Janus-Faced Mothering and a Cruel Story of Blame:
The Representations and Lived Effects of Mothering an Autistic Child

Karen Williams

(BA. Management/marketing (Hons))

Thesis submitted in fulfillment of the requirements for the degree of Doctor of Philosophy

Department of Sociology, Criminology and Gender, School of Social Sciences

University of Adelaide

March 2019

TABLE OF CONTENTS

ABSTRACT

There are two main aims of this thesis. The first is to examine how autism and mothers of autistic children are represented and understood. The second is to examine how mothers of autistic children negotiate this subject position and its lived effects. Currently, there is minimal research that explores the representation of mothers of autistic children. Furthermore, as diagnostic rates of autism increase, we have a group of mothers that are increasing in numbers, are potentially vulnerable and are vital to the sustainable functioning of our community.

I apply a poststructuralist, Foucauldian and feminist methodology. The data is drawn from three main sources: Australian newspapers; the website *Generation Rescue* and its president (Jenny McCarthy); and, interviews with mothers of autistic children.

Prior to my research chapters, I provide an overview of what knowledge has already been explored and is central to my research. I also examine how autism has been constructed and how prominent mothers are in this construction.

The first two research chapters analyse public data – newspapers and *Generation Rescue*. The dominant way autism was represented was as the undesirable subject whose existence should be eradicated. Cause dominated the newspapers whilst cure dominated *Generation Rescue*. Mothers were represented as devastated warriors who fought tirelessly for the autism community or to rescue their 'true' child. Both mother-blame and responsibility were prominent. The 'right' to have a non-autistic child, the child a mother 'deserves', was tied up amongst the assumed duties mothers were required to perform to ensure they obtained this child.

Findings from my interviews suggest that whilst the subject position of mother of an autistic child was placed upon all mothers interviewed, how the subject position was negotiated differed. There were various contradictions in the way mothers were invited to negotiate the subject position of autism mother. These contradictions construct a style of motherhood I refer to in my conclusion as 'Janus-Faced Mothering'.

Mothers interviewed held a stronger attachment to development rather than cure. Although engagement in various types of therapy was considered important, mothers felt this engagement

should not override their child’s right to be ‘just be a kid’, nor require engaging in practices they were not comfortable with.

An important finding from my interviews was that when a mother failed to meet the prerequisites of the ‘good mother’, it was the deviant characteristics of the individual mother that were the target of blame. All mothers felt as though they were in a situation where the masses watched the few.

The social institutions of government and education were prominent sites where power was deployed. Mothers were held responsible for the development of their child and the child’s ability to be disciplined. Resistance meant mothers became further embedded in the intensive-mother discourse.

Overall, findings identified the dominance of medical discourse and the ‘good’ and ‘bad’ mother discourse. Medical discourse set the standard for the child, discourses of motherhood set the standard for the mother.

DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship

Karen Williams

ACKNOWLEDGEMENTS

To my supervisors, Anna and Jennifer, thank you for your guidance and support throughout this process. Thank you for believing in the project and sharing your knowledge with me as you guided me through this journey.

A second thank you to my principal supervisor Anna Szorenyi. From the days with the tiny whiteboard at the café to your feedback at the final stages, your supervision has helped me get this project to where it is. I am truly grateful for the wisdom and guidance you have blessed me with throughout this project.

To the University of Adelaide and the scholarship they provided to help me complete this research.

To all the staff and fellow PhD colleagues at the University of Adelaide who have shared this journey with me. You have all helped shape this journey and it has been a pleasure working with you all.

To my friends and family. I love you. Thanks for always being there for me. Special mention to Michael Fietz who despite his positivist approach to research, took the time to read and provide feedback on a social science project.

Finally, to my son Dylan. I love you more than words can say. Keep being awesome xx

* * *

CHAPTER 1: INTRODUCTION

I’d like to start my introduction by talking about a time in my life when I was alone in a small room, my child whisked off to be assessed, an assessment I was not able to be present for nor able to view. After a while a lady entered, sitting down in front of me. The expression on her face is hard to describe. Perhaps the best way is that she looked pensive, like someone who was about to say something they didn’t want to say. She proceeded to inform me that they had done the assessment and that my son had autism. She paused there. I’m not sure if she was waiting for my response or reaction but, after what seemed like an eternity, she asked me if I was ok. I replied that I was and waited for her to continue talking, presuming she had more information to give me. She stated that my son had met the criteria for diagnosis before pausing again to ask me if I was ok. I again replied that I was. Her response this time was to ask me if I needed a moment as this news can be a lot to take in. I was quite puzzled at that moment as I thought to myself, “I’m at Autism SA and you’re telling me my son has autism, this doesn’t seem like a great leap in logic for me to take in. If you had told me my son had cancer or was diabetic then I might have been a bit shocked, but an autism diagnosis from Autism SA, yep that makes sense”. The woman then again asked if I was ok and if I wanted to step outside for a moment. It was at this point I felt like I wanted to cry but had to stop myself. The fact she kept asking me made me feel like I wasn’t OK. I’m not sure if this was standard procedure or how she read my reaction but I left with my son feeling quite odd. However, with 20/20 hindsight, it turns out the experience of the diagnosis had been far more traumatic than the diagnosis itself.

Reflecting upon this experience I began to see the impact of the way autism is spoken about and thought of and what it may mean for the mother. In the coming days, weeks and months after his diagnosis, I began the process of informing my friends and family. I never cried or complained or expressed any distress when passing along the information. Yet, upon hearing the word autism, it seemed as though people had already begun to think on my behalf. Three particular responses stand out in my memory and perhaps represent the overall theme of reaction:

- First, there was the "*I'm so sorry*" response. The word autism automatically brought with it a view of pity, a child lost if you will.
- Another response by a close friend was, "*I always knew there was something wrong with him*". There were many comments along the way (why isn't he doing this, my kid did that at (this age)), but what is of interest is that such a direct comment about there being something 'wrong' with him came only once there was a scientific/medical diagnosis or label to attach. It was almost as if now he could be spoken of in a certain way without repercussion – it was proven there was something different to speak of.
- The final response that sticks in my mind is the "*have you now read everything you can about autism?* To me, there was almost an implicit assumption that this was now my role. That I would now embark on this quest to immediately become an expert in autism, so I could then understand and improve my child.

In combination, these three responses give insight into the way autism is thought of, how we think of a mother whose child is autistic and what we then assume she should do. What was perhaps not apparent to me at the time was that such views were not stagnant and limited to the time of my son's diagnosis but would follow me throughout my life. Similar to research by authors such as Green (2003a, 2003b, 2007), who is herself the mother of a disabled child, the direction of my research was rather unconscious (Green 2003a, p.2). It was the birth of my child that placed with me within the lived experience of disability and exposed me to a new world, 'both as a participant and social observer' (Green 2003a, p.2).

Feminist research over the last few decades has shown a concern with disrupting dominant understandings of mothers, motherhood and mothering (see Goodwin & Huppatz 2010). Despite this, and the diversity of types of mothers we now recognise, the surveillance of motherhood has in many ways intensified since the "golden era" of the 1950s (Douglas & Michaels 2004). The current era is one in which 'intensive child rearing holds parents, in particular mothers, accountable for children's development' (Francis 2012, p.927). So, what happens to the mother when her child fails to meet the standards of 'commodity uniformity and functional predictability' (Phillips 1990, p.850)? What happens when she is then left to make her way within a society that devalues her child and her version of 'motherhood has "failed" to follow the culturally appropriate trajectory' (Landsman 1998, p.77)? Mothers of disabled children consequently enter the role of mothering without a developmental map (Greenspan

1998) and the guidelines offered to her are often 'simply a range of conflicting, contradictory and, more often than not, negative bullet points' (Gregory 1991, p.121).

The category of autism is one that is subject to competing forms of discourse and acceptance. These discourses are diverse, often contradictory and fighting for a position of truth. For mothers of autistic children, how then do they interpret, accept or reject and then construct their own view of their role as mothers, as women in their own right?

Project aims and research questions

My research draws upon the work of Michael Foucault (1926-1984). Although discussed in greater detail in chapter four, Foucault's identifies discourses as knowledges and that power is implicit in the production of knowledge and subjects are always located in power/knowledge relations. Foucault contends that 'it is in discourse that power and knowledge are joined together' (Foucault 1978, p.100). For Foucault, power is a productive force that 'produces reality' and 'produces domains of objects and truth' (Foucault 1978, p.194). The regimes of truth in each society determine the types of discourses accepted by a society, and those a society makes function as true. As I am interested in how knowledges of autism and motherhood shape perceptions and experiences of mothers of autistic children, Foucault's work is particularly relevant.

There are two aims of my research:

First Aim: To examine how autism and mothers of autistic children are represented and understood.

There is a pervasive discourse of motherhood that pervades our society. Whilst this standard is perhaps impossible for all mothers, it is the standard by which mothers are judged and often judge themselves. Mothers of autistic children are not mothers in the conventional terms that permeate our society. Yes, she is a mother as she undoubtedly has a child (Gregory 1991), but her mothering experience is not that of the mother who mothers a non-disabled child (Greenspan 1998, p.44). Studies into the construction and dominant discourses of motherhood have opened up dominant understandings of motherhood, yet they are largely limited to the subject of the mother herself.

The central issue (at least in the first instance) is not whether autism or the mother is spoken about but 'to account for the fact that they are spoken about' – to discover who 'does the speaking', 'the positions and viewpoints from which they speak', and the 'institutions which prompt people to speak and distribute the things that are said' (Foucault 1978, p.43). What is at issue is, 'the over-all "discursive fact"', the way in which autism and motherhood are constituted in power/knowledge relations (Foucault 1978, p.43). This leads to the first research question of my study:

RQ:1) How is autism and how are mothers of autistic children represented within public sources of information and data?

For mothers of disabled children, the gap between the actual and the ideal portrays them as producers of defective merchandise (Landsman 1998). Mothers of disabled children are also presented as a contradiction: on the hand, one who 'loves her child no matter what' and, on the other, one that hopes for a cure, that her child would be normal, that she would take away her child's impairment in a second if they could (Landsman 1998; Larson 1998). This conflicting 'mentality' raises several questions regarding the mother of an autistic child's own self-governing as well as the task of understanding the origins of the conflict. It also negates the idea of any kind of normalcy or true acceptance.

Consistent with the first aim of my study I seek to examine what forms of knowledge of autism and the role of the mother are presented, and with what authoritative knowledge of truth? The use of the term 'representation' in this thesis does not mean there is a pre-existing object being represented. Rather, how autism and mothers of autistic children are "thought" of. As stated by Bacchi (1999, p.37), 'there is no assumption that there is a reality that stands outside representation'. Regardless of the absence of a pre-social autistic or mother subject, discourses on autism and motherhood not only formulate the production of domains and objects but are linked to effects that are real (Foucault 1978, p.55). This leads to the second research question of my study:

RQ:2) What are some of the discursive and subjectification effects produced by the representation of autism and mothers of autistic children?

For the purpose of my study, two impacts of representation as outlined by Bacchi (2009 p.15) will be assessed:

- *Discursive effects*: effects that follow from the limits imposed on what can be thought and said; how it closes off other possibilities.
- *Subjectification effects*: the ways in which subjects are constituted in discourse.

Motherhood is one of the oldest anthropological endeavours within modern society yet has shifting standards and continues to take new forms (Hays 1996; O'Reilly 2016). Although there may be various forms of motherhood available to women, it remains that there will be a dominant discourse that, regardless of class and race, all women are 'disciplined into and judged against' (Hays 1996, p.107). Whilst being a member of a group that is outside what dominant discourses suggest motherhood should look like can enable those on the outside to see things differently, it also makes 'expressing a self-defined standpoint more difficult' (Collins 1991, p.26). Oppressed groups are 'placed in a situation of being listened to only if' they frame their 'ideas in the language that is familiar to and comfortable for the dominant group' (Collins 1991, p.xiii). This leads to the second aim of my study:

> Second Aim: To examine how mothers of autistic children negotiate this subject position and the lived effects of this position. I also aim to explore how this knowledge can contribute to our understandings of motherhood.

Just as feminist research should not seek to merely *add* women to discourse, the same applies to research for mothers who are mothering in nonnormative situations. Given that mothers of autistic children are exposed to the dominant ideals of motherhood as well as representing a minority group within this category, it is possible to theorise that mothers of autistic children experience both the traditional and a marginalised culture of motherhood. Their position as an 'other' makes it possible for us to not only understand their situation but also reveal something about the dominant ideologies of motherhood in our culture. This leads to my final research question:

RQ:3) How do mothers of autistic children negotiate with the subject position of mother of an autistic child and what are some of the lived effects of this subject position?

There is a need and importance for mothers, regardless of their situation, to 'resist silencing, censoring and "disappearing" (themselves) for the sake of holding up the cultural image of "good mothering"' (Greenspan 1998, p.44). Challenging and revealing the silencing of these mothers can help to reduce the feeling of difference brought on by any gaze of the dominant standpoint of normality and maternal responsibility.

Justification for the research

The number of children formally diagnosed with autism and carers registered to receive a Carer Allowance has doubled in the five years from 2004 to 2009 and 2005 to 2010 (Buckley 2012, p.6). At 31%, autism now makes up the largest disability group within the NDIS scheme. The rising number of children diagnosed with autism means that we have a group of mothers' that are rapidly increasing in size.

I focus on mothers, rather than parents or fathers, for multiple reasons. Women still perform the majority of care for children and domestic tasks within the private sphere (O'Reilly, 2016). Furthermore, when it comes to disability, Bourke-Taylor, Howie and Law (2010) estimate that over 90% of informal carers are female. Of particular concern is the level of subjective wellbeing among informal carers which has been identified as the lowest of any group in our society (Cummins et al. 2007). Furthermore, female carers have been identified as having lower levels of subjective-wellbeing in comparison to men (Cummins et al. 2007) and mothers of autistic children have been frequently found to have poorer mental and physical health and a lower quality of life compared to mothers of mainstream children as well as mothers of children with other impairments (Herring et al. 2006).

'Informal (non-paid) caregiving continues to be a crucial part of health and social care provision in the developed world' (Hughes, Locock & Ziebland 2013, p.78). Mothers of autistic children form one group of informal caregivers. The role provided by informal carers (in Australia) is estimated to be worth approximately $41.4 billion per year. The level of care provided by informal caregivers also exceeds the responsibilities of formal care. So much so that a 10% decrease in the number of carers, will translate into a 40% increase in demand for formal care (Disability Investment Group 2009). As identified above, we have a group of mothers whose enormous contribution comes at a substantial 'cost' to the individual mother. Consequently, we have a group of mothers that are dramatically increasing in numbers, potentially vulnerable, providing care, often to the detriment to their own well-being, yet who are vital to the functioning and sustainability of our community.

Significance of the research

Whilst over the last forty years feminist theory has grown as a scholarly field, there is a relative absence of a feminism that embraces the specific needs/concerns of mothers (O'Reilly 2016). Feminist theory has been revised and expanded over time and now includes numerous theoretical models that aim to represent the diverse viewpoints and concerns of various groups of women (queer feminism, global feminism, womanism and third wave feminism). However, this inclusion has not been so apparent for maternity:

> motherhood is seen as a patriarchal institution that causes women's oppression, and thus the feminist 'solution' to such is avoiding motherhood both in theory and

> practice. Relatedly, because feminists are uncomfortable with anything that suggests gender essentialism … motherhood becomes highly problematic (O'Reilly 2014, np)

Given the role performed by mothers and the specific needs and concerns of mothers that differ from those that arise from her identity as a woman, further attention is required that places mothers at the centre of its research.

Whilst mothers have been marginalised within legitimate scholarly and feminist research, work on mothers of disabled, or autistic children, is even more so. In edited works such as *The Good Mother* (2010) and *Feminist Mothering* (2010), that bring together a collection of essays on various 'types' of mothers such as lesbian and single mothers, there is a complete absence of any work on mothers who mother children with any kind of disability. Similarly, even within the collection of publications available on *Demeter Press*, an independent feminist press 'committed to publishing peer-reviewed scholarly work' on 'mothering, reproduction, sexuality and family' (demeterpress.org), there is still an absence of any dedicated volume on mothering a disabled or autistic child. I expand on this aspect later in chapter 2, but to give some insight into this absence, *Demeter Press* has 31 (at time of writing) collections available on motherhood: aside from one on mothers who themselves are disabled, there is no dedicated volume dedicated to mothers of disabled children.

Finally, there is minimal research that takes a multi-method approach into the area of mothers of autistic children. In my study, I incorporate an analysis of newspapers, a small case study of a celebrity mother (Jenny McCarthy) and the autism 'advocacy' group of which she is president (*Generation Rescue*), and interviews with mothers of autistic children. This triangulation of research offers multiple perspectives and aids in identifying any patterns that may appear, whilst also offering new knowledges, or previously subjugated knowledges that have been either hidden or marginalised.

Scope of the project

There are two main factors that define the scope of my study. The first, as discussed above, was the decision to limit my study to focus on mothers rather than fathers or parents. As explained above, it is mothers who perform the majority of caring roles and who also have lower levels of reported subjective-wellbeing.

The second key delimitation was the decision to limit my study to mothers whose children are under the age of 18. Firstly, it has been previously identified that the 'burden of care' is thought to be greatest when caring for a child with a disability as opposed to an adult (Cummins et al. 2007). Secondly, extending the focus of my study to include mothers of children who are over 18 is beyond the scope of my research. There is an assumed normative development and progression of children and consequently, an assumed or normative role by mothers as their child ages and develops. As such, limiting my focus to mothers whose children are under 18 allows me to focus my examination on the motherhood of children rather than how that practice may differ when mothering an adult.

In summary, the direct contribution of my study is to build an understanding of mothers of autistic children in both the public and private spheres. It is concerned with challenging the dominant discourses of motherhood and autism and the knowledges and effects produced by these discourses.

Structure of the thesis

My thesis is structured into four sections. The first section consists of my introduction, overview of relevant literature (chapter two) and a genealogy (chapter three) of how autism came about and of the emergence of mother blame (for the autistic child) during the 20th century.

The second section outlines the theoretical lens (critical, constructivist, poststructuralist, Foucauldian and feminist) my research applies (chapter four) and a detailed description of the methods used to collect and analyse the data (chapter five).

In the third section, I present and analyse my findings. There are four chapters in this section. The first is my findings from the newspaper data collected (chapter six), the second is my findings from the *Generation Rescue* website (chapter seven) and the final two chapters present the findings from my interviews (chapters eight and nine). Mother-blame and responsibility were prominent across all data sets.

Both sources of public data examined (chapters six and seven) represented autism as unwanted and to be avoided. Autism was represented as something that could eventually be eradicated by science, medicine and the appropriate demanded behaviour of the mother. Although autism was represented as something that had 'happened' to the child, there were differences in when this 'happening' was thought to occur. Newspaper data predominantly represented this 'happening' as something that occurred during pregnancy. *Generation Rescue* as something that happened after the child was born. Importantly, regardless of when this ‘happening’ was said to occur, the responsibility (of cause, prevention, cure) lay with the mother.

In both the public data examined and for mothers interviewed, the baseline for the ‘good’ mother was normative development of the child. Mothers interviewed spoke more of development than they did of cure. Conversely, that their child was deemed to not be developing according to dictated measurements meant they had knowledge other mothers do not have. This type of knowledge was knowledge the “good” mother doesn’t need to have.

The final section consists of one chapter (chapter ten) where I bring together the findings from my research and address my three research questions. I bring together some of the major themes that highlight the complexity and often contradictory subject position mothers of autistic children are expected to occupy. I have categorised this subject position as Janus-faced mothering. I conclude this chapter with some recommendations for future research and concluding thoughts on the project. I argue that in furthering my understanding of non-normative motherhood, specifically that of mothers of autistic children, it became evident how dominant certain constructions of motherhood are. I reiterate the dominance of the medical discourse when setting standards for individual children but that despite this dominance, discourses of motherhood (such as what characteristics mothers should have), are powerful enough to override the medical discourse.

CHAPTER 2: REVIEW OF SECONDARY SOURCES

In the forthcoming chapter, I cover some of the theoretical and evidential work previously carried out in the areas of motherhood, disability, autism and mothers of autistic children. This chapter is separated into three parts. I first provide an overview of motherhood in western culture. I offer insight into a dominant discourse of the 'good' mother with an exploration of intensive-mothering. I also recognise normative motherhood and the marginalization of the mother of the disabled or autistic child within this discourse. I conclude the first section with an overview of mothering a child who is 'other' and the contentious place occupied by mothers of disabled children within both the disabled people's movement and academic research.

In part two I discuss the classification and representation of autism. I first provide a medical classification of autism. I then offer insight into the category of autism and some of the consequences that come with this. I next explore the idea of autism through various disciplines, such as the media, and how the power of the media has influenced and shaped representations and thinking about autism. I conclude this section by offering a competing discourse on autism.

The third part looks at some of what we already know about mothers of autistic children. Previous research that has utilised interviews with mothers of autistic children is presented. The main themes from previous research identified were predominantly related to assumed expectations of motherhood, reactions to diagnosis, stigma and the different roles mothers of autistic children took up. I conclude this section with a discussion about the role or position of mothers as advocate or activist and the emergence of the warrior-mother discourse.

Motherhood

In the West, the gendered nature of care colonises and continues to construct women as 'natural' subjects of the role (Crittenden 2002; Hochschild 1983; Krane & Davies 2007; O'Reilly 2016). Often couched within the de-gendered language of parenting, the moral regulation of the population through family positions women as responsible and culpable for the production, maintenance and protection of the health and wellbeing of others (Ladd-Taylor & Umansky 1998).

Despite its representation as a natural enterprise for women, the apparatus of motherhood is still held accountable to disciplines whose discourses position how best to perform this role. The position of mother is regulated throughout disciplinary institutions such as state agencies, social, medical and educational services (Malacrida 2009, p.101). The mother is presupposed as being the carrier who can continue the population, its next wave of citizens. However; conceptualization of what is 'work' results in these caring activities, performed in the main by women, remaining unacknowledged (Bacchi 2009).

The gender-coding of care has further increased the responsibilities viewed as private as a more neoliberalist culture sees the retreat of the state from responsibility for individuals (Berger & Guidroz 2010). Neoliberalism increases the self-reliant obligation of individuals (Barry, Osborne & Rose 1996) and sets the standard for normative citizenship (Ong 1999). The normative subject position of the mother as a citizen is entangled within the idea that whether social or health-related, numerous problems can be explained, and or fixed, based on the quality of parental care provided (see Smyth 2012, p.2).

Neoliberalism eliminates public or community good, replacing it with individual responsibility (Martinez & Garcia 2000). The removal of many services once provided by the state has been devolved onto mothers (O'Reilly 2016, p.57).

> Mothers today are not only responsible for this downloaded work, but they are also responsible for how their children fare under neoliberalism. If children do not succeed, the blame rests solely with the mother, as it was her responsibility to ensure that they could and should (O'Reilly 2016, p.57).

Dominant discourses of motherhood are still driven by the conservative view that 'the only 'good' mother is the self-sacrificing saintly figure who performs the moral, caring work of society at the expense of her own equality and aspirations' remains (Crittenden 2002, p.7).

The 'good' mother (Intensive-mothering)

Modern motherhood presents and represents mothers as having more choices than at any other point in history (O'Reilly 2016). In addition to choices surrounding nutrition, extra-curricular activities and the array of entertainment options as a result of advancements in technology, mothers also have access to labor-saving devices, such as take-out food, microwaves and washers/dryers, that supposedly assist reducing her time spent on domestic duties (O'Reilly 2016, p.50). Women are no longer consigned to existing only as housewives 'without any opportunity to enter the workplace and become successful wage-earners', and 'no longer expected to be subservient to men on a social scale; they can "choose" to enter the workforce or stay at home' (Henderson, Harmon & Houser 2010, p.232-233).

Whilst not the only model available to mothers, the dominant discourse of the good mother in Western culture is one of intensive-mothering (Hays 1996). Hays (1996, p.8) argues that intensive-mothering is categorised by three themes: "the mother is the central caregiver', 'mothering is regarded as more important than paid employment' and that 'mothering requires lavishing copious amounts of time, energy and material resources on the child'. O'Reilly (2016, p.56) argues that the rise of intensive-mothering in the 1990's grew out of the emergence of neoliberalism in the same decade. Because of changing cultural and economic conditions, the practice of normative motherhood was rewritten (O'Reilly 2016, p.57). The increase in the social and economic independence of women that took place in the 1970's and early 1990's created what O'Reilly (2016, p.57-58) describes as the "perfect storm":

> It seems just as women were making inroads and feeling confident, a new discourse emerged that made two things inevitable: that women would forever feel inadequate as mothers and that work and motherhood would be forever seen as in conflict and incompatible.

Intensive-mothering - Theme 1: Central caregiver

It is not in question that children have needs. Indeed, as a species, humans are not capable of survival without the nurture and protection of others. It is not the fact that children have needs that make discourses such as intensive-mothering oppressive to mothers. As argued by Bueskens (2017, p.81), 'the problem is not the fact of this requirement but rather that meeting this need has come to rest exclusively, and in isolation, on the shoulders of biological mothers'. Intensive-mothering is child-centred. As opposed to children during the 1950's and 1960's who were supposed to been seen but not heard (O'Reilly 2016, p.50-51), children became sacred and only to be raised by their mothers (Hays 1996, p.99).

Although the mother is required to be the central caregiver, she must turn to the experts for instructions. Although bearing all the responsibility, she has limited authority from which to mother (O'Reilly 2016). The practice of mothering is subject to politicization and expert efforts to establish professional authority and status over mothers and children (Smyth 2012, p.2). Contemporary 'authority of nature, tradition or female experience has been gradually replaced with that of science, psychology, anthropology and medicine in defining the contours of the role' (Smyth 2012, p.3). Whilst still viewed as a natural enterprise for women, the authority of mothering has shifted towards the political and economic, the scientific and medical, the social sciences of psychology, psychiatry and anthropology as the ones who are able to speak truthfully about the subject position of the good mother.

A common narrative that sees mothers increasingly responsible for following 'expert' guidance is what Beck (1992) describes as a "risk society" and the need for mothers to minimise the risks their children encounter (Knaak 2010; Lee, 2008; Murphy 2004). Mothers are swamped by narratives embedded and driven by fear whereby the reconstituted subject position of mother means they must not only listen to 'expert' guidelines but also become experts themselves (Henderson, Harmon & Houser 2010). Ideals of motherhood insist 'that mothers acquire professional-level skills such as those of a therapist, paediatrician ('Dr. Mom'), consumer products safety inspector, and teacher' (Douglas & Michaels 2004, p.5). As argued by Henderson, Harmon and Houser (2010, p.233):

> it is no longer okay to let your children walk to school solo, as it was in the 1950s. Parents have to be hyper-vigilant about recalled toys and car-seats, the presence of unsafe chemicals in the plastic of baby bottles and in infant formula.

The 'expectations about the work needed to raise a child successfully have escalated to at a dizzy rate' (Fox 2003, p.237) and within the discourse of intensive-mothering, it is only the biological mother who can best protect their child whilst providing for these ever-increasing needs.

Intensive-mothering - Theme 2: More important than paid work

Vandenbeld Giles (2014, p.5) argues that 'the neoliberal model, which emerged in the 1980's and 1990's is an individualised and economic one where mothers are "positioning children as social capital to be invested in'. The idea of children as social capital focuses on productivity and demand mothers to 'reproduce socially appropriate neoliberal subjects' (Vandenbeld Giles 2014, p.5). Whilst such a mindset is 'consistent with the free-market focus on choice and individual responsibility' (Vandenbeld Giles 2014, p.5), it is an economy that still relies on the free labour, or the assumed maternal devotion and desire of the mother.

Although for many mothers their involvement in the workplace has produced a double workday, within the discourse of intensive-mothering the placement of her own convenience or material wealth above that of her child is strictly forbidden (Hays 1996, p.150). The 'good' mother takes on the roles within the private sphere of family in a manner that is self-sacrificing of her own needs and interests (Bassin, Honey & Kaplan 1996, p.2). Whilst as argued by Crittenden (2002, p.5) we 'talk endlessly about the importance of family', 'the work it takes to make a family is utterly disregarded'. The discourse of intensive-mothering intensifies the work of the 'good' mother and is the final theme of Hays's intensive-mothering discourse.

Intensive-mothering - Theme 3: Copious amounts of time and energy

Consistent with the rhetoric that children are pure, priceless, and deserving of special treatment and protection (Hays 1996), the child-centred mantra of intensive-mothering prioritises the needs of children over mothers (Hays 1996; Lee 2008). The 'good' mother is "involved". Rather than simply physical proximity, contemporary motherhood requires what 'expert' discourse describes as 'quality time' (O'Reilly 206, p.49). Whereas children in the 1950's and 1960's 'would jump rope or play hide and seek with the neighbourhood children or their siblings', today's mothers go to mum-n-tots dance, swim and craft programmes, or take karate and French immersion (O'Reilly 2016, p.49). Despite the decrease in the number of children (per family) and the massive movement of women into the workplace, mothers spend as much, if not more, time with their children as mothers did in the 1960's (Crittenden 2002, p.20). 'As women advance, they stop having babies and start raising children' (Crittenden 2002, p.20).

As argued by Hays (1996, p.21), 'we are told that [intensive-mothering] is the best model, largely because it is what children need and deserve'. Assumptions about what children need and deserve are in-part driven by 'anxieties about children's future, nostalgia for the way they imagine families used to live, and from the assessment of dangers in the world today' (Nelson 2010 p.174). The mother must be vigilant and must be present. Furthermore, intensive-mothering, as explained by Hays is about:

> grooming their children for their future class position by providing them with the appropriate cultural capital and demonstrating their own class status relative to mothers who cannot afford such luxuries or do not recognise them as an essential element of good childrearing (Hays 1996, p.159).

Although intensive-mothering is viewed as normative and the standard by which all mothers are judged, the parenting styles across class lines are thought to be quite distinct. Fox (2007) argues that due to the personal and material resources available to them, intensive-mothering is most likely to be practiced by middle-class women:

> Middle-class women come to motherhood with a strong sense of accomplishment and competence, and, thus have 'a strong sense of self-efficacy … to take on and

> persist in the considerable challenges of intensive mothering, display a ‘sense of ownership’ and time and ‘feel entitled to spend their time on the baby (Fox 2007, p.255).

In contrast, Nelson (2010) argues that rather than intensive-mothering being practiced by middle-class mothers, it most likely to be practiced by what she refers to as the “professional middle class” and that ‘working and middle-class parents are more concerned with skills that will ensure self-sufficiency’ (Nelson 2010, p.8). Nelson argues that the copious amounts of time and energy required within intensive-mothering are about securing a competitive advantage for children and preserving class privilege. Trying to “secure status reproduction” (Nelson 2010, p.7) or what Milkie and Warner (2014, p.66) term “status safeguarding” is attributed to parental anxiety about their children’s future. Good mother discourses such as the intensive-mother discourse emphasise that children’s future can be perfected, but they must be nurtured in a way that provides them with the best social, cultural and economic capital (Nelson 2010, p.8).

The idea of successful motherhood is harnessed by the media who present a new form of the ideal of motherhood (Douglas & Michaels 2004). Campaigns that revolve around fear and guilt are placed alongside those of celebrity-mothers who do-it-all and look good while doing it. Mothers now often have an income of their own and have a say in how household income is spent and ‘mothers, more so than fathers, are the consumers of items children want or need’ (O’Reilly 2016, p.52). Whilst there are numerous consumer items designed to perform and facilitate intensive-mothering, mothers must be careful about what they buy and remain ever vigilant. News stories circulate narratives that repeatedly caution mothers about “threats from without”: Sanitation, ‘abduction, consumer-safety problems with car seats, toys, cribs’, and, of course, food allergies (Douglas & Michaels 2004, p.85). Motherhood is now about more than being responsible for children’s basic needs (food, clothing, discipline), mothers must also protect children’s innocence, coordinate and/or participate in their social activities, be a paediatrician, therapist and be a consumer safety proficient (Hays 1996; Lareau 2003; Douglas & Michaels 2004).

Emerging in the 1970’s, the celebration and interest of the celebrity-mother exploded in the 1990’s (Douglas & Micahels 2000). Profiles show celebrity-mothers juggling work, family, mothering and all with a smile in ‘glowing pictures with their healthy, well-behaved children’ (O'Brien Hallstein 2011, p.112). The perfection of how celebrity-mothers are represented sees mothers remain/become intensively managed subjects of ‘post-feminist, gender-aware biopolitical practices of governmentality’ (Rose 1999; cited by McRobbie 2007, p.723). Douglas and Michaels (2004) argue that although women can now work outside the home and take up roles that were previously limited to men, they can only do this if they maintain an idealised feminine appearance that allows them to remain attractive to men. Whilst she then remains desirable, she is also less threatening. Her adherence and commitment to feminine ideals work to mask ‘her rivalry with men (i.e. her wish for masculinity), and to conceal the competition she now poses’ (McRobbie 2007, p.726). Adoption of the ideals put forward, what McRobbie (2007, p.726) describes as the mask of feminine submissiveness, is not considered entrapment but a statement of choice. Within a consumer culture, the celebrity-mother, or yummy-mummy ties into a language of self-perfectibility that is dependent on exceptionally high levels of personal consumption (McRobbie 2007).

Rather than the media being the ones that drive the impossible standards of motherhood, Henderson, Harmon and Houser (2010) argue that it is the informal surveillance by mothers themselves which perpetuate such standards and ideals. Henderson, Harmon and Houser (2010, p.231) argue that social control of motherhood is not dependent on institutional enforcement but rather standards of perfection which are perpetuated through interpersonal communication and observation: mothers surveil themselves and other mothers. Henderson, Harmon and Houser (2010, p.240) argue that whilst the media ‘provide a pathway by which mothers learn about and practice’, surveillance is most powerful at the interpersonal rather than the structural level. Rather than seeing the media as part of a system that produces ideals and expectations that become normative representations of what the ‘perfect’ mother is, ‘when mothers are not quite measuring up to those ideals, they look to each other and to themselves for the source of the problem’ (Henderson, Harmon & Houser 2010, p.241). The self-blame and guilt experienced by mothers are not directed at the media, it is directed internally; mothers blame themselves (Henderson, Harmon & Houser 2010).

Internalizing blame and guilt creates even higher levels of expectations to be perfect (Henderson, Harmon & Houser 2010). Dominant discourse of the ‘good’ mother is both descriptive and prescriptive. The power of the ‘good’ mother discourse sees women wanting to be good, the process of subjectification in the Foucauldian sense (Goodwin & Huppatz 2010). Modern motherhood requires mothers to:

> put on the doting, self-sacrificing mother and wear it at all times. With intensive-mothering, everyone watches us, we watch ourselves, and we watch ourselves watching ourselves. Motherhood has become a psychological police state (Douglas & Michaels 2004, p.6).

Assumptions surrounding the idea that women are “natural mothers” and have “no further identity” (Rich 1976, p.22) opens up a space ‘for mothers to be found inadequate when they fall short of behaving like perfect, self-sacrificing beings who never fail to put their children first’ (Reimer & Sahagian 2015, p.3). The dichotomy of the ‘good’ mother means if she isn’t good she must be bad. Furthermore, the mother could be easily be blamed for whatever is ‘wrong’. For example, Caplan (2013, p.592) found throughout her clinical work that, ‘no matter what was wrong, no matter what the reason for the family coming to the clinic, it turned out the mother was always assumed responsible for the problem’.

In addition to ‘good’ mother discourses requiring that mothers ‘act responsibly’ and present themselves in ‘culturally recognizable and acceptable ways’ (Miller 2005, p.86), mothers are expected to be fully satisfied in the role they perform. As stated by Johnston and Swanson (2003, p.23), ‘a good mother is a happy mother’. The binary consequence of this is that ‘an unhappy mother is a failed mother’ (Johnston & Swanson 2003, p.23). Similarly, as argued by Parker (1997, p.18), ‘the mother who exhibits or admits maternal ambivalence is judged harshly and is the object of shame and disbelief by other mothers and herself’. ‘Good’ mother discourses attribute responsibility for the conditions of motherhood to the individual while ignoring the wider social system (Johnston & Swanson 2003, p.23). Whilst there is the potential for personal development, liberation and transformation from the act of child raising, it also brings oppression and subordination (Marshall, Barnett & Sayer 1998; Roxburgh 1997).

As purported by Ladd-Taylor and Umansky (1998, p.3), ‘bad mothers’ have been categorised into one of three groups: ‘those who did not live in a ‘traditional’ nuclear family; those who would not or could not protect their children from harm; and those whose children went wrong. The pervasive ideals of motherhood essentialise idealised notions of appropriate behaviour and hold mothers independently responsible for every facet of children’s wellbeing or potential harms that may arise from industrialization and modernization (Afflerback et al. 2013).

Good mother discourse dictates that the needs of the child come before the mother’s (O’Reilly 2016, p.61). A consequence of the ongoing and deepening knowledges that enable mothers to be governed by the dominance of discourses such as intensive- mothering is that ‘it marginalises and renders illegitimate alternative practices of mothering’ (O’Reilly 2016, p.19). ‘As a normative discourse, it polices all women’s mothering and results in the pathologizing of those women who do not or cannot perform normative motherhood’ (O’Reilly 2016, p.19).

Normative Motherhood

Due to the impact of dominant discourses that shape and construct our views of the endeavour (Bacchi 2009), the lives of mothers are presumed to be lived in specific ways. For example, Arendell (1999, p.3) describes the ‘good’ mother as ‘heterosexual, married, and monogamous. She is White and native born’. Whilst there is much work on different types of mothering, the value of different types of mothering remains specific to the culture itself (O’Reilly 2016, p.82). Alternative meanings and experiences of mothering are marginalised, rendered illegitimate or considered deviant (O’Reilly 2016, p.82). ‘Normative discourses of mothering position the experience of white, middle-class women as the real, natural and universal one’ (O’Reilly 2016, p.82). It is this ideal type of mother that forms the backdrop of assessment and against whom all others are measured (Goodwin & Huppatz 2010).

As the white-middle-class women’s experience has been taken as the norm and other women’s experience treated as ‘different’, normative discourses of motherhood have also been that of mothers who bear standardised (normal) children (Morris 1992). The pathologizing of motherhood, as argued by O’Reilly (2016, p.75) means that ‘non-normative mothers – whether by age, race, sexuality, or biology - can never be the “good” mothers of normative motherhood … so they must rely on and develop nonpatriarchal practices of mothering to raise their children’ (O’Reilly 2016, p.75).

As noted in my introduction, in the book *The good mother: contemporary motherhoods in Australia,* edited by Susan Goodwin and Kate Huppatz (2010), a collection of essays unpacks a variety of embedded constructs surrounding motherhood. It examines lesbian, adoptive, single, Aboriginal and working mothers; women who work in manual trades, and a class analysis of the categories of ‘yummy’ and ‘slummy’ mummies. There is however no reference to mothers of disabled children. Likewise, the book *Feminist Mothering* (2008) includes a collection of essays that explores: entering motherhood for professional women, maternal representations in fiction, depictions of mothering in Hispanic literature, African American mothers, lesbian mothers and parenting in third wave feminism. Although in both collections there is an unpacking of motherhood from marginalised and nonnormative mothers, the reason for the absence of mothers of disabled children may be that the ‘difference’ does not lie within the mother but within her child. She may well be white, middle-class and a mother, but it is the presupposed understandings of the child she is culturally expected/desired to have that now construct her as an ‘other’.

Similarly, at *Demeter Press*, an independent feminist press ‘committed to publishing peer-reviewed scholarly work’ on ‘mothering, reproduction, sexuality and family’ (demeterpress.org), there is again an absence of any dedicated volume to mothering a disabled or autistic child. Whilst not exhaustive, topics written on motherhood include; mothers in public and political life; abortion, miscarriage and stillbirth; mothers and social media; religion and spirituality; single parenting; domestic violence; mothering and sex work; mothers in conflict areas; indigenous mothering; adoption; stay-at-home mothers; queering motherhood; gender fluid parenting practices; breastfeeding; incarcerated mothers; step-mothering; mothering in hip-hop culture and mothering and blogging. At this point, I note that I am not suggesting that the diversity of work being done is not valuable and important. Rather it is the absence in this list of mothers who care for a child classified as disabled, or specifically autistic, that is of concern.

Motherhood and the Other

Established judgments of normality create a process of distinguishing people based on their perceived normality or abnormality, what Foucault calls dividing practices. Dividing practices separate populations. For example, the ‘healthy from the sick, the sane from the mad or the heterosexual from the homosexual’ (Danaher, Schirato & Webb 2000, p.60-61). For mothers of autistic children, this creates a separation of both their child and themselves from normality. Mothers of nonnormative children become defined by their difference given to them by a history of discursive practice that distinguishes their children as a particular kind of subject and themselves now a mother engaged in a fundamentally different experience (Greenspan 1998).

