA programme and was able to say “look my child was severely affected by autism but is now in a mainstream school without a teacher aide, we’ve seen wonderful progress”. That’s a great success story and I know it doesn’t apply to every child but these are things that give you hope and motivation and the world crashes down around you when you receive a diagnosis like that

Taken together, the negative aspects of the first diagnostic encounter discussed above, such as being given inadequate (if any) information about autism, not being referred for a comprehensive assessment to establish the child’s unique profile of strengths and weaknesses, receiving little or no recommendations regarding the child-specific treatment plan, and not being offered a follow-up appointment soon after the diagnosis took place were construed by the parents as messages of no hope from the diagnosing clinician. The professionals were depicted as pessimistic about the child’s future, not believing in possibilities for a positive prognosis for the child and therefore withdrawing from involvement with the family after the diagnosis has been given, leaving the parents unsupported. Notably, none of the parents (apart from Anna in the first section of this chapter) reported being overtly encouraged to organise interventions for the children or learn to work with their children themselves to stimulate learning and/or change maladaptive behaviours, nor did the parents describe being given hope and reassurance about the possibility of improvement and/or the family’s successful adaptation to the child’s condition.
John: (...) we were pretty roughly told that there’s nothing we can do for him [the child]... um and that you know the prognosis with autism-they didn’t know where he was on the spectrum and don’t bother coming to see me again

Pauline: (...) and then the guy saying to me [giving the diagnosis](...) and he said “and here’s a list of-“ and some people didn’t even get this list “and here’s a list of” he goes “talk to other parents, see if you get value for money but here are some options” you know and that was that and I said “oh do I come back” and it’s like “well there’s no point in coming”. You learn early on (slows down) that um a lot of these medical people it's like just may as well throw away the key, there’s no hope, no point... he was very much like that (...) like there’s nothing you can really do... here’s a list of stuff but talk about it with other parents... see what you think. But he doesn’t condone or believe in anything that we do, none of the doctors have, none of- no doctors at [name of children’s hospital] have ever you know- so you don’t get any of that support67

Low expectations?

As has been argued earlier in this chapter that the diagnostic encounter does not take place in a social vacuum (see McLaughlin, 2005), and parents experiences and expectations are affected by the existing societal discourses of autism, including the discourses associated with the diagnostic encounter itself, and the role and input of ‘experts’ vis-à-vis parents. Parents portrayed themselves as the ones who have been the driving force behind the interventions for their child (doing their own research, being

67 Notably, Nissenbaum et al.’s (2002) study found that parents and professionals differed significantly in their portrayals of the outcomes for individuals with autism. Parents’ outlook was positive, whereas professionals mainly talked about negative outcome. The earlier qualitative study (Gray, 1993a), which examined the relationship between parents of autistic children and staff at a treatment centre in Australia, concluded that staff were in the “unenviable position of being able to offer little hope for even a partial recovery” (p. 1046, emphasis added). Gray describes how parents, who initially had hoped for significant improvement and even recovery for their children, in time abandoned their hopes in favour of “the staff’s definition of reality” and generally accepted that the child would be institutionalised. Gray (1993a) suggests that this change towards a more pessimistic outlook was due to the parents facing the actuality of their children’s (slower than expected) development as well as special techniques and resources, purposefully used by the staff, to reduce parental expectations.
“at the forefront” or “on the cutting edge” of investigating autism treatments, with professional support lacking.

*Sabine:* (...) the parents are the ones on the cutting edge... they are the ones who are actually you know on the Internet trying to find new things (...) I think it’s been parents it’s been parents who are the ones who’ve been putting ideas of different things- (...) you wish that the professionals were more supportive (...)

Considering the themes discussed above, it is unsurprising that even before the diagnostic encounter (and possibly as a result of talking to other parents about their experiences of the diagnosis) some parents in this study had formed quite low expectations of the ‘expert’ input. In Gavin’s account below, a visit to a paediatrician to obtain a diagnosis is portrayed solely as a means to access the funding and support available from the government. Referring to other parent’s accounts, which depict the “gloomy”, no-hope prognosis as a typical outcome of the diagnostic encounter, Gavin and his wife appear to be *a priori* pessimistic about the value of the potential expert input (in the form of useful information and treatment recommendations). They manage this by boosting their expert status, increasing their knowledge and expertise, making their own decisions about the child’s treatments, and therefore ceasing to be “in need of expert input” (Avdi, et al., 2000b, p. 331 ). Even if suggestions regarding treatments were in fact offered by the clinician, in his account Gavin dismisses them as not memorable as he assigns far more value to his and his wife’s expertise on the subject.

*Gavin:* (...) we didn’t really go for treatment options to see the paediatrician... my wife already she had the whole thing at that point she was starting to map out what we were going to do and why and so we got the diagnosis from the paediatrician so we could get help from the government and get funding and all this sort of stuff and all the different options that she wanted to try

*M.E.:* did he volunteer any advice or- anything?

*Gavin:* I can’t remember I can’t remember... I’m not sure if this actually happened to us or if it’s just from what I’ve heard of other people saying but I seem to recall that um that the information you get from
paediatricians is pretty gloomy… it’s like hmmm “you better give up any options you've had for life in the future because you will be looking after him until you die”

Concluding comments

As a result of my analysis of the interviews with parents of children with autism around their experiences of the diagnosis, I identified several themes (in van Manen’s terms “structures of experience” (2006, p. 79) that suggested high levels of dissatisfaction with certain aspects of the process of the diagnostic encounter that took place in New Zealand, mostly in the Auckland region in the several years leading up to when the research was conducted. The analysis, which started with a mini-case study of one mother’s journey through the diagnosis, and included her positive as well as negative experiences, then focused on the negative experiences of the diagnosis and criticisms that dominated parental talk. Without negating the value of obtaining the definitive diagnostic label (the “official” diagnosis) in a timely manner, parents talked about the need for the diagnosis to be “a working tool”, a starting point en route to obtaining services and individualised treatment for the child as opposed to “an end in itself”.68

Positioning themselves in the parent-professional dyad as having overall responsibility for the child’s development and progress, parents portrayed themselves as experts on their children in need of professional expertise and guidance to inform their treatment choices. In the majority of the diagnostic encounters reflected upon by the parents in this study, their expectations were not adequately met. To summarise, parents described their negative experiences resulting from the lack of thorough assessment, cursory diagnostic examination of the child, inadequate, if any, information about the diagnosis and treatment options, lack of recommendations regarding the treatment plan for the child, lack of continuity of care in the form of a follow-up appointment, worst-case-scenario prognoses and messages of no hope. They also emphatically objected to what they portrayed as being made the focus of the assessment, a position which, as I have

68 “Diagnosis is a tool, not an end in itself” (Boucher, 2009, p. 259). See also Howlin and Moore (1997) who state that “diagnosis in itself is a crucial but not sufficient step in improving the outlook for children with autism and their families” and that “wherever possible, diagnosis should be accompanied by practical help and support” (p. 161). Siegel (2008), who describes the diagnosis without the treatment plan as only “half of the story”, suggests that parents who receive just that consider consulting a different (better?) clinician.
argued, is incompatible with parents’ co-expert role within the parent-professional dyad, and which has negative discursive connotations of the early parent-blaming etiological attributions of autism.

The small number of parents involved in this study makes it impossible to generalise, although the results mirror many of the findings reported previously in qualitative as well as quantitative studies about parental dissatisfaction with the diagnosis of autism and other significant childhood illnesses and disabilities (e.g. Cottrell & Summers, 1990; Howlin & Moore, 1997; Leff & Walizer, 1992; Mansell & Morris, 2004; Nissenbaum, et al., 2002; Whitaker, 2002). It is also difficult to speculate about the role that the broader contextual factors played in parents’ experiences. For example, one might argue that the constraints imposed by the structure and availability of health-care and educational service provisions for individuals with autism in New Zealand at the time when the diagnoses were made could have contributed significantly to the dynamics of the diagnostic encounters, imposing restriction on what the clinicians could offer parents. A systematic analysis of the services available to and accessed by parents at the time of diagnosis was not undertaken. The 2002 report prepared for the Ministry of Education stated that “currently in New Zealand there is no one coherent programme that offers an optimal service for children with ASD” but that “there are some good programmes available at a high cost to families” (Godfrey, et al., 2002). Subsequently, the New Zealand Autism Spectrum Disorder Guideline recommends that “the feasibility of establishing publicly funded, ASD-specific behavioural services should be investigated” (Ministries of Health and Education, 2008, p. 139). However, despite the lack of publicly funded interventions, all the families involved in this study reported using or, in case of one newly diagnosed child, planning to use non-publicly funded interventions available either in New Zealand or overseas, often at a very high cost (see Chapter 2 for more details of the interventions used). Some parents learned to use focused behavioural interventions themselves, others became trained practitioners of more comprehensive treatment models, such as RDI). Two families reported being actively involved in setting up intervention programs not previously available in New Zealand (e.g. The Precision Learning Centre in Auckland69). Therefore, there was certainly an opportunity (in most cases – a missed one) for a diagnosing clinician to engage with the parents, providing education and guidance in selecting, implementing

69 (Dalziel, 2000)
and evaluating treatments. Within the family-centred model of care in child services, it is recommended practice that parents and professionals work together, that the professionals respect family members’ perceptions, priorities and preferences, encourage family members’ active participation in assessment and intervention, and work towards the shared decision-making with the family (Klein & Gilkerson, 2006; Woods & Wetherby, 2003). Somewhat worryingly, many parental accounts in this study portrayed the parents as the main or the only driving force in the parent-professional dyad, with the professionals construed as the unresponsive party: lacking in knowledge, unsupportive, pessimistic about autism treatments, and disinclined to explore and contribute to the families’ goals – selecting and organising the best possible child-specific intervention.