Normative representations of motherhood tend to be of the standardised child. Combined with the neo-liberalistic approach that assumes the normality of the ablest citizen, this creates a precarious position for the mother whose course has failed the culturally desired trajectory. The constitution of difference ‘imposes a law of truth that people recognise in themselves and that others recognise in them’ (Foucault 1982; cited by Vakirtzi 2010, p.26). Foucault (1982) theorises that the self comes into existence through the power relations which form knowledge. The exercise of power plays a productive role in creating knowledge that perpetuates, categorises, marks and attaches to an individual their own identity (Foucault 1982). Dominant discourses on motherhood see either an absence or negative portrayal of disability. Whether by omission or representation of something that is unlikely and to be avoided at all costs (Gregory 1991), a particular form of knowledge and power is created as to how motherhood is to be understood, related to and organised (Yates 2005). Furthermore, when mothers are constructed as ‘little more than the architect of the perfect child’ (Eyer, 1996, p.6), ‘this challenges the self-identity of mothers of disabled children’ (Ryan & Runswick-Cole 2009, p.45).

Motherhood and Disability

The mother’s non-disabled status (assuming no disability of the mother) places her in a contentious position regarding the role of the non-disabled within the lives of the disabled and disability research (Ryan & Runswick-Cole 2008, p.199). In addition to her place as an ‘other’ within the framing of traditional motherhood, mothers of autistic [disabled] children also occupy a ‘complex, contradictory and marginal position’ within the field of disability (Ryan & Runswick-Cole 2008, p.199).

Parents have been described as wanting to ‘normalise’ their children at the expense of valuing diversity (Harrison & Freinberg 2005). Likewise, their suitability as role models for their children is questioned given their non-disabled status (Middleton 1999). This representation is further complicated with mothers accused of acting as a constraint to their children’s prospects and desires (Veck 2002). Whilst dominant discourses of motherhood engender a mentality of care that underlines an attentiveness of others and is ‘personal, empathic, and loving’ (Dietz 1985, p.23), for the Disabled People’s Movement, care is often demonised and represented as a substantial barrier to the liberation and independence of disabled people (Hughes et al. 2005).

The rise of neoliberalism in a capitalist society which values independence and achievement (Oliver 1990) and a society in which ‘health, beauty and independence are highly valued’ (Green 2003b, p.1361), creates a veneer of acceptance where disability is only tolerated or accepted as it is socially or politically correct. The social rejection and stigma faced by disabled people are important to acknowledge. In addition to the oppression and exclusion this creates for the disabled person, it also has a flow-on effect to the carer (Mak & Cheung 2008). Goffman (1963) refers to this as courtesy stigma - the stigma associated with disability that is then ‘contracted’ by others because of their relationship with an individual who is stigmatised by others. Although research has largely focused on those who ‘bear the stigmatizing trait’ (Green 2003b, p.1362), those who experience the flow-on effects of courtesy stigma are likely to experience emotional distress and social isolation (Blum 1991). It has been argued that the social rejection and stigma, combined with an inadequate service system, may be the greatest barriers preventing those who care for a disabled child accessing and fully participating in mainstream society (Green, 2007).

Autism

Autism lacks the physical aspects we easily associate with impairment yet violates many of the socially approved standards of behaviour that perpetuate our society. Autism is categorised as a life-long neurodevelopmental disorder of unknown aetiology. Autism is defined as a developmental condition that affects individuals in two main areas; impaired communication and social interaction; and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association (APA) 2013). Due to the complexity and fluid nature of what autism ‘is’, I explore the emergence of autism as a distinct category and how it has been problematised in greater detail in chapter three (genealogy). Whilst there was a ‘scientific’, even ‘moral’ goal in establishing criteria to position what we understand autism to be, the interventions that produced the autistic subject have subsequently produced a taken-for-granted status of what it means to be categorised as autistic Once categorised autistic, individuals become defined by their diagnosis, as subjects of their label’s representation. A representation which confines and limits expectations of them (Molloy & Vasil 2002).

In the case of autism, categorizing the subject has not been enough. The positioning of the autistic child is also seen as one we need to alter, to correct its path towards one of our understandings of normality and functionability. This need to correct and steer the individual towards a predictable form of functionality inevitably links itself to the role of the mother.

Certain fields of knowledge are positioned where the acceptance of truth regarding their knowledge is the legitimacy by which knowledge is accepted. In contrast to the forms of knowledge surrounding fields such as philosophy and politics, scientific knowledge is not thought of as new knowledge that needs to be created but rather knowledge that merely needs to be discovered (Wickham & Kendall 1999). Regarding modern day representations of autism, the need to remedy is also constituted in the rising number of children diagnosed.

An 'Epidemic'

The rise in the number of children diagnosed with autism has seen a growth in the public interest, capturing the public imagination with the disorder regarded as both 'threatening and fascinating' (Eyal, Hart, Onculer & Rossi 2010, p.79). The statistical growth in autism diagnoses has seen the term 'epidemic' frequently used to describe its rate of increase. The term epidemic places autism within a particular public consciousness:

> An epidemic is a public health emergency. A serious and devastating illness is spreading rapidly in the population. We all know what must be done about epidemics. It's a call to action. Detection centres must be rapidly established so new cases can be isolated and treated. Money, lots of money must be thrown at scientists so they will come up with an explanation and a solution. The number of new cases must be brought down, the trend reversed (Eyal et al. 2010, p.2).

The association between autism and epidemic creates (at least) two problems. Firstly, it creates the representation that there is actually an autistic epidemic occurring. It fails to consider, as suggested by Eyal et al. (2010) that it may be the other way around: 'it was not the epidemic that made autism visible but the visibility of autism that created the epidemic' (Eyal et al. 2010, p.2). Secondly, it positions autism as an illness in need of eradication, eliminating other positions for the category.

The practice of representing autism as an epidemic is not merely the idea or thought of what it means to be autistic, it is rather how autism is thought of, conceptualised and problematised - how it becomes a social issue. It is how autism is dealt with as a specific kind of phenomenon (Bacchi 2009). An example of this can be seen in the industry which autism has become; an industry which silences the autistic voice, aside from the odd tokenistic gesture (Dziobek et al. 2008). Consequently, instead of holding the assets to produce their own representation, the autistic subject becomes the product of its industry, the object that is intervened in (Dziobek et al. 2008).

One of the most powerful mediums in the representation of autism is that of the media. Representation of autism in media coverage influences its 'audience's understanding of and attitudes toward autism and autistic people' (Kang 2013, p.245).

Autism in the media

Altheide (2002, p.232) describes media frames as being 'like the border around a picture that separates it from the wall and from other possibilities'. Popular media has tended to highlight features of autism 'considered to be the most unique or interesting to the public' (Sarrett 2011, p.145). This representation makes the abnormal traits of autism clearly visible, creating knowledge through the representation of deviancy. Autistics are portrayed as: those not being "whole" people, those trapped or imprisoned by their condition (Sarrett 2011); the dangerous, uncontrollable and unloved child; a heartbreaking, irresolvable 'problem' for parents/caregivers (Jones & Harwood 2009); as a personal responsibility more often than a social one (Kang 2013) and as a 'tragedy that will break up a family and its individual members' (Sarrett 2011, p.146).

As portrayals of autism have increased within the media and popular culture, so has interest in autism research from an academic standpoint (Mallett & Runswick-Cole 2012). Regarding the representation of autism, several studies have been conducted that cover a number of different mediums and countries (Bie & Tang 2015; Billawala & Wolbring 2014; Garner, Jones & Harwood 2015; Holton, Farrell & Fudge 2014; Kang 2013; Sawchuk & Clarke 2015; Tang & Bie 2016). Whilst several studies were found that explored the representation of autism, the only research found that was conducted within the context of Australian media was Jones and Harwood (2009) who investigated the 'extent, and nature, of coverage of 'autism spectrum disorders' in the Australian print media between 1996 and 2005'. Whilst my research provides an opportunity to extend on the work and findings of Jones and Harwood (2009), my research also aims to extend previous knowledge by focusing on the representation of mothers of autistic children rather than simply the autistic subject themselves. It is important that we fill this gap as media representations influence its audience's understandings of a subject and provide us with insight into how knowledge about a subject is spoken about, related to and organised. Furthermore, media representations also provide further insight into how mothers of autistic children are invited to understand themselves and negotiate the subject position.

Autism and entertainment

Cinematic representations of disability have long provided a public source of entertainment and dramatization of what it means to be disabled (Bailey 2011; Richardson 2016). The use of disabled people within or for entertainment, however, is nothing new. Disabled children were thrown under the hooves of horses at the Coliseum; the 'ship of fools' which after sailing from port-to-port for public ridicule would abandon the disabled at the end of tour; and the use of disabled people in circuses and exhibitions for public humiliation are all such examples (Anti-Defamation League, 2005). Whilst such practices are no longer socially acceptable, the cinema, as argued by Conn and Bhurga, (2012, p.55), offers a 'safe, politically correct and ethically permissible forum for our curiosity'.

Released in 1988 was the Oscar-winning Hollywood film *Rain Man*. Prior to the movie's release, the subject of autism was not of mass cultural interest and was for most, an unknown identity. The success of the movie *Rain Man* thrust autism into the limelight, immediately and dramatically increasing its public profile (Conn & Bhugra 2012, p.56). Actor Dustin Hoffman's portrayal of autistic-savant Raymond Babbitt was based on the real-life character of Kim Peek. Although Peek had been diagnosed with FG Syndrome (a rare genetic disorder), the performance by Hoffman connected the savant uniqueness of Peek and its (savant abilities) association with autism (Howell 2015).

The film won four Academy Awards, grossing $354,000,000 worldwide (www.imdb.com; cited by Conn & Bhurga 2012). In addition to being a pivotal moment in the cultural shaping of autism, as Draaisma (2009, p.1476) makes note, 'up until 6 or 7 years ago, many movies featuring autistic characters had a scene in it in which an expert, usually a psychiatrist, explained about autism and savant skills'. Such a scene, to describe what autism is, is no longer such a necessity. No longer was the examination of autism confined to the clinic.

Autism and Journalism

Although the verification of information is what separates journalism from fields such as entertainment, propaganda, fiction, or art, the practice of framing the news, issue, communication and source shape its representation (Kang 2013). This framing makes particular aspects more salient, giving the news subject 'an identifiable slant' (Bloch-Elkon 2007, p.25).

Between 1981 and 1999, *Time* published 14 autism-related articles. In contrast, between 2000 and 2009, 157 articles were published (Skubby 2012, p.2). *The New York Times* published 'an annual average of 16.6 articles on autism from 1981 to 1999, but published an average of 104 articles per year on the topic from 2000 to 2009' (Skubby 2012, p.2). Within the Australian print media, Jones and Harwood (2009) found a similar pattern. No articles were found using their search terms ('autism OR autistic OR Asperger's) prior to 1996. In 1996, there were nine articles published and this number progressively increased over the next five years (13 in 1997; 26 in 1998; 63 in 1999; 68 in 2000 and 112 in 2001) (p.8). 'In 2002 coverage more than doubled to 247 and has stayed at a high level since this time, with 291 articles in 2003, 380 in 2004 and 310 in 2005' (Jones & Harwood 2009, p.8).

In their review of Australian print media, Jones and Hardwood (2009) found the main areas of focus were; funding, education, fundraising and donations, research, the MMR vaccine, diagnosis, impact on families, criminal cases and community support stories. A particularly interesting finding of Jones and Harwood's study was the framing of the story as positive or negative. The 'negative' articles highlighted:

- The social and physical difficulties of caring for a child diagnosed with autism and the impact on families (particularly in regard to marriage breakdown),
- 'Difficulties with diagnosis, misdiagnosis, overdiagnosis, and the lengthy delays experienced in obtaining diagnoses' (p.12),
- Portrayed autism as a 'disease'
- Focused on 'hypothesised causes of autism which were a result of actions or inactions of the parents, including issues related to the birth of the child' (p.11) and implications 'that potential causes, or triggers, of autism had been 'covered up' by those who stood to gain financially' (p.11).

There were a small number of articles on the achievements of people with autism but themes of 'positive' articles were primarily around that of:

- increased government or community funding.
- That research was being conducted, 'new research findings with the potential to result in better 'treatments' (or in some cases even 'cures')' (p.11).
- 'Improvements in diagnosis, the success of early diagnosis and a portrayed hope for the future in improving diagnosis and "prognosis"' (p.12).

Of note is that while some articles were presented as 'positive' this was not positive in regard to autism but positive regard for others involvement or the 'resolution of a problem inherent in being 'an autistic'' (Jones & Harwood 2009, p.14).

Impact

The lack of voice given to the autistic subject reinforces the idea that autism is always abnormal, whilst constituting a violation of human rights for those labelled autistic (Clarke 2012, p.194). Effects of the term autism have become more significant than the nature of the child, with the diagnosis of autism often having a devastating impact on parents, who up until that time had been doing an excellent job (Hodge* 2005). The label of autism has been found to disempower parents who then begin to question their ability to raise their child without specialist help and question their child’s future based on what they heard and read (Hodge* 2005).

Stigma created by dominant representations contributes to what Inzlicht and Good (2006, pp.129-131) have coined “threatening environments” - those where individuals are disparaged as a result of how they have been portrayed. Effects of the representation of autism can be seen in the community in South Australia who objected to Autism SA’s attempts in 2005 to set up a respite home for up to five autistic children (Jones & Hardwood 2009). Residents reported they did not want this kind of service operating in that area. There were concerns about potential risks to their own safety, their kids' safety and how such a service might devalue their properties. The outcome of this opposition was that the respite home did not go ahead (Jones & Harwood 2009). Of interest is that none of the residents opposed to the project would voice their objection on camera. The objections stated they were not against the concept, just not in their street and that must be a more suitable location elsewhere (Jones & Harwood 2009). Such attitudes reflect a cycle between disregard and paternalism regarding differences such as autism and we can also see how any current positive regard for autism is perhaps only wafer thin, hiding an embedded notion of fear and rejection of those who are different. It also reflects the values of a capitalist society (property prices over care) whilst raising the question of why people have such strong views of autism, particularly regarding their safety.

A competing discourse on autism

Autism is not necessarily the debilitating condition it is portrayed to be. O'Neil (2008) cites how many within the autistic community give emphasis to position autism as a difference, neuro-diverse, not a disorder or something that needs to be cured. Many self-labelled Aspies (someone with Asperger’s) proudly differentiate themselves and refer to others as Neurotypicals (Clarke & Van Amerom 2008). To many, the idea of a cure would amount to destroying their personalities and the real injustice lies in the way non-autistics treat those with autism (Barnes & McCabe 2012).

Drawing upon the social model of disability, interventions by autism advocates attempt to undermine its (autism’s) taken-for-granted status as something that is “true” and “real”. Directing the blame towards a society that has failed to fully include the neuro-diverse opens up for examination the complex relations that produced it (autism) and its effects. This is in contrast to the dominant medical model which pathologises the individual as disabled and in need of medical intervention, treatment and, possibly, cure (Clarke & Van Amerom 2008). A model which as Aspies for Freedom (2006; cited by Veyne 1997, p.154) point out, once also considered homosexuality a disorder.

Mothers of autistic children

The dominant/normative representations of what it means to be a well 'human' and the debilitating portrayal of autism deliver a consistent message that the mother's life will be an ongoing struggle (Jones & Harwood 2009). The categorization of individuals places an imposition of truth regarding how they are marked and recognised by others and how they should behave due to their own recognition of their position (Foucault 1982). The subject position of the mother of an autistic child is one that is influenced by the dominant representations of mothers being thought of as the producer of the standardised child. Normalization forms the basis by which all are judged and considered to conform or not. Normalizing judgement, however, is not simply comparing individuals in a binary way - good/bad, mad/sane, hetero/homosexual. The 'good' mother is also the 'standard towards which all individuals should aim, work towards, seek to achieve, and against which all are measured' (Carabine 2001, p.278).

Once the diagnosis of autism is given, dominant discourses then position maternal responsibility as one where mothers are responsible for the onerous undertaking of accessing suitable early interventions (Lilley 2011, p.135). Simply undertaking the path of early intervention positions the mother as one seeking a certain something. The mother herself is influenced by the normality of this role, the representations of the problematization of autism and her own experiences, understandings and desires of her child. Mothers who embark on this quest for answers, help or instruction, become encased within a labyrinth of debate and controversy within a field that itself has become a commodity. Autism interventions are characterised by competing claims and controversy (Lilley 2011), often supplemented with the notion that 'with intense intervention, the child and family can be whole and functional again' (Sarrett 2011, p.146).

Research (Mass media)

Whilst, as mentioned above, there has been research into the representation of autism within the mass media, the same cannot be said for mothers or even parents. After an extensive search, the only academic research I was able to find that looked at a collection of articles from the media was by Clarke (2012). Clarke (2012) investigated the representation of autism in magazines ‘directed toward differently gendered audiences, including women’s magazines and magazines for both men and women from 2000 to 2009, published in the United States, and directed toward English-speaking North Americans’. The research questions of Clarke were not directly related to parents or the mother but rather included the three research questions: *What is autism? What is said to cause it? What can and should be done about it?* Although fathers were seldom mentioned in magazines directed towards either audience, in magazines that targeted a female audience, such as *The Oprah Magazine*; *Baby Talk*; *Parenting*; *Working Mother* and *Good Housekeeping*, Clarke observed four key themes about the mother.

Firstly, mothers were regularly described as reacting emotionally and as seeing the child’s developmental differences as tragic. They were ‘described as emotional and suffering great sorrow and stigma because of the fate of her child’ (Clarke 2012, p.187). An example of this from one of the magazines studied by Clarke is given below:

> “I was alone the day I received Will’s diagnosis. A gun pressed against the side of my head. Bullets ripped through my skull: autistic, autistic, autistic. I couldn’t cry. I couldn’t breathe … People walked by as if nothing had happened … Didn’t they know the world had just ended?” (Mahoney, Parents, 6 February 2006).

Secondly, mothers would describe the stigma and isolation they experienced because of their child’s difference. It was not just the “tragedy” of autism or the “unusual” child, stigma would spread to the mother. This idea of the stigma spreading to the mother is consistent with the idea of courtesy stigma (Goffman,1963) discussed earlier in this chapter.

Thirdly, the isolation was reinforced by the idea that treatment was ultimately down to the mother (Clarke 2012, p.188). Mothers were represented as solely responsible, ‘even if this meant challenging doctors. Clarke (2012, p.192-193) identified that mothers were represented as: willing to challenge doctors, schools, and health systems, able to evaluate the different medical and other opinions she receives. They were an independent entrepreneur of the health and health care of her children and portrayed as if they are “good mothers” willing to dedicate themselves to their child(ren)’.

Fourthly, this solitary mother acts heroically to found schools and charitable organizations to provide for her kid, and others ‘suffering’ a similar fate. Whilst mothers were described as initially seeking help from doctors, it was only after they realised that little help was forthcoming that they turned to other avenues (Clarke 2012, p.193). Clarke (2012) discusses how this portrayal represents a medicalised and non-medicalised perspective. The first actions of mothers are indicative that autism is medicalised and limited to doctors. It is 'only after they realise that little help is forthcoming do they turn to other avenues or solutions (Clarke 2012, p.193).

The subject positioning of mothers of autistic children found by Clarke (2012) adhered to and reinforced the portrayal of the 'good' mother discourse and the notion that mothering is and should be an intensive activity (Hays 1996). The representation of the role of the mother was clearly defined – she is 'responsible and absolutely dedicated to making things better for her child' (Clarke 2012 p.192). Extending the work of Clarke (2012) to explore how mothers of autistic children are represented in newspapers rather than magazines is a key point of my research. Rather than magazines that are targeted towards particular categories, newspapers are considered more generic in their target audience. This is not to say that newspapers report the truth. Knowledges reproduced and packaged in newspapers are not random (Hall 1977). Rather they reflect the assumptions, intentions and interest of dominant groups (Hall 1977). As such, extending our understanding to newspapers offers another site of discursive practice to examine.

Interviews (previous research)

In addition to understanding more about how autism and mothers of autistic children are represented in public discourses, through the use of semi-structured interviews I also seek to further examine the lived effects of this representation and what discourses are drawn upon by mothers of autistic children. Numerous authors have conducted research that included interviews with mothers of autistic children. This research has been conducted across numerous disciplines including nursing (Lutz, Patterson & Klein 2012), sociology (Faigura 2009), family relations (O'Brien 2007) and motherhood (Gill & Liamputtong 2011). Different approaches have also been utilised when using the interview method. These include narrative research through a constructivist lens (Lutz, Patterson & Klein 2012), naturalistic research and the interactive process (Gray 2002), phenomenology and feminism (Gill & Liamputtong 2011). My research aims to further our understanding of mothers of autistic children by drawing upon some of the methods used and locating my research within a post-structural, Foucauldian and feminist framework.

With the use of use the interview method, several authors have looked specifically at the process of diagnosis or have had diagnosis emerge as a theme from their research. The process surrounding having a child diagnosed as autistic is often complicated, lengthy and a waiting game that causes distress (Schall 2000). Previous research has identified that the absence of a suitable diagnosis can result in the questioning of one's parenting skills (Lasser & Corley 2008). In contrast, research has also suggested that a diagnosis can be resisted by mothers where they deny or question the diagnosis (Shuntermann 2002). In recognition of this, my study aims to further explore what it was that resulted in a diagnosis being sought or given and mothers feelings about this diagnosis.

Research into reactions to receiving an autism diagnosis has identified that initial reactions often include grief and uncertainty (Lutz, Patterson & Klein 2012; Schall 2000; Shuntermann 2002). A study by O'Brien (2007) explored this from the perspective of ambiguity. O'Brien (2007, p.136) who, drawing upon a model of grief used to previously access families response to chronic illness and to Alzheimer's ((a) a lack of clarity in diagnosis, (b) difficulty in predicting outcomes, (c) day-to-day changes in functioning of the ill person that affect family relationships, (d) the fact that the ill individual may give an outward appearance of health thus raising expectations for his or her behaviour and functioning within the family, and (e) fear that important emotional relationships will be affected by the illness) conducted interviews with 63 mothers of autistic children 'to identify whether mothers express feelings of ambiguous loss when talking about their child. Relating to feelings about a diagnosis, O'Brien (2007, p.142) identified the ambiguity of autism (such as the 'lack of knowledge surrounding its etiology, symptoms, treatment, and outcome') as a contributing factor. Furthermore, assumptions or expectations about the child mothers thought they 'would have' and a diagnosis that meant this would not be the child they 'do have' means that parental expectations are challenged (O'Brien 2007, p.135). O'Brien (2007, p.142) argues that the 'altered outlook' required 'for a family to continue to function' post ASD diagnosis 'is a process that few families can be expected to negotiate easily'. In contrast, it has been found that a diagnosis can help mothers' move forward now that they understand what is 'different' about their child (Williams & Murray 2015). In addition to how mothers of autistic children are represented, my research seeks to learn more about how mothers negotiate the subject position of mother of an autistic child and some of the lived effects of this subject position.

O'Brien (2007) argues that ambiguity is intensified due to parents hearing/reading about children who have been '"cured" through intensive intervention or a new dietary or medical therapeutic approach'. Regarding cure, I discuss later in this chapter the emergence of an identity categorised as the warrior-mother and her mission to cure/eradicate autism. As my study seeks to examine the lived effects of knowledge production, I seek to learn more about how the idea of a cure is represented, learn more about how mothers view the possibility of cure and mothers approaches to intervention and therapy. I also seek to further investigate what forms of authority and credibility are given to the various knowledges regarding cause and cure that are presented.

Seeking advice and information has been identified as a coping mechanism utilised by many mothers' post-diagnosis (Lutz, Patterson & Klein 2012). As identified earlier in this chapter, a study by Lilley (2011), discussed how the labyrinth of information mothers are exposed to results in mothers being presented with competing claims, each fighting for a position of truth (and often money). My research seeks to further our understanding of where mothers turn to for information and support, what advice is taken up and what is dismissed.

Research from interviews has also explored how mothers adapt to the 'loss of a "typical" child' over time (Lutz, Patterson & Klein 2012). A study conducted by Lutz, Patterson and Klein (2012) focused on the mother's perceptions of the impact of autism on the family unit across different stages of the life cycle. From their interviews with 16 mothers, coping strategies drawn upon were identified to be: seeking answers to help deal with the grief that emerged following the initial stressor of the autism diagnosis. For example, seeking answers about why and how their child became autistic and what they could do (i.e., treatments and educational placements) to help their child, revising dreams and future planning to help deal with the disappointment and sacrifice, and taking up multiple roles to help deal with guilt and doubt. Mothers expressed feeling guilty about the attention they gave their autistic child in comparison to their other children, feeling guilty about seeking a diagnosis, feeling guilty about not including the autistic child in family outings and feeling guilty about making them participate in therapy. To deal with this, mothers spoke of strategies such as learning to appreciate the little things in life – what one mother described as 'making lemonade out of lemons' (p.210) – and taking up additional roles such as advocate for their own and other disabled children.

Disappointment about 'how life was "supposed to be"' was evident in many interviews conducted by Lutz, Patterson and Klein (2012, p.210) and the revising of dreams and spending time trying to plan for the future was how many mothers coped with this disappointment. The final theme identified was the seeking of support, socialization and spirituality to help deal with dis-ease and relationship strain. Dis-ease is a concept in psychiatric and family literature which is the opposite of ease and described as 'the state in which a family is not able to discover, experience, and/or actualise a sense of meaning or purpose in life' (Marcel 1956; cited by Lutz, Patterson & Klein 2012, p.209). Relationship strain was experienced across three dimensions of dis-ease – 'psychological (fear and anxiety), physiologic (burden of caretaking and physical symptoms of stress), and social (feeling stigmatised, socially isolated, and financially burdened)' (Lutz, Patterson & Klein 2012, p.209). Mothers expressed the need for help from others and also identified spirituality as a coping mechanism drawn upon for support. The application of these coping strategies and adaption was something that occurred over time. Mothers adjusted their homes, lifestyles and plans to meet their children's needs.

An aspect that impacted mothers identified by Lutz, Patterson and Klein (2012) was the stigma surrounding autism. The stigma surrounding autism and its impact on parents who care for an autistic child has been a consistent theme identified by many researchers, in particular, since the work of Gray (1993). The work of Gray (1993; 2002) highlighted the stigma experienced by parents of children with high functioning autism. The invisibility of autism (particularly high functioning autism) was found to influence the stigma experienced. As quoted by one mother in Gray's (2002, p.743) study, "God! I wish he were Down's syndrome because people would leave me alone. They would see the Down's syndrome [and] know there was a problem". Gray (1993; 2002) also found that mothers felt more stigmatised by the community than fathers. Reasons for this were thought to be a combination of mothers being more likely to be exposed to public encounters, societal perceptions of the mother as the one with 'the highest degree of responsibility', and guilt felt for their child's disability (Gray 2002, p.744). As a result, mothers are thought to be the parent who experiences 'the responsibility' if 'presentation fails' (Gray 2002, p.744).

A previous research project that explored some similar interests to mine was done by Gill and Liamputtong (2011). Using in-depth interviews with 15 mothers of children with Asperger's and solicited diaries from six of the 15 participants, Gill and Liamputtong (2011) investigated the experiences of mothers with children who have Asperger's Syndrome. Whilst my research expands the mothers interviewed to include both an autism and/or Asperger's diagnosis, I also expand on our understandings of the effects of dominant representations to include not only lived effects but also subjective and discursive effects.

Being a post-structural Foucauldian study, my research rejects the idea of the pre-social subject and any singular truth regarding autism and mothers of autistic children. Rather, my approach aims to critique knowledge claims (McLaughlin 2003, p.91). Analysing the discursive effects of the knowledges represented allows these knowledges to be critiqued and identify any limits imposed on what can be thought or said. Furthermore, examining subjective effects allows me to investigate the ways mothers are constituted in discourse (Bacchi 2009, p.15).

The interviews conducted by Gill and Liamputtong (2011, p.46) were semi-structured with the main questions being:

- What is your view of an 'ideal' mother?
- How do you perceive yourself as a mother?
- Can you tell us about any social situation you have been in, where you have felt embarrassed/anxious about your child's behaviour?
- How would you rate your physical/emotional health, does this change day to day, what sort of things make you feel tired? How do you re-energise, take time out for yourself?
- Are there any other things you would like to tell us about your experiences with having an Asperger child?

An aspect of the research by Gill and Liamputtong (2011) that I seek to extend upon is the influence of the social construction of motherhood and ideal motherhood. Gill and Liamputtong (2011, p.49) identified that although mothers of Asperger's children recognised that there was 'no ideal motherhood, they were aware that society still placed great expectations on them and there was a real need for them to meet these expectations'. The data collected revealed that when mothers spoke of the moral career of motherhood, mother-blame was a central issue (p.51). My study seeks to further explore this finding by Gill and Liamputtong (2011) and extend on it by further examining the effects of the power/knowledge relations that produce the dominant constructions of motherhood (for example, the good and bad mother) and the subject position of mother of an autistic child. Furthermore, my study seeks to learn more about the role of blame from both an individual and societal level.

Regarding mother-blame, Gill and Liamputtong (2011, p.51) found that prior to diagnosis, society would blame mothers for their child's inappropriate behaviour. However, once a diagnosis was obtained, others began to see the inappropriate conduct as a behavioural issue rather than the result of individual parenting practices (p.52). As a result, mothers stopped blaming themselves (p.52). Interestingly, however, although the diagnosis of autism negated aspects of blame, revealing their child's diagnosis to others outside of their immediate family or other mothers of Asperger's children was something mothers often resisted doing (Gill & Liamputtong 2011). My research seeks to further explore the role of a formal diagnosis and what protection this offers the mother (from a societal and individual level).

Drawing again upon the moral career of motherhood, Gill and Liamputtong (2011, p.49) identified that mothers of autistic children felt guilty about spending time on themselves and would make sacrifices, such as giving up employment or cutting back on work hours, as they felt it 'was their 'duty' to be at home to nurture their children'. My research seeks to further our understanding of how mothers of autistic children became subject to this 'duty' and where this duty comes from. Furthermore, my study seeks to identify any forms of resistance to this 'duty'.

Previous research has identified the multiple roles performed by mothers of autistic children. For example, the role of educator, caretaker and advocate (Lutz, Patterson & Klein 2012; Hornby & Seligman 1991; Klein & McCabe 2007). My research is interested in the various roles available to mothers of autistic children and how responsibility for these various roles is felt or prescribed to these mothers. Two roles previously examined in detail have been those of advocate and activist.

Advocate and activist

With mothers of autistic children positioned as 'responsible and absolutely dedicated to making things better for her child' (Clarke 2012, p.192), for many mothers of autistic children, advocacy and activism are a major part of their experience (Ryan & Runswick-Cole 2009). From interviews with 36 mothers of autistic children, Ryan and Runswick-Cole (2009) argue that rather than traditional articulations of activism, activism and advocacy by mothers of autistic children is experienced across a continuum. Post the tragic heartbroken mother of an autistic child, positive portrayals of mothers of autistic children are those who then go on to '"move heaven and earth" to fight for their child and "normality"' (Clarke 2012, p.182).

Beyond how mothers of autistic children are viewed by others, it is critical to point out that some forms of advocacy require that it be the mother's own child who experiences much of the exclusion, or negative consequences, during the process of change they are fighting for (Williams & Murray 2015, p.331). The normative structure of formal institutions such as public schools has seen mothers of autistic children be either told they were not welcome or their lives made difficult when their child did attend (Williams & Murray 2015). Whilst advocating for their child to attend may result in them being able to send their child to a particular school and break ground for future autistic children, it would be their child that would have to exist in an environment that had previously told them they were not welcome.

Whilst resistance in situations such as encounters with professionals may evoke negative reactions, it is still seen as ‘good mothering’ (Todd & Jones 2003) and the role of an activist is compatible with the role of ‘good mother’ (Ryan & Runswick-Cole 2009). However, the representation of mothers of autistic children often ignores the idea that she might have competing needs and responsibilities - ‘that she may have another occupation or a life outside of motherhood is invisible’ (Clarke 2012, p.192). Whilst her role in ‘advocacy and activism can be seen as an unselfish act and reinforces the image of “saint-like” mother’ (Ryan & Runswick-Cole 2009, p.46), her involvement in other activities such as paid work might be seen as ‘selfish’ (Shearn & Todd 2000).

Warrior-mother

A prominent and emerging version of activist for mothers of autistic children is the warrior-mother. Warrior-mothers are those who ‘despite the high personal and financial costs to themselves and their families’, wage battles against ‘social and political forces to gain medical and educational interventions for their children’ (Sousa 2011, p.220). Regarding autism, the message and role of the warrior-mother is not simply recovery is possible, but ‘one of recovery at all costs’ (Douglas 2013, p.172). She is ‘supposed to be a child-saving hero, expected and encouraged to do anything and everything in pursuit of normalcy’ (Waltz 2015, p.355).

Guided by instinct and depending only on herself, the ‘good’ mother (of the autistic child) must undertake the immensely expensive and labour-intensive task of navigating the numerous claims to knowledge made within the complex landscape of knowledges about autism (Chivers Yochim & Silva 2013; Lilley 2011). As she navigates the competing claims and controversies offered to mothers surrounding issues such as schooling, treatment and therapy, the warrior-mother must engage in medicalised motherhood – a process that that is skilled and scientific (Lee 2008) and attached to the acceptance of the bio-medical paradigm (Whitmarsh 2008).

The heroic efforts of the warrior-mother are particularly prominent for middle-class women. As noted previously, intensive-mothering is thought to be most likely performed by middle class or professional middle-class women. Of interest is that when autism first became a distinct diagnostic category in the early to mid-20th century it was the middle class/professional class mother, or ‘refrigerator mother’, who was blamed for causing her child’s autism. I expand on this change later in chapter three (genealogy) but in contrast to other mothers who were problematised as ‘bad’ mothers in the 20th century, ‘refrigerator mothers’ were subjects of privilege (Jack 2014). They were white, educated, middle-class women.

In order ‘to gain authority to speak about autism’, warrior-mothers draw upon an imagery of power – ‘the mother-as-hero who could help save her child from autism’ (Jack 2014, p.4). The warrior-mother discourse fits neatly within a ‘media environment riddled with women who do it all’ (Chivers Yochim & Silva 2013, p.423). She is ‘sexy, successful, loving *and* instrumental, she is an agent in control of autism and their future well-being’ (Douglas 2013, p.172). She “re-invents” and intensifies a ‘troubling form of contradictory neoliberal feminine subjectivity’ (Douglas 2013, p.167). The mother is ‘culpable for the “right” interventions and for her child’s recovery’ and after having ‘“naturally” moved through love and grief, the “good” autism mother undertakes inhuman feats of advocacy and relentless treatment regimes to rid her child of autism’ (Douglas 2013, p.172). Entangled within a discourse of ‘good’ mothering, the warrior-mother recruitment campaigns involve ‘a call to mothers that is also a duty’ (Douglas 2013, p.174). Mothers ‘abandon their “natural” place as proximate to their own child so that they might promote it’ (Douglas 2013, p.174).

My decision to study McCarthy and *Generation Rescue* in this thesis stems from the emergence of the modern-day warrior-mother and her global campaign against autism (Douglas 2013). Douglas (2013) is herself the mother of an autistic child and her paper ‘*As If You Have a Choice: Autism mothers and the remaking of the human*’ explores similar interests to my own. I draw upon Douglas’s work regarding the ‘emergence of “autism mothers” as a new category of identity’ and the eradication of autism as part of her (“autism mothers”) global campaign. Douglas (2013, p.167) suggests the feminine-warrior both “re-invents” and intensifies a ‘troubling form of contradictory neoliberal feminine subjectivity’. This orientation ‘conceals a violent and unethical duty’ – ‘to eradicate the unique autism life’ in front of her (Douglas 2013, p.172).

Although she does not specifically look at McCarthy, Douglas (2013, p.172) does mention McCarthy as an example of this contradictory and intense global figure. An important part of my research is to examine the rhetoric of McCarthy in further detail. Given that the role of the warrior-mother is one of ‘recovery at all costs’, examining celebrity mother Jenny McCarthy, who claims to have cured her autistic son, will expand current knowledges about how the subject of the mother of an autistic child is represented and how this position can be negotiated.

Other researchers have looked at McCarthy. In their paper, the ‘*Everyday Expertise, Autism, and “Good” Mothering in the Media Discourse of Jenny McCarthy’,* Chivers Yochim and Silva (2013) aim to gain a better understanding of contemporary discourses surrounding mothering, expertise and gender by examining McCarthy’s mediated crusade to cure and prevent autism. Chivers Yochim and Silva (2013, p.424) argue that the message of McCarthy ‘challenges women to be evermore responsible for making impossible, individualised choices about their children’s health’. They also highlight how McCarthy credits her “mommy instinct” for her triumph ‘over autism in the face of a skeptical medical establishment’ (Chivers Yochim & Silva 2013, p.414). Although Chivers Yochim and Silva (2013) mention that McCarthy serves as the current president of *Generation Rescue*, their examination does not focus on the content or narrative of that particular website. As such, in addition to furthering the work of Douglas (2013) and the warrior-mothers crusade against autism, I also aim to further work of Chivers Yochim and Silva (2013) by examining a source of information (*Generation Rescue*) previously unexamined. Furthermore, I also seek to further understandings of the effects of these representations by interviewing mothers of autistic children.

Summary

Throughout this chapter, I have provided evidence for why mothers of autistic children are a population that warrants further attention. Constitution of difference categorises mothers of autistic children as other. Making sense of motherhood in a society that categorises autism as deviant, subjects mothers of autistic children to not only the power/knowledge relations that have produced dominant understandings of motherhood, but also subjects them to a version of motherhood that is considered deviant. As such, further examination into the lives and knowledges of mothers of autistic children is both warranted and necessary.

An understanding of how institutions such as journalism have and continue to help produce motherhood, disability and autism demonstrates the importance of further examination of how mothers of autistic children are represented. Whilst the representation of autism in the media has received much attention from academic researchers, the same cannot be said for mothers of autistic children. Furthermore, in recognition that research into representations of both autism and mothers of autistic children are limited within an Australian context, the examination of newspapers within an Australian context and an examination that focuses primarily on the representation of mothers of autistic children contributes a better understanding of how mothers of autistic children are thought of and how they may come to think of themselves.

The ongoing positioning of mothers as not only the ones responsible for raising children but also for raising successful children has further entrenched dominant discourses of good mothering as being “labour intensive” and the “true duty” of women was made evident throughout this chapter. In addition, I also presented evidence for how mothers have been represented as taking up this duty. Given that previous research has identified that the emerging identity of the warrior mother is to do everything in her pursuit to recover her child, regardless of the high personal and financial costs to themselves and their families, further examination regarding how this duty is represented to mothers and how discourses of both autism and motherhood have resulted in the availability or need of this duty is needed. Furthermore, as representations have effects that are real (Bacchi 2009) and my research does not aim to merely add mothers of autistic children to discourse but undertake research that is beneficial for them, it important to also consider the possible effects of this emerging identity and what assumptions are made within it.

CHAPTER 3: GENEALOGY

This chapter aims to explore how autism has been constructed and how power/knowledge relations identified the elements of autism and consequently, how power/knowledge relations have produced autistic children. A genealogical analysis of autism gives insight into how a subject position unheard of until the 1940's, and once considered extremely rare, has now become one of both public fascination and fear. Furthermore, the use of a Foucauldian genealogy presents an opportunity to use history to understand how present knowledges of autism and mothers of autistic children have come about and some of the possible effects of this representation.

This chapter aims to highlight mechanisms and classifications that have allowed for the identification, classification and ordering of the subject position of autistic children and consequently, mothers of autistic children. There are two main purposes of this chapter, the first is to examine how autism became a positive product of power, incited by techniques of surveillance and examination during the 20th century. The second is to examine how mothers became objects of blame.

A genealogy is an instrument which aims to 'record the singularity of events outside of any monotonous finality' (Foucault 1971, p.139). The singularity of events that may have a particular impact is then understood within the context of their environment at the time. A genealogy is not about tracing the level of a field as it progresses toward truth. Rather, a genealogy aims to give a close analysis of power/knowledge relations and the shifts in triangles of power and their effects. Power was important for Foucault. For Foucault, '[p]ower is everywhere; not because it embraces everything, but because it comes from everywhere' (Foucault 1978, p.93). The three forms of power, or 'triangle' of power, spoken of by Foucault include sovereignty, discipline and government (governmentality) (Foucault 1991, p.102).

Discipline and governmentality are important concepts to understand as both this chapter and remaining dissertation rely heavily on institutions such as the family. Whilst discipline and governmentality are of particular importance to my research, before expanding on these two concepts I first provide a brief overview of sovereign power and how it differs from governmentality and discipline.

For Foucault, sovereign power makes use of law, regulations, legislation and censorship (Dean 1999, pp. 105–106). Sovereign power is easily recognised and when operated, we know we've acted upon (Foucault 1977). Actions taken by the state cannot by themselves bring about the desired ends of the state and is only one form of governing. Regarding governmentality, Foucault does not argue that governmentality replaced sovereignty but as 'existing side by side with the sovereign power' (Bacchi 2009, p.28). Foucault's concept of governmentality refers to the' techniques and procedures for directing human behaviour' (Rose, O'Malley & Valverde 2006, p.83).

Foucault distinguishes between a sovereign power that is repressive, and a productive normalizing power (Lilja & Vinthagen 2014). Sovereign power operates through its visibility whilst disciplinary power is exercised through its invisibility. Within a sovereign regime of power, the individual remained below the threshold of transcription (Foucault 1977 p.191). In contrast, disciplinary power, or the scientific knowledge of humans as species, aims to make subjects permanently visible and document knowledge for future use (Foucault 1977).

Disciplinary power

As argued by Foucault (1977, p.170), '[d]iscipline 'makes' individuals; it is the specific technique of power that regards individuals both as objects and as instruments of its exercise'. Subject formation and the relation of oneself with oneself and with others is 'subjugated and subordinated to an order by disciplinary strategies' (Lilja & Vinthagen 2014, p.109). Seeking to know individuals as objects in relation to others that can be known (Johnston 1991) means that those who deviate can be categorised as abnormal (Lilja & Vinthagen 2014) and subject to techniques which aim to manage, modify, correct and reform (Johnston 1991).

As outlined by Foucault (1977) in *Discipline and Punish: The Birth of the Prison*, disciplinary mechanisms include spatializing practices or *the art of distributions* which organise individuals and space according to function and rank. 'Particular places were defined to correspond not only to the need to supervise, to break dangerous communications, but also to create a useful space' (p.143-144) (For example, hospitals and schools); Temporal arrangement or *control of activities* (timetables/schedules) which would 'establish rhythms, impose particular occupations, regulate the cycles of repetition' (p.149); Documentation that creates an individual history from birth to death, documents that capture and fix them (p.189); *Genesis* (developmental stages),

> arranging different stages, separated from one another by graded examinations; drawing up programmes, each of which must take place during a particular stage and which involves exercises of increasing difficulty; qualifying individuals according to the way in which they progress through the series (p.159)

and finally, *combination of forces* (the body as part of machine) where (1), '[t]he individual body becomes an element that may be placed, moved, articulated on others.' (p.164), (2) '[t]he various chronological series that discipline must combine to form a composite time are also a piece of machinery' and (3) '[t]his carefully measured combination of forces requires a precise system of command' (p.166).

Mechanisms of discipline are reinforced by generalised instruments. These instruments include: *hierarchical observation,* an apparatus where the 'techniques that make it possible to see' also 'induce effects of power' (Foucault 1977, p.170-171); *normalising judgment*, where one does not measure up to the rule (Foucault 1977, p.178); and *examination* where the techniques of an observing hierarchy and those of normalizing judgment are combined (Foucault 1977, p.184).

For autism, techniques of disciplinary power are particularly relevant. For example, in this chapter, I aim to demonstrate how techniques of observation, normalizing judgement and examination have been deployed in order for autistic children to be knowable. Furthermore, by understanding the mechanisms of disciple, we can examine how and where the effects of the mother-child/infant relationship have been examined and represented by various scientific discourses.

Governmentality

Whilst disciplinary power 'targets individual bodies and use techniques of surveillance and normalization', 'governmentality operates at the level of population' (Bacchi 2009, p.27). Foucault's concept of governmentality is a way of thinking about the practice of government. By the practice of government, rather than a single state being responsible for governing, a variety of authorities govern in different sites. The question then becomes, '[w]ho governs what? According to what logics? With what techniques? Toward what ends?' (Rose, O'Malley & Valverde 2006, p.85). Rationales of government, such as liberalism, welfare and neo-liberalism make governing practical. For example, in liberalism, rather than a state that starts from the position that human behaviour should be governed, liberalism begins with the assumption that human behaviour should not solely include the interests of the state' but include the interests of society as a 'realm external to the state' (Rose, O'Malley & Valverde 2006, p.84). In liberalism, as argued by Foucault (1977, p.74-75) that 'one can observe the emergence of the distinction between state and society'. From a Foucauldian theorization, neo-liberalism is a rationality of government and rationales for a free market economy extend over non-economic institutions (such as family and reproduction). Neo-liberalism denotes a method of rationalizing the exercise of government that obeys the internal rule of maximizing the economy (Foucault 1997, p.74). For the goals of a neo-liberal rationale to be achieved, individuals must recognise and act upon themselves as free but also responsible (Rose 1999, p.68). In contrast to a welfare rationale of government where wealth is redistributed and the economic and social wellbeing of all citizens is protected by the state, neo-liberalism develops techniques to direct individuals without being responsible for them. Unemployment, illness and other social risks are not the responsibility of the state, individuals are responsible for their own 'self-care' (Lemke 2001, p.210).

Governmentality is the "conduct of conducts" through which 'capillary forms of power insert themselves into actions, attitudes, and discourses' (Foucault, 1980, p.39). Governmentality refers to the techniques and procedures used to guide the conduct of the population (Rose, O'Malley & Valverde 2006, p.83). Although for Foucault power is not an institution, institutional power still circulates to guide conduct. Governing forms part of the complex series of strategies that produce and affect behaviour and works through institutions, bureaucracy and research (Miller & Rose 1993). Institutions, such as hospitals, and research, such as the effects of behavioral treatments, have impacted current knowledges of autism and mothers of autistic children and are traced in this genealogy.

Genealogy

The following chapter identifies key individuals within the production of autism who, conferred with authority, are mediums through which power is deployed - vectors of power. For example, the psychiatrist is a subject produced within psychiatric discourse and it is the authority of the subject position that shapes what is visible, thinkable and doable. As proposed by Foucault in a lecture in 1976, individuals are not actors with 'original notions of how, when and where to deploy power' (Skubby 2012, p.323), rather, they are vectors of power. 'Individual psychologists or individual physicians do not play a role in power; they are a medium through which power is deployed as a result of being subjected themselves to a scientific discourse' (Skubby 2012, p.323).

20th century

1900 -1940

In 1908, psychiatrist Eugen Bleuler used the word autism in a lecture at a meeting of the German Psychiatric Association in Berlin. Bleuler used the word autism to describe one of "the four A's" of *dementia praecox*, what he was then revising to be named schizophrenia (Fusar-Poli & Politi 2008). Bleuler's work was a revision of Kraepelin's *dementia praecox* and was challenging the accepted wisdom of the time. Bleuler did not believe the condition was a single disease, rather something he referred to as a "whole group" of schizophrenias (Bleuler 1911; cited by Fusar-Poli & Politi 2008). Whilst Kraepelin utilised descriptions of symptoms and their progression from patient records, Bleuler collected material directly from his clinical work (Fusar-Poli & Politi 2008, p.1407). Bleuler spent twelve years living among his patients, accommodating himself to the spatial and temporal environment (Stotz-Ingenlath 2000). Blueler would publish his work in 1911 in a book entitled, "*Dementia praecox or the group of schizophrenia"*. Unlike Freud who wanted to try and explain schizophrenia, Bleuler was interested in the symptoms (Stotz-Ingenlath 2000, p.155).

"The four A's" Bleuler described as the main symptoms of schizophrenia were; the loosening of associations; disturbances of affectivity; ambivalence; and autism (Stotz-Ingenlath 2000, p.157). Each of these symptoms was considered fundamental however only the *loosening of associations* was considered primary (Moskowitz & Heim 2011). *Autism*, as Bleuler described it, 'could only be understood in relation to affectivity and loosening of associations and was thus a ''secondary manifestation'' phenomenon (Bleuler 1950, p.354; cited by Moskowitz & Heim 2011).

Bleuler defined *autism* as "detaching oneself from outer reality along with a relative or absolute predominance of inner life" (Bleuler 1911, p.304; cited by Stotz-Ingenlath 2000):

> Patients lose their connection to the environment. They no more perceive their senses and the dream reality is their only reality. The outer world is only a disturbing factor and has no real value for them anymore. The autistic ideas are almost incorrigible (Stotz-Ingenlath 2000, p.157).

Bleuler suggested that autistic thinking could be found in healthy persons also: in fantasy and daydreams (Bleuler & Freud 1912; cited by Stotz-Ingenlath 2000):

> Creative people often do not take reality into account and even cut out reality. Sometimes even scientists may not see errors or become infatuated with certain ideas in an autistic manner.

The integration of psychiatry with medicine at the beginning of the 20th century saw a shift in attention towards gaining knowledge from patients rather than that of simply providing care (Romano 1975). The shift in location from the asylum to the research hospital facilitated this transition (McGovern 1985). This shift enabled the approach of Bleuer and also the mechanisms used by Kanner – an authority who is today often referred to as the pioneer of autism.

1940's

In 1943, Kanner was a psychiatrist at Johns Hopkins Hospital and published what would become a landmark case study in the history of autism, "*Autistic disturbances of affective contact*":

> Since 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits – and I hope will receive – a detailed consideration of its fascinating peculiarities (Kanner 1943, p.217).

Kanner's paper mentions the fact that the children in his study had been observed in his hospital since 1938. Coincidentally, five years prior to Kanner's publication in 1943, an Austrian psychiatrist named Hans Asperger used the term "autistic psychopaths" in 1938. Spoken in German in a lecture at Vienna University Hospital. Asperger would submit a paper in 1943, published in 1944, titled, "*Autistic psychopathy in childhood*" ("*Die 'Autistischen psychopathen' im kindesalter*").

Both Kanner and Asperger's adopted the term 'autistic' from Bleuler's work. During the 1940's, Asperger's work was still only available in the original German. The decision by both Kanner and Asperger to 'describe their patients in terms of the concept of autism' is not surprising giving that 'autism was a phrase with wide currency and applicability, particularly in German psychiatry' (Nadesan 2013, p.40). Both Kanner and Asperger were describing what they believed to be a 'new' distinct condition, and both described similar behaviour. For example, Kanner describes his patients as demonstrating; 'Impairment in social interaction, impairments in communication, and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities…' and Asperger described his as those with; 'Special interests, abnormal fixations, stereotypic play and movements, such as rocking, and ritualised behaviours' (Pearce 2005, p.205). Kanner's work, however, would achieve far wider recognition than Asperger's, in part because Asperger's work was written in his native language of German. However, as Bush (2010 cited by; Feinstein 2011, p.16) points out, one might have expected the scientific minded German-speaking or German immigrants to be able to read and or be aware of Asperger's work. Bush (2010 cited Feinstein 2011, p.16) suggests that given the Nazi regime and politics of that time, Asperger deliberately couched his work in Nazi-style vocabulary to protect the children in his care and consequently may have been viewed as Nazi propaganda. It would take another three decades for the work of Asperger to penetrate dominant Western narratives.

Following Kanner's identification of early infantile autism, debate within the English-speaking Western world proceeds to focus on two areas of debate. These can probably be best described as knowledges surrounding *classification* and *cause.*

Classification

In 1952, almost a decade after Kanner and Asperger's original publications was the first publication of what many would describe as 'the bible of psychiatry', the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). Impeded by differing classification systems, there was a desire for a standard classification system to facilitate communication among professionals (Sanders 2011, p.394).

The DSM serves a guiding post for this chapter as it helps highlight when a 'new column' or change in thinking is reflected. It also helps illustrate the everchanging way autism has been categorised and known. The first DSM (1952) featured 106 disorders, of which autism was not a distinct category. Children who demonstrated autistic-like symptoms were classified as 'childhood-schizophrenic' (Billawala & Wolbring 2014).

Up until this point, the field of psychiatry and the role of childhood development had been dominated by Freud's psychodynamic and developmental theories which were concerned with the aetiological factors of mental disorders (Vakirtzi 2010). The DSM, however, was dominated by 'Kraeplin's nosological approach which attempted to classify, categorise, and describe psychiatric disorders as discrete entities' (Kirk & Kutchins 1992, p.5). As to why this may have occurred, Vakirtzi (2010) suggests that it links to a desire for psychiatry to be a discipline recognised as scientific. Kirk and Kutchins (1992, p.24) note how 'description and classification are basic to all science' and highlight three phases that necessitate it as being scientific: 'convincing definition of the illness; a system for identifying its characteristics; and, a procedure of locating it in some classification scheme that differentiates it from other phenomena'.

Blueler had used the word 'autism' as a component of schizophrenia and aside from the overall absence of hallucinations, for Kanner, a point of difference was the aspect of *withdrawal* versus *failure to develop*:

> While the schizophrenic tries to solve his problem by stepping out of a world of which he has been a part … our children gradually compromise by extending cautious feelers into a world in which they have been total strangers from the beginning … there is a remoteness at least from the human portion of the external world (Kanner 1973, p.95).

In addition to the debate surrounding its separation from schizophrenia, critiques would also question its separation from categories such as mentally retarded children or defective children (Bender 1959). The reason for this was their lack of social skills and bleak future prognosis (Bender 1959, p.2)

An important point that arose from the questioning of Kanner's identification of autism was family background:

> It is not clear what he means by saying that there is evidence that autistic children have greater intellectual potentialities unless he is referring to the family background of his colleagues, professors and intellectual sophisticates who have selected his services (Bender 1959, p.82).

Bender identifies a key component here, the family background of those who accessed the service. Part of the success in differentiating autism as a unique category was the family background which these children stemmed from, their social class and intellectual capabilities. Both Kanner and Asperger used 'similar strategies to describe the children they examined. In doing so, they demarcated both parents and children as being from a class background and lineage superior to that of the feebleminded, who were usually depicted as poor, slovenly and dimwitted' (Jack 2014, p.17). Kanner and Asperger's work came at a time when, in the early 20th century, the idea of 'race suicide' was prominent. White settlers in Australia and other westernised countries were concerned with white middle-class women not having enough children, and 'other' women (migrant, Indigenous or working class) having too many (Bartlett

2004). The fundamental interests of colonised nations and the health of the white race meant the reproduction of white citizens became the political and patriotic duty for white women (Bartlett 2004).

Cause

The operating climate during the 1940's was dominated by psychoanalytic thinking (Hanbury 2005). The dominance of psychiatric thinking produced an environment where thinking around autism began to 'form around theories of parenting and in particular the role of the mother in nurturing the child' (Hanbury 2005, p.6). Whilst Kanner's work speculated about a link between the parent and the autistic child, the target for blame would be the mother. The influence of Freud and his theories of emotional disturbance (experiences in childhood) was pivotal in shaping the pursuit of knowledge and way of thinking at this time. Medical experts in the 1940s searched for emotional causes for autism and identified the origin of autistic symptoms to be the most dominant figure in the early years of childhood, the mother.

Kanner's work speculated a biological origin, however, just as 'mental health professionals had always suspected there was something different or unusual about the parents of schizophrenics' (Neill 1990, p.500), Kanner also noted the similarities in behaviour and personality of the parents (Nadesan 2013, p.87):

> It is not easy to evaluate the fact that all our patients have come from highly intelligent parents. This much is certain, that there is a great deal of obsessiveness in the family background (Kanner 1943, p.250).

In addition to identifying aspects such as intelligence and obsessiveness, Kanner would also refer to what he perceived as a 'cold' environment:

> One other fact stands out prominently ... there are very few really warm-hearted father and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited interest in people … The question arises whether or to what extent this fact has contributed to the condition of the children (Kanner 1943, p.250).

Kanner's questions appear to be based on observations he had made through his work with the children he observed. Kanner's later work and thinking moved away from descriptive based observations to theorizing about the effects of parental behaviour:

> Most of the patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only. They were the objects of observation and experiment conducted with an eye on fractional performance rather than with genuine warmth and enjoyment. They were kept neatly in refrigerators which did not defrost. Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude (Kanner 1949, p.425).

Kanner, however, was not convinced of even his own speculation, stating: 'One is also entitled to wonder why some of these parents have been able to rear other children who did not withdraw' (Kanner 1949, p.426). Kanner separated the generic term of parents, and the characteristics and behaviours of fathers were noted:

> Most of the fathers are, in a sense, bigamists. They are wedded to their jobs at least as much as they are married to their wives. The job, in fact, has priority. Many of the fathers remind one of the popular conception of the absent-minded professor who is so engrossed in lofty abstractions that little room is left for the trifling details of everyday living (Kanner 1949, p.422).
>
> Many of the fathers hardly know their autistic children. They are outwardly friendly, admonish, teach, observe "objectively," but rarely step down from the pedestal of sombre adulthood to indulge in childish play (Kanner 1949, p.422).

A relevant question then becomes, if it was 'parents' that were in some part thought to be the reason for the [behaviour] of these children, why then would it become 'mothers' who were then targeted and readily accepted as responsible for causation?

During the 1940's psychiatry extended its position into the community and attention began to 'focus on the family and its role in psychogenesis of pathology' (Neill 1990, p.499). During this time, the popular characterization of women was those who withhold nurture, subsequently causing their children's emotional disturbance (Nadesan 2013). Along with the work of Freud, which had become so famous it had penetrated mainstream culture, 'popular renditions of object relations theory promulgated by figures such as D.W. Winnicott held mothers responsible for their infants' successes or failures in achieving stable egos (Nadesan 2013, p.87).

Following World War II there was a strong behaviourist influence (stressing the role of experience as the primary cause of development) and a particular focus on the mother, the child and the mother-child relationship (Kagan 1989). Psychoanalytic research was conducted with the [specific] focus on the impact of life experiences and this focus coincided with the return of men from the war. During the war, women were encouraged to work and 'celebrated for doing so' (O'Reilly 2016, p.45). Upon the return of men from the war, women were told to go home, and take up their domestic duties (O'Reilly 2016). This move was underpinned and driven by an 'ideological redesign of what constitutes good motherhood', notably Bowlby's, who had been directly influenced by Freud's, psychological teachings of attachment theory (O'Reilly 2016, p.45). Rising divorce rates, teenage pregnancy and the mothers who had left the house to work, leaving their children with surrogates, drove an uncertainty within the middle-class about the standard of mother-infant bonding (Kagan 1989).

According to Bowbly (1951; cited by Thurer 1994), 'maternal deprivation was as damaging in the first three years of life as German measles in the first three months of pregnancy. 'Good' maternal attention was to be full-time:

> constant attention day and night, seven days a week and 365 in the year, is possible only for a woman who derives profound satisfaction from seeing her child grow from babyhood, through the many phases of childhood, to become an independent man or women, and knows that it is her care which has made this possible (Bowlby 1951, p.67)

Normative motherhood during the post-war period emphasised proximity. Two beliefs emerged in the 1950's: 'children require full-time stay at home mothering'; and 'children, without fulltime mothering, would suffering from what was termed "maternal deprivation"' (O'Reilly 2016, p.45). Although the metaphor of being 'kept neatly in refrigerators which did not defrost' was introduced by Kanner (1949, p.425), it was Bruno Bettelheim that popularised the "refrigerator mother" theory.

Bruno Bettelheim

The importance of 'socially constituted actors in the social production and circulation of knowledge' (Keller 2006, p.43) again becomes apparent with the available cultural sources enabling authoritative voices such as Bettelheim's to be widely heard and readily accepted. Although Bettelheim's later work and authority was that of autistic children, Bettelheim's initial work focused on another topic of recent (Northern) American inquiry and fascination, the Holocaust.

Bettelheim, a Holocaust survivor who was freed from a concentration camp in 1939, published his first academic essay in 1943 titled, "*Individual and Mass Behaviour in Extreme Situations*". In this paper, Bettelheim offered 'a psychoanalytic account of the mental deterioration of the camp prisoners at the hands of the SS guards' (Severson, Aune & Jodlowski 2008, p.67). Bettelheim's paper became one of the first widely read essays on the Nazi Concentration camps, positioned Bettelheim as an "expert" in the area, made his name in psychoanalysis whilst referring to science to give authority to his proclamations (Severson, Aune & Jodlowski 2008, p.67).

In addition to his work on concentration camps, Bettelheim's role as the director of the University of Chicago's Orthogenic School for disturbed children from 1944-1978 positioned him as a voice of authority and credibility regarding children with behavioural disorders. Rejecting any notion of a biological cause, Bettelheim noted similarities between the behaviour of autistic children and concentration camp inmates (Ong-Dean 2009).

Bettelheim's work was not confined to academic journals and the simplicity of his writing made it accessible to a lay audience (Nadesan 2013). However, Bettelheim's work was questioned by the scientific community and 'on finding that legitimate scholarly articles did not accept his "science" merely on his word (his last essay in a scientific journal was in 1950), Bettelheim turned his attention towards almost entirely to writing for a mass audience' (Severson, Aune & Jodlowski 2008, p.67). Bettelheim's most famous work, *The Empty Fortress: Infantile Autism and the Birth of the Self*, sold over fifteen thousand copies by 1969 and his work 'was excerpted in Reader's Digest, made into television dramas, and explained by Bettelheim himself on talk shows' (Ong-Dean 2009, p.116). Although he tailored his work towards a mainstream audience, he was still located at the University of Chicago and thus conferred with the authority of this position. Bettelheim's notion, 'that the source of autism was the infant's relationship with their "refrigerator mother" soon became the accepted explanation in popular and some professional circles' (Sverson, Aune & Jodlowski 2008, p.65). Bettelheim's *The Empty Fortress* became the go-to guide for parents if for no other reason than it was often the only book on [the subject] available in the public library (Jack 2014).

A second reason why mother-blame became so popular was the ensuing debate surrounding autism and its place in relation to schizophrenia. Schizophrenia had its own mother-blaming terminology and causation, that of the schizophrenogenic mother:

> The schizophrenic is painfully distrustful and resentful of other people due to the severe early warp and rejection he encountered in important people in his infancy and childhood, as a rule mainly the schizophrenogenic mother (Fromm-Reichmann 1948, p.150).

Although Fromm-Reichman's quote identifies 'important people', it was the mother who was singled out. The cultural environment that began to emerge and dominate during the 1950's and 1960's was one where:

> It was suddenly discovered that the mother could be blamed for almost anything. In every case history of the troubled child … could be found a mother. A frustrated, repressed, disturbed, martyred, never satisfied, unhappy woman. A demanding, nagging shrewish wife. A rejecting, overprotecting, dominating mother (Friedan, 1964; cited by Neil 1990, p.503).

As noted by Neil (1990, p.500), 'two concepts were central in the notion of the schizophrenogenic mother' - the notion of maternal overprotection and maternal rejection. Both concepts were presented as theories for the causation of autistic children. Although Bettelheim would emerge as a prominent figure, mainly through his own design, he was not alone in this way of thinking. As noted by Nadesan (2013, p.81), the 'prevailing socially constituted ideas about disease shape and constrain medical researchers' observations, interpretations and interventions'. The idea of mother-blame became so accepted that little work or consideration was given to any other factor. Once the idea of mother-blaming was imposed, one could start to see it everywhere. From the mother's physical absence, whether by returning to work or leaving their children in the care of the rotating nurse (nanny), to her intelligence or success as characteristics not associated with femininity and maternal components that are required to form the appropriate emotional connection, the behaviour and characteristics of the mother could seemingly be used to explain the outcome of the autistic child. This acceptance resulted in the un-thought dismissal of research into any other factor:

> mother-infant involvement was to be accepted as the sole key to everything that goes on within and around the neonate; it alone was supposed to determine his destiny (Kanner 1965, p.417).

By this time Kanner had begun to question the role of parents as causal agents. This questioning represents a discontinuity in the unified acceptance of mother-infant bonding as the assumed causal agent. Furthermore, with it becoming apparent that label of autism was being [misused] from the manner in which Kanner intended, aside from the confusion caused, the wider effect of this was a sudden increase in the number of ‘autistic’ children.

> Moreover, it became a habit to dilute the original concept of infantile autism by diagnosing it in many disparate conditions which show one or another isolated symptom found as a part feature of the overall syndrome. Almost overnight, the country seemed to be populated by a multitude of autistic children, and somehow this trend became noticeable overseas as well (Kanner 1965, p.413).

In the 1960’s, the ‘adoption of diagnosis clichés’ would find a new ‘handy label’ (Kanner 1965, p.414), that of “the brain-injured-child”. This new category somewhat replaced the widespread and fanciful fashion of autism. Rather than being categorised as autistic, ‘the many would-be autistic children who [were] not autistic’, were rubber-stamped as “the brain-injured child” (Kanner 1965, p.414). In Kanner’s (1965, p.414) opinion, the driving of ‘acrobatic jumpers onto another bandwagon’ freed up research to focus on those who ‘pledged to diagnostic accuracy’ and made it easier to single out ‘properly designated cases that were not lost in the shuffle of a peculiarly miscellaneous deck’ to further investigate pathognomonic characteristics.

Rimland

Published in 1964 was a book by Bernard Rimland entitled ‘*Early Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behaviour*’. With Kanner writing the foreword, the book was given credibility, particularly amongst professionals in the field. Whilst by this time Kanner had come to believe that autism had a neurological cause, the ‘refrigerator mother’ theory was still the standard and readily accepted theory. Rimland who had a PhD in experimental psychology and research design was the first to readily dispute Bettelheim’s claims. Together with the support by Kanner and his professional credentials, Rimland’s voice had a level of authority that could speak out against Bettelheim’s research and question his conclusions.

In addition to his professional credentials, Rimland was also the father of an autistic boy named Mark. Following the release of his book, Rimland began to receive letters from parents asking for his help (Eyal et al. 2010). Such a reaction to his work created a space in which new discussions could emerge, particularly the voices of parents who may have previously felt [ashamed/silenced] by their supposed role as causal agents. Although Rimland did not himself have an answer for questions associated with diagnosis or causation, Rimland called a meeting in Teaneck, New Jersey, at the house of one of the families, and this small group of parents would become the nucleus that founded the Autism Society of America (Patel & Greydanus 2012). This was also thought to be the birth of parent activism and a site within a discursive practice that challenged who was able to speak about autism.

Although Rimland disputed Bettelheim's claims surrounding cause, there were commonalities between their works. Both presented a bleak picture of life with an autistic child. Bettelheim (1967, p.79) wrote, 'they did it because they could not help themselves to do otherwise … they suffer more than enough in having such a child'. Along a similar theme, Rimland (1964, p.65) wrote, 'to add a heavy burden of shame and guilt to the distress of people whose hopes, social life, finances, well-being and feelings of worth have been all but destroyed seems heartless and inconsiderate in the extreme'.

Behavioural Psychology

During the 1960's, behavioural psychology joined psychiatric medicine in the scientific investigation of autistic children. As emotions could not be measured via reliable or valid scientific methods, the theoretical assumptions associated with emotional disturbance that psychiatry had attempted to argue were the result of poor parenting, were replaced with procedures that could be followed, duplicated and measured:

> New practices would be organised on to bodies of autistic children to produce real effects. These effects would have little to do with the emotional since at this point emotion could not be measured with reliability or validity. Nor would these effects be about producing a healthier, happier child. These real effects would have to do with a characteristic that *could be measured*: behaviour (Skubby 2012, p.322).

Behavioural psychology aimed to produce children in a psychological sense and in its own image (Skubby 2012). Although not published until 1987, an article entitled, '*Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children'* by O. Ivar Lovaas saw the field of behavioural psychology enable knowledge originally designed to be about the control of autistic children, become a position that laid claim to being able to cure. Serving as a medium through which the power of behavioural psychology could be deployed, Lovaas's study argued that the autistic child could be cured.

The children experimented on by Lovaas were not viewed as human, rather shells of humans that had to be constructed and built. In an interview with *Psychology Today* Lovaas stated:

> you pretty much start from scratch when you work with an autistic child. You have a person in the physical sense; they have hair, a nose and a mouth, but they are not people in the psychological sense … You have the raw materials, but you have to build the person (Chance 1974, p.2).

Based on reinforcement theory and in contrast to psychiatry where parents had been excluded from treatment, they would now become part of the process:

> behavioral treatment gains by treating autistic children during most of their waking hours for many years. Treatment included all significant persons in all significant environments (Lovaas 1987, p.3).

Rather than being blamed for producing the autistic child and excluded from treatment, parents would be enlisted as part of the therapeutic process. The introduction of parents had nothing to do with any kind of emotional, biological or natural bond, rather they were simply a dominant presence in the child's environment and one that the child would interact and rely upon (Skubby 2012). The strict behavioural approach of behavioural psychology meant that any disruption or inconsistency regarding reinforcement would have an adverse effect on the child. The required approach needed to be systematic and consistent with the guidelines set. In order to be able to follow these guidelines in the systematic manner required, parents first had to be trained to be therapists themselves:

> The mother had periodically observed three sessions from behind a one-way screen. After the child was brought to the point where the imitative paradigm was effective in establishing new verbal behavior, the mother was trained to take over the job of rehabilitating her child.
>
> Through this experience the mother learned to rely on the reinforcer, rather than urging or prompting, to increase the child's behavior. She learned that the procedure was effective in establishing general classes of behavior in addition to

> those specific behaviors which were reinforced. And she learned that the effects of the procedures would generalise to new tasks and new situations (Risley & Wolf 1964; cited by Skubby 2012, p.331).

The knowledges produced by behavioural psychology not only allowed wider surveillance of children by medicine, but they also required it (Skubby 2012). In turn, parents were now part of this discipline and production to reform the abnormal child.

Whilst Kanner's work enabled a 'production of a truth about the autistic child being an object to be examined', behavioural psychology was now 'producing a truth about practices in the treatment of autistic children' (Skubby 2012, p.321). This truth was technology of power deployed onto the bodies of autistic children. The deployment of this power saw autistic children subjected to experiments involving 'coercion, pain, and punishment' and this would serve as 'technologies of surveillance of the social body' (Skubby 2012, p.368). Whilst notable figures within the field of autism, such as Bruno Bettelheim, would liken such techniques as the reduction of autistic children to the "level of Pavlovian dogs" (Bettelheim 1967, p. 410), a new discourse had emerged. Behavioural psychology and Lovaas's experiment would legitimise a therapy now known as Applied Behaviour Analysis (ABA) (Cipani 2008).

Deinstitutionalization

The changing knowledge of autism that was occurring during the late 1960's and 1970's also coincided with another significant change in the landscape of disability - that of deinstitutionalization. Deinstitutionalization emerged out of the anti-psychiatry movement and was largely based around theories of social role valorization, the philosophy of normalization and enhancing the quality of life of those contained within these facilities (Vitello & Soskin 1985).

Deinstitutionalization is largely recognised as the removal of people from large scale isolated environments, to smaller community serviced facilities and family care (McVilly & Rawlinson 1998). This process, however, was not purely about removal, it was also about preventing intake. Figures suggest that 'the proportion of children 15 or younger in out-of-home placement in Great Brittan declined from 30% in 1970 to 3% in the mid-1980's. For Australia, in 1999 the corresponding proportion was 1.1% and it too represented a sharp decline from earlier decades' (Eyal et al. 2010, p.103). As a result of deinstitutionalization, it became paramount to '[demarcate] the mental problems and needs of children and adults who had previously been confined but were now being integrated into the population' (Evans 2013, p.11). Consequently, deinstitutionalization also encouraged the intensification of the surveillance of childhood (Eyal et al. 2010, p.64).

With children who had previously been institutionalised now most likely being cared for by a family member, autistic children (and others) were exposed to the general population. Whilst the rather sudden increased exposure of autism in the community perhaps increased the fears of an autism epidemic (as discussed in chapter two), it may also help us to understand why people were so fearful of the condition. Wolfensberger (2011) suggests that the previous segregation of the disabled is also thought to have a negative effect on society, reducing wider communities' tolerance and understanding of different individuals.

DSM III and DSM-III-R

Following widespread deinstitutionalization in the 1970's, the 1980's marked official changes to the classification of autism and the removal of hallucination and fantasy from autism symptomatology (Evans 2013, p. 21). The DSM III was released in 1980 and for the first time included autism as a distinct category - *infantile autism*. Autism was described as a pervasive developmental disorder. Six characteristics were listed and each of these six characteristics needed to be present (APA 1980):

1. Onset before 30 months of age
2. Pervasive lack of responsiveness to other people
3. Gross deficits in language development
4. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal
5. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects
6. Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia.

Although behavioural psychology had introduced a shift regarding treatments that could be measured, diagnosis remained something that could only be determined based on hierarchies of aptitude – a positioning in relation to the norm. This is evident by the use of classification terms such 'peculiar' and 'bizarre'.

As a response to some debate regarding the descriptor *infantile*, the category was altered to *Autistic Disorder* in 1987. The change allowed for an autism diagnosis beyond that of infancy to include that of childhood when more latent or more subtle problems with social interaction and communication became visible (Verhoeff 2013, p.452). This name change was reflected in the differences between the diagnostic criteria of the revised DSM III (DSM-III-R) and the DSM III. There was a shift away from the strict criteria of the DSM III to more flexible diagnostic criteria in the DSM-III-R which listed sixteen characteristics of which eight were required to be present. Criteria were split into three categories, with a diagnosis requiring at least two items from A, one from B, and one from C; A) Qualitative impairment in reciprocal social interaction; B) Qualitative impairment in verbal and nonverbal communication and in imaginative activity; and C) Markedly restricted repertoire of activities and interests (APA, 1987).

Described by the APA as criteria that were ‘more concrete and observable’, a flow-on effect of the changes saw a rapid increase in the number of autism diagnoses (Factor, Freeman & Kardash 1989). In addition, as noted by Verhoeff (2013, p.445), Kanner’s work became confidently connected to the criteria of autism with both ‘continuity and refinement’.

Following the release of the DSM III, debate would begin again - this time shifting its focus to the ‘forgotten’ work of Asperger and its place within the autism debate. Although ‘Asperger's work was introduced to English readers by Van Krevelen in (1971) … arguing for the separation of the syndrome from Kanner's autism’ (Wing 1986, p.513), it wasn’t until the 1980’s that Asperger’s work penetrated English speaking culture. Rather than being introduced as a separate category, Asperger’s became part of the ‘umbrella’ of autism.

Wing (1981) presented evidence that Asperger's, together with Kanner's syndrome and other conditions as parts of an autistic spectrum. It is the work by Wing which is credited with rediscovering Asperger’s work and bringing attention to high functioning autism ‘with which Asperger syndrome is often equated and this culminated in the birth of the autistic spectrum’ (Wolff 2004, p.205).

DSM-IV

The fourth edition of the DSM, DSM-IV, was released in 1994 and several subtypes to the autism spectrum were added (Asperger’s - 50 years after it is identified, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Whilst the widening of criteria reflects yet another way of thinking and classifying autism, the knowledge stipulated in the DSM IV followed rather than started this clinical trend.

Vaccines

What still had not been answered was what caused people to be autistic? A condition that only a few decades ago was considered extremely rare, how now infiltrated the general population and seemed to be growing. During the late 1980's and 1990's there were the beginnings of the discussion of a possible connection between vaccines and autism which penetrated Western culture (Jack 2014). As argued by Jack:

> the rhetorical momentum behind the vaccine movement stemmed in large part from stories: stories told in speeches, on blogs, and in YouTube montages, stories that dramatise a child's shift from being a "normal" baby to one who has been "damaged" by vaccines (Jack 2014, p.67).

What the vaccine theory was lacking, however, was the authority to make its claims. The vaccine theory needed a doctor or theorist an authority figure who can give it a compelling name and narrative (Showalter 1997, p.19). Enter vector of power, Dr Andrew Wakefield.

Wakefield was a British gastroenterologist whose 1998 study was commissioned by lawyers seeking to sue vaccine manufacturers on behalf of parents of autistic children (an ethical conflict not disclosed at the time) (Jack 2014, p.67). Published in the internationally accredited academic journal, *The Lancet*, Wakefield et al. (1998, p.639) reported 8 children's (n=12) whose first symptoms of autism appeared within one month of receiving the MMR vaccine – 'the uniformity of the intestinal pathological changes and the fact that previous studies have found intestinal dysfunction in children with autistic-spectrum disorders, suggests that the connection is real and reflects a unique disease process'. The idea of a link between vaccinations and autism spread rapidly and like the work of Bettelheim, penetrated newspapers and talk-shows (Jack 2014).

The 1998 paper by Wakefield et al. was partially retracted in 2004 (after the conflict of interest regarding funding was brought to light and ten of the 12 authors retracted their name and support) and fully retracted in 2010. The full retraction followed an ethics investigation by the General Medical Council who concluded Wakefield et al. had acted "dishonestly and irresponsibly" in the conduction of his research prompting a second review by *The Lancet* who concluded that Wakefield et al. were:

> guilty of ethical violations (they had conducted invasive investigations on the children without obtaining the necessary ethical clearances) and scientific misrepresentation (they reported that their sampling was consecutive when, in fact, it was selective). This retraction was published as a small, anonymous paragraph in the journal, on behalf of the editors (Rao & Andrade 2011, p.95).

Prior to the retraction, a notable effect of the wide-spread acceptance of a link between vaccinations and autism was a decline in vaccination rates:

> In the United Kingdom, the Health Protection Agency attributed a large measles outbreak in 2008 and 2009 to a concurrent drop in the number of children receiving the MMR vaccine. Pockets of measles — which can be fatal —have also cropped up in Canada and the United States as a result of parents' refusal to vaccinate (Eggertson 2010, p.199).

Whilst vaccines are credited with virtually eliminating incidences of many diseases, improving life expectancy, and lowering health care costs (Reich 2014), the problem with science, however, is that it lacks the ability to completely undo its own creation. For whilst the [countless] studies since have found no evidence to support the idea that there is a causal link between vaccinations and autism (Eggertson 2010), science cannot prove a negative and thus fear and debate remain:

> Despite the retraction, many autism advocacy groups and parents continue to defend Wakefield, as they are making clear on blogs such as the Age of Autism, in electronic comments responding to articles about the retraction, and on the website of Generation Rescue, a group founded by actors Jenny McCarthy and Jim Carrey.
>
> The "conspiracy theory" that vaccine manufacturers are hiding the truth about MMR and autism is fuelled by parents' need to know what is causing autism, says Margaret Spoelstra, executive director of Autism Ontario, despite the fact that no large study has replicated Wakefield's findings (Eggertson 2010, p.200).

The penetration from academia to the mainstream that resulted in a new wave of parents who were anti-vaccination, the fact that discourses surrounding the link still exist, and continue to have an effect, highlight the fear of autism within society. As a result, parents, particularly mothers, are faced with the choice between autism and preventing diseases considered less threatening (even though diseases such as measles can be fatal).

DSM V

As demonstrated above, what autism is, its boundaries and inclusions have been influenced by the cultural and political shifts of knowledges (Wolff 2004, p.206). This flux of knowledge was again represented with another change when the DSM-V was released in 2013. This was the [fourth] change since autism became its own diagnostic category in the DSM in 1980. The DSM-V removed the 'umbrella' of autism and its sub-types, returning it to a singular category but with a focus on severity. Of interest, those who no longer meet the criteria but display some of the components will be given the diagnosis, 'social development disorder' - a label which seems to directly say, 'there is something wrong with you' – disorder over difference.

The DSM V offers the latest and newest era for the shaping and reshaping of autism. Autism is not a stable entity. Autism is an ongoing category formation that produces a child of unequal status and observation.

Summary

In this chapter, I have demonstrated how power/knowledge relations have produced autistic children by identifying elements of 'autism' and how autistic children only exist in power/knowledge relations. Whilst the elements of the autistic child and what should be done about and with autistic children were in constant flux, what remained consistent was that the elements of the autistic child were not considered normal. Autistic children were viewed and treated as deviant. In turn, mothers were also viewed as deviant and blamed for the autistic child.

Mothers were viewed as responsible for causing their child's autism and also enlisted to be part of the scientific method towards a cure. The mother's knowledge was not privileged and her relationship to her child was positioned by whatever the expert authority discussing her child viewed or required it to be.

What was also apparent in this chapter was the penetration of autism from the clinic to a point of national conversation. I explore both the national conversation on autism and the narrative of one celebrity-mother, specifically her narrative on treatment and cure, later in my thesis. Before presenting my findings from the data collected, I first outline the methodology and methods used in the remainder of my study.

CHAPTER 4: EPISTEMOLOGY AND THEORY

This chapter identifies the theoretical lenses applied to address the two primary aims of this study as well as explore the core research questions (1-4) outlined in chapter two. This study seeks to employ a poststructuralist, Foucauldian and feminist epistemology. The nature of each approach is given followed by a justification for its use in my study. Throughout this chapter, I present the theoretical framework in which my research is located.

Poststructuralist

A post-structural approach argues that in order to understand how an object is brought into effect, one must to study both the object and the systems of knowledge that produced the object. As argued by McLaughlin (2003, p.91), post-structuralism 'seeks to deconstruct claims of knowledge to show that they are particular interpretations that have been selected from the many that are possible rather than representing definitive truths'. Post-structural critiques are employed in order to think differently about the same occurrence, 'to open up what seems ''natural'' to other possibilities' (St. Pierre 2000, p.479).