Having discussed what parents reported to be lacking at the time of the diagnosis, I would like to conclude this chapter by drawing the reader’s attention to a number of potentially harmful consequences of some of the concerns and issues raised by parents in this study. Firstly, as I have argued earlier in this chapter, stripping parents of hope and giving bleak pessimistic forecasts about the child’s future may negatively affect their belief in possibilities for the child. In practical terms, it could reduce parents’ motivation to organise (or implement) treatments for the child or participate in publicly funded parent-focused interventions (such as the EarlyBird), which, in turn, could be detrimental for the child’s progress and the family functioning. No-hope messages at the time when the diagnosis is communicated to the parents are also likely to significantly (and unnecessarily) increase parental emotional suffering over and above the pain associated with receiving the news of the child’s condition. Secondly, considering the history of early psychogenic attributions of autism, diagnosing clinicians need to exercise extra care that parents do not see themselves (and the family dynamics) as the focus of diagnostic assessment. The accounts of two mothers analysed in this chapter demonstrate that this can lead to a significant parental distress and mistrust of professionals. Finally, inadequate information about available services and supports provided at the time of diagnosis can lead to very ‘real’ negative consequences for the family, such as delays in access to allowances, respite, and other carer support services. As reported by parents in this study, lack of information and professional advice also results in increased demands on parents’ time and resources as they search for ways to help their child.
Chapter 7: Conclusions and Recommendations

The concern is not just with how the person ‘is’, but how they come to be in specific socio-cultural contexts (Marks, 1999, p. 187)

In this thesis, my concern was with parents’ stories as located within the current and historical context of the knowledges about autism. Instead of engaging in an enquiry of parental coping, which typically focuses on an individual and decentres or ignores the role of the wider socio-cultural context, in this research I approached such context as being essential to parents’ experiences and our understandings of them. One of my goals has been to demonstrate the ways parents’ stories are constituted by a multiplicity of discourses of autism etiology, interpretation, and remediation, and to examine the impact these discourses have on parents’ day-to-day lives. Such focus reframes ‘coping’ as making sense and negotiating meanings and identities. The topics of analysis in this research (causes of autism, stigma in autism, and parental experiences during diagnosis) have been selected based on a number of factors. They were informed by the history of autism as a clinical entity with its pathologising and stigmatising constructions of parents as causing their child’s condition. They were influenced by my own personal interests as a researcher that stemmed from my earlier work with families. I have addressed these in Chapters 1 and 5 of this thesis. The selection of the foci of analysis was also ‘data-driven’ in a sense that the topics that were selected featured prominently in the parents’ accounts. In focussing on the process of the diagnosis of autism, my goal was also to give voice to the parents and validate their accounts, doing justice to their lived experiences.

In this final chapter, I discuss the contributions of this thesis as a whole to the current knowledges of and understandings about autism and the ways having a child with this condition affects parents. I start with the summary of my findings across this study, followed by a discussion of the usefulness of the analytic frameworks that have been selected to approach the data, and some practical recommendations based on the findings of this research. I conclude by addressing potential directions for future research in the area.
Summary of thesis chapters

My analyses in Chapter 4, 5, and 6 are based on the interview accounts of 26 parents (14 mothers and 12 fathers) of children with autism. To analyse these data I used a combination of discourse analysis underpinned by a social constructionist orientation and a thematic content analysis informed by critical realism. As a background for my analysis in Chapter 4, I provided a review of the current ‘expert’ literature on the etiology of autism.

In Chapter 3, I reviewed and presented the body of research and professional knowledge on the causes of autism as a three-level-model of explanation: the original or “root” causes of autism, currently understood mainly as genetically-determined with some bioenvironmental contributions, the “brain bases” – the pathology of the brain produced by the original causes, and the psychological problems, resulting from the brain pathology, which was produced by the “root” first level causes. To summarise, autism was construed within the bodies of knowledge of science and medicine as a predominantly genetically-determined brain-based disorder of impaired cognitive function manifest in the abnormalities of behaviour. Existing research however, also showed that potential bio-environmental contributions to autism (e.g. environmental pollutants) had been for many years significantly under-funded and under-researched, remaining the domain of the print media. In my review, I also discussed the early psychogenic theories of autism, and argued that the parent-blaming attributions, although discredited, were not entirely extinct.

In Chapter 4, I investigated parents’ portrayals of the causes of autism. I demonstrated that parents used both the genetic and the bioenvironmental discourses (almost in equal proportions) to account for their child’s problems, however, I also showed that the discourse of the psychogenic causation was still present in some accounts. I argued that since the genetic view of autism had gained dominance within basic science and medicine, while the environmental discourse had been widely debated in the (print) media, parent-blaming attributions had not faded away. Rather, they took on different forms as parental, and particularly maternal “responsibility” for the child’s autism, constituted by the dominant discourses of procreation and mothering in Western society, broadened to include ‘defective’ genes and exposure to multiple environmental ‘triggers’, while the psychogenic discourses did not vanish completely. I discussed the
ways parents made sense of the available discourses, managed their identities, and negotiated discursively imposed responsibility and blame.