Consistent with a poststructuralist approach and the overall aims of my study, is the work of Michael Foucault. Rather than aiming to completely free the 'truth' of mothers of autistic children from every system of power, applying Foucault to my research aids in "detaching the power of truth from the forms of hegemony, social, economic and cultural, within which it operates at the present time" (Foucault 1980, p.133). Foucault's work also brings with it a number of significant insights to critical theory (White 1986) and a constructivist perspective, particularly regarding his understanding of the subject.

Foucault

Foucault's post-structural work greatly contributed to our understanding of discourse and the power and knowledge they carry. Much of Foucault's work was focused around discourses (a set of rules for making truth claims), produced within the discursive practices associated with professions and the human sciences (Sawyer 2002). 'These truth claims can be described as 'knowledges', rather than as 'knowledge', to assert their contested status' (Bacchi 2009, p.35). In Foucault, the 'term "discourse" refers to knowledge - what is "within the true", rather than to language, as these discourses play a key role in how we are governed (Bacchi & Bonham

2014, p.174). Foucault asserts that discourse is the means by which we know what we know (McHoul & Grace 1993). Discourses define what can be known or said about a particular thing. The capacity of which is often given by established bodies of knowledge (disciplines such as medicine) and thereby linked to institutions and forms of social organization.

For Foucault, power is not merely repressive but productive. Foucault's main tenet of power is that it is a productive force that 'produces reality; it produces domains of objects and 'truth'. The individual and the knowledge that may be gained of him belong to this production' (Foucault 1977, p.194). In contrast to language or how people "practice discourse", Foucault's (1972) concept of 'discursive practice' 'describes those practices of knowledge formation by focusing on how specific knowledges ("discourses") operate and the work they do' (Bacchi & Bonham 2014, p.174).

Foucault contends that 'it is in discourse that power and knowledge are joined together' (Foucault 1978, p.100). For Foucault knowledge is inextricable from understandings of power (and vice-versa). Knowledge implies power and power implies knowledge (Foucault 1977; Smart 2002). The regimes of truth in each society are the types of discourses accepted by society and which sources of knowledge are most legitimate (Foucault 1977).

Although aspects of his work were concerned with the institutional location (or apparatus) within which power is practiced, Foucault did not view power as an institution. Similarly, Foucault did not view power as a structure or a certain strength one is endowed with. Rather, 'power is everywhere' and 'comes from everywhere' (Foucault 1978, p.93). As argued by Foucault (1982, p.778), 'while the human subject is placed in relations of production and of signification, he is equally placed in power relations which are very complex'. Foucault's work made necessary the need to 'expand the dimensions of a definition of power if one wanted to use this definition in studying the objectivizing of the subject' (Foucault 1982, p.778).

Subjectivity

For Foucault (1982, p.781), there are two meanings of the word subject: 'subject to someone else by control and dependence; and, tied to his own identity by a conscience or self-knowledge'. Kelly (2013, p.513) outlines several propositions about the subject that Foucault asserts in his work which we can 'take as definitional': Firstly, 'Foucault takes subjectivity to be something *constituted'* and 'specifically something historically constituted'.

Second, the ‘subject *constitutes itself*’, ‘a process that Foucault calls “subjectivation”’. As practices and techniques vary across history, ‘so too does subjectivity itself’. Foucault (2000a, p.277) believed that “Techniques of the self”, “can be found in all cultures in different forms”. Foucault (2005, p.61) defines “technologies of the self” as ‘reflected and voluntary practices by which men not only fix rules of conduct for themselves but seek to transform themselves, to change themselves in their particular being, and to make their life an *oeuvre*’. Referred to as either practices or techniques, “practices of the self” are those which “the subject constitutes itself in an active fashion” (Foucault 2000a, p.291). “Practices of the self” are “not something invented by the individual himself. They are models that he finds in his culture and are proposed, suggested, imposed upon him by his culture, his society, and his social group” (Foucault 2000a, p.291).

Thirdly, Foucault ‘associates subjectivity with “a reality ontologically distinct from the body” (Foucault 1984)’ and as per Kelly’s (2013, p.513) fourth proposition about Foucault’s meaning of the subject, the subject “is not a substance. It is a form, and this form is not primarily or always identical to itself” (Foucault 2000b). Thus, and consistent with how practices of “self” are not invented by the individual, the constitution of the subject is not ‘the subject producing itself out of thin air’ (Kelly 2013, p.513).

Although for Foucault power is not an institution, institutional power still circulates to guide conduct. Governing forms part of the complex series of strategies that produce and affect behaviour and works through institutions, bureaucracy and research. Rather than a single state being responsible for governing, various authorities govern across different sites, each with their own desires and aspirations (Miller & Rose 1993).

Subjects ‘are no longer confined to a physical space and where state institutions are the only ones doing the watching’ (Gane 2012, p.630). Whilst the state still surveils, they intervene only when necessary. The act of observation is seen as adequate involvement with people normalised into self-policing (Gane 2012, p.611). Foucault (1991, p.100) suggests that the ‘ultimate end’ of government is to direct the actions of a population, in particular, the individual subject. The interest of government to maximise the ‘well-being of populations has a particular resonance in maternity’ (de Souza 2013, p.16). Douglas (2013, p.174) argues for mothers of autistic children, that as a subject, they are bound to autistic life that they bore and are ‘paradoxically *tied* to this historical identity by a so-called nature given duty to protect our child from threats like autism’.

Bio-power

Bio-power works to ‘analyse, explain, define and shape individuals and their behaviours’ (Danaher, Schirato & Webb 2000, p.ix). The central focus of bio-power is the body and the concern for life expressed through politics. A form of bio-power is medical knowledge. The motives and capabilities of the state to extend into the governance of life itself have been driven by the increase in power of medicine and the privileged position that medical knowledge and professionals occupy within a socially and politically produced matrix of power. Within this matrix of power, individuals are encouraged to regulate themselves. To know and act upon themselves within certain regimes of authority and knowledge and to transform themselves into the good citizen (Rose, Malley & Valverde 2006). Technologies of self are formed alongside technologies of domination such as discipline (Rose, Malley & Valverde 2006). Rather than being merely obedient, the subjects created by discipline would produce the means of government by fulfilling themselves and be obliged to be free in particular ways (Rose 1990).

Bio-power is ‘a set of mechanisms through which the basic biological features of the human species become the object of a political strategy’ (Foucault 2007, p.1). ‘If disciplinary power is about training the actions of the bodies, bio-power is about managing the births, deaths, reproduction and illness of a population’ (Foucault 1978, p.197). “Bio-power is the increasing ordering in all realms under the guise of improving the welfare of the individual and the population” (Dreyfus & Rabinow 1982, p.xxii). That with the appropriate techniques, manoeuvres, and tactics, every aspect of the body can be altered and improved (Dreyfus & Rabinow 1982).

Foucault and feminism

The use of a Foucauldian approach to develop an understanding of autism, motherhood and mothers of autistic children means that ‘rather than asking about the truth of an argument, Foucault’s approach suggests that we should ask how, why and by whom truth is attributed to particular arguments and not to others’ (Sharp & Richardson 2001, p.197). As such we do not need to interrogate the truth of autism, nor the truth of the role of the mother, but simply to understand from where the view is produced, reproduced and ultimately constructed from the standpoint of the mother of an autistic child.

Foucault’s work is not a feminist perspective but it has been argued that Foucault’s conception of the subject is useful for feminists (McLaren 1997, p.53). Foucault’s work has been prominent in feminist research as feminists have been ‘prominent among those who insist we appreciate and take into account the social context of people’s lives’ (Ells 2003, p.213). Diamond and Quinby (1988) argue there are four main areas where the theoretical positions of feminism and Foucault come together: the body as a target of power; power as local; the role of discourse; and criticisms of the privileging of the masculine in the West.

Foucault’s analysis of power relations, and how they affect and shape who we are, offers a way of thinking about our situation in the world in a way that compliments and possibly extend feminist understanding (Ells 2003, p.213). As argued by McNay (2013, p.2-3), feminists have often used Foucault’s theory of power and its relation to the body, particularly his writing from *Discipline and Punish* and the first volume of *The History and Sexuality*, to explain aspects of women’s oppression. Although there is almost a complete absence of gender analysis in his original work, Foucault’s work has been of particular value to feminists as it supported the need to ‘analyse the politics of personal relationships of everyday life’ and account for our own ‘participation in reproducing systems of domination despite our conscious protests against specific forms of it’ (Sawicki 1991, p.10).

The application of Foucault’s ideas helps us further understand how the functioning of power informs knowledges of gender and how gender informs the dynamics of power (McLaughlin 2003). Sawicki (1991, p.1), argues that Foucault ‘would have rejected the view that the power of phallocentric discourse is total’. Rather, for Foucault, ‘discourse is ambiguous and plurivocal’, the site of ‘conflict and contestation’ (Sawicki 1991, p.1). Furthermore, the post-structuralist argument that instead of the humanist argument where individuals have a ‘fixed core or essence, subjectivity is constructed’ within power/knowledge relations and is, therefore, an ‘open-ended, contradictory and culturally specific amalgam of different subject positions’, has been drawn upon extensively by feminist researchers (McNay 2013, p.2).

Feminism

Feminist work is often a subset of critical approaches. The addition of critical-feminist epistemology allows for the critique of dominant knowledges of motherhood. Investigating forms of motherhood that seem *other* reveals something about these forms as well as those considered ‘normal’. The branch of feminism employed in my study is post-structural. Post-structural feminism is concerned with “how gender power relations are constituted, reproduced, and contested" (Weedon 1987, p.vii):

> Although the subject in post-structuralism is socially constructed in discursive practices, she none the less exists as a thinking, feeling subject and a social agent capable of resistance and innovations produced out of the clash between contradictory subject positions and practices. She is also a subject able to reflect upon the discursive relations which constitute her and the society in which she lives and able to choose from the options available (Weedon 1987, p.125).

Post-structural feminism aims to deconstruct the liberal-humanist subject (Anderson & Damarin 1996). Rather than the free, rational, self-determining, essential individual, post-structuralists view subjects as socially constructed (Anderson & Damarin 1996). Post-structural feminists, view "subjectivity" as the "conscious and unconscious thoughts and emotions of the individual, her sense of herself and her ways of understanding her relation to the world" (Weedon 1987, p.32). Subjectivity is a continual process, a site of contradiction, conflict, disunity (Anderson & Damarin 1996; McNay 2013), and “constantly being reconstituted in discourse each time we think or speak" (Weedon 1987, p.33). As such, it is important to examine both how mothers of autistic children are spoken of, and how they speak of themselves.

As within Foucault, post-structural feminism notes that discourses speak people (Anderson & Damarin 1996) and that language is never gender-free (Diamond & Quinby, 1988, p.xv). The use of post-structural feminist approaches provides an avenue to make the power relations of parenting and dominant discourses of motherhood visible. In addition to drawing upon the way in which gender produces and is produced by social experience, this study seeks to utilise the two stages to the development of feminist research; that where women were added to previously male-dominated views of the world, and that where ‘rather than just adding women to the subject matter of research, theories and methodologies had to be fundamentally challenged’ (Morris 1992, p.160). By examining the understandings of mothers which we see as *other* we can see more clearly the largely unconscious but dominant discourses of ‘the family, the child and motherhood’ (Smith, Surrey & Watkins 1998, p.201).

Summary

My aim in this chapter has been to identify the specific theoretical framework my research utilised to further our understandings of how mothers of autistic children are represented and how the subject position of mother of an autistic child may be negotiated. The theoretical frameworks discussed in this chapter demonstrate how there is no pre-social subject and how the post-structuralist work of Foucault helps further our understandings of how it is that in discourse, ‘power and knowledge are joined together’ (Foucault 1978, p.100).

I also outlined how a Foucaldian approach can be useful in a feminist study. Applying post-structural feminism to my study brings attention to some of the unconscious ways of thinking about motherhood and autism whilst creating a space for the dominant discourses of motherhood and autism to be challenged.

CHAPTER 5: METHOD

This chapter outlines the methods used to address the core research questions of my study. Being an exploratory study, a qualitative method was considered the most appropriate for my research, with a mixed method approach employed. The chosen methods inform and enrich each other. Justification for this choice of approach is provided. This chapter concludes with a discussion of how qualitative rigour was ensured and important ethical considerations.

A Qualitative Approach

Qualitative research is a method of inquiry employed across multiple fields and disciplines (Sofaer 1999). Via disciplined inquiry, qualitative research examines the lives, stories, behaviours and the meanings individuals assign to their own thoughts and experience (Richardson 1994). Qualitative research is primarily explorative and seeks to gain an understanding of underlying reasons, opinions and motivations (Neuman 2011). I have previously outlined the purpose of this project, its aims and specific research questions which are consistent with the exploratory method of inquiry qualitative research aims to pursue. Although guided by my research questions, being based on inductive reasoning, themes were free to emerge from the study, rather than being limited to pre-determined ideas (Baker, Edwards & Doidge 2012). Rather than focusing on what we already know and aiming to quantify it, qualitative methods aid in developing our understanding of context as well as offering rich and in-depth descriptions of the topic under examination (Patton 1990; Sofaer 1999).

Whilst exploratory, qualitative research still needs to be systematic and rigorous (Sofaer 1999). Accordingly, the following sections outline the specific methods used to ensure both the quality and integrity of my study.

Overall Method

The overall method of this study followed an adaption of Carol Bacchi’s (2009) *What’s the Problem Represented to be* (WPR) approach which is grounded on the work of Michael Foucault. Although Bacchi’s approach focuses directly on policy, the WPR approach is a valuable tool to apply to other forms of discourse in order to interrogate its sources and operations further (Bacchi 2009). Applying this approach allowed me to build a descriptive picture of the ways in which statements of knowledge regarding autism and mothers are managed (Stevenson & Cutcliffe 2006). This approach aided in looking for what presuppositions or assumptions underlie the representation of mothers of autistic children. The objective of which was to uncover unexamined ways of thinking that lie behind the discourse (Bacchi 2009).

Three data sources were used to investigate my research questions; newspapers, the internet and interviews. I now turn my attention to outlining why each data source was chosen.

Newspapers

As highlighted in chapter two, the discipline of journalism positions its subject in a particular way. This framing makes particular aspects more salient, giving the news subject 'an identifiable slant' (Bloch-Elkon 2007, p.25). Representation of autism and mothers of autistic children in media coverage influences its 'audience's understanding of and attitudes toward autism, autistic people' (Kang 2013, p.245) and mothers who care for an autistic child. Subsequently, an analysis of mainstream media offers insight into what shapes wider society's forms of knowledge, and how people are to be understood, related to and organised (Yates 2005). Furthermore, by examining concepts that speak of autism and mothers of autistic children, we can learn more about how mothers of autistic children are invited to understand their role and identity.

Data Collection

Similar to the approach used by Jones and Harwood (2009), all newspaper data was collected through Factiva. Two specific search terms were used in conjunction - mother* and autis*. The use of a Boolean operator (*) allowed for the search to include such terms as mothers, motherhood, autism and autistic. As the focus of my study was mothers of autistic children, I searched for the terms in conjunction.

Given the release of the DSM V in 2013, and the aim of identifying current discourses on autism and mothers of autistic children, I decided to use 2013 as a starting point for my data collection. My search included, but was limited to, articles published between the (30/03/2013 to 30/03/2015). The search included four newspapers across Australia; *The Advertiser* which is the highest selling newspaper in the region where the study took place; one newspaper with a Fairfax affiliation (*The Sydney Morning Herald*); one paper with a Newscorp affiliation (*The Herald Sun*) and *The Australian*, a publication available across the entire country. Although the aim of this study was not to compare the reporting of different corporations, it was deemed that any bias would be minimised if at least one paper from each subsidiary was used.

Often the search terms produced articles that were not deemed to be relevant to the study. These were not included in the final total. The final total of articles examined is represented in table 1.A:

Newspaper	**No. of articles**	**Location**	**Affiliation**
The Australian	40	National	NewsCorp
The Advertiser	49	South Australia: Adelaide	News Corp
Herald Sun	34	Victoria: Melbourne	News Corp
The Sydney Morning Herald	29	New South Wales: Sydney	Fairfax Media

Jenny McCarthy and *Generation Rescue*

My second source of data was the website, *Generation Rescue.* Changes in technology have rapidly increased the amount of information available and how and where this can be sourced. The internet has increased access to information whilst also a reliance on it as a source of information. The Department of Public Welfare (2004, cited Rothbaum, Martland & Jannsen 2008, p.120) found that parents of autistic children indicated that they relied on the internet more than on any other resource. Given this, I felt it crucial to explore a narrative on this medium. Although further reasoning and background are provided at the start of chapter seven, my decision to study celebrity mother Jenny McCarthy and *Generation Rescue* stems from the emergence of the modern-day warrior-mother and her global campaign against autism (Douglas 2013). Similar to my reasons for examining newspapers, by examining Jenny McCarthy and *Generation Rescue* we learn more about the concepts and images through which mothers of autistic children are invited to understand their role.

Data Collection

The data collected from *Generation Rescue* was mostly limited to the information provided on the website link: http://www.generationrescue.org/.

Interviews

Although interviews were the final set of data collected, they were the first collection method decided upon and considered crucial to my study. There were several reasons for this. Firstly, interviews provided the opportunity to learn about the individual experiences of mothers of autistic children rather than make generalisations about them. Qualitative research is interested in gaining a deeper understanding of participants; the "goal is to look at the 'process' or the 'meanings' individuals attribute to their given social situation, not necessarily to make generalizations" (Hesse-Biber & Leavy 2007, p.119). Furthermore, as argued by Hesse-Biber (2013, p.7), interviews serve as a process to get "at the subjugated knowledge of the diversity of women's realities that often lie hidden and unarticulated". It is important to note however that the narrative of individual experiences and their views on mothering an autistic child are not merely expressions of mothers' thoughts and beliefs about a subject. Rather, they will be better understood if viewed as descriptions that are permeated by wider social and ideological meanings that echo the operation of discourse in individual experience (Nettleton & Gustafsson 2002, p.110).

Data Collection

Recruitment

Recruitment of interview participants took place via two methods: through an autism support agency and later through the social media website, Facebook.

Initial attempts to recruit participants were made by contacting a local support agency in South Australia. In addition to protecting the identity of potential participants, this also allowed participants to self-select to participate. My contact details were placed on the information package sent out and potential participants invited to contact me directly. This approach meant that I was unaware who had been sent the information and the agency was unaware who had agreed to participate.

After gaining formal consent from the local support agency, all relevant information was emailed to the agency to ensure it met their criteria of appropriate and ethical research. In addition to providing the agency with an overview of the purpose, aims and methods of my research, a recruitment package was also assembled. This package included; a *participant information sheet* (available in appendix one, a *consent form* (available in appendix two and a *contacts and independent complaints procedure* information sheet (available in appendix three). Once the details of the information package had been finalised (both with the support agency and University of Adelaide Human Research Ethics Committee), I printed and packaged the information into envelopes and delivered them to the support agency. As stated above, the support agency took responsibility for who received the information packages from their membership list.

Although I recruited several participants from the mailout, the response rate was lower than desired, and I felt that further interviews were needed. Given this, ethics approval was then obtained to utilise a Facebook page for recruitment. The information provided on this page was consistent with that included in the original mailout. This form of recruitment also allowed potential participants to self-select and their interest in participation was protected by being able to contact me directly in a private manner.

Sample size and demographics

In total 15 mothers were interviewed for this study. Interviews lasted between 60-120 minutes. Participants were aged between 26 - 49; their autistic children were aged between 6 - 17; 13 were the biological mother, one had adopted her child from overseas and one was a fulltime stepmother; three of the mothers worked in full-time paid employment, one was engaged in full-time study, one had just started her own (self-described) ‘hobby business’ from home, five worked part-time and five did not engage in paid employment. Whilst I did not ask specifics about income, the residential locations of my interviewees ranged from lower/working class suburbs to high income/elite areas. Three of my interviewees had immigrated to Australia and for each, English was their second language. The remainder were born in Australia.

Participants were required to meet four main criteria:

- They were the mother of a child with an official autism or Asperger’s diagnosis
- They were over 18
- Their child was under the age of 18
- Their main place of residence was within South Australia

Although I was conflicted about using a medical diagnosis in a study that critiques such discourses and knowledges, I felt this criterion gave consistency to my method and excluded mothers who had self-diagnosed their children.

Format

Consistent with the qualitative approach employed, a semi-structured interview process was employed and open-ended questioning techniques used throughout each interview (Judd, Smith

& Kidder 1991). A copy of the interview protocol guide used has been provided and can be found in appendix four. A semi-structured interview method was chosen as it was appropriate to explore the deeper meaning, opinions and perspectives of the participants (Barriball & While 1994). A key benefit of using a semi-structured approach was that a set interview guide and pre-established questions provided structure to the interpretive design, whilst still allowing flexibility to follow deeper themes of inquiry that emerged during each interview (Patton 1990). This was particularly important as mothers of autistic children are not a homogenous group and the use of semi-structured interviews allowed me to explore the meanings that participants attach to certain events (Popay, Rogers & Williams 1998, pp.344-345).

To gather further detail about the meanings or issues, probing questions were used. Probing questions are follow-up questions used to elicit further responses when a participant’s response is unclear or incomplete (Neuman 2011, p.345). In addition to adding further depth to my data, these probing questions aided in minimising my own possible bias by allowing the issues explored to be those experienced by participants rather than any assumed expectations or knowledge I may have of these issues (Neuman 2011).

To maximise the consistency of my method and direction of the interviews, I was the sole interviewer in the study (Miller & Brown 2005). In addition to consistency, I had extensive knowledge of the purpose and aims of my research. This allowed for a greater level of exploration and depth to be achieved than data collected by someone who was less familiar with the topic (Miller & Brown 2005). I felt comfortable in the role of interviewer as I had previously conducted semi-structured interviews for both academic and government purposes. In addition, I had previously interviewed mothers of autistic children as well as interviews with and for, other minority and oppressed groups.

The location of each interview was chosen by the participant. Locations ranged from the participants’ home, local cafes and restaurants, community centres and the university where I was located. All interviews except for one took place face-to-face. One interview was conducted via Skype. This was done as the participant had recently moved to a regional area and I was unable to travel to her location. I decided to proceed with the interview as she met the appropriate criteria and I had already conducted several other interviews and felt at ease with the interview process and emerging themes. Therefore, the less personal nature of this interview did not compromise my ability to explore necessary themes nor compromise the validity of my study.

Each participant was reassured of the confidentiality of their participation prior to the beginning of each interview. It was encouraged that interviews take place without either the participant's child/ren or partner (if applicable) present. There were two main reasons for this: 1) allowing the mother to feel comfortable disclosing personal information (Neuman 2011) and 2) allowing a free-flowing interview where deeper exploration could occur without distractions. Although it was not always possible to conduct the interviews without the mother's child/ren present, all interviews were conducted without the partner (if applicable) present.

Transcription

Each interview was transcribed in full upon completion. Although not each interview was able to be fully transcribed before the next took place, transcription took place during the time-period interviews were being undertaken. This assisted in familiarising myself with the data and also in determining when to cease data collection (Creswell 2003, p.190). I decided to cease collecting interview data after 15 interviews. I came to this decision as at that point no new themes were emerging and I had sufficient data that was rich enough to cover the main aims and questions of my study – a process known as thematic saturation. As thematic saturation has been found to typically occur within the first twelve interviews of a study (Guest, Bunce & Johnson 2006), a sample size of fifteen was consistent with achieving thematic saturation.

I was aware that although transcription aids in identifying codes and being able to analyse a text line-by-line, some information and detail are lost in the transcription process (Drisko & Maschi 2015). One loses the prosody, tone and inflection of the speaker (Drisko & Maschi 2015). To minimise this loss, details such as laughter, pauses in speaking, ummms and ahhhs were included in the transcripts. Furthermore, in addition to listening to each interview at least once after completion, I utilised the recordings when unsure if things such as meaning (say sarcasm may have been used) of certain statements were unclear.

Although there were different data sets used, each data set followed the same analytical process. The steps in this process are described next.

Analysis

Analysis of each data set involved open and axial coding, followed by a critical discourse analysis. Although reflexivity was involved at each stage of my analysis, as discussed later in this chapter, given the nature of my research and my own position as the mother of an autistic child, reflexivity was paid particular attention.

Before beginning open and axial coding, I engaged in a process of reading and re-reading the data obtained in each method of collection. This was done to strengthen the validity of my approach and familiarise myself with my data. After familiarising myself with the data, my second aim was to identify themes, categories and 'objects' of the discourse.

Open coding

I first employed open coding to identify patterns and main categories within the data (Creswell et al. 2007). Whilst the coding was informed by my aims and research questions, categories were not determined in advance but identified as they emerged. Although topics emerged in my genealogical analysis, these served as topics to identify reoccurring patterns or themes, rather than serving as a purely formal tool for analysis.

Although mothers were the primary focus of my research, I first coded the data by identifying themes relevant to the representation of autism. I considered it important to understand the representation of autism as this may influence how a mother may interpret her child, how others may view her child, how she may then view herself and how potential (future) mothers may view autism. Furthermore, as seen in chapter three, the myriad of counter-narratives and understandings of autism have previously seen 'widespread patterns of mother-blame' (Stevenson 2007, p.197). As such, the representation of autism was important to understand to help determine if such patterns are still occurring. Once completed I began analysing and coding the data with a focus on the mother.

An initial reading of the text during this process was literal (Colaizzi 1978; Moustakas 1994). Also known as manifest coding, this involved noting directly observable characteristics/themes in the data. As patterns started to emerge, I utilised manifest coding to aid in the reliability of my research. This involved taking key terms that had been identified (such as 'school', 'therapy', 'cause', 'vaccinations', 'pregnancy' / 'pregnant') and using these to electronically search the entire data pool.

In addition to the process of manifest coding, latent coding was also employed. This involved looking for underlying and/or implicit meaning in the context of the text (Neuman 2011, p.365). This process allowed me to move away from explicit, obvious or surface content in my data. Although latent coding lacks the reliability of manifest coding, it increased the validity of my analysis (Neuman 2011).

Axial coding

Once open coding was completed, axial coding was used to identify the core categories that emerged from the data (Creswell 2014). At this stage of my analysis, I began to explore the concepts and how they were related. I re-read the data whilst using the concepts and categories I had already identified. The categories identified within the axial-coding process were checked to ensure they were internally consistent, yet externally divergent (Marshall & Rossman 1999, p.154). The categories were also checked to ensure that all data identified in the first stage of the analysis, fit within these core categories.

Critical discourse analysis

Once open and axial coding had been completed, I commenced critically analysing the knowledges that were evident in the data. During this process, I dedicated additional attention to the themes identified throughout my content analysis, and examined the data in a manner that took into consideration any assumptions, or implied concepts, that emerged (Wetherell, Taylor & Yates 2001). My aim was not to investigate any 'underlying reality' or truth of the data or the situation being discussed. Rather, my aim was to discover deep-seated ontological and epistemological commitments within the discourses (Bacchi 2009, pp.34-36).

As suggested by Foucault (1978), discourses not only produce domains and objects but are linked to effects that are real. It was during my critical analysis that I began to scrutinise both the discursive and subjective effects produced. During my method, I drew up a list of questions informed by my reading of Bacchi and Foucault. These broad questions were then applied and asked of the data I collected:

1) What power/knowledge relations are being used to produce the object/subject being discussed?
2) What 'truth' is being conveyed?
3) What forms of credibility, legitimacy and authority are used?
4) What binaries or dichotomies appear in the data?
5) What resistance and counter-discourses are evident?
6) What is left unproblematic? Where, or are, the silences? Can something be thought of differently?
7) How could what has been said be disputed, questioned or replaced?

It was important to understand how a category was spoken of, particularly so for people categories as they 'have significant effects on how we are governed and how people think of themselves and others' (Bacchi 2009, p.9). The identification of the 'object' within this part of the analysis is twofold, it was the topic of which the discourse speaks, and also, the purpose of the discourse – what was the message they were aiming to deliver?

Qualitative rigour

Assessing the quality and credibility of qualitative research is often done so through a concept called rigour (Popay, Rogers & Williams 1998). To ensure the credibility of my research, several steps were taken. Part of ensuring credibility has been this chapter, by providing a detailed account of how data was collected and analysed my research aims to stand independently so that 'another trained researcher could analyse the same data in the same way and come to essentially the same conclusions' (Mays & Pope 1995, p.311). In addition to this, Mays and Pope (1995, p.311) note the raw data collected in qualitative research is often in a relatively unstructured form. They suggest that one of the main ways to ensure that their research can be retested is to maintain meticulous records of data such as interviews. Regarding interviews, recordings and transcripts were kept in a locked filing cabinet at the university and will be for the next five years. Transcripts were stored on a password protected computer. All transcripts were saved with pseudonyms already in use.

Regarding newspaper data, I was careful to provide correct and adequate information about where and how the data was sourced. Although the identical search should produce identical data, copies of the articles produced were kept, including the contents list produced by Factiva. Included in this are all articles deemed irrelevant and not used in my analysis.

The *Generation Rescue* website was perhaps the most difficult to ensure duplicates of information were kept. However, where possible, data was highlighted and copied and then saved in a word document. Although privacy was not an issue this time, these documents were then stored on a password protected computer.

Rigour was also ensured through the process of triangulation. Triangulation involves using multiple methods, data sources and theories to examine the topic under study, resulting in an examination from multiple perspectives (Jick 1979). Triangulation helps to provide a more comprehensive, rounded and contextual portrayal of the topic under study (Jick 1979, p.603) and is useful in aiding in overcoming the bias that may result from the use of any one single source (Liamputtong 2006, p.40). Furthermore, triangulation helps identify patterns and similar themes across different data sources. This allowed elements of context to be illuminated, increased the validity of my findings and also allowed for thick description as new or deeper meanings emerged (Jick 1979, p.603).

In qualitative studies, the role of the researcher and research are inevitably intertwined and see the researcher embedded within the research process (Neuman 2011). In both acceptance and acknowledgment of this, a measure taken to 'minimise' any bias was a continual process of reflexivity.

Reflexivity

Reflexivity locates the researcher as part of the data produced (Mason 2002). The process of reflexivity sees the researcher both acknowledge and reflect upon their role in the research process (Draper & Swift 2011). Reflexivity involves both, the exploration of one's own role and perspective in the generation and interpretation of the data, as well as systematically attending to the effect of the researcher at each stage of the research process (Mason 2002, p.149). As argued by Sawicki (1991, p.2), 'reflection upon the conditions governing individual choices is vital if we are to avoid unwitting capitulation to the very forces that we [feminists in the academy] are resisting'. As I was the primary "instrument" of design, collection, analysis and dissemination of this research, reflexivity was deemed crucial (Russell & Kelly 2002). Making reflexivity a key aspect of my research aided in helping me recognise what *allowed* me to see, and also identify what may have *inhibited* my seeing (Russell & Kelly, 2002).

In addition to being a key aspect of both feminist and post-structural research, reflexivity was crucial regarding my own position. From a feminist perspective, the process of reflexivity helps the researcher recognise that there are multiple truths and other realities are just as valid as the one she experiences (Hesse-Biber & Leckenby 2003). As discussed in my introduction to this study, my own existence and experience as a mother of an autistic child helped shape and inform the purpose of this research. The disclosure of any stake I may have in this research allows readers to make up their own minds as to how my position may influence my findings (Green 2003a, p.2). Whilst acknowledging my own position is important, engaging in reflexive practice goes beyond simple acknowledgement. Regarding the specific group that is the focus of my research, I am an insider – I am the mother of an autistic child.

Insider research has been defined as research into one's own social group or society (Naples 2003, p. 46) or by someone who is a member of the of a group that shares the same characteristics (cultural, biological, occupational, etc.) (Loxley & Seery 2008). One issue that influences insider/outsider research is positionality. Due to the difficulties associated with determining what graduation of social experience determines how positionality is classified, no clear definition has been produced (Chavez 2008). In addition, positionality can shift during the research process (Greene 2014). Chavez (2008, p.475) describes positionality as ‘the aspects of an insider researcher’s self or identity which is aligned or shared with participants’. Chavez (2008, p.476) also identifies two types of insiders: ‘total insiders, where researchers share multiple identities (e.g., race, ethnicity, class) or profound experiences (e.g., wars, family membership)’ and, partial insiders, ‘who share a single identity (or a few identities) with a degree of distance or detachment from the community’. Reading this, I would argue that I could be both. I could be considered a total insider due to the profound experience that can be mothering an autistic child. I could also be considered a partial insider due to the fact that being the mother of an autistic child is the sole identity that I share with the group I am researching. I have never been involved in the autism community beyond my own experience as a mother. I have never been part of a mother’s group nor been to any events or part of any online groups. Regarding McCarthy and *Generation Rescue*, I have not met or interacted with McCarthy, am not a member of *Generation Rescue* nor have I met or interacted with anyone who is. Regarding my interview participants, whilst I shared commonalities with some of the women I interviewed, such as university studies and being a single mother, I had not met any of them prior to undertaking this research project.

Van den Hoonaard (2002, p.123) argues that ‘If we are to take self-reflexivity seriously, we must recognise that we are always producing two works - a research biography and an autobiography’. Rather than the binary way of viewing there being a subject/object and a researcher and being overly concerned if one is an insider or outsider (Greene 2014), the researcher should strive to be both “inside and outside the perceptions of the researched” (Hellawell 2006, p.487). Whilst what is and isn’t an insider regarding research is not the central theme of my study, learning more about what is and isn’t considered an insider in research aided in my ability to be reflexive throughout my research. It made me aware of some of the advantages and disadvantages of being an insider created.

Advantages

In addition to possessing pre-existing knowledge of the context of the research (Bell 2005), being a member of a group brings with it the likelihood of acceptance (Dwyer & Buckle 2009). Furthermore, participants are usually happy to talk and discuss issues with someone who understands (Bell 2005). The insider researcher is also less likely to experience culture shock, less likely to stereotype (Aguilar 1981), and possess the 'ability to ask meaningful questions and read non-verbal cues' (Merriam et al. 2001, p.411).

Disadvantages

Although being an insider may be an advantage in gaining access to a group, it can be a disadvantage in gaining access to information. For example, one may be seen as too much of an insider and the participant may assume that the researcher knows what they are talking about or about a given situation (Greene 2014). This was a problem encountered in some interviews when participants would cut descriptions short and say things such as, 'you know what I mean' or 'oh what am I telling you for, you know'. To combat these assumptions, I would ask for more detail from the participants or discuss with them that whilst I had my own experiences or thoughts about a situation, I was particularly interested to hear what theirs were.

Ethical considerations

Research of any kind should be conducted in a manner whereby the participants involved are not harmed in any way (Veal 2006). Each stage of my study was conducted in accordance with the ethical protocols and guidelines outlined by the University of Adelaide and with approval from the Human Research Ethics Committee.

Participants in the study were informed that their participation was voluntary, and they had the option to withdraw their consent to participate in the study at any stage up until submission. Each participant signed a consent form at the start of the interview. Participants were also ensured that all possible measures would be taken to protect their anonymity. Measures taken to protect the identity of participants included; the use of pseudonyms for each participant and any other family, friends or colleagues mentioned, the secure storage of audio from the interview, and the removal of any other identifying information such as places of work or location of children's schools.

Participants were not pressured to answer any questions they did not wish to and were informed that they were free to stop the interview at any time. Although it was not anticipated participants would experience any distress, I was aware that interviews may raise some sensitive issues for participants that may cause minor discomfort. At the start of each interview, participants were told that they may elect to skip questions at any stage during the interview and that they may ask for the interview to stop. Participants were also told that they should only provide the information they feel comfortable sharing. Although it did not occur, in the unlikely event that a participant became too uncomfortable to continue the interview, I was prepared to stop the interview and if appropriate the interview be rescheduled. Participants were made aware that if after the interview they were uncomfortable with all or part of what they had disclosed during the interview, this contribution would be removed. To facilitate this, participants were also offered a transcript of their interview upon request.

Summary

Throughout this chapter, I have detailed the methods I employed to design and explore the main aims and research questions of my study. I outlined the sources of data collected and the reasons for selecting these sources. I also outlined how each data source was collected and analysed. The chapter concluded with how qualitative rigor was ensured and the ethical considerations of my study.

The applied methods for my study have been combined with the methodological views outlined in chapter four. The mixed method approach and multi-layer analysis applied in my study assisted me in developing comprehensive and rigorous findings. The remaining chapters of this thesis focus on exploring and presenting my findings.

CHAPTER 6: MEDIA ANALYSIS

The following chapter presents detailed findings from an analysis of the representation of mothers of autistic children within the Australian print media from 2013-2015. There are two central aims of this chapter. The first is to identify not only whether autism or mothers of autistic children are spoken about, but to account for the fact that they are spoken about - to discover 'who does the speaking', 'the positions and viewpoints from which they speak' and 'the institutions which prompt people to speak and distribute the things that are said' (Foucault 1978, p.43). The second aim is to identify what forms of knowledge of autism and the role of the mother are presented and with what authoritative knowledge of truth?

This chapter makes steps towards addressing the first two research questions of the study:

RQ: 1) How is autism and how are mothers of autistic children represented within public sources of information and data?

RQ: 2) What are some of the discursive and subjectification effects produced by the representation of autism and mothers of autistic children?

In addition to the production of domains and objects produced through the analysed discourse, this chapter explores the effects that are linked to this discourse. This was done by utilising two impacts of representation as outlined by Bacchi (2009, p.15):

- *Discursive effects*: effects that follow from the limits imposed on what can be thought and said; how it closes off other possibilities.
- *Subjectification effects*: the ways in which subjects and subjectivities are constituted in discourse.

As discussed in chapter five (method), data were first coded by identifying themes relevant to autism. Consistent with this approach, I first present my findings relevant to the representation of autism.

Medical Classification

The first theme identified was the classifications of autism. For the most part, descriptions of autism tended to fall within one of three categories: 1) a descriptor of a developmental disorder,

2) a format that fell within the 'triad of impairment' and 3) autism as that which needed no description, since the word autism was itself a definition. In addition to its medical description, I identified that there was concern that the classification of autism was being used in a manner not intended - essentially multiplying its use through the introduction of new content and ways of constituting what is autism.

The first category identified was the classification of autism as a descriptor of a developmental disorder. These descriptions tended to be brief, such as; 'Autism spectrum disorders cover a range of developmental problems' (Cuddle hormone 'help for autism', *The Australian*, December 4th, 2013). Although brief, the use of the full diagnostic label, 'Autism Spectrum Disorder', lets readers know that autism is thought of as a 'disorder'. The term disorder represents something that is in a state of confusion, chaos and failing to meet the functions of neat arrangement. The addition of the term 'problems' intensifies this subject positioning as one that is bad or difficult and something that needs to be corrected.

The second form of classification identified were those that fell within the triad of impairment (impairment in social interaction and communication and demonstrating repetitive or stereotypical behaviour that lacks imagination):

> Autism causes communication and social difficulties as well as repetitive and stereotypical behaviour (Pregnant stress linked to autism, *The Advertiser*, 4th June 2014).

As noted in chapter three, the triad of impairment is/was a common format for classifying autism introduced in the revised version of the DSM-III, the DSM-III-R in 1987. Although autism has now become a dyad of impairment in the current version of the DSM, what is of interest here is the phrasing of which causes which. The phrasing suggests that one is not diagnosed with autism because they have communication and social difficulties, combined with repetitive behaviour, it is autism that causes one to have these traits. The representation here suggests that autism has become a matter of fact. Autism is represented as having a 'positivity' that causes certain behaviour, as opposed to the grouping of traits that one then labels autistic.

The third theme identified was that where there was no description and the word autism was its own definition. The absence of a description demonstrates that a medium which produced no records for the search terms "autism" OR "autistic" OR "Asperger's" prior to 1996 (see Jones & Harwood 2009) now discusses the topic with an assumed constitution of a norm and readers have knowledge of this norm and what it represents. The self-evidence, where one assumes that things don’t need to be demonstrated or explored, is evident in how the word autism can now be its own definition. This is of interest as, as demonstrated in chapter three, even the medical classification of autism is not a stable entity.

In addition to the criteria outlined above, the classification of autism was also discussed from the perspective that the diagnosis was not being correctly applied. A couple of the articles analysed raised concerns regarding the overuse of autism:

> These days, any child who's a bit naughty, inattentive, cheeky, quick or slow (that is, any child who is childish) is diagnosed as suffering from Attention Deficit Hyperactivity Disorder, or is autistic or has Asperger's syndrome. Few children warrant the diagnosis. As Davies says, there is an ``out-of-control medicalisation of normality" (Relax and just embrace life's trials, says book, *The Advertiser*, 27th May 2013).

Here the number of diagnoses of autism are disputed and how our current culture organises and produces knowledge surrounding what is normal is blamed. The article simultaneously challenges medical knowledge about what is normal and the practice of medicalised knowledge by clinicians. The “out-of-control medicalisation of normality" is suggested to be allowing for classifications that are not consistent with how the diagnosis should be thought of and used. The article suggests that there are children who do warrant the diagnosis, but these children are few. Whilst there is something “real” being regulated, it is not autism. The rules applied to what it is to be a normal child are changing, being produced through current practices of medicalised knowledge. Records of children as being ‘autistic’ or having ADHD participate in producing ‘new’ content on autism and it is this new content that is being questioned.

As demonstrated in chapter three, since the classification of autism in the1940’s there has been confusion regarding what autism is. A contributing factor to this was believed to be the confused and confusing use of the term infantile autism where “the abuse of the diagnosis” was threatening “to become a fashion” (Van Krevelen, 1953; cited by Kanner, 1965, p.413). The places where confusion is produced has extended beyond the ‘clinic’, or experts charged with implementing the rules of diagnosis, and into the public arena. Whether due to the salience of autism, the ever-changing diagnostic description of autism or the fact that those who have the authority to diagnose autism are not fully trained in the area, autism continues to be represented as something that is overused and misdiagnosed.

Autism often presents with no obvious physical identifying mark of deviance. This, in combination with a pervasive condition that violates many of the standard forms of accepted behaviour, makes understanding and acceptance difficult (Gray 1993). Further issues may arise if perceived to be overused. For example, this could make it difficult for mothers to gain acceptance or understanding from others, particularly so in the current neoliberal climate where 'stigma may be exacerbated by heightened public stinginess toward those deemed unproductive or burdensome' (Blum 2007, p.203). Whilst there are negatives associated with the category, the category can also offer protection for the mother. If her protection is diminished, it increases the possibility where her child's behaviour may be seen by others as simply naughty or a symptom of bad parenting. Narratives that problematise autism as 'simply a case of bad parenting, largely attributable to the lack of a proper paternal role model' and '"a racket" concocted by poorer families to squeeze disability payments parasitically from an overburdened government' (Lilley 2011, p.135) already exist. The ``out-of-control medicalisation" which we are told sees "few children warrant the diagnosis", increases the space for the potential for discourses that problematise autism to gain further credibility.

Description of Autism

Description was deemed to be a separate theme from classification. In this category the way autism was spoken of extended beyond that of classification and into how the knowledge of autism presented helped form its representation – so 'why' the topic was being put into conversation and the context in which it was discussed. There were a small number of positive descriptions, yet for the most part, descriptions tended to be negative. Similar to the results found by Jones and Harwood (2009), even when an article was framed as positive news, it was often embedded within a negative discourse.

A dominant theme in descriptions of autism was that of the rate at which it appears to be increasing:

> Autism … is the fastest-growing developmental condition in the western world (Pregnant stress linked to autism, *The Advertiser*, 4th June 2014).

In my literature review and genealogy chapter, the rate at which autism is said to be increasing was found to have been both represented and produced as an epidemic. Whilst we see here articles that infer such an idea, these descriptions were used as the basis for discussions to provide background and reasoning for a particular issue. For example, the statement above from *The Advertiser* utilises the growth of the condition as a background for presenting stress during pregnancy as one possible cause of autism. What I feel it important to note here is the idea that, whatever the topic, the use of the increasing rates of autism helped justify the importance of the point being made.

The knowledge discussed within the media articles analysed was often positioned to demonstrate credibility, legitimacy and necessary authority to make the claims asserted. Interestingly, however, when it came to the description of rates and growth of autism, this credibility, legitimacy and authority was surprisingly absent. As seen in the example above, although represented as the ‘fastest-growing developmental condition in the western world’, there is a complete absence of source of the information, credentials of those providing the knowledge or processes by which the information was gathered. The authors did not deem it necessary to provide justification for the statements being made. This suggests that this knowledge has become an accepted fact or that unless it can be put in these terms it isn’t worthy of attention.

Within descriptions surrounding rates of autism, there were assumptions about the diagnosis: ‘It is estimated one in 100 Australians suffer the condition’ (Pregnant stress linked to autism, *The Advertiser*, 4th June 2014). Here the term ‘suffer’ is used to position those who are diagnosed as autistic. The definition of the term suffer as per the *Merriam Webster* (2016) dictionary is one who experiences ‘pain, illness, or injury’, something ‘unpleasant (such as defeat, loss, or damage)’ or ‘to become worse because of being badly affected by something’. Representations that a person diagnosed with autism is suffering produces autism as something that is automatically viewed as negative and a person that is defective, damaged and inferior to others.

The medical model of disability was the dominant lens through which autism was described:

> Can it lead to cures? Can we stop multiple miscarriages? Help prevent stroke or heart attack? Bring a child with autism back to his or her parents for good? Can all of this knowledge be converted into effective and life-improving treatment backed by robust scientific studies? (INTO THE light, *The Advertiser*, 7th March 2015, p.12).

The idea of bringing a child back to their parents reflects, produces and reproduces a representation of autism of a child that has been taken. This type of thought is not dissimilar of that in an article from 1967 by Bruno Bettelheim in *The Chicago Tribune* entitled, "*The Children Who Never Were*". This article suggests that autistic children are incomplete, that the child must be freed by taking purposeful action and that something is missing that can be regained (Sarrett 2011, p.146). The idea of the taken child invokes the grief and fear of parents and has been used by charities who liken autism to that of a mass kidnapping and a national emergency (Stevenson, Harp & Gernsbacher 2011). The image of the taken child portrays autism as something that is less than human, something that is there but needs to be brought back. Although there has been a shift away from a psychogenic focus popularised by Bettelheim, this way of thinking, the taken child, is still today a dominant representation of autism which as seen here and as stated by Douglas (2013) remains remarkably unchanged since Bettelheim.

The above excerpt from *The Advertiser* also uses autism as an example of the possible medical breakthroughs that may exist in the future. Here science is positioned as the saviour of one from autism, firmly aligning the autistic subject something that is produced through the medical model. This subject positioning is further entrenched by autisms placement along-side the loss of a child and life-threatening heart attack or stroke. This type of grouping was a common theme in the articles analysed and contributes to how autism is positioned and categorised.

The positioning of a subject can produce shortcuts into ideas which convey messages about how that subject should be regarded (Carabine 2001). In addition to the positioning of autism alongside subjects that provoke imagery of grief and death, it was common for autism to be grouped among other disabilities and medical conditions. The consistent placement of autism within the medical model of disability positions autism via characteristics that are damaged and need to be fixed (Sarrett 2011, p.147). Take for example the excerpts below:

> examining the electrical activity of 100 billion cells, and trillions of brain connections, scientists could find new ways to help treat depression, autism, stroke, brain injury and schizophrenia (Baby, we're smart, *Herald Sun,* 26th December 2013).
>
> New research shows the babies of teenage boys are 30 percent more likely to have abnormalities such as autism, schizophrenia, low birth weight and spina bifida. (Babies of teen dads at risk, *Herald Sun*, 19th February 19, 2015).

My research is placed in a contentious position here where it has not focused on the lives and representation of other conditions such as schizophrenia or cancer and does not mean to disrespect such issues. What was apparent however was that the consistent placement of autism alongside other categories that are considered undesirable further entrenched its representation as something that should be avoided and for the most part could and should be eradicated if we develop the appropriate treatments. Of interest, was the consistent use of both schizophrenia and autism. Although as discussed in chapter three the two are now thought of as distinct conditions, they were still often found to be grouped together.

The use of grouping helps position autism without necessarily describing it. A second way autism was positioned without being described was using binary representations. Binaries tend to simplify complex relationships and can shape our understanding of a particular topic or issue (Bacchi 2009, p.7). Use of terminology such as ‘abnormalities’ as seen in the example above titled, ‘*Babies of teen dads at risk*’, positions autism as something that is not normal. The constitution of normalisation produces homogeneity through processes of comparison and differentiation. For the mother of an autistic child, this separates both her child and herself from normality. Her child is not the ideal, they are not normal. She then becomes defined by her ‘abnormal’ child, a process that differentiates her from other mothers.

In addition to being measured against what is normal, autism was also measured against what is considered healthy:

> The study looked at more than 1300 children diagnosed with autism and 2200 with ADHD and matched them with healthy control children (Pregnancy drug link to ADHD, *The Advertiser*, 27th August 2014).

Health, in this case, is the absence of autism (and ADHD). The use of the word ‘healthy’ positions the control group as the desirable form of measurement and consequently positions autism as unhealthy. Here autism is no longer simply abnormal but something that can be thought of as a disease. Binary terms that highlight difference reiterate and reinforce that difference. In addition, they also contribute to a culture where a mother’s autistic child is seen as unacceptable and in need of medicine or cure. As seen throughout this thesis, this need to discipline and control is often seen as the responsibility of the mother.

Criminal – Victims or perpetrators

Another element of grouping that was apparent was the representation of autism and criminal behaviour and the law courts as another site in which autism was constituted as a problem.

Within this theme, those with autism were represented as either those responsible or the victims themselves. In the below example, it is not known if the individual indeed does meet the current criteria of autism and we again see a dividing practice used here to describe autism:

> Mieglich has pleaded guilty to murdering Graham Mieglich, 56, by shooting him twice in the head in his bed on June 6. Justice Michael David said it was perfectly obvious Mieglich "is not well", although psychiatrists reported he did not have a mental illness but might have an autism spectrum disorder (YOUR STATE - WA, SA & NT, *The Australian*, 29th April 2014).

The idea that the individual involved, "is not well", again sees descriptions of autism categorised against what is normal and what is healthy, well versus not well. This time however there is an added element of fear by association. Autism is mentioned or suggested as likely, which contributes to fear within the community about the behaviour of those labelled autistic. This was a consistent theme within articles that reported criminal behaviour.

In the example below, although clarified later in the article that autism is not associated with violence, the imagery of a violent gunman, an array of weapons, images of a dead person covered with blood and plastic are then positioned alongside owning books on autism.

> He loaded the weapons into his car, drove to Sandy Hook Elementary School, blasted his way into the building, and within five minutes fired off 154 shots … Having slaughtered 20 first-graders and six educators, he killed himself ... a recluse who played violent video games in a house packed with weaponry … The inventory of items found in the home included books on autism, a vast array of weapons paraphernalia, and images of what appears to be a dead person covered with plastic and blood … The weapons used in the shooting had all apparently been purchased by Lanza's mother … She was found dead in her bed; Lanza had shot her on the morning of the massacre … Adam Lanza was said to have been diagnosed with Asperger's, an autism-like disorder that is not associated with violence (Newtown gunman had huge arsenal, *The Australian,* 30th March 2013).

Given the clarification that Asperger's/autism is not associated with violence, it seems peculiar as to why it was even necessary to mention. The Sandy Hook massacre made headlines around the world and we see here knowledge produced that lets people know the perpetrator of this crime had 'been diagnosed with Asperger's, an autism-like disorder'.

The second way autistic individuals were represented within the theme of crime was as victims of violent behaviour. The first example below describes an attack on an autistic teenager and quotes from his mother about the impact this has had. The second example describes reports made regarding the treatment of autistic children at the special school they attended:

> An autistic teenager who was savagely beaten up by a cowardly thug on a bus is now too scared to go outside alone. Liam's mother … said he had been using the bus for only two weeks. "Catching buses and trains was a pretty big deal to do on his own. He hasn't been on a bus since. He won't go up to the shop on his own," she said. "He was going so well, and now we're starting from scratch. It will probably take years to build confidence up." … Sergeant Cassandra Stone said. "It's pretty appalling, considering (the man's) picked on vulnerable, disabled people ... It was definitely unprovoked." (Cowardly bus thug hunted, *Herald Sun*, 17th October 2014).
>
> AUTISTIC children have been repeatedly locked in a darkened room for up to 20 minutes for misbehaving at a special school, staff and parents claim ... mother Rebecca Cobb, 37, said she found her tearstained autistic son … lying on the floor of the bare room with a bloodied nose (Kids' dark terror, *Herald Sun*, 19th May 2014).

A commonality between the representation of autism being associated with criminal behaviour and a victim of crime is the scare story. A discourse of vulnerability creates a subject position of fear and mistrust for the mother. A mother who needs to remain ever vigilant and responsible for dealing with the fallout.

Description of Mothers

The next section looks at how mothers were represented by the media and the voices of mothers themselves.

Media – third party

Descriptions of mothers whose children were autistic fell into two dominant categories. The first category was that of burden and tragedy. Two examples of how the mother of the autistic child was spoken about revolved around Autism Awareness Day and Mother's Day:

> For those few short hours, parents of children with autism will feel less alone than they do on the other 364 days of the year … Tomorrow, a mother will walk out of a diagnostic centre with fear in her heart, tears in her eyes and a piece of paper in her hand saying her child has autism. Her family's life will never be the same (Why O'Farrell needs to see the (blue) light, *The Sydney Morning Herald*, April 2, 2013).

In this example from *The Sydney Morning Herald*, the overall sentiment appears to be one of sympathy and reaching out to mothers in support. What it also does, however, is produce the notion that having an autistic child is inevitably devastating, that mothers of autistic children feel alone and her family will never be the same. The narrative suggests the path to helping mothers is support for this tragic occurrence, ignoring other possibilities such as shifting overall attitudes towards what it is a diagnosis of autism can mean.

The theme of tragedy regarding the lives mothers of autistic children was again notable in the following example:

> To remember also the women burdened with the lifelong care of offspring whose lives have been made difficult by autism or other disorders. To those women - and particularly those women - we offer our thanks and congratulations tomorrow (More than a day for cards and chocolate, *The Advertiser*, May 11, 2013).

The purpose of this narrative again appears to approach the idea of the mother of an autistic child from a place where she deserves our understanding and support. What it again does, however, is reinforce the idea of their child as a burden. It is not being a mother that is celebrated, but that we must celebrate the work she does dealing with this burden. Furthermore, we see the assumption that this burden will be a ‘lifelong’ experience and this experience is the mothers. The child is not society’s burden as the responsibility of care is on the mother. There are an assumed responsibility and expectation of the mother and the longevity of care she will provide.

The second dominant way mothers were represented was the celebrated woman who became the hero for a cause. This type of representation was one of the few where the individual mother was no longer muted behind a discourse of tragedy, but celebrated for turning her tragedy into direction for a cause:

> ‘INSPIRATION Fiora Christou … the mother of a son diagnosed with autism was faced with the challenge of deciding whether to place her son in a school where

> children had intellectual disabilities or a mainstream school where he could fall prey to bullying. She decided, instead, to set up the first autism school in SA. Her dream, Treetop Autism Specific School, has now been given a site and funding. It is scheduled to open in 2015 and has already received more than 1000 enrolment requests (My husband, my saviour, *The Advertiser*, 2nd October 2014).

Although framed as a positive story, the actions of the mother are embedded within a discourse of struggle or misfortune. This finding is consistent with that of Todd and Jones (2003) and Clarke (2012, p.192) where the dominant ways mothers of autistic children are described in a positive manner is heroically - finding 'ways to help their child, founding schools and charitable organizations to support their and similarly diagnosed children'.

Mothers own words

The articles examined that included quotes from mothers described mothering an autistic child as both a struggle and joy. A consistent theme within these quotes was the representation of stereotypical attributes associated with autism:

> Children with autism struggle to fit into a world that isn't the same as the one inside their heads. They are misunderstood when the media trivialises Asperger's syndrome as being cool because it isn't cool in my house, it's exhausting. They can suffer depression, anxiety and worse. Some families are ripped apart under the strain of dealing with an autistic child (Why O'Farrell needs to see the (blue) light, *The Sydney Morning Herald*, 2nd April 2013).

This description highlights the impact that stereotypical representations can have. On the one hand, positive representations can help break-down barriers. In contrast, however, and as described by the mother in this article, if these representations are not consistent with one's own experience, they can diminish the challenges such individuals and groups may face.

There were limited articles that portrayed mothering an autistic child in a positive manner:

> I adore my extraordinary son. Despite all the angst and exhaustion, he has brought such joy, humour, love and compassion into my life. And also wonder. Jules is Wikipedia with a pulse. People on the autistic spectrum have a lateral, literal logic which is vivid, hilarious, honest and original. My son is one of the most interesting people I have ever met (MY SON SHINES IN THE DARK. *The Australian*, 2nd April 2013).

In contrast to other representations where positive representations are awareness and compassion, here we see a mother talking about positives that are directly related to the autistic child. Whilst we again see raising an autistic child associated with negative qualities such as angst and exhaustion, the above excerpt also places a positive outlook on the experience. Here the mother refers to her son as a person. Unlike dominant representations of autism that portray autism as trapped or something less than human, there is a positive representation of the qualities associated with the human aspects of autism.

Cause

Descriptions of cause tended to fall within three main categories; the individual mother; genetics; and social and environmental factors. A dominant theme of each of these categories was pregnancy.

Pregnancy

With pregnancy becoming the site of focus, autism is targeted towards a wider audience. The subject becomes not only the concern of mothers of autistic children, but that of a pregnant woman, or even women thinking about becoming pregnant. In addition, the positioning of mothers becomes how public discourses understand and interpret prenatal impact and responsibility.

Knowledge related to cause ranged from, environmental factors that existed outside of the mother, to events that had happened to the mother and factors that were within her own body. Regarding environmental factors, a link between traffic fumes and pollution was proposed across several papers:

> EXPOSURE to traffic fumes and industrial air pollution can dramatically increase a mother's chances of having a child with autism (Autism link to fumes, *The Herald Sun*, 17 March 2014).

The excerpt above is the opening statement of the article. The language used is simple and makes the reader aware of the dramatic increase associated with traffic fumes, pollution and autism. In the second paragraph of the article, readers are made aware of the credibility of the research by the presentation of statistics and the introduction of where the research was conducted and published:

> Researchers studied insurance claims of 100 million Americans, and used congenital malformations in boys as an indicator for parental exposure to environmental toxins. The University of Chicago study, published in PLOS

> Computational Biology, looked at birth defects associated with parental exposure to pollution and found a 1 percent increase in defects corresponded to a 283 percent increase in autism (Autism link to fumes, *The Herald Sun*, 17 March 2014).

The use of words such as malformations and defects again links autism to qualities that are abnormal or something that isn't right.

Whilst traffic fumes are something a mother is exposed to, cause was also attributed to factors within the mother's body. Factors that were within the mother's body related to issues such as thyroid function and iodine deficiency. These issues were represented as deficiencies within the mother that create a deficiency in her child:

> ALL pregnant women should be screened for thyroid function and iodine deficiency to prevent brain damage in children, according to a leading Australian thyroid expert. Sydney University Endocrinologist Professor Creswell Eastman said a growing body of evidence suggests a link between pregnant women who do not make enough thyroid hormone and autism spectrum disorder (Pregnancy screening warning, *The Advertiser*, 30th September 2013).

The excerpt makes it clear that 'all' women should engage in this risk reduction behaviour. The 'good' mother does everything she can for her child and in a Western post-industrial society, it is increasingly science that dictates the necessary practices the 'good' mother must engage in (Apple 2006). The consequences of a mother's failure to engage in such a practice are made clear via the risk of a possible brain damaged, autistic child.

Authority is given to the claims surrounding thyroid function by indicating to readers that the voice making the claims is able to do so. The use of terms such as 'leading expert' and 'Professor' contribute to the authoritative power making the claim. Both the leading expert and the professor reflect disciplinary power – power that works not by restraint but by creation. Rather than placing a limit on a mother's liberty, disciplinary power creates mothers to be certain kinds of people. Based on expertise and specialised knowledge, direction is applied and a population becomes the individual subject. Practices such as thyroid screening increase the maternal responsibility and self-surveillance of the individual mother (Smart 1996, p.47) whilst simultaneously creating the possibility that if she fails to self-regulate, other 'experts' may hold her accountable (Hays 1996, p.71). It is not simply a mother's biology that is accountable, but her engagement in tests that are consistent with 'good' mothering practices.

In addition to thyroid function and iodine, mothers' immune systems were suggested as a possible cause:

> AUTISM has been associated with the immune system of pregnant women by research which could lead to an early diagnosis test (Autism diagnosis hope, *The Advertiser*, 10th July 2013).

The idea of an early diagnosis test raises several questions. On the one hand, it offers the mother/parents the chance to prepare, research and adjust their mindset to a mothering role that may not coincide with previous expectations. On the other hand, it may also introduce ideas surrounding termination. Ideas of termination may be heavily influenced by dominant representations of autism that portray autism as something that is heartbreaking, undesirable and unwanted. Issues surrounding termination, when an abnormality is detected, is a study on its own. Putting aside the individual choice of the mother, the value of human life changes when disability is involved (Shakespeare 1998) with some doctors, who whilst opposed to performing abortions make exceptions when an abnormality is detected (Farrant 1985).

Narratives regarding the aetiology of autism may create situations where mothers of autistic children could be placed in a position where they may begin to doubt or question their own actions. The article below not only represents autism as being subject to the conditions of a pregnant mother's mood, it simultaneously engages with the medical model and represents knowledge that autism is something one develops:

> The research raises the possibility that levels of stress in pregnant women may have a role in development of autism (Pregnant stress linked to autism, *The Advertiser*, 4th June 2014).

Linking a mother's stress to the development of autism creates the further possibility for mother blame. Causes of stress are not identified and the levels of stress are described as maybe having a role. In an article in *The Australian*, we see a specific experience linked to the likelihood of producing an autistic child, and this time there is a rate of increase specified:

> WOMEN who have experienced abuse as children are three and a half times more likely to have a child with autism, according to a new study (Study links childhood abuse with risk of autism, *The Australian*, 10th April 2013).

In many ways, the research positions victims of child abuse as damaged goods. Procreation from this point now comes with risk. The decision of the mother, if she knows there are potential risks, can result in a sub-group of mothers questioned or even vilified if they make the decision to procreate. The positioning of autism subsequently becomes critical. As seen below, the representation of autism within this article amplifies the gravity of autism by referring to it as a ‘serious disability’, whilst simultaneously making readers aware that it is new research that has emerged - like yay!!, it’s new!!!:

> The new research is the first to suggest childhood abuse not only harms those who directly experience it but also increases risk of serious disability in the next generation (Study links childhood abuse with risk of autism, *The Australian*, 10th April 2013).

Whilst childhood abuse minimises the blame for the initial experience, when the authors hypothesise about factors that weren’t measured, but may play a role in the outcome, we see direct blame projected upon the mother and her diet:

> The study, to be published in the Journal of American Medical Association, concluded increased biological reactions to stress was a possible cause, but also noted it could also be unmeasured prenatal factors like poor diet amongst high-level abuse sufferers (Study links childhood abuse with risk of autism, *The Australian*, 10th April 2013).

Here we see not what has happened to her proposed as the reasons for her autistic child, but her reaction to this abuse. The limitations of the research see a bargaining for an acceptable solution. In this case, the compromise gives potential control back to the mother, but with this, also the blame.

A final point identified within the theme of cause was the process of reification. Reification is the process by which something is converted into a concrete thing. Reification occurs whilst positioning the knowledge as objective and unbiased. It appears as fact because it appears to remain uninfluenced by the opinions or selection practices of human researchers or human authors (Turner 2006, p.503). Medical or scientific claims distance was often achieved using non-specific references:

> A second study published in the same journal looked at offspring of eight rhesus monkey mothers who, during pregnancy, were exposed to human antibodies from mothers of children with autism spectrum disorder. The offspring of these monkeys made inappropriate approaches to unfamiliar peers. The male offspring had

> enlarged brain volumes consistent with some imaging of children with autism. (Autism diagnosis hope, *The Advertiser*, 10th July 2013).

By drawing the reader's attention to a second study, the author gains further acceptance that their idea is true and valid. Similar practices were found throughout the articles examined. For example, when discussing the link between autism and traffic fumes the article in *The Advertiser* (Autism, pollution link, 17th March 2014) states that 'several studies have shown a link'. Another example from *The Advertiser* (Pregnancy screening warning, 30th September 2013) when discussing thyroid function, stated there was 'a growing body of evidence suggests a link'. These practices of reification position the information or knowledge as consistent and conclusive.

The introduction of men

Knowledges surrounding the cause of autism also included research that suggests a relationship between the age of male sperm and autism. It must be noted that fathers were not the target of the data I collected and consequently the knowledge referred to is limited. This, however, is still of interest – particularly when it comes to the language used. Two key points of interest taken from the data were that: 1) we are seeing an emergence of how the male's sperm may play a role and 2) The focus of this role appears to be directed towards the age of the father and biological changes that are out of his control.

Often discourses surrounding conception work upon the notion that the success or failure of the male begins and ends with their ability to fertilise an egg. 'Historical understandings of male virility render sperms completely invulnerable to harm from the toxicity of particular agents and exposures or to, conversely, be rendered completely infertile if damage does occur (Daniels 2001, pp.313-314). Both the young teenage male and the older male were represented. Both because of mutation;

> … it has emerged teenage boys have mutated sperm. Research shows the babies of teenage dads are 30 percent more likely to have abnormalities such as autism, schizophrenia, low birth weight and spina bifida (Teen link to sperm mutation, *The Advertiser*, 19th February 2015).
>
> The extra genetic mutations that build up in older men's genes are already known to raise their children's risk of autism, schizophrenia and some other diseases (Older dads and ugly facts, *The Australian*, 24th March 2014).

In comparison to the discourse surrounding the pathology of autism as a maternal practice, the father's sperm is not represented as something within his control. Returning to the example from *The Advertiser* seen earlier regarding thyroid production, it was, 'pregnant women *who do not make enough* thyroid hormone and autism spectrum disorder', in comparison to teenage boys who 'have' mutated sperm and the genetic mutations '*that build up* in older men'. For females, it is presented as something she has failed to do, for the male it is something they have or happens to them. Sperm is not represented as something that may be influenced by stress, toxins or other meditating factors but simply the result of how his own biology functions through no fault of his own or that of wider society. Rather than being the fault of the man, the implication is that these men fall short of the masculine ideal. There is the implication that if young or old, one is not a 'real man' and should not have children.

Vaccinations

Vaccinations were discussed in ten of the articles examined, each, with the exception of one, making mention of the proposed link between vaccinations and autism. Both the belief that vaccinations cause autism and the belief that there was no connection were represented. Other themes identified were the concept of free speech, vaccination policy and the influence of the celebrity mother. Interestingly, the specific vaccine, the MMR vaccine, which posts the paper by Wakefield et al. (1998) was at the centre of every debate surrounding autism and vaccinations, has all but disappeared from the discourse. Only one of the articles mentioned the MMR vaccine specifically.

The one article that specifically mentions the MMR presented an image of acceptance that there is no connection between the vaccine and autism:

> The science is in. Vaccines work, and most anti-vaxx scare-myths have been thoroughly busted; in particular the MMR-autism link myth. A 2014 study by Sydney University Associate Professor Guy Eslick collated data from 1.25 million children. Eslick found a "consistent ... lack of evidence for an association between autism, autism spectrum disorders and childhood vaccinations" (Juggling truth, science and rights to extremism, *The Sydney Morning Herald*, 8th January 2015).

Whilst the medium of newspapers across the Western world had previously 'published sensational headlines reporting a link between MMR vaccine and autism' (Jones & Harwood 2009, p.7), the articles examined in this study were largely critical of any link between vaccines and autism, and, as seen above, even going as far as to refer to such narratives as ‘anti-vaxx scare myths’.

Extending upon the knowledge that sought to debunk a link between vaccinations was a quote from a mother of a five-year-old autistic boy where she expressed her frustration over the continuing debate:

> The mother of two welcomed comprehensive research that found no links between the vaccines given to children and autism … “I’m sick of arguing with everyone about it. My son is not autistic because of vaccines,” she said. “I’ve always believed in vaccinations. “I think people want something to blame, but it (autism) is just part of your genetic make-up” (JAB NOT TO BLAME FOR JED’S AUTISM, SAYS MUM, *The Advertiser*, 24th May 2014).

The mother talks about others need to blame something. If something is different we often feel the need to determine why. The lived effects of this need are represented here where there is a continual need for her to discuss causality – surely her son is the way he is because something went wrong. Even though the dominant representations regarding a connection between vaccines and autism have shifted, she still spends her time arguing with others, the topic still infiltrates her life and is something she is called to account to speak of.

Whilst the narrative connecting vaccines to autism was represented, it was often done in a manner that made readers suspicious of those who support the connection. In the example below, the author disparages the ‘she’ who owns the health food shop. Her shop is placed in “scare quotes”, indicating to readers that we should be suspicious of her claim to be able to sell ‘health’:

> When Fairfax approached the owner of the "nutrition and health" shop, she refused to be interviewed, instead offering a free DVD from a stack she keeps behind the counter warning about the links between vaccines and autism (A pox on both your parents, *The Sydney Morning Herald*, 13th April 2013).

Those who could not talk the science of autism included celebrity mothers. The response to the penetration of the views by celebrity mothers such as Jenny McCarthy was one of contempt and fear regarding their ability to so widely spruik views that are not seen to be evidence-based:

> You'd possibly laugh off such folksy babble were their stands on such life-savers as vaccination not given the intuition/superstition treatment. McCarthy said vaccination caused autism in her child, but a special diet fixed it (Celeb baby tips remind us what clueless truly means, *Herald Sun,* 30th April 2014).

Typically, 'expert' authority is maintained by not overstepping the boundaries of one's own understanding (Schermerhorn et al. 2014, p.341). The crafting of motherhood by the celebrity then becomes quite the paradox – if women are considered the natural experts on child rearing, then it makes sense that the women we see given a voice will be experts within the field. What comes into play here, however, is how the status of "truth" created by the celebrity is produced. The celebration of the ''celebrity mom'', paired with the 'emergence of the aspirational ''yummy-mummy''' (Jermyn 2008) sees not 'truth' represented but a particular discourse of motherhood. As argued in chapter two, versions of motherhood represented by celebrities in the media that revolve and the fear and guilt are placed alongside mothers who 'do it all' and look good while doing it (Douglas & Michaels 2004, p.4). These representations 'present a highly romanticised view of motherhood in which the standards for success are impossible to meet' (Douglas & Michaels 2004, p.4).

It was not only the standard set by these mothers that articles were critical of. These celebrity mothers were not viewed as having the expertise or credible evidence that would allow someone to legitimately offer the claims they make:

> One problem is that given the appearance of "perfection" some Hollywood mums can appear to have achieved, you may be tempted to attribute some weight to their pronouncements on everything from harmful "chemical" foods you must not give your baby (formula) to the "dangers" of vaccination. None of it is evidence-based (Celeb baby tips remind us what clueless truly means, *Herald Sun*, 30th April 2014).

A second shift from previous vaccination discourses was vaccination policy. The current decline in vaccination rates has seen government intervention. The government has begun to link vaccinations to things such as access to childcare (and a few weeks after this data was collected, family payments). This debate sees autism continue to be a focal point:

> Vaccination sceptics believe the policy is unfair, saying parents have a right to choice and claim vaccinations can cause health problems such as autism, allergies

> and auto-immune conditions (Vaccination a no-brainer, *Herald Sun*, 1st March 2015).

The debate surrounding linking vaccinations to family payments is a complex one. Whilst no one is being forced to vaccinate their children, the freedom of choice to not vaccinate is one that is more readily available to the wealthy or the self-functioning neoliberal citizen who isn't reliant upon government payments.

The idea of choice and freedom is represented here, but it is about protection from things such as autism, which is referred to here as a 'health problem'. This focus is often driven by the fear and or devastation of having an autistic child. Interestingly in the second example shown below, it is again the mother and, in this case, even the grandmother who one should speak to regarding this devastation:

> Spend a week with a mother or grandmother of an autistic child that became autistic because of the response to immunisation ... Parents should be paid NOT to have children immunised! (WHAT YOU ARE SAYING, *The Advertiser*, 21st August 2013).

As seen in the examples above, vaccine responsibility, refusal and impacts are often gendered processes which see women accountable for circumnavigating aspects of health versus necessary risk and intervention when deemed appropriate. We also see that despite the debunking of the MMR autism connection, there are many who still firmly hold this belief.

The gendered approach to vaccinations was also evident in the article by Corderoy (2013) 'A Pox on Both Your Parents'. The article looks at the issue of vaccination, particularly in wealthier suburbs. From the headline, the article appears to focus on the role of parents within this issue and is in favour of vaccination. The article uses the term parent throughout the article, using it a total of six times. What is notable however is what happens when the term parent is gendered. The number of times the term parent appears is equal to the number of times the term mother (six). In direct comparison, however, the term father appears, a total of zero times.

Aside from the absence of fathers within an article framed as parenting, it was particularly interesting when the term parent was used and when the term mother was used. Take the example below which is a statement from John Dwyer, the president of Friends of Science in Medicine:

> He says “part of the problem is clearly that parents are stressed and time poor, making keeping track of vaccines difficult” … "Although I can't see why a busy working mother from a lower socio-economic group wouldn't be subject to the same stresses as wealthier mothers," he says (A pox on both your parents, *The Sydney Morning Herald*, 13th April 2013).

In the first part of the statement, the term parents is used when the justification for not doing something is given – “parents are stressed and time poor”. In the second part of the statement however, the term parent becomes mother and it is in this second part of the statement where it appears mother’s time is what facilitates the process. When a form of absolution is given it is parents, when blame is given it is the mother.

We also see mothers put on the same platform of opportunity regardless of socio-economic status. Society despises poor women (Seccombe, James & Walters 1998). They have reproduced without the necessary means. Ignoring the fact that the only necessary means for reproduction is reproduction itself, ‘women who have followed the advice of New Labour and have postponed childbirth until they have secured wage-earning capacity, become deserving subjects’ (McRobbie 2007, pp.731-732). The lower socio-economic mother in-turn becomes what society sees as the deserving subject of the same expectations regarding the performance of good motherhood.

So…what should a woman do if she doesn’t want a child with autism?

She should avoid having sex (or becoming pregnant) by a male in his teens (Teen link to sperm mutation, 2015) or an ‘older’ male (Older dads and ugly facts, 2014); avoid high levels of stress (Pregnant stress linked to autism, 2014); possibly avoid antidepressants although this was not deemed significant (Pregnancy drug link to ADHD, 2014; ADHD link if mum on drugs for depression, 2014); avoid traffic fumes and industrial air pollution as this can ‘dramatically’ increase a mother’s chances of having a child with autism (Autism, pollution link, 2014); don’t live on or near a busy road (Have your say, 2013); understand her immune system can be a contributing factor and ‘if pathologically significant, medical interventions that would limit fetal exposure to these antibodies might prove helpful in reducing risk of ASD symptom development’ (Autism diagnosis hope, 2013; Hope of a new test for autism, 2013); understand the role of an underactive thyroid and the importance of iodine (Pregnancy screening warning, 2013; Researchers find thyroid function link to autism, 2013); understand that if she has experienced moderate levels of abuse as a child she will be 60 percent more likely to have a child with autism (Study links childhood abuse with risk of autism, 2013); continue to weigh up the decision to vaccinate and possibly avoid procreation all together because of her own genetic make-up.

The totality of what a mother should do to avoid having an autistic child covers almost every aspect of life. From where one lives, to who one has intercourse with to what experiences they had as a child. As such it almost always possible to find a reason for her child's autism and whilst each reason on its own may be presented as avoidable, when put together it becomes apparent how convoluted such expectations are.

Cure/Treatment

There was limited discussion surrounding cure and treatment. The main discussion points surrounding cure related to drugs and, the introduction of the 'cuddle hormone' and the establishment/effectiveness of ABA.

Drugs/vitamins

Another group that was represented as having the 'true' knowledge of autism were drug or pharmaceutical companies. Within the articles examined there were three drugs that were represented as having the potential to improve the functioning of those deemed to be 'with autism' – folinic acid, folinic acid in combination with methyl B12 and oxytocin. Whilst either folinic acid or folinic acid in combination with methyl B12 was represented as improving the autistic children who were part of the studies, it was the study on oxytocin that the bond between the mother and child was introduced:

> Oxytocin, nicknamed the "cuddle" or "love hormone", plays key roles in social activity. Research has shown that it helps to seal the bond between loving couples, as well as mothers and their babies (Cuddle hormone 'help for autism', *The Australian*, 4th December 2013).

The reference to oxytocin being something that facilitates a bond between a mother and her baby ties into theories of mother blame, particularly the cold unloving 'refrigerator mother' whose child would withdraw and seek comfort in their own solitude.

The knowledge of oxytocin as a treatment for autism also positioned the need for such treatments as urgent:

> In the study, oxytocin caused the brains of autistic children to respond more to social stimuli - such as faces - and less to non-social stimuli, such as cars…"Our

> results are particularly important considering the urgent need for treatments to target social dysfunction in autism spectrum disorders," said Gordon (Cuddle hormone 'help for autism', *The Australian*, 4th December 2013).

The idea of urgency is not uncommon within contemporary autism discourses. Having previously been related to the need to address the autism epidemic (Eyal et al. 2010) and the need for parents to seek early intervention (Lilley 2011), in the example above, urgency is used to highlight the need to correct the social behaviour of those who are autistic.

ABA

Applied Behavioural analysis (ABA) is a form of intensive therapy that is ‘recognised as an essential and scientifically valid method of educating and managing children and youth with autism spectrum disorders’ (Simpson 2001, p.68). Although only the one article was found regarding the treatment, this article was of interest given the areas of knowledge found to be included within. In addition to ABA being represented as ‘the only specific early intervention the federal Families Department rates as effective based on "established research evidence"’, the article also raises issues such as funding and the idea that children with autism can progress to a stage where their diagnosis is removed:

> The government's Helping Children with Autism program provides families of children with autism $6000 a year for two years. About 19,000 children used that funding in the program's first five years. But the annual cost of applied behaviour analysis therapy - the only specific early intervention the federal Families Department rates as effective based on "established research evidence" - is $40,000. That research shows about 50 percent of children with autism are able to reach a normal educational outcome by age six (Scheme will cover the cost of autism treatment, *The Sydney Morning Herald*, 11th May 2013).

The application and methods of ABA are not without their critics. Whilst some ‘embrace ABA methods with almost a religious fervor … based on the belief that ABA exists as the single salvation for a child and family’ (Simpson 2001, p.69) others see the therapy as ‘rigid, dogmatic, and likely to produce prompt-dependent children’ (Simpson 2001, p.69). The success rate represented raises some interesting questions. Whilst for 50% of children the therapy is represented as delivering children back to normal standards, that still leaves 50% of children and families who have spent $40,000 on evidence-based programs that haven’t achieved the results perhaps hoped for. Navigating the knowledge surrounding these programs is often the responsibility of the mother (Lilley 2011) and it seems that there is no limit to the number of “cures” for autism that are being promoted (Simpson 2001, p.68). Navigating this knowledge is made even more difficult given the costs associated with certain treatments.

Interestingly, within this article a diagnosis of autism is referred to as something children can make progress towards no longer warranting:

> "Autism is not a stagnant diagnosis," she said. "If we give children with milder forms of it really intensive, evidence-based intervention, some of those children will go on to come off the diagnostic criteria for autism and will go on to have completely independent lives, and that should be the outcome of the NDIS" (Scheme will cover cost of autism treatment, *The Sydney Morning Herald*, 11th May 2013).

This is the first time, outside of the highly criticised celebrity knowledge, that we see such a prognosis given in relation to autism. The idea that autism is not stagnant raises further questions regarding the role of the mother. If such results are possible and she can transform her child into the independent citizen so valued in Western society, does this then alter her responsibility to not only her child but also wider society? If there is the possibility of transforming her child into that which meets the standardised forms of development, ‘commodity uniformity and functional predictability’ (Phillips 1990, p.850), what happens if she fails to do so or fails to even explore and try every possibility? The idea of what happens is explored further in the next chapter.

Summary

Throughout this chapter, I have identified the dominant ways in which both autism and mothers of autistic children were represented in mainstream Australian newspapers. Autism was represented as a problem, a disorder, something that should be avoided, eradicated and of growing concern. Mothers were represented as devastated or heroic but never normal. Embedded in this and a theme I explore throughout this thesis, was mother-blame and responsibility.

The articles analysed were dominated by the medical model of disability. Medical discourse was privileged and represented as the singular authority that was able to speak about autism, its cause and possible treatments. In addition to its medical description, I also identified that there was concern that the classification of autism was being used in a manner not intended

- essentially multiplying its use through the introduction of new content and ways of constituting what is autism.

As knowledge of autism continues to cover areas such as the ‘rate at which it is increasing’, continues to live within issues such as vaccinations and diet and penetrate multiple aspects of pregnancy - the discourse continues to be multiplied rather than rarefied (Foucault 1978). By this I mean, the distance from which autism and the life of the mother of an autistic child are beyond the concern of the ordinary is continually reduced. The manner in which it is reduced however is predominantly one of fear and tragedy.

Limits were imposed on who could lay claim to being able to speak the ‘truth’ of autism. Celebrity mothers and other celebrity experts were vilified as lacking the appropriate knowledge, qualifications and supporting evidence to be able to speak this ‘truth’. Even further, their narrative was categorised as dangerous.