In Chapter 5, I built on the analysis in the previous chapter (Chapter 4), which explored the parent-blaming attributions of the current discourses of autism causation. I provided a brief overview of theoretical and empirical research on stigma, and introduced my own formulation of stigma. I defined stigma as a subject position socially constructed as being outside of or in opposition to the existing valued discourses of identity, and experienced as adverse. I emphasised the lived-in moral-emotional dimension of stigma, whereby it affected parents’ daily existence in their local social world, threatened their valued social identities and was experienced as a range of negative emotions including embarrassment, shame, fear and anger. I discussed parental constructions of stigma associated with the diagnosis of autism, and demonstrated how discourses of disability, ‘perfect children’, and parental responsibility converged to create devalued and stigmatised subject positions for the parents. I concluded the chapter by exploring the ways parents negotiated their subject positions to reduce stigmatisation.

Taking a critical realist approach to the interview accounts in my final empirical chapter (Chapter 6), I reported on parents’ experiences of the diagnostic process. The only entirely positive account of the diagnostic process (in Australia) present in the data, which I approached as a mini-case study, portrayed the diagnosis as a working tool. It included the following characteristics of the diagnostic process as valuable and helpful: comprehensive assessment by a multidisciplinary team yielding child-specific information, and guidance regarding a treatment plan for the child.

The mother in this case study positioned herself as a party with the overall responsibility for the child’s treatment and development, valuing “expert” input only if it provided her with what she needed – the “education” on how to best help her child. She found it valuable when the expertise was shared in ways that facilitated the educational process (e.g. clear explanations and lay-friendly language), and affirmed her position as an equal partner within the diagnostic encounter. I presented the accounts of negative experiences and areas in need of improvement having organised them into the following themes: “look and diagnose” approach (lack of thorough assessment, cursory diagnostic examination of the child); “it’s not about me” (parents’ objections to being
made the focus of diagnostic assessment); “go home and do your best” (inadequate information about the diagnosis, interventions and support networks, lack of a treatment plan); lack of hope and bleak forecasts; and low expectations of the diagnostic encounter. In line with previous research findings, parental accounts in this study indicated high levels of dissatisfaction with the diagnostic process. Although the lack of autism-specific publicly funded interventions at the time of the diagnosis was likely to impose constraints on what clinicians could recommend to parents, many parental accounts portrayed the professionals in the parent-professional dyad as the disinterested and unresponsive party, lacking in knowledge, unsupportive and overall pessimistic about autism interventions, leaving the parents to their own devices in organising treatments for the child. I argued that even in the situation where the publicly-funded treatment options for autism were not available, clinicians working within a family-centred model of care still had many opportunities to assist parents by engaging in a collaborative professional relationship with them, providing advice and recommendations, and working towards shared decision making with the family. Having considered what was lacking for parents during the diagnostic process, I concluded the chapter with a discussion of potentially harmful implications of stripping parents of hope, giving bleak prognosis, and inferring that the child’s problems could be associated with the family dynamics. In line with the chosen critical realist approach, I also highlighted the very ‘real’ negative consequences for the parents stemming from the lack of important information at the time of the diagnosis, such as delays in access to funding, respite and other services, and time – and sometimes money-consuming search for information that was not provided by the professionals.

**Contributions**

In this section I discuss the contributions of this work and the approaches used in this research to the knowledge about the impact of having a child diagnosed with autism on the parents. I also discuss the recommendation for practice stemming from this study.

As I demonstrated in Chapter 1, after the early aetiological attributions of autism had lost dominance, the main body of research on parents of children with autism focused on the levels of stress and parental individual coping with having a child with this condition. This model of theorising tended to view the relationship between the “stressor” – the child’s problems, and parental “adaptation” to it as a linear and
unidirectional process (Avdi, et al., 2000b) mediated by parental coping strategies. This type of research has made important contributions to understandings of the problems parents face on a daily basis, their unmet needs, strengths, and resources. However, its individualistic focus has also meant that the broader socio-cultural context within which parental “coping” and “adaptation” takes place and in which “family meanings about disability are embedded” (Avdi, et al., 2000b, p. 242) has been left largely unexplored. The corollary of studying the individual as isolated from the social is the implicit (or sometimes not so implicit) assumption that parents are culpable for the problems they are facing. In an attempt to overcome the individualistic bias of such research, this study aimed at contributing to the (so far very limited) body of empirical research that has approached parental experiences with autism as being embedded within and constituted by the matrix of social and cultural meanings of autism, parenting, disability, and identity (Avdi, et al., 2000a; Avdi, et al., 2000b; Farrugia, 2009; Gray, 2001; Rocque, 2010). Fundamental to achieving this goal was my choice of the two epistemological paradigms used in this study: social constructionist and critical realist frameworks with their focus on language as constructive of social reality.

**Analytic and methodological approaches: Reflecting on usefulness**

As stated in Chapters 1 and 2, the aims of this research were not to generate new facts or ‘uncover’ the truth about the impact of autism on the family, but to open up new ways of thinking about parental experiences and meaning-making, the ways that make explicit the constitutive power of societal discourses on parental subjectivities and practices. In line with Burns (2004), this study has demonstrated the usefulness of approaching participants’ accounts from more than one perspective in order to focus on different aspects of the issue under examination.