One mother that emerged in the data analysed was American mother Jenny McCarthy. In addition to researching the global medium of the internet, my next chapter investigates the narrative of celebrity mother, Jenny McCarthy.

CHAPTER 7: JENNY MCCARTHY AND GENERATION RESCUE

In the following chapter, I turn my attention to a narrative available on the internet – *Generation Rescue* and its president, celebrity mother Jenny McCarthy.

This chapter continues to address the first two research questions of my study:

RQ: 1) How is autism and how are mothers of autistic children represented within public sources of information and data?

RQ: 2) What are some of the discursive and subjectification effects produced by the representation of autism and mothers of autistic children?

In this chapter, I unpack the idea of the Train A mother and the fake child. I argue that the hope for the recovery of the true child is cruel for the mother and for the child. The idea of hope is cruel yet so is the idea of giving up. The techniques and procedures analysed construct the autistic child as false, taken and trapped. This sees the mother of an autistic child directed down a path that is biomedical, confusing and celebrity endorsed.

I explore the idea that the 'successful mother' of an autistic child is one who is able to 'recover their true child'. The 'good' mother model represented in the data analysed is self-managing, privileged and western. There is not only 'hope for recovery', but this 'recovery is also real' and one must simply 'keep trying'. I also explore the 'other' mother this creates – the Train B mother.

Autism in this chapter is something that has happened to a child, they were not born autistic. The autistic child is false. The autistic child is not real, they have been taken and are now trapped. The true child is one the mother sees 'glimpses of' and intuitively knows is the child that 'should be'. As with any good story, there is a villain and there is a hero. The villain is autism, and the hero, the 'successful guilt free Train A mother'. This mother never gives up hope. Hope is what gets her up in the morning. Hope makes her a warrior and sees her fight. Even if unsuccessful, she keeps fighting. She loves her child and would do anything for them, but it is not the child she has she is fighting for. She fights for the child she doesn't have. This child has been taken from her by the villain that is autism. In addition to buying into the idea of the hope within the vision of the true child, the mother also buys in an economic sense. She commits her time and her wallet. The good autism mother consumes.

Due to the fact this medium is visual as well as written, I also focus briefly on the appearance of McCarthy. I contend that the performance of appearance McCarthy represented in her crusade of the 'Train A' mother can only be recognised due to already established and establishing types of femininity, beauty and motherhood. I describe how the panoptic gaze encourages McCarthy to discipline her appearance within that of the patriarchal ideal. I argue that the "reinvented femininity" McCarthy performs through her appearance sees the imagery of the 'Train A mother' subscribe to a culturally hegemonic standard of beauty and a making of the self into the neo-liberal reinvention of a successful, post-feminist bourgeois subject (Ringrose & Walkerdine 2008). I also argue that McCarthy represents "the exemplary female prototype" (Cortese 1999) of the western women, epitomised by constructions of beauty types (Ashmore, Solomon & Longo 1996). By drawing upon predetermined types of beauty McCarthy enacts a self-reflexive subject who appropriately adapts and self-transforms.

Why look at Jenny McCarthy?

Since the classification of autism in the 1940's the commentaries by mothers of autistic children have been influential. This influence, however, has paled in comparison to the commentaries of established disciplines such as psychiatry, psychology, science and medicine. For example, '*The Siege*' (1982) by Clara Carbine, is one of the most influential books of its time (in regards to parenting an autistic child), yet is predominantly referred to as a cult classic (Jack 2014). Prior to the 1990's there was only a handful of parental experiences published (Langan 2011). The rising numbers of autism diagnosis and the void of an agreeable truth regarding the condition have seen the new millennium filled with parents (especially mothers) 'blogging, writing, networking, talking and campaigning for and about their children's condition' (Chivers Yochim & Silva 2013, pp.406-407). The new millennium has seen a change to not only the mediums through which mothers of autistic children voice their thoughts but also the claims being made. Previously parents had limited their objections to areas such as psychogenic theory (for example that of "the refrigerator mother"), but are now challenging the 'epidemiology, aetiology, pathology and therapeutics' proposed by 'mainstream scientific and medical authority' (Langan 2011, p.198). Whilst both mothers and wider disciplines such as science previously had an assumed common interest, that is, what is best for the child, within the current field of autism ‘this alignment does not seem to exist’ (Chivers Yochim & Silva 2013, p.413).

In 2007, McCarthy published her book *Louder than words: A mother’s journey into healing autism*. *Louder than words* would have a major impact, particularly in the USA (Langan 2011), largely due to the claims being made and the star power harnessed by McCarthy. McCarthy claimed that vaccinations were the trigger for her son’s autism and that she was put on this earth to be ‘Evan’s mother—and thus to lead other moms of autistic children in a massive movement of healing’ (Chivers Yochim & Silva 2013, p.417). McCarthy promoted her book and her thoughts on vaccines and healing autism through highly visible formats such as *Oprah*, *Larry King* and *CNN*. Such promotion saw McCarthy become a celebrity spokesperson and her narrative enter the mainstream.

The narrative offered by McCarthy can be found across various mediums (books, television, various internet sites). McCarthy currently serves as both the president and face of autism advocacy group *Generation Rescue*. As such, analysing McCarthy’s narrative within the framework of *Generation Rescue* provides an opportunity to explore a highly accessible web-based narrative that encompasses the everyday expertise of the mother as well as that of the celebrity-expert.

Generation Rescue

I use the *Generation Rescue* website as the point of collection for all information discussed in this chapter. Whilst the narrative of McCarthy is the main focus, I thought it important to provide a brief overview of the website itself.

When logging onto the *Generation Rescue* website, readers are provided with the slogan - ‘hope for recovery’. This slogan is consistently attached to the *Generation Rescue* logo throughout the website. Whilst autism is often represented as a ‘lifelong disorder’, *Generation Rescue* represents autism as something from which there is hope that an individual can recover. The use of the term recovery suggests autistic children are damaged in some way and a more desirable existence is hoped for. Recovery and hope are closely connected and often drawn upon by parents of autistic children when articulating their ideals for their child (Broderick 2009, p.263). Given the dominance of historical constructs of autism that have been embedded with a sense of hopelessness, it is not difficult to imagine the appeal a discourse grounded in hope may have (Broderick 2009, p.264).

The first image on the homepage is a smiling child on a swing with the banner, 'recovery is real'. This statement brings the idea of 'hope' for recovery from being that of aspiration and desire to something that exists - a thing occurring as fact. The idea of hope for recovery positions *Generation Rescue* as an advocacy group that does not advocate for autism but advocates for its elimination.

When scrolling down the home page, visitors are presented with the mission statement of *Generation Rescue*.:

> We are dedicated to recovery for all children with autism spectrum disorders by providing guidance and support for medical treatment to directly improve the child's quality of life for all families in need.

This statement, although brief, allows us to see the type of autism advocacy represented by *Generation Rescue*. The first agenda we are made aware of is recovery. The second is that it is children they seek to recover. This child-only focus sets the parameters for the agenda of *Generation Rescue* and whilst doing so, confines autism to children.

When clicking on the recovery tab, viewers are offered the following dialogue as representations of recovery:

> ***Generation Rescue believes in autism treatment that brings hope for recovery.***
>
> A 12-year-old boy looks at his father and calls him Dad for the very first time.
> A 5-year-old girl becomes fully potty-trained.
> A 6-year-old boy is finally sleeping through the night.
>
> Families affected by autism do not take these milestones for granted. They are the daily victories that prove there is hope for recovery. Autism treatment and recovery are individual for each family. Here are powerful tools for your journey.

Recovery is represented as progress. The 'hope for recovery' is not framed within a context of non-linear development but a modernist perspective that 'hope lies in the gradual, scientific production of improved approximations of truth' (Danforth 1997, p.94) - truth being the ability to perform certain desirable tasks. Although the term prove is not often used by established, respectable medical institutions when discussing their research, *Generation Rescue* state that achieving these tasks are proof that the child can recover from autism. Recovery is privileged over development - there is hope the child can be cured. If it is development, they may learn new skills but will remain autistic.

Story of Recovery – Jenny McCarthy

I now turn my attention to the specific story of recovery told by McCarthy on *Generation Rescue*. I do not go into a great deal of analytical detail in this first section as the main themes, techniques and procedures are discussed in detail later. My first aim is to tell the story of recovery McCarthy offers visitors to the website.

The opening message provided by McCarthy, titled: ‘A message from Jenny McCarthy: *Generation Rescue* President’, sets the scene for how autistic children are viewed across the website:

> It’s too common a story, becoming ever more common. A parent sees glimpses of a vibrant young child—their child. They know these glimpses are who their child should always be (McCarthy).

McCarthy’s opening statement is another example of the trapped child, the narrative popularised by Bruno Bettelheim in the mid-twentieth century. This time, however, it is not a now disgraced ‘psychologist’, nor a representation in a newspaper (as seen chapter six – media analysis), it is the mother herself claiming her child is untrue. Essentially McCarthy talks about two children, the fake child and the true child. A fake child who is present but not wanted, and a true child who is not present but desired.

McCarthy describes to viewers how she felt when she received her son’s diagnosis:

> I remember the doctor saying I’m sorry he has autism and there’s not much you can do, and I died in that moment … all I knew about autism was Rain Man and I remember him being in an institution and I thought oh my god this can’t possibly happen to me (McCarthy).

The autistic child is presented as a negative first by the doctor. The words ‘I’m sorry’ position the coming information as negative. The reaction of McCarthy that she ‘died in that moment’ is again consistent with the portrayal of the grief-stricken mother - even though McCarthy acknowledges that beyond a common stereotype, autism is something she knows nothing about. McCarthy also talks in a manner where the future becomes immediately present – the idea of her child in an institution.

McCarthy describes how upset she was to have received the news of her son’s diagnosis. This sadness however quickly turned to anger and sees her pray to God to help her fix her boy:

> I went home … and I cried … then I got really upset, I started to get angry with the doctor who told me there was nothing you can do. How you can possibly cut off hope, miracles happen every day. So I had a conversation with God and that was, God if you help me and you show me the way to heal my boy I promise I'll teach the world how I did it (McCarthy).

The idea that her boy needs fixing is another example of how the autistic child is viewed - broken and in need of repair. There is an absence of hope given to her by the doctor and McCarthy does not accept this. Although she doesn't know what to do, McCarthy tells viewers she knew she had to do something:

> I had no idea what to do. But I knew I had to do something! So I became a detective. Thanks to Google research, the support of UCLA and my doctor, and my friendship with other autism moms, I discovered all the organizations, foundations, therapies, and diets that can help pull kids out of autism (McCarthy).

Having found sources of information that contrasted the life sentence given by her doctor, McCarthy describes the two options presented to her:

> I thought I've got two options here, one from the doctor called no hope and one from *Generation Rescue* called hope, which one am I going to take, I think I'll take the one called hope (McCarthy).

McCarthy's tells viewers how she got straight to work:

> When my son … was diagnosed … I was devastated. But, finally, there was a "tangible" place for me to start. That very same night I got on the computer and went to work. It really is work—and since you're reading this, you most likely already know that (McCarthy).

McCarthy interpellates the mother as hard working. She speaks of and to the mother who, as described by (Douglas 2013), is "called to duty". One gets to work. One becomes an autism mother by recognising the call of her true child. McCarthy is not a mother who would simply leave her child trapped whilst feeling sorry for herself. She is not a mother who resigns herself to carrying around her fake child:

> My goal was to learn everything I could about autism and its treatment. I looked far and wide. I dug deep. I like to use a train analogy. There's Train A: You do

> absolutely everything you can for your child, no matter what anyone tells you. There's also Train B: Woe is me. I'm a Train A person (McCarthy).

Like there are two types of children described by McCarthy, there are also two types of mothers. Rather than the good or bad mother binary, mothers of autistic children are either Train A or Train B. There is no C, D, E or F, one either does everything they can for their child or wallows in their own self-pity. A mother either 'recognises herself and turns to act' (Douglas 2013) or she feels sorry for herself.

McCarthy represents herself as a mother who was desperate for answers and abandoned by the medical community:

> I wished to God the doctor had handed me a pamphlet that said, 'Hey, sorry about the autism, but here's a step-by-step list on what to do next.' But doctors don't do that. They say 'sorry' and move you along (McCarthy).

Doctors are represented as uncaring and abandoning a mother in need. McCarthy, on the other hand, is the mother who never stopped trying and has succeeded in recovering her true child:

> I read every single testimonial *Generation Rescue* posted. I tried every single option, followed every single piece of advice. I did this very methodically, and very privately—just me, a mother trying everything to recover my son. Eventually, wonderfully, I succeeded (McCarthy).

Although earlier McCarthy recognised other sources she utilised (UCLA, her doctors, other autism moms), her story here is all about her own journey and how she herself was responsible for her success in recovering her true child. To 'pull' her son 'out' of autism and regain her true child McCarthy outlines some of the steps involved:

> I started the diet and within two weeks Evan said a five-word sentence and a few weeks after that after starting vitamins Evan said a seven-word sentence, then after that, I detoxed him and implemented many more therapies and within one-year Evan was undiagnosed (McCarthy).

McCarthy describes how a change to her son's diet and environment were key factors in 'recovering' her son. Here, McCarthy participates in the discourse of food and environmental toxins and the role they played in the recovery of her son. The detail, however, is limited, particularly with the description of her success including 'many more therapies'. There is the absence of a clear step-by-step process to follow. McCarthy simply tells viewers to 'try everything' and to have hope - 'Hope is the only thing that will get us up in the morning' (McCarthy).

The story of McCarthy does not end there. Now that she has recovered her true child, she is honouring what she offered in exchange – to teach the world how she did it:

> But the journey wasn't over. In profound solidarity with all the families still struggling, I decided to speak up. I wanted to give voice to options too often unspoken, and share hope for victories within reach (McCarthy).

In the past, mothers of disabled children have been criticised for becoming crusaders to attain normalisation and then withdrawing from activism once this has been achieved (Ryan & Runswick-Cole 2008, p.205). McCarthy is self-described as not one of these mothers and attempts to avoid this position by ensuring that it is clear to readers that she is an activist and supporter for other mothers whose children also need to be healed:

> I'm just as active today as when Evan recovered from autism. I still travel the country lecturing on autism, am the president and board member of *Generation Rescue* and actively fundraise throughout the country for the foundation. My journey now is for the other parents whose voice hasn't been heard (McCarthy).

McCarthy represents herself as dependable. Not only is she a mother who would stop at nothing to tirelessly rescue her true child, but she is also now doing this for others. McCarthy positions *Generation Rescue* as dependable and trustworthy and herself as one who has the expertise to lecture others. *Generation Rescue* is described by McCarthy as 'her home station' and 'Whether you're in need at 3 PM or 3 AM, you have come to the right place. We are here for you, together resolving our heartaches and celebrating our victories. We ride Train A together'.

McCarthy's overall message is that there is hope for recovery and that with dedication the Train A mother can reclaim her true child. Having presented an overview of her story, I now turn my attention to some of the techniques and procedures evident within her narrative.

Analysing techniques and procedures

In this section, I look at some of the techniques and procedures evident within the *Generation Rescue* narrative. I look at the biomedical nature of the discourse, confusing representation, the expertise demonstrated and the idea of the celebrity-expert.

Confusing, complex and vague

There was a certainty offered in the narrative of McCarthy. Recovery is real and McCarthy positions her own son as evidence of this. At times a simple narrative, other times quite detailed. It was vague regarding a specific blueprint, yet specific regarding progress and end-result. The simplicity of the process McCarthy describes is highlighted below:

> It was changing my kid's diet, getting rid of sugar, getting rid of dairy, wheat, giving him vitamins, detoxing him, pulling out rugs, changing the paint, getting clean air (McCarthy).

In addition to its simplicity, the process is described as non-invasive. The procedures involved sound healthy and something one does not require a high level of scientific or medical expertise to perform.

Drawing upon a quote used earlier in the story of McCarthy, when discussing implementation, the process becomes vague but the progress towards recovery remains specific:

> I started the diet and within two weeks Evan said a five-word sentence and a few weeks after that after starting vitamins Evan said a seven-word sentence, then after that, I detoxed him and implemented many more therapies and within one-year Evan was undiagnosed (McCarthy).

What are presented as simple processes (a change in diet and the introduction of vitamins) are also represented as having almost immediate measurable results. McCarthy isn’t specific about the types or quantities of vitamins used. She is even less specific about the strategies applied. Her approach is simply ‘many more therapies’. McCarthy then provides a ‘measurable’ claim of recovery, that her son was undiagnosed. As will be further discussed when exploring diagnosis, it is the medical classification of autism that she relies on to qualify her success.

The stories of other mothers presented on the website were similar to McCarthy’s. A main point of difference, however, was the listing of specific dietary changes, vitamins and therapies utilised. The lists of helpful therapies presented by the selected mothers demonstrate the work ethic and commitment of the Train A mother whilst simultaneously highlighting the confusing, complex and vague nature of the approach:

> GF/CF diet with a lot of fruits, vegetables and protein “Alex had an IGG and IGE performed and he is allergic to eggs, corn, and sensitive to gluten and casein, as

> well as mushrooms, brewer’s yeast and lemon); Chelation (Epsom salt baths, malic acid/magnesium malate, alpha lipoic acid, rectal suppository of DMSA/Glutathione 3 days on/11 days off); supplements (glutathione cream, vitamin D-3, calcium with vitamin D, DMG, selenium, lithium cream, MinerAll, Spectrum Complete Multivitamin, probiotics, cod liver oil, carnitor, L-Carnosine, Detox-Aid, PhosChol, B6, B12, folic acids); other biomedical treatments (Deplin, Diflucan, Nystatin, natural remedies like grapefruit seed extract, and Brainchild Nutritionals Yeast Killer Package); HHV-6 was treated with Valtrex; occupational therapy/sensory integration; ABA/VB; speech therapy; social skills group, reading comprehension tutoring. “I am a physical therapist so I worked on his motor planning and hypotonia.” (Cindy)
>
> GF/CF diet; Specific Carbohydrate Diet; mild hyperbaric oxygen therapy for huge speech gains; Methyl B12 injections for more speech improvement; chelation to remove toxic metals; anti-fungal therapies; anti-viral and anti-fungal medications; supplementing vitamins, minerals and essential fatty acid. “For Quinn, traditional therapies have also helped a lot, including play therapy, behavioral therapy (Applied Behavioral Analysis using Discrete Trial Training then Natural Environment Training), speech therapy, occupational therapy and a social skills group. These therapies have been intensive, totaling 30-45 hours per week, and he has always had additional inclusive experiences with typical peers including Music Together and dance classes” (Holly).

The extensive lists of helpful therapies represent mothers as having what Hays (1996) describes as the assumed skills and expertise to be able to perform this act of intensive-mothering. If we compare the list of Cindy and Holly to that of the summary provided in chapter six (media analysis) under ‘*So…what should a woman do if she doesn’t want a child with autism*?’, we see a similar length of protocol. If we add the two together, we start to see how convoluted it can get for the mother of an autistic child. A prominent issue then becomes, how does one make sense of all this information? What knowledge does one listen to, how many discourses does she draw upon and how does she privilege the information given?

Vaccinations/cause

Regarding what causes autism, McCarthy says she doesn’t know: ‘What causes autism, I don’t know, we don’t know’ (McCarthy). This statement is in contrast to previous statements given by McCarthy and those analysed by (Chivers Yochim & Silva 2013, p.418) where McCarthy is quoted as saying: “Without a doubt in my mind I believe vaccinations triggered Evan’s autism”. On *Generation Rescue* McCarthy doesn’t explicitly link vaccinations with autism but she does describe how vaccinations and other toxins are too much for their true children to process. Take for example the excerpt below where she is speaking on an American talk show, *The View*:

> Picture these kids having a bucket and their bucket is the ability to process toxins, infections and let’s say vaccines. Now, these kids have a weaker immune system so they can’t keep these things in their bucket without overflowing’ (McCarthy).

Regarding vaccinations, McCarthy has previously served a crucial rhetorical function. For those who discard the relation between vaccinations and autism, she has been a target (see for example websites such as ‘www.jennymccarthybodycount.com’ - which dedicates itself to highlighting the number of deaths and preventable illnesses that have occurred since 2007 in comparison to the number of autism diagnoses scientifically linked to vaccinations). For those who support the theory, she became an authority figure. The stance taken by McCarthy sees her clarify her position:

> I’m not anti-vaccine … We do need them. I’m not, nor is the autism community, anti-vaccine, we are an intelligent group of parents that know the importance of having vaccines but we do believe it’s about time we had safe ones (McCarthy).

Whilst McCarthy admits she doesn’t know what causes autism, she does lay the groundwork for someone trying to establish her message as trustworthy in the absence of confirmatory scientific evidence:

> This autism community can show you enough evidence that something is going on with our environment that is causing this disorder … and they all said the same thing, all these parents said that something happened (McCarthy).

Here McCarthy represents the autism community as a whole, a single collective group who all think alike. The idea that the collective beliefs of the autism community specifically blame vaccines are demonstrated in videos such as the one described below:

> **Host an event:** Please if you are the parent of an autistic child please stand up (we see an entire room of hundreds of people stand up). If your child is one of those who became autistic after receiving a vaccination and you believe, you are

> confident, that it was the vaccine that caused your child's autism please raise your hand (we see what looks like the entire room raise their hands). If you can document with videotapes or photographs or whatever that your child was normal and became autistic after the vaccine wave your arms (we see what looks like the entire room wave their arms).

Although it may only be a small group, the image presented by McCarthy is that there are many who share and support her message.

In contrast to the previous chapter where pharmaceutical companies were represented as the ones with the answers, on *Generation Rescue* they are the villains. In the same video we see attendees at a conference speak about their views on pharmaceutical companies:

> **Unidentified person A:** 'They are stopping us from treating them'.
>
> **Unidentified person B:** 'There is a huge disincentive to admit that this is a problem'

Pharmaceutical companies are represented as having an ulterior motive. Such accusations are not surprising and the question of when it becomes possible to challenge the scientific evidence of the pharmaceutical industry is beyond the scope of this thesis. Having said that, leaving the more suggestive dialogue to others simultaneously removes McCarthy from being the one to make the claim and helps validate her position.

Of the seven stories of recovery presented, all seven mention immunisations or vaccinations as either the sole cause or a partial cause. These descriptions are listed as 'determined causes':

> "An overload of heavy metals and contaminants in his body, and too many immunizations!" (Jessica)
>
> "Vaccinations" (Kathy)
>
> "environmental toxins, including vaccines, dietary toxins and lead poisoning" (Holly)

The stories told by the mothers on *Generation Rescue* contribute to a competing discourse surrounding vaccinations than the knowledges that emerged in chapter six (media analysis). This results in a complicated mantra as to how and to whom one attributes the privilege of knowledge.

Vaccinations are represented as one of many causes for 'losing a child to autism'. As evident in the story told by McCarthy and the supporting stories of other mothers, vaccinations are not the only possible reason for autism taking a true child from their mother. There are others, and plenty of them. Although these factors range from carpets and paints to heavy metals and dietary toxins, one thing they have in common is that they are all external factors. Whilst in some cases it may be that the genetic disposition of the child was described as the reason their child could not handle this exposure, it is always something that has happened to them.

Attributing having an autistic child to external factors firmly places having an autistic child within a risk-based society. Whilst factors that occurred during pregnancy dominated the medical discourse within newspapers, here the risk is once the child is born. If autism is something that can happen to a child, the mother must remain ever vigilant. It is not enough to have a 'successful pregnancy', she must continue to be aware of and manage appropriately the risks of autism that can be triggered by things such as paints, pesticides, food and of course vaccinations.

The social role of the woman and the culture of motherhood create 'choices' that exist within certain spheres of production and possibility. As described by Salganicoff, Ranji and Wyn (2005), in regards to vaccinations, these choices are practiced within 'meanings of health, necessity, risk, and state intervention'. The decisions made by mothers have become a complex site within the development of a risk-centered society and risk-consciousness (Lee, Macvarish & Bristow 2010). What we have seen represented here is that the risk mothers must negotiate is complicated by multiple causes of autism. Even being a loving parent who follows the advice produced by experts within the medical model is not enough.

So, who does one listen to and why should one listen to McCarthy? As seen in the previous chapter, the everyday-expert is one whose 'authority comes from somewhere other than education or credentialing groups. Their expertise is self-taught, experiential, and instinctual' (Chivers Yochim & Silva 2013, p.411). Recent decades have seen celebrities become influential in not only the endorsement of both products and causes but are now taking on the roles of experts and activists (Demaine 2009). Current cultural systems have seen particular individuals gain voice due to a new status within the current cultural system, 'the status of the celebrity expert' (Chivers Yochim & Silva 2013, p.417).

As a celebrity, McCarthy has or is provided with access to a global audience. Her story is not confined to the backwaters of the internet or the limited audience of a mother blog. McCarthy reminds viewers of other sources who have listened to and promoted her story. In a video, available on the website, we see clips from popular television shows where McCarthy is described in the following terms:

> ***Larry King***: 'Tonight Jenny McCarthy and her relentless quest to help her autistic son'.
>
> ***Fox News***: 'Can a child recover from autism? Actress, author and autism advocate Jenny McCarthy sought for answers when the developmental disorder struck her son Evan'.
>
> ***Oprah***: 'I'm here with Jenny McCarthy who has become one of the most vocal advocates for parents of children with autism'.
>
> ***The Dr's***: 'She has made it her personal mission to encourage parents and give them new hope for recovery'.
>
> ***(20/20)***: 'For Jenny McCarthy, it was a tough call. She decided to defy the experts and try to find a treatment herself'.

Earlier we saw how McCarthy says her quest is now for other mothers. The addition of well-known media sources and personalities adds another layer to her story. In addition to her own dialogue demonstrating the quest, McCarthy also makes us aware of how her quest is viewed by others.

The perceived capability of a source to make a valid proclamation is linked to the expertise they are deemed to possess (Ohanian 1990). Not possessing any formal or accredited expertise McCarthy must find other ways to go about positioning and demonstrating her expertise. The dominant ways McCarthy goes about this were; promoting the expertise of the everyday-expert (in this case the mother), promoting the visibility of other group members who support her claims and promoting her association with others who do possess formal/recognised credentials.

A notable example of how the expertise of McCarthy was constructed and positioned was how her authored works are promoted to visitors of the website. *Generation Rescue* offers readers a recommended reading list and a store where there are books available for purchase. Aside from one, a children's picture book which is not on the topic of autism, all books available for sale are authored or co-authored by McCarthy. The salience created by the dominance of McCarthy’s work positions her as the go-to source in the area. In the books on autism published by McCarthy, there is an evolution to the construction of expertise associated with McCarthy’s message. She evolves from the individual mother sharing her story to one who adds further strength to her armour through the addition of other group members and then finally association with external sources of ‘recognised credibility’.

These qualities of the everyday-expert align with ‘notions of gendered authority’ which ‘box women into naturalised discourses of the “good mothers” who naturally know what’s best for their children—and who dedicate their lives entirely to ensuring their children’s health and happiness’ (Chivers Yochim & Silva 2013, p.410). Having elsewhere on the site made visitors aware that this was a journey she undertook very privately, ‘just herself as a mother trying to recover her son’, McCarthy documents this success in her book *Louder than words: A mother’s journey in healing autism* (2007) and is described as:

> *Louder Than Words* follows Jenny as she discovered an intense combination of behavioral therapy, diet, and supplements that became the key to recovering Evan from autism. Her story sheds much-needed light on autism through her own heartbreak, struggle, and ultimately hopeful example of how parents can shape their child's life and happiness.

Both the title and promotional text describing *Louder than words* explicitly give McCarthy expertise in the area of curing autism by claims that she has been successful in her quest. The liberal discourse of the autonomous individual who is the agent of her own success minimises other aspects such as resources and privilege whilst elevating the capability of and authoritative voice of her own role. Aside from her child who represents the evidence of her claims, there is no mention of anyone beside McCarthy, it is ‘she discovered’, ‘her story’ and ‘her own heartbreak and struggle’. This description places McCarthy as solely responsible and the sole producer of this knowledge.

As a singular entity McCarthy’s position as an expert has little capital if there is no surrounding group to protect her message from being pushed out and either forgotten or condemned to the backwaters of legitimate knowledge. Part of the volume of capital possessed by McCarthy are those who help give credibility, legitimacy and authority to what she is saying – creating a productive force that is greater than its individual elements.

One group McCarthy draws upon to help establish her expertise is the other mothers. McCarthy acknowledges the women who came before her and whilst these women are not visible – or at least not to the level that McCarthy is visible – they serve as a form of architecture around her and as a form of credibility for her position. Published in 2008 and as with *Louder than words,* also presented to visitors to the site as recommended reading was McCarthy's book *Mother Warriors: A nation of parents healing autism against all odds*:

> In Jenny's book, she shares recovery stories from parents across the country. *Mother Warriors* shows how each parent fought to find his/her own child's perfect "remedy of interventions" and teaches parents how to navigate safely through the many autism therapies.

Here McCarthy has moved from herself as an individual and her discovery to sharing the stories of others whose stories support her own. By increasing the number of written accounts McCarthy can increase confidence one may have in her as a communicator and the validity of her claims of recovery. Here other mothers serve as a function where bottom to top relations serve to further establish and hold the McCarthy network together. By being part of this network, mothers serve to "hold" the whole together by crisscrossing it in its entirety with effects of power that derive from one another (Foucault 1977, p.176-177). McCarthy's claims are supervised in the sense that other mothers support McCarthy claims with their personal experience, yet are themselves supervised by whose stories McCarthy chooses to share. There is a hierarchical network within the group. Within this network, there are groups of people, some from above, some lateral and some from below and what makes McCarthy's visibility perpetual is her position at the top of this. As noted in the description it is 'Jenny's book' and it is she who is sharing these stories, she is the matriarch of this expertise and her flock supports her claims.

McCarthy's first two books help to establish both her own position and a network to support her claims. What McCarthy's claims were missing was a source outside of her group – support beyond other mothers. This is particularly problematic for any source of a claim that is contradicting the knowledge of Herculean disciplines of science and medicine.

In the third of McCarthy's authored work on autism, *Healing and Preventing Autism: A complete guide* (2010) she extends not only her network of support to include credentialed backing but also extend credit beyond her own actions:

> Jenny McCarthy has teamed up with Dr. Jerry Kartzinel, the doctor who recovered her son, to write *Healing and Preventing Autism*. Their new book provides all the necessary information about biomedical treatment from diagnosis, dietary interventions and environmental changes for the home, to advanced therapies that doctors use today.

Here we see almost an abandonment of the self-proclaimed discovery previously orated whilst almost but not completely the giving of credit – as Chivers Yochim and Silvia note (2013, p.421) the 'traditional medical expert is acknowledged and then minimised in the use of the title with the familiar first name'. Even when giving credit, the expertise of McCarthy is not positioned below the Dr, rather alongside - they have 'teamed up' and it is 'their new book'. By teaming up the book is suggested to contain 'all the necessary information' needed and thus this is the pinnacle of need to know knowledge. The positioning of McCarthy with Dr Jerry Kartzinel gives credibility and attributes knowledge to McCarthy beyond that of the mother instinct she claims as the basis for her success. This allows for McCarthy to simultaneously associate her message with that of the warrior-mother and the also masculine knowledge associated with credentialed expertise.

Definition of autism

In this section, I briefly look at the definition of autism and how it is described. I examine the terminology used and how autism is confined to children. What we see in this section is how autism becomes the villain within the narrative of McCarthy and *Generation Rescue*. Similar to my findings in chapter six (media analysis), autism was something to fear and was associated with a mass kidnapping and national emergency. Autism was described as having taken a mother's true child, the true child is now trapped, and a fake child present.

Terminology

McCarthy talks about how her child is now healthy and a typical little boy. Interestingly, in comparison to the discourse analysed from newspapers where ADHD was represented as unhealthy, here, the mother's child is healthy if they only have ADHD. It is autism that makes them unhealthy:

> ADHD yeah, autism no, after one year of treatments he became a typical, healthy happy little boy' (McCarthy).

A similar description of health is told by Kathy and again, like McCarthy, comparison to other children is made:

> He was able to have conversations with us, show emotions and became like his peers. He is not even on the spectrum anymore. He does have ADHD, but that is nothing compared to the utter hell we went through for a few years there (Kathy).

Drawing on comparisons between other children, what are typical ties into western biomedical frames of normative identity (Douglas 2013). Comparison to the child's peers is used to determine what the child should be.

Within the above description by Kathy we also see the consequences of having the fake child present, they make the parents' life 'utter hell'. Types of difference are ranked by Kathy, and whilst her child may have ADHD that is nothing compared to the hell that is the fake autistic child.

As we are made aware of by McCarthy, this true child was not always trapped - 'something happened to them' (McCarthy). It is made clear to viewers what has happened to these children, they have been taken by autism:

> I knew my greatest accomplishment in this life was being his mother. Little did I know at the time, that the future held something else for us to accomplish together. That was to bring him back from the disorder that took him…….autism (Sabrina - ellipsis in-text).

There is a hatred for autism demonstrated. We see quite clearly in the example from Sabrina the idea of the villain that is autism and how it can kidnap a child. Autism becomes not only something to hate but to fear. Autism is the threat and as discussed in detail later in the chapter, the warrior-mother the saviour.

The fear that autism may take a mother's true child is further entrenched by the rate at which autism is described to be increasing. McCarthy talks about it being a 'too common a story' that is 'becoming ever more common'. In a video placed above McCarthy's message as president, background information is presented to the viewer with information such as:

> 'In 1983, 1 in 10,000 children developed autism' – 'Today 1 in 91 children will develop autism'.

Similar to statements made in the previous chapter (regarding 'autism being the fastest-growing developmental condition in the western world), there is a complete absence of a source of the information or processes by which the information was gathered. Again, the information is simply presented as a fact. Autism is an issue that is threatening our children and doing so on an epidemic scale. Autism is again not part of the person. It is something they develop.

The confinement to children

The narrative of McCarthy limits autism to children. McCarthy has recovered her son and so he does not grow into an autistic adult. She does not advocate for services or facilities to help autistic adults; her fight and her journey are now about the recovery of other children. This is consistent with the slogan of *Generation Rescue*:

> We are dedicated to recovery for all children with autism spectrum disorders by providing guidance and support for medical treatment to directly improve the child's quality of life for all families in need.

It is 'children' *Generation Rescue* is dedicated to recovering and the quality of 'children's lives' they seek to improve. Whilst family is mentioned, it is by association. Fix the child, fix the family.

Whilst the child-centred focus places the mother as a key player, confining autism to children creates several other issues. In their research surrounding the child-centred focus of autism, Stevenson, Harp and Gernsbacher (2011) identify and explore a number of these issues. *Generation Rescue* are not alone in their child-centred focus. When picturing an autistic individual, members of the public are far more likely to envision a child, rather than an adult (p.1). The concept of the autistic adult has no traction. Adults are not seen as cute or innocent or as beacons of hope for the future' (p.7). Taking the concept further, Stevenson, Harp and Gernsbacher (2011, p.2) bring to light discourses produced by the autism "advocate" community who suggest that autistic adults do not exist. This may be simply attributed to radical or [minority] views, but when one considers that the most prominent U.S. autism charity, *Autism Speaks*, reports the number of "autistic children to be identical that of autistic people", this is the denial of the existence of the autistic adult (Dawson 2008; cited by Stevenson, Harp & Gernsbacher 2011). The representation of autism on *Generation Rescue* is something children can recover from and eliminating autistic adults links to this rhetoric. If children can recover from autism, technically, none should become autistic adults.

Good mother

As per one of the main aims of my project, an aim of this chapter is to gain an understanding of what this knowledge is telling us about mothers of autistic children and what are some of the effects. I am particularly interested in what we are told the 'good' mother of an autistic child looks like. How does she behave and how she presents herself? Similarly, I am also interested in what the 'bad' mother looks like.

Similar to Douglas (2013) I draw upon Foucault's second meaning of the subject, and as Douglas (2013) suggests, possibly in a way he may not have intended. Foucault (1982, p.781) argues that the subject is 'tied to his own identity by a conscience or self-knowledge', implying that 'we come to know ourselves as subjects through identity as a particular, and embodied, historical possibility' (Douglas 2013, p.174). In the current climate of understandings of difference and disability, 'it appears beyond question (and almost cruel to suggest otherwise) that *because of* her loss (the loss of her child's normal and healthy development), a mother is grieving' (Douglas 2013, p.169). For McCarthy however, there is no acceptance of her grief. She has hope and ultimately her hope, bargaining and hard work have paid off. McCarthy does not accept the child in front of her and ultimately her story suggests she does not have to. She does not have to accept the false, autistic version of her child because as a successful and dedicated Train A mother, she can recover her true child. Her acceptance is the acceptance of having her true child.

The work of the Train A mother is similar to that of the warrior-mother discussed by Sousa (2011, p.227) in that they are required to develop 'new knowledge, skills, and expertise specific to them'. 'Mothers become the primary advocates, spokespeople, service providers, researchers, and first responders for their children' as they perform 'feats of superhuman strength' (Sousa 2011, p.228). It is the Train A mother who must accept the diagnosis of doctors so that they can then defy the advice of doctors and believe in the idea of her true child.

The story of blame is different in this chapter to the previous (media chapter). Rather than being blamed for creating the autistic child, recovery produces a new form of identity for the good mother. The mother who was once held responsible is now the agent of recovery. Rather than being represented as mothers who have 'failed', these mothers are represented as dedicated and 'successful'. In contrast to the prevalent discourse of the 1950's where mother-blame created the autistic child, here we see external factors blamed and the mother becomes the saviour. Taking up the position of saviour, however, raises a new form of responsibility for the mother. If she is capable, she is also responsible.

Rather than the behaviour of the distant mother causing her child's autism, the preoccupied, or 'woe is me' mother can now be held responsible for failing to produce her child's recovery. Particularly suspect within the 'refrigerator mother' theory during the mid-

20th century were highly educated mothers. Here, however, the educated mother is represented as bringing with her knowledge that can be used to reclaim her child. Mothers must educate themselves on what works and what doesn't for their own child. And as demonstrated earlier, there is an extensive list of things, such as different foods, therapies and injections, she must learn.

The successful Train A mother works hard. What is evident in McCarthy's narrative, is that, with the work that is required, and only with this work, the true child can be reclaimed. Whilst earlier (and across the website) McCarthy spoke of the deal she made with God, God did not miraculously fix her boy, concurrent with the deal she made, God showed her how to do it. The idea of hope that drives the Train A is somewhat guided upon the idea of faith and the protestant work ethic one can see embedded within her story.

McCarthy's way of thinking and being a Train A mother, not only encourages but also dictates the work and responsibility of the mother. If one is to heal her child, one must not only believe in the possibility, one must also commit themselves completely. In many ways, McCarthy legitimises the condition of autism as being something the mother of a lower work ethic has relegated herself to. Much as work was the path to godliness and sloth was the path to sin, the road to recovery is hope and dedication and the path to never freeing your true child is 'woe is me'. McCarthy's good mother narrative not only represents her as a particular type of mother but also creates an imagery of what she is not – i.e., a bad mother. In this case, good mothers have good children and bad mothers have bad children. Or more specifically, Train A mothers have their true children and Train B mothers have their fake autistic version.

As argued by Ladd-Taylor and Umansky (1998, p.3), 'bad mothers' have been categorised into three groups: 'those who did not live in a 'traditional' nuclear family'; 'those who would not or could not protect their children from harm'; and 'those whose children went wrong'. If a mum can recover her taken-child, she not only no longer has a child that went wrong, she can also reclaim what autism has threatened to take away. The train B mother, however, remains a 'bad' mother. Her 'woe is me' approach to mothering fails to see her dedicate her focus to her child. The current climate surrounding intensive-mothering sees others hold mothers accountable for their child's development (Francis 2012, p.927). The attitude of the Train B mother is represented by McCarthy as one who would rather feel sorry for herself than work hard for her true child.

Although McCarthy's warnings of vaccinations and other environmental factors create a space where it becomes possible to attribute blame to a mother who fails to heed these warnings, the Train B mother is not actually blamed for creating her fake autistic child. She is however blamed for her maternal performance. The dichotomous split between mothers represented by McCarthy creates conditions where individualised mother-blame is possible. The mother can be held accountable for leaving her true child forever trapped by the villain that is autism. She has failed in her maternal responsibility and will remain with the version of her child that went wrong.

McCarthy associates blame and reward in a self-serving manner. McCarthy's narrative attributes cause to external factors (i.e., the environment and vaccinations) and attributes success to internal factors (her instinct and hard work). This narrative is one that ignores or minimises differences surrounding class and gender (Douglas 2013). Whilst the outsourcing of blame in this chapter is prevalent, the power of the mother is equally so. Mothers can change the outcome of their child. Stories of recovery discussed within a space where privilege can be transmitted, particularly regarding one's ability to access and invest in resources for their children (Lareau 2003).