In Chapter 4, conducting my exploration of parental accounts from a social constructionist viewpoint allowed me to demonstrate how parental stories of the causes of autism are constituted by multiple discourses of autism etiology, and how these discourses together with the discourses of parental (and particularly maternal) responsibility for bearing healthy offspring produce subject positions conducive to parent-blame. I deployed a form of discourse analysis proposed by Wetherell (1998) and Wetherell and Edley (1999), which combines the focus on the action orientation of
people’s talk with the attention to macro-level societal discourses, in order to explore how parents negotiated these discursively constructed subject positions.

In Chapter 5, I used the same analytic and methodological approach to explore stigma in autism. Addressing the issue within social constructionist framework made it possible for me to offer a formulation of stigma as a socially constructed subject position, and thus avoid the pathologising essentialist stance of previous stigma research, locating stigma within an individual. Using the same form of discourse analysis described above I was able to demonstrate how parents actively negotiated subject positions created by the dominant discourses of disability, ‘perfect children’ and parental responsibility.

In Chapter 6, approaching parental accounts from a critical realist position allowed me to give voice to parents, making their stories more “visible” within the landscape of other, more dominant stories constituting knowledge about autism and the impact of autism on the family. In line with Sims-Schouten et al. (2007), I also considered locating parents’ stories within the realities of the day-to-day life that they have to negotiate to be ethically important as an approach doing justice to and validating parental experiences.

**Implications for practice**

Within social constructionism, one of the two paradigms that have been used in this research, discourse is considered to be constitutive of practice which can be defined as “all the ways in which people actively produce social and psychological realities” (Davies & Harre, 2001, p. 262). Therefore, I consider it important to discuss here some of the implications for practice stemming from this work.

In Chapter 4 and Chapter 5, I have demonstrated that despite previous suggestions by some authors that biological causative theories of autism could result in decline in parent-(self)blame and the reduction of stigma (Avdi, et al., 2000b; Gray, 2002; see also Schmidt, 2007), parents in this study did not construe either genetic or bioenvironmental attributions of autism as benign and blame-free. The analysis in Chapter 5 highlighted the negative aspects of the diagnostic label of autism, and discussed stigmatised subject positions allocated to the parents of children with autism by the discourses of parental responsibility for the bearing and rearing of ‘less-than-perfect’ children. Practitioners working with the families of children with autism are
likely to benefit from familiarising themselves with these findings, in particular – with the lived-in moral-emotional dimension of stigma that I emphasised in my analysis, whereby stigma is not an abstract concept but a powerful negative “force” that affects parents in their day-to-day existence in the local social world.

My analyses in Chapter 5 indicated that in some parents’ associations, such as community and online support groups, high parental involvement with various autism treatments has become a new ‘norm’, with stigmatising consequences for the parents who were construed (or construed themselves) as not doing “enough”. Ironically, the determination and active efforts of some parents in attempt to help their child with autism created a normative discursive landscape within some support groups, which other parents described as stressful and unsupportive. It is therefore important for practitioners as well as policy-makers working in the area of autism to be aware that support groups (although undeniably an important source of support and information for the parents) are not necessarily and always supportive, and for some parents participation in such groups can constitute a source of stress. As I argued in Chapter 5, lack of public funding for autism-specific behavioural services in New Zealand was likely to play an important role in the experiences of stigma and increased stress for lower-income parents, who might blame themselves for “not doing enough” for their child and feel compelled to fund the interventions privately at a significant cost to the family.

My analyses in Chapter 6, where I discussed parental experiences of receiving the diagnosis, have important practical implications for clinicians involved in the diagnostic process as well as for policy-makers in the area of autism. Worryingly, many parents continue to report lack of thorough assessment, “look and diagnose” examinations of the child, lack of information about the condition itself, interventions, support networks, and treatment plan for the child. These criticisms have been reported by previous research in relation to the diagnostic process for autism as well as other childhood illnesses and disabilities. Parents emphasised their dissatisfaction with the no-hope messages and bleak forecasts received during the diagnostic encounter – they reported feeling generally unsupported by professionals in their attempts to organise the optimal treatment for the child, and many had low expectations of the professional input. A common feature of the majority of accounts of the diagnostic process in this study was the lack of continuous dialogue and consultation between clinicians and parents.
Parents did not report instances where the diagnosing clinicians acted in the spirit of family-centred care to elicit and address parents’ problems, concerns, and expectations in a collaborative and respectful manner. Significantly, one mother’s entirely positive account of a diagnostic encounter, presented in the chapter in the form of a case study, emphasised the value and importance of the diagnosis as a working tool for organising the treatment for the child, and highlighted the need for a family-centred partnership model, emphasising respectful collaboration between parents and professionals. It is also important that clinicians involved in the diagnosis of autism stay aware of the historical discourses of psychogenic causation of autism and the pathologising effect they continue to have on parents. When systemic information about parents is sought during the diagnostic interview, it is important that the rational for that is discussed with parents and that their consent is obtained. If certain (relevant) aspects of family dynamics are discussed during assessment, clinicians need to take care that these discussions are not misconstrued by parents as implying the possibility of a causal attribution.