The power given to the autonomous, self-governing mother is based around her entitlement to consume information and services (Reich 2014). McCarthy and *Generation Rescue* highlight that if mothers wish to move from mother of an autistic child to mother of their true child, they have work to do. This positions mothers of autistic children as a group towards whom unique offerings can be introduced.

Consumption

Mothers are represented on *Generation Rescue* as aspiring towards the recovery of their taken and now trapped child. These aspirations are represented as achievable - not only through knowledge but by buying the appropriate tools. On *Generation Rescue* there is a store where mothers can shop for the products promoted on the website. Here mothers can shop for and find links to products such as: enzymes to control yeast overgrowth; enzymes to enhance digestion; therapeutic proteolytic enzymes to increase immune health; ultimate sauna detox environment; probiotic lysate; omega 3; Dr. Bo's® Kids Focus; functional lab testing; master detoxifier; medical grade sleep products, toxic-free kids and baby mattresses and hyperbaric chambers. Excluding the cost of purchasing and maintaining the larger scale products such as 'master detoxifiers' and hyperbaric chambers, if one was to try every vitamin product recommended or promoted on the *Generation Rescue* website the initial expense would be approximately $627. This is based upon only ordering the product one time. This denies or limits access for many to perform the role of the successful Train A mother. It is also reflective of why the experience of intensive-mothering is experienced predominantly by the middle and upper class (Reich 2014). Whilst the discourse of intensive-mothering has pervaded motherhood at all socioeconomic levels, it is those who have the resources to 'invest most heavily in their child's development' who intently experience or engage in the practice (Reich 2014, p.681).

In addition to the countless products and services the successful-Train-A mother consumes in her quest of recovery, the successful-Train-A mother also consumes for herself. Whilst traditionally the feminine subject has been the object of consumption, the neoliberal, post-feminist subject is able to construct her identity through the consumption her independence offers her (Ringrose & Walkerdine 2008). McCarthy tells visitors to the website how excited she is to have discovered the *True Goods Website* and she can now 'obsessively shop'.

In a society where consumption has replaced production as the primary marker of identity (Svendsen 2016), the Train A mother can now construct her identity through consumption and do so in a manner that is attached to the good mother who does not put her true child at risk. As stated by McCarthy, 'happy guilt-free shopping'. The successful-guilt-free-Train-A-mother can obsessively shop. She can consume herself into being. For the successful-guilt-free-Train-A-mother, the right labels are those that are toxic-free. The toxin-free approach becomes her marker of identity.

McCarthy provides her 'Top 3 Picks': an SPF 34 anti-bug sunscreen, a multi-purpose organic cleaner, and a FIG+YARROW clay mask. McCarthy describes how after finding the chemical and toxin-free bug spray she is now beside herself with happiness and 'one happy momma'. How the organic cleaner 'smells yummy' and her 'countertops are now always clean and safe'. The gendered nature of her role is apparent. The successful-guilt-free-Train-A-mother can perform her role as caregiver, keep her true child safe from bugs and UV rays as well as perform her domestic role and maintain a home that has a kitchen that is always clean and smells yummy.

In addition to caring for her child and maintaining an appropriate private space, the successful-guilt-free-Train-A-mother can also commit herself to her appearance:

> I especially love this product because I know when I make a commitment to using it, I also allow some down time to myself … I can feel my skin tightening and my pores shrinking. When it comes off, my skin is as smooth and soft as when I get a professional facial. A perfect product to treat yourself with from True Goods! (McCarthy)

In a society that is tending towards a neo-liberal mindset, one is considered free of the ties of class and considered responsible for their own destiny (Rose 1999). Individuality and responsibility for taking care of one's physical appearance have become an important moral issue (Bordo, 1993). The socio-political landscape summons women to reject feminism so they appear contemporary, sexy, and cool (McRobbie, 2009).

Treatments that 20 years ago would have been reserved for the 'very rich are now advised as necessary and routine' (Littler, 2013, p.230). McCarthy combines her status as a wealthy woman who can afford the luxury of professional treatment, and thus has reputable knowledge of the area, with that of the busy mum who makes the commitment in a manner that coincides with her chemical and guilt-free approach. The do-it-at-home nature of the product means the mother doesn't abandon her child to spend time on herself at a salon, and the onus of the commitment to such beauty treatments then becomes, regardless of socioeconomic status, that of the self-governing subject to regulate herself rather than neglect herself in the 'woe is me' fashion of the Train B mother. Such influences are part of a broader image of neoliberal responsibility for the mother of the autistic child. Whilst positioned as individual responsibility, both the dedication to rescuing her child and her compliance with what is youthful and attractive, the appearance of things such as tight smooth skin, is framed as one of power, control and pleasure.

Both Douglas (2013) and Chivers Yochim and Silva (2013) discuss physical appearance in their analysis. Douglas (2013) describes the feminine-warrior as instrumental, sexy and successful. She describes how the gown wearing, low neckline, high heeled mother, poses as ready to run, fight, box, pose '"Charlie's Angel's" style or stand with motorcycles, ready to race'. This feminine-warrior imagery may aim to contradict forms of femininity that associate the female with weakness, but it does so with an exaggeration of the accomplished, yet almost trophy, wife prototype. Chivers Yochim and Silva (2013, p.422) note how: 'In this and all of her media appearances, McCarthy presents herself as the mom-next-door. The formerly raunchy comic has softened her look—toning down her makeup and cutting her hair into a sweet bob'.

Following on from my analysis that looked at the verbal or written narrative of McCarthy, I now turn my attention to the visual – the representation of the exterior body in social space (Turner 1984, p.91). Whilst McCarthy exhibits imagery of the feminine-warrior identified by Douglas (2013), she also adheres to the more recognised forms of femininity and conservative or restrictive images of motherhood identified by Chivers Yochim and Silva (2013). What is also notable is that these are not the only visual identities taken-up. Before discussing the performance of McCarthy regarding her appearance, I would first like to revisit the disciplinary gaze described by Foucault and its applicability beyond the role of motherhood I have mainly used it for up until this point.

Appearance

The successful-guilt-free-Train-A-mother represented by McCarthy is not the 'abject working-class woman who fails as a subject/object of desire and consumption, and lacks requisite qualities of self-reflexivity necessary for reinvention' (Ringrose & Walkerdine 2008, p.228). She can remain young, desirable, presentable and consumable whilst simultaneously identifying her success and status through the consumption of appropriate Train A products. The well-put-together image McCarthy portrays suggests her success as an autism mum. There is an absence of visible stress or time pressure, a mother whose fatigue has caused her to neglect herself. 'Like the neoliberal, postfeminist "yummy mummy," this feminine-warrior "has it all" – kids, career and beauty' (Douglas 2013, p.177).

Disciplinary gaze

The panoptic gaze described by Foucault is comparable to the gaze that surveys women 'for possible "transgressions" against the patriarchal ideals of femininity' (Duncan 1994, p.50). The panoptic gaze represents 'a state of conscious and permanent visibility that assures the automatic functioning of power" (Foucault 1977, p.201). The power enacted is fluid, it is not held by an institution or an individual. As described by Bartky (1988, p.74), 'the disciplinary power that inscribes femininity in the female body is everywhere and it is nowhere; the disciplinarian is everyone and yet no one in particular'. The circulating power is productive. There is a normalising process of the body where individual women embody particular ways of thinking, being and acting (Azzarito 2009). Women become both spectator and spectacle to surveillance (Spitzack 1997). As spectators, women self-monitor their appearance, becoming objects of their own gaze (Duncan 1994, p.50).

Femininity in the west is constructed as ‘attractive, deferential, unaggressive, emotional, nurturing, and concerned with people and relationships’ (Wood 1999, p.22). Cultural representations of beauty are largely homogenous, emphasise the feminine ideal of slenderness and firmness (Bordo 2003; Hesse-Biber 1996) and privilege whiteness (Collins 1991). Although hegemonic, image norms are produced depending on the role being performed. Rights and rituals of “doing gender” and sexuality are guided by behaviours, beliefs and symbols that ‘reinforce heterosexuality and male dominance and “naturalise” stereotypical images of women’ (Kwan & Trautner 2009, pp.771-772). Constructions of beauty ‘types’ include; classic beauty/feminine, sensual/exotic, cute, girl-next-door, trendy and sex kitten (Ashmore, Solomon & Longo 1996). The classification of beauty ‘types’ produces ideas of normality and abnormality based around these norms. and these procedures provide a measure of difference, a basis of comparison, between subjects.

Ringrose and Walkerdine (2008) suggest that successful femininity is bourgeois. Neoliberal reinventions of femininity place a new importance upon the feminine subject and her possession of the necessary skills to change oneself across key sites of social formation (Aapola, Gonick & Harris 2005). Motherhood is one such site of formation. The yummy-mummy is a title that ‘signifies a woman who appears to be successfully juggling motherhood, career, and sexuality, as well as looking stylish and trendy *all the time’* (Pitt 2008, p.7).

McCarthy’s physical appearance adheres to western bourgeois standards, she is ‘slim, fit, white and flawless’ (Douglas 2013, p.176). This western bourgeois standard serves as a platform for McCarthy to authorise her position as a successful-Train-A mum. This authority, however, is constrained and subject to possible “transgressions” against the patriarchal ideals of femininity. This sees the accomplishments of the Train A mother disciplined to a self-regulatory and ever adapting form of performance without “transgression”.

Classic beauty

Earlier in the chapter, I discussed the progression of McCarthy’s authored works. An interesting observation regarding the books discussed is that although McCarthy adapts the imagery in the way of who is pictured, her individual appearance remains consistent. On the cover of *Louder than words*, where McCarthy represents the successful, autonomous individual who is the agent of her own success, we see only McCarthy and her child pictured. In *Mother*

Warriors where McCarthy moves from her as an individual and her discovery to sharing the stories of others whose stories support her own we see McCarthy and her son as the central picture and then surrounded by other parents and their children (three are just the (assumed) mother and child and two are both the (assumed) mother, father and child). Similarly, on the cover of *Healing and preventing autism* where we see her extend her network of support to include a credentialed doctor (symbolised by his white coat), we see McCarthy pictured with Dr Jerry and surrounded by various smiling children. On each cover, McCarthy represents a clean family-friendly image. She is conservative, well-groomed, smiling and embracing either her own or other smiling children. I argue here that McCarthy is drawing on the good mother and domestic goddess discourse of the 1950's (groomed yet chaste) and the classic beauty discourse. The classic beauty discourse represents 'fair skin, feminine, glamorous, and sophisticated' (Frith, Shaw & Cheng 2005, p.12). The images are consistent with a loving, caring mother and the close bond they share. McCarthy's blonde hair is perfectly styled. There is no aggression, no cleavage, but rather a clean-cut styling that is soft and nurturing – an image representative of the topic of 'healing' and the idea that this comes from a mother's love.

Strong and assertive

Traditional femininity is not aggressive. The reinvented femininity enacted by McCarthy sees her, at times, reject this ideal. The strong and assertive image embodied by McCarthy can be seen in articles such as '*Whose afraid of Jenny McCarthy*' where 'McCarthy speaks out about vaccines and how she found the "window" to her son Evan through biomedical treatment and therapy'. In contrast to the previous image, we see a stern face of strength, confidence a woman not to be messed with. She does not shrink into space, rather extends into it (Young 1980). Rather than the domestic goddess (groomed yet chaste) of the 1950's McCarthy embodies the working mother of the 1980's (powerful and besuited) (Woodward 1997).

The cropped image and rollneck sweater limit any sexualised focus and any possible association or distraction that may arise from her surgically enhanced chest. By eliminating her body from view, McCarthy limits the site of her 'otherness' – her breasts, her hips, her waist and buttocks (King 2004, p.34) remain out of view. Her body is not a spectacle but she remains a spectator to the disciplinary gaze of what is strength, and strength is not the otherness of the female form. By eliminating her body from view, McCarthy eliminates the femininity associated with it.

Any transgression against traditional femininity, however, is balanced with traditional aspects of femininity, beauty and the successful bourgeois subject. Her white skin and perfectly dyed blonde hair stand out in contrast to her dark sweater. Her cropped blonde hair is tousled, slightly windswept and matches the perfectly applied make up to highlight features such as her cheekbones. Even when resisting patriarchal ideals, McCarthy is consequently still 'doing' femininity. She portrays the alluring and desired feminine object of heteronormative gaze (Butler 1993) but with 'traditionally masculine subject positionalities' such as assertiveness, strength and autonomy (Ringrose & Walkerdine 2008, p.231).

Sex kitten

An interesting observation regarding how McCarthy disciplines her appearance is the distinction between when she embraces the conservative yet well-groomed mother and a more sexualised and sexually desirable individual. McCarthy promotes her *Holiday Bash* to raise money for autism (specifically *Generation Rescue*) with the slogan 'come be naughty or nice'. The promotional image used, in combination with the 'naughty and nice' slogan, sees McCarthy return to her Playboy sex kitten persona. The sex kitten is characterised as 'sexually attractive, usually wears sexy attire or revealing clothing' (Frith, Shaw & Cheng 2005, p.12). McCarthy dons a slinky short red dress, paired with what are often referred to as stripper stilettos (stilettos that include a platform base), tousled long blonde hair, flawless skin, heavy eye make-up and lipstick. Crouched on her knees, the image is far from the domestic servant there to scrub one's floors, nor is she praying to God for guidance. This image is in direct contrast to that of the clean-cut image represented on the cover of many of her books where her target audience is that of the mother or potential mother. The imagery of McCarthy across the website shows her adaptability. Her success allows her to inhabit whatever form is necessary for a situation.

Cruelty

The final point I would like to explore in this chapter is the idea of cruelty. Much of the cruelty described within this chapter is disguised within the cloud of hope, after all, the idea of hope is everything for McCarthy: 'Hope is the only thing that will get us up in the morning'. The guise of hope offered casts the individual mother along a very direct bourgeois path, coded as universal, normal and attainable for us all (Ringrose & Walkerdine 2008, p.228). This creates an environment which can see the mother caught in a cruel attachment to possibility or what Berlant (2006) refers to as "cruel optimism".

Cruel optimism

'"Cruel optimism" names a relation of attachment to compromised conditions of possibility' (Berlant 2006, p.21). The idea of 'cruel optimism' sees one attached to the idea of possibility. The possibility offered by McCarthy is the mother's true child.

'When we talk about an object of desire, we are really talking about a cluster of promises we want someone or something to make to us and make possible for us' (Berlant 2006, p.20). As Douglas (2013, p.169) says, 'stories about mothers fighting against autism make sense to us – mothers must do so, and do so out of love, *in order to* give their child future happiness and success'. It is however not simply the future of the child at stake. Representing a child free of autism as a mother's 'true child' links back to the idea that there is a certain standard of child we think the mother should have. The attachment to possibility described by Berlant (2006, p.21) is 'not merely inconvenient or tragic' but rather that 'one might not well endure the loss of their object or scene of desire'. A mother's true child has been taken. By offering mothers hope against the threat of autism, McCarthy and *Generation Rescue* portray the autism-free child as the object of the mothers' unquestionable desire.

With autism represented as a threat to health, happiness and wellbeing of individuals, families, communities and nations, an issue perhaps arises when one '*inevitably'* fails (Douglas 2103) in their quest to recover their true child. The message represented by McCarthy is not simply that of hope and that recovery is possible, but that if one strategy does not work, the mother should never give up and simply change strategies. There is no end-point offered other than recovery. No limit to the strategies she can or should try, she should just keep trying:

> "Never, ever, ever, ever, ever, ever give up! Keep individualizing treatments and find the right protocol that works for your child. Every child has the potential for greatness. It is our responsibility as parents to help them achieve that potential." (Kelly);
>
> "Hang in there! When you don't see the changes you're hoping for, don't give up! Change strategies, diet, supplements, doctors, therapies, etc. Be relentless, go to conferences. Keep visualizing the future you want for your child and your family. There is always hope" (Holly).
>
> "Each child is different. Just move on if a treatment does not work, and go to the next one. It can be discouraging, but sometimes you have to go through what does

> not work to get to what does. Children can recover. Don't give up. It takes time, but it’s well worth it.” (Kathy)

Mothers are told to keep trying, keep fighting for their child. The future of their child and their life as a mother is at stake.

What isn’t mentioned is what personal and financial expense comes with chasing this possibility. The secondary, if existent at all, considerations of the mother’s interests beyond her child are situated firmly within that of the ‘good’ mother discourse. The ‘good’ mother devotes ‘limitless time, energy and resources to their children’s development while disregarding any self-interest that may conflict with children’s needs and desires’ (Sousa 2011, p.220).

Whilst the offerings of McCarthy may be cruel towards the mother, the Train A mother becomes cruel herself. Until she recovers her true child, the Train A mother can never accept the child she has. The promise of her true child cruelly rejects the autistic child. The loving mother continually focuses on what is wrong with her child. If she sees autism as something that has happened to her child, the mother must reject her child. She may fight for her trapped child, but ultimately she does not and cannot love or accept the child in front of her.

Summary

The ‘good mother’ discourse represented by McCarthy is the Train A mother. The Train A mother does everything she can for her child. She works hard, is self-disciplined, self-reflexive, has hope and is both a healer and a fighter. She is also successful and able to consume. The successful Train A mother lives a toxin-free, guilt-free life whilst maintaining a flawless, youthful, yet appropriate appearance. The Train A mother does everything she can for her child. It is not the child she has, however, that she does everything for. As we have seen throughout this chapter, the Train A mother fights for the child that autism has taken from her. She fights for her true child that is now trapped by the cloak of autism. She is not the Train B mother who is ‘woe is me’. ‘Good’ mothers are presented with and recognise a moral duty to rescue ‘their’ child. This discourse works to simultaneously both entrap and empower the mother (Ruddick 1980).

McCarthy presents a clear view within an ideological debate. Her view does not consider the autistic child as anything other than something that should be eradicated. This eradication can be achieved by consumption and hard work. Rather than ‘good mothers’ having good children and bad mother having bad children, Train A mothers have their true children and Train B mothers have their false, hell driven autistic version.

The Train A mother does not resist the traditional sphere of motherhood, she embraces it. In contrast, she does not embrace mothering until it is the appropriate child she has to mother. Whilst the message is clear, the narrative reads more as a ‘choose your own adventure’. The commodification of mothering of an autistic child creates a platform where the notion of miracle cures for autism often creates unrealistic hopes and expectations for both parents and the wider community (Baird, Cass, & Slonims 2003). This where hope becomes cruel. Such hopes or expectations tie into the notion of mother’s compliance and submission to ‘best practice’, attaching mothers to the oppressive practice of intensive-mothering which limits their freedom and reduces their well-being.

So, what can be drawn from what mothers are being told by McCarthy and *Generation Rescue*? Overall, mothers are presented with an interesting dilemma. Engage in practices that actively seek to eradicate the child they have or be thought of as lazy and uncommitted. The knowledge produced within the website creates an uncomfortable place for a mother to inhabit.

CHAPTER 8: INTERVIEWS (PART A) OBSERVATION, BLAME AND RESISTANCE

Chapters six (media analysis) and seven (Jenny McCarthy and *Generation Rescue*) analysed the information available to the public. The dominant way that autism was represented within the data analysed was that of the undesirable subject whose existence should be avoided or eradicated. Cause dominated the newspapers analysed whilst cure dominated the narrative on *Generation Rescue*. Mothers were represented as devastated and as warriors who fought to either make life better for the autism community (as per chapter six) or fought tirelessly to rescue their true child (chapter seven). Both mother-blame and responsibility were prominent across both sets of data. The right to have a non-autistic child, the child a mother deserves, was tied up amongst the assumed duties the mother was required to perform to ensure she obtained this child.

Across the next two chapters (chapter eight and nine), I present the key findings from my interviews with mothers of autistic children. These two chapters focus on addressing the final research question of the study:

RQ: 3) How do mothers of autistic children negotiate the subject position of mother of an autistic child and what are some of the lived effects of this subject position?

Chapter eight examines the shift from 'mother' to 'mother of an autistic child'. Chapter nine examines institutional power, discipline and authority. Both chapters examine the dominant discourses identified in my interviews. Similar to the results found in chapters six and seven, these discourses include mother-blame, the 'good' mother, the 'bad' mother, intensive-motherhood and the medical discourse of autism.

In this chapter (eight), I demonstrate how both the family unit and 'expert' knowledge functioned as a mechanism for observation. Mothers' children were measured against standards of normative behaviours and led to a new identity for mothers, becoming mothers of autistic children.

A key discourse identified was 'mother-blame'. This was consistent with the findings of chapters six and seven. Importantly in this chapter, I also found that up until a point, mothers were effectively compliant with the ‘mother-blame’ discourse and participated in its reproduction. Mothers discussed ways they blamed themselves and the ways they were blamed by others.

Another important finding was that blame by others was often directed at the ‘failings’ of mothers as individuals. The construction of what is a ‘bad’ mother and what is a ‘good’ mother dominated how mothers believed they were viewed, perceived and treated. They felt it was the deviant characteristics of an individual mother (her marital status, her age, her nationality) that were the target of mother blame. Autism disappeared. When it came to mother blame, the strength of the ‘bad’ mother discourse was dominant enough to override the medical discourse of autism.

Another dominant discourse identified was intensive-motherhood and again mothers were active participants in its reproduction. There was some resistance to the institution of motherhood (as responsible and intensive) but ultimately, rather than question the discourse, mothers tried to find a place within it. When resistance did occur, paradoxically it resulted in mothers becoming even more deeply immersed in the intensive-mother discourse.

As mentioned above, mothers were not always passive participants in accepting the discourses of ‘mother-blame’ and intensive-motherhood. Although early parts of the chapter identify ways in which mothers were compliant with and actively reproduced dominant discourses, as I move through the chapter I identify how mothers were not wholly constructed by any one discourse.

For Foucault, ‘a discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling point of resistance and a starting point for an opposing strategy’ (Foucault 1978, p.100-1). To resist is not in the quest for the ‘absolute’ truth but ‘of detaching the power of truth from the forms of hegemony, social, economic, and cultural, within which it operates at the present time’ (Foucault, in Rabinow 1991, p.75). The detachment of mothers from the offerings of discourses such as schooling and mother blame meant mothers were able to carve out a space where they could perform motherhood in a way that felt more comfortable.

Although still located in prevailing power relations, mothers spoke from other subject positions. Although the diagnosis called mothers to action, after being called, mothers often questioned the subject position they were being asked to take up. After receiving their child’s diagnosis mothers turned towards information specific to the new identity being pressed upon them. Of importance, after ‘turning towards’ information or expectations, mothers would often ‘turn away’. ‘Turning away’ did not mean that they refused the subject position of ‘autism mother’ as they would ‘turn back again’ but with the desire of finding a different way to negotiate the position. Whilst they always eventually ‘turned towards’ the subject position, they navigated their way through which kind of autism mother they would be.

Discourses of motherhood meant ‘autism-mothers’ could never be, ‘good’ mothers. The pervasive good mother discourse immersed mothers of autistic children in a never-ending loop of failure. Furthermore, even though mothers interviewed engaged in practices ‘normative mothers’ did not have to, these experiences, or knowledges, were not privileged. This additional mothering knowledge was something the ‘good’ mother did not require. Whilst still subject to the ‘good’ and ‘bad’ mother discourse, ‘autism mothers’ were disciplined to engage in intensive-mothering practices but had to do so from a deviant position. Nonetheless, whilst mothers often questioned the information available and imposed on them as an autism-mother, rarely did they question or resist the dominant constructions of motherhood.

My interest in this first section of the chapter is the contingent and fragile nature of identity (Zembylas 2005, p.936) and how it was mothers came to be reconstructed as ‘mothers of autistic children’. As vectors of power (activity of shaping) some mothers were hesitant to place the subject position of autism on their child. However; I found no evidence of any resistance or disagreement as to whether their child would be classified as autistic through the medical discourse. By this I mean they did not disagree with the diagnosis but were sometimes hesitant to share that diagnosis.

The Becoming of the Other

Although there was no singular experience of mothering an autistic child and mothers were from a variety of demographic categories (e.g., age, nationality, suburb of residence), there was one thing all mothers shared and that was having a child diagnosed as autistic. As such, there were experiences that regardless of circumstance or individuality, all mothers experienced. Even though some mothers were single, some were in paid employment, for some English was their second language, all mothers experienced there being a need or a trigger to have the category of autism placed on to their child, all experienced how it felt for that category to be given and all faced the issue of if, when or how to disclose that information to others.

Trigger for diagnosis

The first experience mothers shared was there being a reason/s to seek or be given a diagnosis of autism for their child. My interest here was developing an understanding of what drove, or resulted in, the mothers' procurement of a new identity for both themselves and their child – the shift from mother to mother of an autistic child. Identity, which is the placing of a subject position (something that is continually constituted and in an ongoing formation), cannot transpire without the normative assessments of a particular discourse (Walkerdine 1987). A post-structuralist concept of identity views it as something that has and is being constructed in and through knowledge-making practices (Stronach et al. 2002). Western mothers are already positioned within the knowledge of paediatrics and childhood development. What emerged throughout my interviews was that it was often the mothers' knowledge and understanding of typical childhood development, rather than an understanding of what autism 'is' that led to there being a diagnosis.

The becoming of the other was largely driven by observation of the child. Mothers participated in techniques of observation, participating in knowledge making, its effects and possibilities for regulating populations. Essentially bringing the family unit into bio-power (the analysis, explanation, definition and desire to shape individuals bodies and their behaviours (Danaher, Schirato & Webb 2000, p.ix)). For some mothers, the reason to seek a diagnosis came about due to something they themselves noticed due to comparison to a sibling, which was then reaffirmed by a comparison between their child and those of a similar age group. Essentially, mothers are vectors of power and other children were used as a mechanism of comparison. An example of this type of observation emerged during my interview with Jessica:

> **Jessica -** Harry is our second child, and so we noticed that he wasn't hitting the same milestones … the first thing we were worried about was the lack of speech. So, his first diagnosis was a severe language disorder … as time went on, we knew that the gap between Harry and his peers was becoming greater. And I'd see these other accomplished little boys and think, "Harry can't do that, or won't do that, or isn't able to do that." Um, and so we actually then started asking about a diagnosis ... But I think we were at a point there when we went, we actually need an explanation for why there is a gap, and why he hasn't improved over time.

The previous experience of having a neurotypical or 'normal' child had allowed Jessica to see and observe a particular trajectory of development. That her second child had not met the same observable milestones as her first child caused concerns and resulted in an initial diagnosis of severe language disorder. However, as stated by Jessica, once further interpersonal observations were made between her own son and what Jessica describes as “accomplished little boys” there became a blurring of boundaries between what the child needed and what they as parents needed, particularly regarding the need to seek further understanding and clarification. This desire is particularly evident when she states, “we actually need an explanation for why there is a gap”. The observation of difference, or failure to be ‘accomplished’, was notable enough that Jessica herself intervened in order to seek an understanding or direction to correct. The ‘answer’ of autism provided an understanding of her child’s ‘lack’ of development but also offered a means of parental control.

The family unit was only one place where observation of children took place. Foucault highlights that power is exercised by those who are able to legitimately observe and pass judgment. The disciplining of the body and disciplinary techniques of surveillance as argued by Foucault (1980, p.106) are concerned with one’s accordance with social norms and constituted by expert knowledge. It was this expert knowledge that was the other core theme when examining there being a need for testing or diagnosis.

The Expert

In addition to the comparisons drawn by mothers themselves, the other main driver for there being a need for diagnosis was the recommendation of a figure who had observed their child within a formal institutional setting. In most cases, this was a teacher or early childhood educator. Within a post-structural feminist discourse, ‘the early childhood teacher is positioned as an interventionist’ (Ortlipp, Arthur & Woodrow 2011, p.57). The institutional setting of many schools and early childhood learning facilities not only produced a site for surveillance and identification of the delinquent child who could not or would not obey the necessary rules of functionality, but it also offered a mechanism of individual surveillance where mother and child could be positioned in relation to the ‘norm’.

> **Diana -** … he was just having major issues. The school was ringing me all the time, we’ve got problems, he’s not engaging, he’s not following instructions, he walks off all the time … and eventually the school got in the education department and they decided what they would do, so the women from the education department just went and sat in the classroom and just watched. None of the kids knew why

> she was there and what was happening … and she said I believe he's got Asperger's. I'd never heard of Asperger's.

Despite there being different paths to receiving a diagnosis, what was consistent regarding there being a need or prompt for a diagnosis was that there was something different about their child. This difference was measured against normative standards, themselves participating in constituting what is normal - what a child should be doing and achieving and how children 'should' behave. It was this comparison that enabled them to think differently about their child.

Feelings about the diagnosis and mother-blame

In chapter three (genealogy) I demonstrated how autism was constituted within power and knowledge incited by techniques of surveillance and examination during the 20th century. Within chapter three and also in chapter six (media analysis) I presented some of the public health and medical discourses that have helped shape a complex web of technologies of power through which mother blame for creating the autistic child became possible. When my interviewees attempted to make sense or understand their child's diagnosis, self-blame was evident. It is this idea of self-blame (by the mother) that I analyse in this next section. Although compliance, self-surveillance and a reflexive focus on self were evident, mothers also displayed ambivalence about their self-blame.

Making sense of their child's diagnosis was difficult for some mothers. They still had the same child, yet their vision of (or for) their child and their life as mother was now different:

> **Liana -** there's an element of grief for sure that you have to make sense of with a child that isn't developing normally. I remember during that time my mum died, my dad died and you go oh that's grief that's how that feels and you feel aspects of grief but you don't have a word that help makes sense of it and that strange feeling of something you can't quite touch has gone and how you thought your child might be and it was never there, it was never real in the first place but its somehow gone from you and there's an aspect of grief in that ... that your parenting life will be different … I think sometimes there is a bit of, maybe a slight smugness in having a normal child as though you did something right and on the flip side of that is that you did something wrong to have a child that isn't.

Liana expresses grief in the sense that her parenting life will be different from what is normal and what is expected. Whilst Liana could describe herself as the mother of an autistic child, what that meant was difficult. The struggle by Liana demonstrates the power of normalising discourses constituting how motherhood should be understood, organised and related to (Yates 2005). Assumptions about what mothering should be and what child she should have had, or at least have expected to have, are evident. It was, however, the availability of a comparative knowledge of what it was like to lose important humans (i.e., the death of her parents) that gave Liana a point of comparison to help her at least try and make sense of what she had actually lost. Furthermore, as discussed by Liana there exists an element of blame attached to the diagnosis, that her son's diagnosis was due to something she did wrong.

As discussed in chapter two, when mothers are constructed as 'little more than the architect of the perfect child' (Eyer 1996, p.6) this challenges the self-identity of mothers of disabled children' (Ryan & Runswick-Cole 2008, p.45). Although they still had the same child, the formal diagnosis of autism made or allowed them to think and respond differently. The diagnosis of autism became centrally related to and entangled with their own identity. An interesting example of this was how they were now no longer referred to, positioned or classified as a mother but rather a carer:

> **Liana -** So, things around the semantics of disability and so why are you suddenly getting a carers payment or getting called a carer as opposed to just being a parent. Are you somehow other?

Whilst care and caring are often 'the central process through which gender is defined' (Hughes et al. 2005, p.261) and feminist theorists have often argued that it is through caring that a woman's identity emerges (Graham 1983), the meaning of motherhood and care changed when the child was labelled autistic. Collett (2005, p.328) argues that although 'parenthood begins with a biographical incident', a woman truly becomes a mother 'by playing a socially defined, publicly visible role'. The role being played by mothers of autistic children is not the socially constructed version of what motherhood should look like or be. There is a change in identity. Rather than raising a child, they are caring for one that isn't right.

Throughout my interviews, it emerged that once the diagnosis of autism was given, there was a reflexive form of engagement. As discussed by Diana, reflexivity was focused on what she might have done during her pregnancy:

> **Diana -** I'm always interested to see what's the latest, there's always something, on this or that … when I fell pregnant with my daughter I was 20 years old, I was

> in Bali, I was drinking, I was smoking I was living like a 20-year-old and I accidentally fell pregnant … just absolute shock, horror ... When I had Paul I planned for it, I ate well, I took folate I did everything by the bloody book and he was born with cleft palate and has Asperger's and so I don't know what the answer is … I went, I did work at a petrol place, maybe I ate soft cheese, did I eat an oyster, you know, I mowed the lawn maybe it was the noisy lawn mower because I never mowed the lawn when I was pregnant with Simone and all this stuff. All these ridiculous things and you're always considering what if, and I think there is always a certain amount of blame that you put on yourself. What did I do, what did I do wrong … but I do prick my ears up when I hear anything still and I'm still interested to hear about things.

The self-surveillance by Diana is evident. When discussing her pregnancy with Paul (her autistic/Asperger's child), Diana describes how she embraced and applied many forms of self-regulation to achieve the perfect pregnancy. Despite her engagement in medical discourse that had seen her 'do everything by the bloody book', Diana still internalised blame. Whilst Diana's ambivalent complicity with medical discourse was evident, the absence of any identifiable cause meant that her failure to produce a 'normal' child left her wondering what she had done wrong. Even in her acknowledgement that some of her thoughts were 'ridiculous' she speaks of her body and her actions as a site where the capacity to produce an autistic child lay. It had become possible to speak in this way.

The blurring of boundaries between their child's diagnosis and the mothers' own sense of self intensified the direct relations between the body of their children and mothers' sense of self. The difference in their child resulted in mothers looking inward. This inward glance was the effect of dominant discourses surrounding normative development and the role of the mother as the one responsible for disciplining her own body to produce a child that meets established norms.

Disclosure

Another experience shared among all mothers interviewed was the issue of disclosure regarding their child's diagnosis. Drawing upon Goffman's (1963) notion of 'spoiled identity', and as argued by Persson and Richards (2008, p.73), the decision to 'conceal or reveal a 'spoiled identity' or a 'discreditable' attribute', 'is to navigate intensely charged lines of power and knowledge'. Although mothers shared the same experience of having to make such a decision, how they thought of and then approached sharing and discussing their child’s diagnosis varied. Some mothers demonstrated what I describe as ‘selected disclosure’. This meant that mothers chose who they told about their child’s diagnosis and how those they did inform should use the information. Similar to the findings of Gill & Liamputtong (2011), some mothers resisted informing those outside the immediate family about their child’s diagnosis. An extension of Gill and Liampottong’s (2011) findings was that this resistance sometimes included sharing the information with other mothers of autistic children they interacted with. In my interview with Jessica she spoke of how she and her husband had informed her son’s school but withheld the information from others, including delaying telling their son of his diagnosis:

> **Jessica -** In my own experience, it actually wasn't spoken about a lot … he goes to a very good um, private school, a boys only school and I know that they have extensive programmes to support um, boys with autism or Asperger's. Yet funnily enough, in the group of mothers and et cetera, it's actually not spoken about ... Um, we made a decision to not just come out and tell everyone because judging our son's personality we sort of went "We think it's best that he not get fixated on it." … We, we did tell him when he was mature enough. So, we sort of inadvertently kept it secret but more so too, to help him get mature enough … But, yeah. Um, I know of a lot of boys that have it but nobody actually sits down and openly talks about it.

Whilst all mothers interviewed shared their child’s diagnosis with the school, many did not want that information then known to other students or classmates. Disclosure of a disability can see the diagnosed individual become suspect and future interactions possibly tainted (Rocco 1997). Whilst disclosure to their child’s school offered access and support to particular services and was thus desired by the mother, the fear of how this information would then position their child saw a number of mothers withhold that information, at least temporarily, from their child. It was common, as seen in my interview with Jessica, for the reason not to disclose to be driven by a desire to protect their child. This desire to protect was often related back to protecting their child’s self-esteem. Whilst this ‘don’t ask, don’t tell’ attitude enables the mother to in some ways pass for and be spoken to as one who is performing normative motherhood, it limits her ability to form support networks and also the ability to speak of autism as a source of pride or specific worth. For the mothers themselves, this leaves them vulnerable to examination but excluded from communication. Although, as seen throughout my thesis, autism is often firmly located within a medical discourse and the absence of disclosure avoided the medicalisation of their child, it simultaneously limited the ability to draw upon this discourse when discussing their child with others.

Also, of interest from my interview with Jessica was the influence her family and their background had on the disclosure of her son’s diagnosis:

> **Jessica -** I'm from European family and … mom and dad had no problem with us adopting and he's from South Korea, so he's quite clearly adopted … But when Sam was diagnosed, I could see my mom having a little internal meltdown about what this meant for her- her- grand- her grandson … she had a very quiet word to me one day and said, "Uh, don't speak about it to the rest of the family." Um, and I get that, you know. From that that generation and that whole sort of outlook that they have is, uh, very, very, very archaic. And I thought, nope, that's fine … Uh, they, they would look at him ... he-he would be really negatively labelled … probably even more so than just your standard society sort of viewpoint.

Although acknowledging that the views of her family were archaic, the choice was still made to not disclose to the rest of the family. We again see how embedded the stigma of autism and difference is and the effects of this. We also see how difficult disclosure can be for mothers as whilst they may not have the same view as others regarding the negativity of their child’s diagnosis, they are making the decision on behalf of their child. It is their child who would then be treated, viewed and negatively categorised.

Continuing the theme of ‘selective disclosure’, other mothers interviewed reverted to ‘selective disclosure’ after seeing the effects the category could have. For example, as discussed by Sally below, the behaviour of other children and the impact this had on the child were influential in directing their decision around disclosure:

> **Sally -** We don't ever use the label and we've asked the school not to because other kids were teasing him about autism and Asperger’s … Maybe it’s appropriate for some kids but he thought it meant there was something wrong with him and it was really damaging his self-esteem.

As stated by Sally, it is not that she was against children having a label of autism, acknowledging that it indeed may work for some. It was not that she thought the diagnosis should not exist but after witnessing the effects of the category, both the teasing from other children and the interpretation of her step-son that it meant something was ‘wrong’ with him, they made the decision to never use the term. As seen in both my interview with Tammy and Sally, mothers were worried not only about how their child would be observed and treated by others but also how their child observed and understood themselves. As mothers, they have a certain authority as to whether to impose or not impose the subject position of autism onto their child/ren. The management of their child’s emotions and perceptions was reflective of the mothers’ understanding of how autism is thought of and the negative effects that come with this subject position.

In contrast to my discussions with mothers such as Jessica and Sally, other mothers, such as Liana, were not bothered about the label or the diagnosis being used or discussed:

> **Liana -** Yeah. I’ve got no issue with the diagnosis. Some people would ask how do you feel about your child being labelled and I thought label smabel, that behaviour will come with its own set of things and people will think what they want with or without a label, so if you’ve got a label it’s like a handle for people to hang things on a concept for them.

Liana discusses how the differences, or the behaviours, of her son will be observed regardless of whether there was a label attached. Whilst not bothered herself by the label, Liana discusses how having one can help others make sense of her child and gives them a concept from which to draw upon and understand the behaviours of her child. Having a category in which others could place her son meant that he could be made sense of.

Mothers’ feelings on diagnosis were not limited to the binary position of being comfortable or not comfortable with it. As seen above, some mothers moved from open disclosure to selective disclosure after seeing the effects the diagnosis could have. What I also found was that some mothers became concerned about the possible effect a formal diagnosis may have in the future:

> **Michelle -** … in a way I regret taking him to Autism SA … Because he wants to be a policeman. But if he is autistic, they are very very branded as autistic ... So that part of it I do not know what the impact of them getting the diagnose … on their future career development ... And while maybe it is quite handy when they're younger to access services ... what's the impact of the diagnosis as they age.

The permanency of the category became a concern for mothers such as Michelle. Whilst the needs and desires of the child changed and continued to change, the label remains firmly attached. The inability to move beyond the attached label saw Michelle regret ever seeking a diagnosis in the first place due to the limits it may place on how her child is viewed and who the self can then become. The label not only contributed to constructing the child, but it also limited their future identity. Similar to restrictions that are placed upon those who have a criminal record, the idea that the person is wrong, or that the attachment of the label made their child wrong, made mothers fear there were limits placed upon their child's future regardless of the ability of the child. That they would be denied full citizenship simply based on how they have been categorised. As seen in this section, and as argued by Persson and Richards (2008, p.73) in their study on experiences of disclosure of HIV, both silence and disclosure, although leading to different paths and experiences, result in effects that are real and shape the experiences of both the mother and child.

The experiences of there being a need or reason to seek a diagnosis, mothers' feelings about their child's diagnosis and their conduct around disclosure provide insight into the subject positioning of the mother, the standardisation of childhood and development and how becoming the mother of an autistic child begins to produce the mother as a particular subject of discipline. The surveillance and normalization of childhood made dividing practices apparent (normal/abnormal) and made mothers question their own accountability. Furthermore, the permanency and pervasiveness of these practices made them question how the category of autism would be viewed when applied to their child.

Continuing with the idea that knowledges produce the subjects of which they speak, in the next section of this chapter I look at ways mothers were invited to negotiate their new identity and subject position of 'autism mum'.