**Directions for future research**

In this final section, I discuss some of the questions that arose in the course of developing and conducting this study, and some potential directions for future research.

In my research, I discussed the history of autism as a clinical entity and the representation of parents of children with autism. I considered the macro-level discourses of autism etiology, based on the findings of other researchers, and the interview accounts in this study. These analyses were conducted using primarily (with only minor exceptions) the bodies of knowledge created by the ‘expert’ discourses of science and medicine. Constructions of the same issues by popular media including the World Wide Web, therefore, were left unexplored and will constitute an interesting area for future research.

In this thesis, I reviewed the existing research on the treatment of autism. Although in some of the interviews parents talked about the factors that influenced their choice of treatments for the child, I did not attempt an in-depth examination of the issue. As the World Wide Web has been consistently described by parents as a major source of information, an investigation of how parents make their choices about treatment will
benefit greatly from a comparative exploration of the ‘expert’ and media discourses of autism remediation. On the other hand, in this study parents consistently constructed treatments for autism as important for their child’s development and quality of life, with all the participants reporting using at least one form of intervention for the child (in addition to the services received from The New Zealand Ministry of Education (Special Education). Although I do not consider this position atypical or uncommon for the socio-cultural context of Aotearoa New Zealand or other similar cultures, it is likely that the process of participants recruitment (through a parents support group, a national autism association, and a private treatment provider) meant that the parents in this study were either interested in having access to resources, support, training, and information, or actively involved in treatment. Further research, either drawing participants directly from the community or via diagnostic services, may be able to explore the views of parents who do not consider ‘normalising’ their children necessary for their wellbeing.

In this work, I based my exploration of the process of autism diagnosis on parental accounts. An analysis of the views of diagnosing clinicians, informed by the findings in this study, will allow us to obtain a fuller and richer picture of the diagnostic process, and will likely yield practical recommendation that would help improve service provision for the families. A recent qualitative study by Nissenbaum et al. (2002) of parents’ and nonmedical professionals’ perceptions of giving and receiving a diagnosis of autism is an excellent example of exploring the views of both “sides” of the parent-professional dyad.

In this study, I demonstrated the usefulness of discourse analysis underpinned by social constructionism for the study of autism. I suggest that this perspective can be successfully used in research that focuses on the cultural specificity of autism. In relation to New Zealand-based research, this paradigm can be utilised in explorations of the multiple meanings employed by Māori families around a child’s diagnosis of autism, and the macro-level societal discourses they draw upon in their constructions of the impact of autism on the family –issues that this study was not designed to do justice to. Currently research on Māori perspectives on autism is represented by a single study, whose results are published in a report commissioned by the New Zealand Ministry of Education (Bevan-Brown, 2004). Although in my work I focused on parents whose children were diagnosed with autism, like Avdi et al. (2000b) I too consider that the findings could inform thinking about the effects of other conditions on families, and that
employing a social constructionist approach can yield valuable results extending and enriching our understandings of these important issues.

**Final thoughts**

When in the course of this research I was asking parents if there was anything gratifying (rather than stressful) about having “a child with autism”, the reply I frequently received was that it was gratifying to *have* Ethan, Dylan, Jack or Sophie. Full stop. What typically followed was a discussion of a multiplicity of material and discursive factors and practices associated with autism that made the experience of parenting a child stressful. For me, the justification for doing this research, its *raison d'être*, was the hope that in some small way it could contribute to positive changes in such factors and practices. Changes that would give parents at least some relief from the stressors and strains they currently experience. Changes that would make descriptions of “having” and “enjoying” children with autism more “visible” in their stories to come.
Appendix A: Recruitment Advertisement

STUDY VOLUNTEERS WANTED

TO PARTICIPATE IN A ONE-TO-ONE DISCUSSION / INTERVIEW

about

AUTISM AND THE IMPACT OF AUTISM ON THE FAMILY
(for parents of children with autism)

Are you a mother or a father of a child with autism (12 years old and under)? For my Doctoral thesis research at The University of Auckland, I am interested in talking with parents of children with autism about their experiences and would like to invite you to participate in my study. You need to be fully conversant in English and live in the broader Auckland area. I am interested in a wide range of parents understandings and views about autism and its impact on the family. Confidentiality is assured.

If you would like some more information or would like to take part, please contact Maia Eremin, Department of Psychology, University of Auckland (mere004@ec.auckland.ac.nz), or call me on 027 3036529
Appendix B: Participant Information Sheet

Parental Accounts of Autism and the Impact of Autism on the Family

INFORMATION FOR PARTICIPANTS

My name is Maia Eremin and I am conducting research on Autism and the impact of Autism on the family in association with my supervisor, Dr Nicola Gavey. Dr. Gavey is an Associate Professor at the Department of Psychology at the University of Auckland. This research is for my Doctor of Clinical Psychology thesis at the Department of Psychology at The University of Auckland and is partially supported by a Winifred Gimblett Scholarship. In this research, I am interested in finding out more about mothers’ and fathers’ understandings of autism, their everyday experiences, including contacts with health professionals and issues about the child’s treatment. I will be also be investigating how various theories of autism and it’s causes impact on parenting an autistic child. As part of this project, I will be interviewing approximately 30 people – mothers and fathers of children who have been diagnosed with Autistic Disorder and are 12 years old or younger.

You are invited to take part in a semi-structured interview, during which I would ask you to talk about your own experiences of parenting a child with autism, your understanding of these experiences, your contacts with health professionals, your choice of treatment for the child if any, your views about the future. This will also involve discussing things you’ve found stressful about being a parent of a child with autism and your ideas of what could have been helpful to you. The exact nature of the questions is flexible, as they will continue to be developed during the course of the study. You would not have to answer any questions that you did not want to, and you would be free to stop the interview at any stage and to withdraw from the research without giving a reason.

Most likely I will ask you to take part in one interview, however, there is a possibility that during that initial interview we touch upon some issues that would benefit from further discussion. In this case I will be seeking consent to re-contact you to organise your participation in the second interview, if time and resources for this project allow. You are under no obligation to do this if you don’t want to, and you do not have to give any reasons if you decide not to participate in the follow-up interview. Each interview will take approximately one and a half to two hours, and be conducted at a place that is convenient to you (e.g. at your home, workplace, or a private room at the university). I will be conducting the interviews myself, and will be discussing them later with my supervisor. I will need to audiotape the interviews, which will then be transcribed into written texts for analysis. To help preserve your confidentiality, both the audio-tape and the written transcript will be labelled with code numbers, and participants’ real names will not be typed into the transcript. All information you provide will be stored in a locked cabinet without your name on it. This may be for six years or longer – so long as it can be kept securely and while I continue to work on related research questions. I may also draw on the information you provide for future scholarly purposes, which may not be directly related to the current project. If you choose to be interviewed you will be asked to sign a Consent
Form. The signed Consent Form will be stored separately from any other information in a locked cabinet at the University of Auckland.

This research project is likely to lead to written publications by myself and my supervisor. In any reports, articles, books, or talks that arise from the research we are likely to present quotes from some of the people who have been interviewed. Any details that may potentially identify you would be altered to protect your anonymity. During the analysis the interview transcripts and the audiotapes will be seen/heard by myself, the person employed for transcribing, and, possibly, my supervisor. The person employed for transcribing will sign a confidentiality form. Short anonymous extracts may be seen by others in research groups to which my supervisor and I belong, and in meetings where we seek to get feedback and share ideas about our research. At all times, your anonymity will be maintained. When the interviews have been transcribed, we can send you a copy of your interview transcript if you would like one for your own interest and we are able to contact you by phone, email or mail to confirm your address at the time. Please note that we would not be asking you to edit the transcript.

Because this research will be asking personal and, at times, sensitive questions about experiences that may have been or continue to be distressing to you, I would ask you please to consider carefully whether you would like to participate. It is quite possible that discussing your experiences, particularly around your child’s diagnosis, could be uncomfortable or upsetting. If you do participate, and later wish to discuss anything relating to your participation in the research, you are most welcome to contact me. I have over two years experience working with children with autism in their own homes and I understand the problems their parents are facing on a day-to-day basis. I will also be reviewing the process of interviews with my supervisor, Dr. Nicola Gavey, who is a registered clinical psychologist, and will be available to provide support. I will routinely contact people in the week after the interview to see if you want an opportunity to talk about any issues or feelings that may have arisen for you in the interview (either on the phone, or in person). I expect that most people won’t feel any discomfort about the experiences we are discussing, although the interview might generate some emotional responses. Either way you may like the opportunity to discuss it and add further thoughts or comment on the interview.

It is hoped that the people who are interviewed for this research will find the experience affirming and interesting. More generally, I hope that this research project results in a positive contribution to the research and practice on autism and the impact of autism on the family.

You are under no obligation to take part in this study. If you do decide to take part you can withdraw any information you have provided, without giving a reason, up until two months after the interview.

Thank you for your time.

If you would like more information regarding this study, or have any concerns you may contact:

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For any queries regarding ethical concerns please contact:  
The Chair, The University of Auckland Human Participants Ethics Committee  
The University of Auckland, Private Bag 92019,  
Ph (09) 373-7599 ext 87830

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 12/07/06 for 3 years from 12/07/06 to 12/07/09. Reference Number 2006/247.
Appendix C: Consent Form

CONSENT TO PARTICIPATE IN RESEARCH

Research: Parental Accounts of Autism and the Impact of Autism on the Family

Researcher: Maia Eremin

I have been given and understood an explanation of this research project. I have had an opportunity to ask questions and have them answered. I understand that I may withdraw myself or any information I have provided from this project at any time up to two months after the interview without having to give reasons.

I agree to take part in this research and I understand that I will be audio taped.

I understand that I will be contacted in the week following the interview to see if I would like the opportunity to talk about any issues or feelings that may have arisen for me in the interview, or to add further thoughts or comment on the interview.

I agree to be contacted to discuss my participation in the follow-up interview. Yes / No

I understand that the audio tape of the interview will be transcribed into written form, and that the person who undertakes this transcription will sign a confidentiality form.

I would like a copy of the full transcript to be sent to me. I understand that this means I will need to be contacted by phone or email to confirm my postal address at the time of sending out the transcript:

Yes / No

Address:

Phone number or email:

I understand that this consent form will be stored in a locked cabinet for at least six years, and that all information I provide will be stored separately from this consent form.

I understand that the information I provide may be drawn on by Maia Eremin for future scholarly purposes that can be different from those of the current study.

Signed:

Name (please print clearly):

Date:

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 12/07/06 for 3 years from 12/07/06 to 12/07/09. Reference Number 2006/247.
Appendix D: Indicative Areas of Questioning


- How much do you feel you know about autism, its causes, treatment options, overall prognosis?
- Sources of information?
- What did you used to think versus what you think now? If any changes, reasons for changes?
- Please describe your first contact with the experts (doctors, psychologists, developmental paediatricians) about the child’s assessment/diagnosis. What questions were you asked? What were you told about the causes, treatment programs, and the prospects for the future?
- Was the treatment plan suggested? Was it discussed with you? How did it impact on your choosing a particular treatment/choosing not to have any intervention for the child’s problem?
- If you have chosen a particular intervention program for the child, what were the reasons? What are your treatment provider’s ideas about possible causes of autism and prognosis for the future?
- What do you think experts (doctors, psychologists, psychiatrists, therapists) think about autism?
- What do they think most people think?
- What impact in your view do these various understandings have on parents of a child with autism?
- Any memorable things people have told you about autism, having an autistic child, role of parents etc.?
- What myths or misunderstandings do you think there are? How common do you perceive these to be?
- Some researchers think that the growing emphasis on the bio-genetic causes of autism are favoured by parents since they are perceived as beyond their personal control. What are your views on that?
- What are your views about behavioural interventions? If your child receives ABA therapy, what are your views about it as a parent? How does it make you feel?
- Do you think you know what works, what is best for your child?
- What are you finding particularly stressful about being a parent of a child with autism? What are you finding particularly rewarding about it?
- Some researchers think there is a certain social stigma attached to being a parent of an autistic child. What are your views on this?
- Please describe the reactions of your family, friends when you first told them your child has autism. Have they changed since? Reasons for that?
- How do you see yourself as a mother/father of a child with autism? Is it different from parenting a typically developing child? If yes – how?
- What are your views on schooling? Do you think it is better that children with autism go to a mainstream school/special school? Reasons for that?
- Have you had any memorable negative/positive experiences in connection to your child’s mainstream school/pre-school that reflected on you as a parent?
- Do you participate in social support groups or have a regular contact with other parents of children with autism? Has it been helpful/unhelpful? Reasons for that?
- If you are participating in support groups or meet other parents of children with autism (whether formally or informally) – do you feel comfortable to discuss various issues about your child’s problems openly when your views about autism (causes/treatment options/prognosis) are different from those of other people?
- Reasons for taking part in the research?
- Have views changed over course of discussion?
- Any questions?
Appendix E: Background Questions

Parental Accounts of Autism and the Impact of Autism on the Family

Participant to complete:

1. Age
2. Sex M / F
3. Ethnic identity
4. Highest educational qualification
5. Relationship situation
6. Occupation
7. Age of the child
8. Sex of the child M /F
9. Year of diagnosis
10. Treatment programs used for the child
11. Do you have other children?
   Age:       Sex:

Researcher to complete:

Date of interview:
Appendix F: Transcription Conventions

// indicates an instance where the interviewer or participant interjects. For example:
M.E.: so do you think that media image is more of this kind of Asperger’s /Rita: yeah yeah/ end of the spectrum /Rita: yeah/ okay

“ ” indicates an instance where the speaker is reproducing talk or thoughts. For example:
Vicki: I had no idea um and he kind of saw him and said “he is clearly autistic”

- indicates a sequence of speech that ends abruptly. For example: “M.E.: June what- I mean he’s obviously in a mainstream school but kind of overall your views of mainstream versus special school”

underlining indicates emphasis of words. For example, “Liz: we’re not teaching him to we’re not allowing him to become an expert at maths because we’re keeping him at 6 year old level maths”

[word] indicates additional words that are not part of the transcript but have been inserted instead of potentially identifying information or to clarify meaning of what has been said. For example “Elaine: he was diagnosed by [Dr X]”

… indicates a short pause

. indicates that a train of speech is completed by the speaker in a way that indicates a ‘finished’ sentence

(laughing) or (crying) indicates nonverbal sounds

(…) indicates that part of the transcript has been omitted
References


Singer, J. (1999). 'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference. In M. Corker & S. French (Eds.), *Disability discourse* (pp. 59 - 67). Buckingham: Open University Press.