Invitations, Representations, Resistance and Technologies of Self

A key component of technologies of self is expertise. As discussed in chapter two, the shift towards neoliberalism sees the idea of the public or community good replaced with that of individual self-responsibility (Martinez & Garcia 2000). Anxieties 'generated when the actuality of life fails to live up to its image' (Rose 1999, p.88), in this case, that an autism diagnosis was not what participants had expected from motherhood (a diagnosis some had never heard of), disciplines mothers' desire for self-development (Rose 1999, p.88). With the new subject position of autism mum came a desire to further understand their new subject position and, in some cases, seek support from others and exposure to new expectations. I begin this section by looking at the types of information mothers sought out. I also identify how after seeking information or support, they often turned away from it. I conclude this section with an analysis of the dominance of the 'bad' mother discourse and some of the lived effects of this dominance.

Turning towards: Information and support

The information available to mothers about autism created narratives they had not previously considered. I argue in this coming section that her becoming an 'other' required mothers to look outside or beyond traditional narratives on motherhood. The discourse of intensive-mothering dictates that mothers do everything they can for their children. Consequently, the intensive-mothering discourse implies that the work of the mother will be extended if her child has a disability or, at a minimum, a different type of work will be required. I use the term 'turn to help' where technologies of self resulted in mothers' active engagement with discourses that encouraged mothers to seek out information or support about mothering an autistic child. Mothers' active engagement and the action of turning saw mothers exposed to narratives that emerged whilst seeking information about the best way to support their child. For example, in my interview with Alicia she recounted the following effects of seeking information:

> **Alicia** – I do. I worry a lot for him. I think the thing that worries me is, it's sort of like this thing where YOUR CHILD IS AT THIS HUGE INCREASED RISK OF BECOMING A DELINQUENT CRIMINAL WITH MENTAL HEALTH ISSUES … when your researching where you can get help and support for your son … these are the sorts of things, these are the other pieces of information that surface

The scenario described by Alicia is reflective of Althusser's (1971, p.163) notion of the ideological recruitment of subjects - interpellation. Knowledges such as the 'huge increased risk' of her child becoming a 'delinquent criminal with mental health issues' saw Alicia recruited by turning around (Ahmed 2007, p.157). The effect of being 'called out' and recognising herself as the mother of an autistic child offered a further invitation for her to invest and identify with – the mother of a likely criminal.

The fluidity of the subject position of mother is captured in the transformation from mother to mother of an autistic child. 'Turning to help', recruited Alicia. Consequently, Alicia was now a mother who was not only concerned about finding ways to help her son, she was now a subject who had been called, influenced and invited to understand and correct the risk of her child's descent into criminal and delinquent behaviour.

Turning 'away' and 'turning back again' – resistance and navigation

'Turning to help' was a common theme that emerged throughout my interviews. Although consistent with the intensive-motherhood discourse where mothers must turn to the experts for advice (Hays 1996; O'Reilly 2016), in this instance it was knowledge specifically related to mothering an autistic child that mothers turned towards. It was found that mothers would often self-select the information to which they exposed themselves. They would seek information or support, 'turn away' from what they found, but then 'turn back again' once they found a position they were comfortable with. For example, in my interview with Liana she discussed how whilst the information she sought out was limited, she as a writer herself would 'turn away' from the information she didn't want to read and seek information by other writers:

> **Liana -** I did join some online groups and I thought oh I can't bear all that whinging, pick a topic, schools, NDIS and well not whinging, they're letting off steam in a public forum and that's cool you got to do that somewhere, but I found that wasn't constructive. I read certain things that suited how my mind works and how I wanted to view it … I found things that were written by writers, so say if someone had writing skills or was a writer before their child had a diagnosis I would find the writing a lot richer and would bring different things to it.

Another invitation Liana turned away from was the therapy of ABA (applied behaviour analysis). As highlighted in chapter three (genealogy), the practice of ABA emerged after the works of Lovaas saw the field of behavioural psychology, a field originally designed to be about the control of autistic children, become a position that laid claim to being able to cure. The children experimented on by Lovaas were not viewed as human beings, rather shells of humans that had to be constructed and built (Chance, 1974, p.2).

Liana had initially turned towards ABA after seeing a segment on the television show *Today Tonight.* Although answering the call, the styles reflected in ABA were not those she wished to perform, largely due to the conflict between the style practiced and her own beliefs:

> **Liana** –I did the two weeks and I could see how it worked but I thought I can't be that person who delivers that sort of therapy in that sort of style

> **Researcher –** what sort of stuff?

> **Liana** – well they, it’s a bit Pavlovian so I guess if you’ve got a little person and it was attached to research so they’d go through and work out what different skills the child had … and then it would be – put in order! And it would be this series of numbers and if they don’t do it or they move or they cry you put your hand on theirs and get them to do it … I thought I can’t kind of do that, it’s not giving him a reason and it will work in the short term … but I just I couldn’t do it, I couldn’t deliver that sort of stuff. I thought there are ways of doing this that felt more like me and that feel more humane I guess.
>
> **Liana –** … he had a fever one day and fell off his chair and it was, well back on the chair and let’s do this until it's finished and I said I can’t actually do this anymore we need to stop this now. And that is the one that you will see that is $40,000 a year and I can see how it works but it wasn’t for me … It’s got a layer of the way I do it is wrong, I need to do it this way to be ok. And to me, that feels a bit yucky. So, I’ve learnt what’s not ok to do.

This learning was at times made easier when given reassurance. For mothers such as Liana, it was still common for some mothers to desire and find reassurance in being told they were doing ok. Surveillance had its advantages for some mothers. For example, for mothers such as Liana, they found reassurance in being observed:

> **Liana -** Sometimes someone telling you that you’re doing a good job, maybe I just need flattery or something but. I think one time he had quite a big meltdown at the OT or physio … but at the same time, I was quite happy for someone to watch me manage that so they’d say yep that’s what you do because you’re restraining your child and it feels awful but that whole thing of keeping them safe … and with that language over the top and so I think left to my own devices I would have muddled through but that support around parenting I found really invaluable.

Mothers gravitated towards information that matched their own values and didn’t make them feel worse for the experience. As discussed above by Liana, she found herself avoiding online groups and particular types of therapy. Such avoidance or removal of one’s self from such an environment was a common occurrence. For Katie she described the bitchiness as the reason for turning away:

> **Katie -** And then all the bitchiness that happens in any mother's group … just got fed up with the whole lot of it. Do you know what? I'll leave all of it, and I did. I left every single group and I've created one group that was predominantly so that I could put all diagnosis information in there, or where to go … Um, I thought it might get 50 members and people would come in, get the information, leave, you know ... Some people aren't aware of it … And that's why I started […] because it's, it's, um, all the information is on there … all your funding options are there, and so many people don't know what the funding options are.

Upon turning away, Katie developed a way to assist other mothers that also minimised her own stress and frustration. Throughout my interview with Katie she discussed how often within the ASD (autism spectrum disorder) community there was an expectation to be a certain type of mother - the type of mother who due to her own subject position as mother of an autistic child, was now supposed to look out for every other mother in that category. That her engagement translated into an assumed responsibility. A responsibility that ran the risk of her own self-destruction. Katie described an experience she had had with a My Time facilitator. My Time is a support group for parents of children with a disability, developmental delay or chronic medical condition:

> **Katie -** she said well you know, maybe you should have been telling her about My-Time and you know, because maybe she needs this sort of support. I'm like, "I come here for my own support. I'm not going to tell someone like that about somewhere where I come every week." And she goes, "Well, you know, that's not being very friendly and ... " And I just shut up. At the end of it I went up to her and I said, "Don't accuse me of not doing anything community. I think I'm doing my fair share … I don't need to extend invitations out to everybody where I get my support from … Where I should get a bit of a break and, and [have to include] every single person that has an autistic child, because you should … I just didn't like being … spoken to like that. Spoken to like that in front of everybody. And ... I took it as being accused of excluding somebody. I was, but I'm not responsible for every ASD family that I come across. And, and it's not my job to promote the My-Time, My-Time doesn't pay me, they pay her ... It wasn't that. I wasn't saying you can't come. I'm not telling you because it's my space.

In chapters six (media) and seven (McCarthy) mothers were represented as heroic warriors for other mothers of autistic children. Newspapers reported the schools' mothers fought to open and *Generation Rescue* the tireless efforts of Jenny McCarthy and her quest to help other mothers. Here Katie resists the criteria of what others thought the subject position of mother of an autistic child meant and the requirements of it. She felt as though there was the assumption that as the mother of an autistic child, this subject position translated into the responsibility for all mothers of autistic children: that because they shared a similar experience she was responsible for other mothers whom she would otherwise not want to be around. Although Katie felt judged and called out as a bad mother, there wasn't the authority by My Time to produce a change in behaviour by Katie. To her, the contract was that they were supposed to be there for her, not her for them or other mothers.

The act of 'turning away' and 'turning back' was a form of resistance by mothers from what they were being called out to be. The requirements of 'autism mother' they were invited to mobilise towards were not necessarily those they felt comfortable taking up. Although the desire for self-development within their new identity was evident, mothers navigated what 'requirements' they would 'turn towards' and 'turn away' from.

Warrior-mother

In addition to turning away from certain information or support, mothers also resisted particular representations. Although not spoken about by all mothers, one representation that was resisted by mothers such as Katie was that of the warrior-mother:

> **Katie -** personally, I hate the warrior-mom title ... I am so good that I deserve a warrior title, you're not a warrior-mom … you've got the people who live autism through their kid's autism. So, they're living their lives through their kids … exactly the same as you'd have those mothers who do it through dancing and acting and stuff … they make it more about themselves and how hard it is on them.

In contrast to the narrative of McCarthy discussed in chapter seven, here it's the warrior-mother described as the 'woe is me' mother. For McCarthy, the 'woe is me' mother was the one who wallows in their own self-pity. For Katie, the warrior-mother was someone who made their child's diagnosis more about themselves than their child. Consistent with the representations discussed in chapter seven, however, it is again the 'woe is me' mother that is thought of as the bad mother. Although what the warrior-mother meant differed, what remained consistent was that if the mother was interrupted as being focused more on herself than her child, she was viewed negatively.

Similarly, Tracey described how she was against sacrificial motherhood. Tracey criticised representations structurally by identifying media rhetoric as the oppressive force, or the site responsible for, representing them as a category of women who are suffering:

> **Tracey -** I, um, I'm very anti the sacrificial mothers. The, "I've sacrificed everything for my children and I'm- I'm suffering so much because of my child," and it's like, "Hm." So I don't like those media representations of us.

The ‘good’ mother discourse requires mothers to be fully satisfied with the role they perform (Miller 2005, p.86). They are supposed to be happy. As discussed in chapters three (genealogy), six (media) and seven (McCarthy), the culturally acceptable representation of the autism mum, however, is that of suffering. From a representation perspective, mothers of autistic children are caught in a never-ending loop of failure to ever be seen as a good mother. A ‘good mother is a happy mother’ (Johnston & Swanson 2003, p.23) but the autism mother can never be happy however as she has a failed child. If she can never be happy, she can’t be good.

The ‘bad’ mother

As argued by Ladd-Taylor and Umansky (1998, p.3), ‘bad mothers’ have been categorised into one of three groups: those who do not live in a ‘traditional’ nuclear family; those who would not or could not protect their children from harm and those whose children went wrong. Moreover, as argued by Ruddick (1980, p.21), ‘social groups require that mothers shape their children’s growth in acceptable ways’ and count ‘failure to meet their criteria of acceptability’ as failure by the mother. In my interviews, an important finding emerged. When it came to blame and judgment, it was often the characteristics of the mother that were perceived as the object of blame. Although the categories of the bad mother were evident for how and when blame was attributed, importantly, it was also the characteristics of the good mother (heterosexual, married, monogamous, White and native-born (Arendell 1999, p.3) that were served as the norm for judgment.

In my interview with Alicia, it was the lack of a husband/father figure that was questioned. Whilst outside of her body, the idea of the father is within that of how we think of the mother, and the nuclear family. The heteronormative order of child raising enabled not only the gaze of normalising judgement but also the observation that qualified and classified what was wrong with her performance as a mother:

> **Alicia -** As a sole parent I think that's where the judgement comes down to … I feel like the little quirks in my son and things like when we're playing footy and all the other parents were there with their dads and a parent and children match and I was the dad and my child was in tears four times throughout that game and just about to collapse on the field
>
> **Researcher –** so you were the wrong gender to perform that role?
>
> **Alicia –** yeah, and little things like he injures himself really easily so I often get this thing like, oh you baby him from other dads and the school … they're not meant to be harmful, but it's this constant sort of stuff … I feel judged, like people feel that my child behaves in these certain ways because I'm mothering him too much, I'm babying him too much and I have to shrug that off because I know that my kid needs me to be like that because he's sensitive and he needs me to do that for him otherwise he'll flip out. He needs me to go in for him, he doesn't need me to tell him to suck it up, sometimes he does … particularly going to a school with a lot of nuclear families, like there's very few, like there are two single parents in his class but they have fathers, they share care, so I feel judged as inadequate. I feel pitied, those sorts of things.

Being a sole parent highlighted to others where blame could be laid for the child's failure to meet acceptable standards of discipline and development. In addition, whilst discursive practices produce the subject position, when assuming that subject position, one tends to 'make sense of the social world from this viewpoint' (Bacchi 2009, p.16). The effect of how others viewed her parenting affected how she viewed her own performance as a mother. Whilst, as discussed above, Alicia felt as though she knew what her child needed, self-doubt about 'babying' her child was also evident:

> **Alicia -** I feel like maybe if you didn't know that maybe you wouldn't be so delicate with them and maybe that would be a good thing. Maybe, I am wrapping him in cotton wool. I don't know, it's that thing where inside your head where maybe I am wrapping him in cotton wool, maybe I am worrying too much, maybe my worry is creating a worry in him. My anxiety about it creating anxiety in him. It's like what comes first the chicken or the egg?

The example given by Alicia demonstrates how those whose knowledge and behaviour is questioned for its lack of conformity to dominant standards of normality are viewed and in-turn how this shaped her views on her own parenting. Rather than being the originator of her own meanings, her actions and meanings were shaped by others (Collins 1991). For Alicia, her failure as a mother was not limited to the autistic child she had produced – she was caught between judgments of her as a single mother and judgements of her as a mother of an autistic child. The abnormal behaviour of her child made her failure to raise her child within the appropriate nuclear arrangement visible. Her subject position as a single mother made it possible to blame the behaviour of her abnormal child on the absence of a father figure and the masculinity required to discipline a child.

Assumptions of the importance of the nuclear family unit were not the only constructions of what appropriate parenting should look like. For Fiona, it was her age:

> **Fiona -** I struggled because … I went to all the mum's [groups] … and the mothers, the perfect mothers, their perfect children, and it's like ... they all think of us as terrible mothers as constantly beating ourselves up. And I was a youngish mum … I was 21 when I had Ash and hadn't been in a relationship very long before I had my surprise babies. I felt really insecure and every time I reached out to someone for help for his behaviours, um, I was treated like … Like a mum that had no idea.

As articulated by Alicia and Fiona, it was not the fact that their child was different from other children, it was the lack of what the 'good' mother should look like that was often the target of blame – her deviance viewed as the cause of her child's 'problems'. The knowledge projected onto mothers and about mothers regarding what was wrong with their child was reduced to what she failed to possess. Her being a young mother 'who had no idea' or the absence of the father figure were visible targets of blame others could draw upon to highlight as the reason for the failure of her child. A further example of this was evident in my interview with Sarah for whom English was her second language and still maintained a strong Eastern European accent. Her English-speaking skills became the assumed reason, whether by her social circle or therapists, for her child's language delay and communication difficulties. That characteristics of the mother, such as her ability to speak appropriate levels of English and her marital status, are reflective of dominant constructions of what mothers should be. There is an ideal of motherhood that Western mothers should meet. For example, as discussed in chapter two, she should be native born and married (Arendell 1999). The totality of what it means to be a ‘good’ mother, as in it is not just the performance of the activity but also the collection of specific characteristics a mother should have and be, meant that when a mother did not meet these standards, it was her deviance that was blamed for the deviance of her child. Autism disappeared. Although this raises the question of whether she stops being an ‘autism mother’ when she becomes a deviant mother, or whether being an ‘autism mother’ becomes part of her deviance, at the end of the day, the issues remain hers regardless.

The binary labelling of the ‘bad’ mother means there must also be the ‘good’ mother. For mothers of autistic children, the criteria they often felt acted as the baseline for the ‘good’ mother was normative development of the child:

> **Liana -** … there’s a whole bunch of places they [mothers of normal children] don’t even have to go into in their mind. And I guess sometimes if I’m having a bad day I’ll think you’ve got no idea, no idea, in that luxury and smugness of normal development, and that sounds a bit harsh and I don’t often go there.

For Liana, her experience of motherhood was something mothers of ‘normal’ children would never have to encounter. I do not argue here that mothers of ‘normal’ children do not face challenges. However, as an outsider looking in on normative motherhood, mothers such as Liana viewed normal development as a luxury. The experiences of mothers such as Liana made them aware that the knowledge of mothers engaged in normative motherhood was limited. As discussed by Liana, however, this limitation of knowledge was viewed as successful motherhood/mothering. As in, mothers who do not have to engage in thoughts or actions related to mothering an autistic child, and consequently are not even aware of the types of experiences or knowledges that mothering a normative child is limited to, are deemed successful or good. This is knowledge a “good” mother doesn’t need or should have. Being the mother of an autistic child meant mothers such as Liana felt as though the knowledges and emotions they experienced only existed by virtue of their inequality and difference. Operating at the margins opened up new ways of thinking and this knowledge was exclusive to the ‘bad’ mother.

As discussed earlier, the category of autism can bring with it various forms of ‘baggage’. It can however also serve as a form of protection and asset for the mother. As argued by Avdi, Griffin and Brough (2000), the label of autism can provide a form of protection from the charge of being insufficient or incompetent parents whilst simultaneously providing a gateway to information, resources and support. An example of the protection the label can offer was particularly apparent in my interview with Magda:

> **Magda -** … the next day … the teachers and the carers were saying, "Oh, there's no such thing as Asperger's now because America's taking it off the DSM or whatever. So, it's just bad behaviour.

If the label or diagnosis was removed, or in this case no longer existed, there was no explanation or 'excuse' for the child's behaviour. Magda's story is perhaps one of the strongest I came across regarding the authority of medical discourse.

Visibility

The violations of expected behaviour by their child made mothers highly visible. Or at a minimum, feel highly visible:

> **Diana -** no one ever came to me and said oh we feel your pain or and I was trying really hard and I used to say to the school and to the education department, I feel like I need a t-shirt that says, "I know my son has problems I'm working on it", because I felt like I'd walk in the gate and all the mothers would be standing there in their group and they'd be looking at you and you'd know that they would be talking about you and your kid, I did feel isolated, I didn't feel like I had support from the other parents or anything like that, definitely not.

Mathisen's (1997) notion of the synopticon posited a 'parallel and reciprocal system of control' (Doyle, 2011, p.283) to Foucault's application of the Panopticon. Rather than the Panopticon where the few watch the masses, the notion of the synopticon sees the masses watch the few. 'Autism mothers' were not part of the 'in' group, rather the 'out-group' being discussed. In addition to judgment, this visibility brought isolation.

Summary

As participants in knowledge production, mothers all participated in the observation of their children - observations such as those that led to a diagnosis of autism, observations of themselves as mothers and observations of how, when and whether to place the subject position of 'autistic' onto to their child. Although there was continuity in mothers' expression of their child as different, there was a discontinuity in their response to this. For some mothers, a diagnosis brought an understanding. For others, it was something they themselves had to make sense of. There was a similar discontinuity when it came to disclosure.

Whilst there was a discontinuity in areas such as reactions to their child's diagnosis, there was continuity in the expression and presence of mother blame. Mothers discussed ways they blamed themselves and the way others blamed them. An important finding was that the failure of a mother to be or obtain the correct characteristics of the ‘good’ mother (single, young, English as a second language) was blamed for the failures of their children. Not only did their identity as the mother of an autistic child serve as a marker of difference and isolation from the normative, but it also made them visible. Using Foucault’s analogy of the Panopticon, this visibility made them the ‘entertainment of the prison’. But rather than acting as a Panopticon type of surveillance (where the few watch the masses), mothers were often subjugated to a synopticon type experience (where the masses watch the few).

The ‘bad’ mother was a prominent theme that emerged from my interviews. When it came to mother-blame, the strength of the ‘bad’ mother discourse was dominant enough to override the medical discourse of autism. Given the strength of the medical discourse that has been evident throughout this project, this is an important finding. Moreover, it was evident that any protection the diagnosis of autism provided the mother – from blame or judgment about the abnormal child – was something that could be instantly removed if the diagnosis was removed. In essence, the medical discourse provided some protection from mother blame, but it was not powerful enough to supersede the expectations of motherhood and was something that could be immediately withdrawn.

CHAPTER 9: INTERVIEWS (PART B)

INSTITUTIONS, POWER AND THE ACT OF CONFESSION

In this final research chapter, drawing again from data obtained in my interviews, I look at institutional power and discipline, authoritative knowledge and the act of the confession. I focus on the infinite examination of mothers within the education system, the rationalities of state and how this translates to the practical implementation of policy. The performance or behaviour of mothers' children, especially once categorised as abnormal, made 'autism mothers' constantly visible. The practical implications of policy, such as what was and wasn't acceptable at school and what therapy should and shouldn't be paid for, led to the intensification of intensive motherhood and resistance to authority. I argue that mothers' engagement with the NDIS (National Disability Insurance Scheme) required the disclosure of mothers' own thoughts and ambitions for their child and the disclosure of both their own and their child's failings.

I conclude this chapter with an analysis of my interviewees' thoughts on therapy and cure. Data from my interviews suggest that although engagement in various types of therapy was something mothers felt was important, they felt that this engagement should not override or dominate their child's ability to 'just be a kid'. Furthermore, the aim of therapy was to enable development rather than try to obtain a 'cure'. There was a consistent theme that it was mothers themselves who could best care for their children.

Education system

The education system emerged as a prominent location of struggle and conflict identified in my interviews. For Foucault, the education system is an institution where knowledge about people and their behaviour has been 'developed, refined and used to shape individuals' (Ball, 2013, p.15). Knowledge produced and developed by the exercise of power is considered 'true' and used to extend interventions that foster particular activities or conduct (Foucault 1981).

Disciplines produce 'subjected and practiced bodies, "docile", bodies' (Foucault 1977, p.138). A docile body is described by Foucault (1977, p.136) as 'one that may be subjected, used, transformed, and improved'. Drawing largely upon the work of Foucault, Ball (2013) acknowledged that the school, in many different forms, divides pupils into the normal and the abnormal. In disciplinary institutions, such as schools, the organisation of space, time and activity have been developed over time to change people's behaviour along with numerous parameters. The organisation of time and activity also allows for examination. It is this examination that allows the determination of whether the individual subject is deemed governable and 'likely to lead a docile, useful, and practical life' (Marshall 1989, p.1). Ball (2013, p.91) argues that the modes of thought ingrained in education policy and practice are not significantly different from those of eugenics. Examination of difference or 'breaks in the species' enables the detection of all those within a group who may be the 'carriers of a danger to it' (Foucault 2003, p.317).

From my interviews, two prominent sources of frustration and blame for mothers emerged– the visible and the invisible child. There were the children whose behaviour violated expected standards and their disruptive behaviour made them highly visible. In contrast, mothers also spoke of how their children would sometimes hide or isolate themselves, making them invisible. Mothers of children who were highly visible were blamed not only for creating the problem child but also their failure to correct their child's deviance. The invisible child didn't draw enough attention, but when issues were brought to other's attention by the mother, the source of the problem remained the same, the mother.

For the visible child, discussion frequently arose about the failure of their children to cope with the organisation of school structures. In my interview with Fiona she discussed how when the organisation of time and space changed, her son did also:

> **Fiona -** … the first school we were at refused to put anything in place to support him, and so we pulled him out and put him into a different school, um, and the first year turned out great. He had support around his anxiety, support with transitions, everything that was recommended … and then this year, he got a new teacher. She's the step-principal. They didn't put anything in place for him. They refused. I argued with them about it … giving them letters from our therapist … but I ended up having to medicate him more … he was getting violent and he's a big boy now, so he hurts … in the past he pushed a girl and broke her arm. Things like that. So, his behaviour can be quite extreme. We think [as parents] we're doing enough, and it got to a stage where his teacher was telling a psychologist that I was the cause of

> the anxiety and, it was my problem, and whatever happened out of school is my problem.

Dominant neoliberal discourse constructs mothers as responsible for the behaviour and outcomes of their children (Novas & Rose 2000, p.507). Whilst mothers such as Fiona felt it was the organisation of time, space and activity within schools that created the non-compliant child, authority figures within these sites, equated the non-compliant child with the performance of the mother.

Although it was common for mothers to view the institution as the source of the problem, responsibility for the abnormal child was something taken up by mothers. Mothers governed their own behaviour in ways such as ensuring their constant availability. For example, in my interview with Sarah, she spoke of how she felt she couldn't move house as that would be too far from the school. She also spoke of how she wouldn't travel far from the school to have lunch with friends:

> **Sarah -** Yeah because we can't move ... like I would say within a certain amount of time from school … If my friends said like oh, we'll go and have lunch at the […]. No sorry, I can't ... It takes too long because ... if you don't, he goes really quickly, really badly so I want to be there in like five to ten minutes to not let him be suspended again.

In order to allow her child to function as an acceptable self-regulating subject in the education system, Sarah tried to be the 'good' mother who was there '24/7'. Her availability meant that her child was her first priority. Consistent with the discourse of intensive-mothering where the 'good' mother takes on the roles in the private sphere in a self-sacrificing manner (Bassin, Honey & Kaplan 1996, p.2), placing her own convenience below that of her child's, Sarah attempts to construct her own version of the 'good' mother in order to enable her child to continue to be accepted by the institution.

For the invisible child, for example, the child who hides or is bullied rather than being the cause of disruption, the location of blame remained the same, the mother and her parenting. For example, in my interview with Alicia she discussed the bullying of her son and how support for her son was being applied in the classroom:

> **Alicia -** If you have a child who has disruptive behaviour, it's brought to your attention very quickly but my child hides, he's technically quite invisible … I've

> kind of had explicit conversations with the school where I'm like … You need to actually stop educating me on basic parenting. I've got this covered … And I've had to put a lot of resources into seeking external support in order to feel like I can have these people advocating on my behalf so I can actually say, I've got these basics covered, I just want to talk to you about what's happening in the school. And because what happens on any of these issues that affect him in the school, that anytime anything is raised that needs to be addressed, it's always just palmed off and comes back to you as a parent teaching him to be more resilient. What can you be doing as a parent at home?
>
> **Researcher -** so when you finally said, oh no you need to stop judging me or telling me what to do in the home, was it confidence you built or frustration?
>
> **Alicia -** Frustration. Absolute frustration. Not out of confidence at all. In fact, even when I go into a meeting now, I feel extremely anxious, I feel a little short of breath as though I'm public speaking, LOL, cos I just, you know, you're going in there to battle I guess and trying not to appear like you're trying to battle to try and get the best outcome for your child.

Alicia spoke of how she had spent considerable time and effort finding external support to help provide legitimacy to her claims – claims that she was not a bad mother, and the problem was not her parenting. As argued by Collins (1991, p.xiii), oppressed groups are frequently 'placed in a situation of being listened to only if' they frame their 'ideas in the language that is familiar to and comfortable for the dominant group'. If Alicia had been willing to accept that the issue was indeed her parenting, she would not have had to go into battle. In this instance, Alicia's frustration with not being listened to, simply blamed, meant she sought external support to have a third-party advocate on her behalf. The authority of medical knowledge to assist her was a discourse that she hoped would help form an understanding of both her son and of her as a mother. The seeking of external support by Alicia highlights a tension between wanting to be believed as a mother and recognising the importance of medical knowledge from accredited professionals.

Mothers did not always believe the version of truth offered by authority figures. In my interview with Magda, she talked about what she was told about her son and how she handled the version of 'truth' about her son being offered:

> **Magda -** [The] deputy principal said to me, “he's not working at school, and he's so dumb, he- he's never going to get past year seven” … I didn't believe it, cause, I thought, you know, at home he does things, he can build computers, he can do all sorts of things … So, I actually had to take him out of school for a year, do homeschooling, because they said, he just couldn't do schooling … I did open-access college for about a year, they actually said, look, I don't know what the school was talking about because he's getting such high mark ... And so, they said, I should put him back in school again … to help him move up to high school, so I put him back in a normal school, and … he did so well, he actually won, um, a certificate for the highest … marks in year nine. So, I took that report to the primary school teacher and told her what it said and said that she was dumb. And she said, “ah, well, I always knew that” (Laughs).

When making decisions surrounding her son’s schooling, Madga draws upon the directive and coercive views of those in a position of authority within that institution. Her conduct is influenced by the overt statements of others regardless of whether she believes what they have to say or does not. Of interest, is that it is only when she possesses formalised institutional knowledge that has been measured and documented, in the form of a report, that she returns to correct the knowledge of the figure whose position of truth she did not believe in the first instance.

Magda was one of several mothers interviewed who had or currently homeschooled their child. Home-schooling was taken up as a form of resistance where they claimed the ability to perform mothering and the education of their child in the manner they saw as the best practice. A trade-off of this, however, was that in their attempts to escape the responsibility of blame they became fully responsible for their child’s education.

Whilst the practice of home-schooling reinforced parts of the intensive-mother discourse (drawing upon the assumption that children can only be properly cared for by the biological mother), mothers removed themselves from the authority of the education/school discourse. Mothers used the intensive-motherhood discourse to challenge the discourse of school and education and make a space for their child. The lack of authority in making decisions about their child’s education saw mothers such as Katie take on the responsibility themselves. From having no say, Katie decided to have all the say:

> **Katie -** I'm just, I really, I'm disgruntled. Because I get to interview my speech therapists. I get to interview Doctors. I get to talk to other moms and go "Oh, well this is a good one. This one's not so good." Or, "This therapy works." Or, "Do it this way." Or, whatever. Yet, when it comes to her school, I don't have a choice. I can either send her mainstream, and you're limited there because (Sighs), You're not going to trust some random teacher. And, when it comes to special, you don't even get a choice on what setting … just be at the mercy of the South Australian Education Department. For them to then decide ... For a group of people who have never met my daughter, to decide what the best education for her is.

Whilst the removal of her children from formal education structures increased Katie’s responsibility, she spoke of how this increased responsibility gave her flexibility in structure, time and activity:

> **Katie -** [I]f you see the benefits of what home-schooling can do, it's hard to then look at the school structure in the same way. Um, for example, this morning was a nightmare for us, but you know what? We can go home. Whereas, if that was in the class, if that was at school and, and I wasn't there, Simone would've escalated a lot worse than what, than what she did. She was only hitting me, but at a school, first of all, she would've been hitting somebody else, and then she would've been throwing things and I knew that she was going to throw shoes so I already was prepared for it. But someone else probably wouldn't.

Despite the empowerment and benefits found by Katie in removing her child from the formal education structure, in her efforts to resist the discourse of school, she embodied an even more intense form of mothering. The self-abnegation by Katie meant that the deviance of her child was ok if was only directed at her. That her child was only hitting her was ok. It was only her, not someone else. In the above quote, Tammy also spoke about how one of the advantages of home-schooling was that she was there, and she could prevent the behaviour escalating further.

Returning to why mothers decided to take up the responsibility of home-schooling, similar to my interviews with Alicia and Madga, in my interview with Fiona, she identified the problem as the structure her child was within, rather than his inability to be docile. This structural analysis, criticism and resistance of the schooling discourse enabled mothers to present themselves with alternatives about what they felt was best for their child:

> **Fiona -** I mean, it was the demanding other things at home by his teacher, plus the assistant principal, other people. After years of loving school, uh, he was self-handling without hitting himself. … and we just had to take him off one of his medications, um, he was having side effects from that. And I'm thinking we're medicating him because school won't help him. And that's just not good enough at all … And so yeah, four weeks ago I said to [my husband], "I don't know what to do anymore." And he goes, "They're not going back there." … They're not going back. Absolutely not. They're not going back. Um, and there we decided to start homeschooling and we've already noticed a massive [change]

The need for medication for her child to be a docile subject that could be disciplined was something that was no longer acceptable to Fiona. Although mothers had limited authority, often feeling as though they were not being heard, mothers did have the ability to supervise the supervisor. The hierarchal observation Foucault (1977, p. 204) meant that mothers were in a position to judge the supervisor but lacked the authority for the subject of their observation – the teacher – to modify their behaviours. Their removal of their child was one of the few options, or in some cases the only option they thought they had. While this was a form of resistance, this resistance sees the relations of power, the school, remain unchanged. Furthermore, and a key finding from my research, by resisting the doctrine of intensive-motherhood that 'experts know what is best' the mother did not resist intensive-mothering, she merely became further embedded in one of the other key criteria, the amount of time and energy she must spend on her child. So, whilst one aspect of intensive-mothering was resisted, this resistance saw an increase in other areas of the intensive-motherhood discourse.

By implementing the change to home-schooling, Fiona thought it made her a better mother. Taking on more responsibility allowed her to mother in a way she felt gave her greater control and also perform the type of mothering she had always envisaged:

> **Fiona -** I just wasn't enjoying spending time with them and it's horrible. Sorry, but I just look back now and go, "Oh my God. That was really not fun at all." And whereas now it's, well they're in my face all the time … but I'm, I'm enjoying sitting with them or reading with them and just having them around. And because they are calmer I actually feeling like I'm getting more done now (laughs) than I was when they were at school because we're doing it together and, and I know I'm teaching them self-help skills as well that they need … And I'm enjoying getting time with

> them … [before] I would be like, do I really have to go pick them up and deal with the meltdowns and tensions … the screaming all day again. I would feel sick and that made me feel like shit. I always wanted to be that attachment parent, you know, the one that enjoyed spending time with their kids and, and it was just, I just wanted them away ... but [now] I'm coping a lot better.

Fiona discusses how when her children were in school, they were becoming children she didn’t enjoy spending time with. The self-governance by Fiona is evident. The ‘policing’ of her own performance as a mother demonstrates the constant monitoring of self so that it is disciplined into a particular way of behaving. For Fiona, the self-regulation of her own performance of motherhood meant that by removing her children from school and making herself and her children less visible, she was able to take some of the pressure off of herself.

The education system was just one site of disciplinary power that was identified. In this next section, I look at mothers’ experiences with the NDIS (National Disability Insurance Scheme).

NDIS and the ritual of the confession

The NDIS (National Disability Insurance Scheme) is a policy (introduced in 2012 and passed in 2013) designed to provide those with a disability, or those who care for them, with what is deemed ‘reasonable and necessary’ (NDIS 2018) support to ‘live an ordinary life’ (Carers Australia 2018). In this section, I argue that the NDIS acts as a procedure that through invitation and assistance allows the effects of power to circulate. I also argue that it acts as a technique for the body of an autistic child not to be treated as a unit but broken down and its parts rearranged (Sheridan 2003, p.149) and a procedure where mothers are situated within and targeted by an accumulation of networks, authorities and institutions whose technologies of power have been enlisted to identify and place upon the mother and child their own desires and aspirations (Miller & Rose 1993).

The introduction of the NDIS provided some of the financial resources required for mothers to perform (mother-care) - mainly the financial resource to access, or pay, for therapy. Access to such economic freedoms was however dependent upon the disclosure (i.e., confession) and docile behaviour of the mother. The procedures of the NDIS and the use of calculative technologies to guide the conduct of the population (in this case mothers of autistic children and ultimately her child) acted as a way to shape activated and responsible citizens.

For Foucault, the confession is central to the production of knowledge and to an understanding of the workings of power. Central to the order of civil and religious power, the confession is not confined to the church. Rather, as stated by Foucault:

> Western societies have established the confession as one of the main rituals we rely on for the production of truth … At the heart of procedures of individualisation … the confession became one of the most highly valued techniques for producing the truth in Western culture (Foucault 1978, p.58-59).

Post ‘the rise of Protestantism, the Counter-Reformation, eighteenth-century pedagogy, and nineteenth-century medicine’, the confession ‘lost its ritualistic and exclusive location’ (Foucault 1978. P.63). The confession has since been employed across various relationships. From students and educators to delinquents and experts (Foucault 1978, p.63).

For the confession to be central to the practice of the NDIS interview, it requires that the journalist, or in this case the NDIS caseworker, take on the role of “listener". Thus, the caseworker becomes an ‘authority who requires the confession, prescribes and appreciates it, and intervenes in order to judge, punish, forgive, console and reconcile’ (Foucault 1978, p.61-62). As ‘confessions operate within, and maintain, power relationships’ (Dent 2008, p.16), the statements made within the confessions must in some way act as a “force” that ‘brings about effects’ (Foucault cited in Davidson 1997p. 5). Hierarchical observation, that rendered visible those who were part of the program, operated to transform both the conduct of the mother and the child. Normalising judgment by both the mother and caseworker differentiated, hierarchised and homogenised (Foucault 1977, p.183) the autistic child.

Rather than considering the confession in its most ancient form: the coupling of confession and torture (Foucault 1978, p.59), I consider the confession as a 'practice of freedom' and as a reinvention of truth and self (Foucault 1991). I view the confession as ‘seeking the fundamental relation to truth not simply in oneself … but in the self-examination that it yields (Foucault 1978, p.59-60). Similar to Mills (1995, p.101) I examine the way in which ‘the confession is implicated in the *exercise of truth* as an exercise of knowledge/power’. I am interested in the formation of mother’s subjectivities within power/knowledge relations that have produced the elements of the autistic child and what that child is not. I view the possibility of any liberation of self only possible because its meaning has been formed within the dominant institutional order that produced the confession to first be necessary. Furthermore, understanding how the NDIS interview acts as a confession adds further insight into how the rituals of the confession have come to function ‘within the norms of scientific regularity’ and how confession within the procedures of the NDIS can be ‘constituted in scientific terms’ (Foucault 1978, p.65).

The confession is bound in power relations and whilst the confessor has authority to tell the ‘truth’ of themselves – what they do, think or feel – they cannot interpret it with any authority (Foucault 1977). The practices involved in NDIS procedures served as a ritual for the mother to reveal the deficiencies of her child, leaving her vulnerable to the judgement of a higher authority. She was required to speak the ‘truth’ of her own observations about her child’s abilities - confess her child’s failings, her aims and goals for her child and the progress being made in meeting these desires.

The process implemented by the NDIS included a pre-set questionnaire format and the free-flowing discussion between each party. I argue that both parts of the procedure were central to mothers’ confessions. Whilst the free-flowing aspect of the interview allowed the confessor to make sense of the speech, the exacting questionnaire acted as a form of interrogation where the scope of the confession extended that which the confessor may have hidden from themselves and ‘incapable of coming to light except gradually through the labor of a confession in which the questioner and the questioned each had a part to play’, ‘forcing a difficult confession into a scientific practice’ (Foucault 1978, p.66).

The ritual of the confession, according to Foucault, is a ‘discourse in which the speaking subject is also the subject of the statement’ (Foucault 1978, p.61). Contrary to the dyadic relationship of traditional confession, in this instance it was not herself the mother sought to transform, it was her child. Rather than the mother being the subject of the statement, it is her child. However, through the confession of her child’s failings, she also confesses what she as a mother has failed to achieve. Neoliberal discourses contend that most societal and health-related problems can be explained and resolved in terms of the quality of parental care (Smyth 2012, p.2). As argued by O’Reilly (2016, p.57), mothers are held responsible for how their children fare under neoliberalism. According to neoliberal discourses of motherhood, if children do not succeed, the blame rests solely with the mother as it was her responsibility to ensure that they could and should succeed. Hence, by confessing her child’s failings, she is also confessing her failings as a mother.

All confessions are produced within relations of power. For mothers in my study, mothers confessed to an NDIS caseworker as this is a position of authority - those demanding the confession. In turn, this confession also served as a mechanism for those in authority to access mothers involved in the scheme and allocate to them what they deemed to be the necessary and reasonable resources required to correct their child. By way of this production, mothers would think things through in a manner they perhaps previously wouldn't have. Such a practice disciplined mothers to think in a particular way about their children:

> **Katie -** when you write your NDIS they get you to set goals of what you want him to be able to achieve in the year. So, they go through each section. So socially, what do you want to him to be able to achieve that he is struggling with, so it's always about that struggle … and then you go ok, so physically what does he need to do. So, ok, he's functioning at a 3yr old level so I'd like him to be able to hop, skip, run.

The reward of financial help was only available by identifying developmental goals – the child must always be 'developing'. As argued by Foucault (1978, p.65), the 'clinical codification of the inducement to speak' and 'combining confession with examination' was one of the ways for the procedure of the confession to be reinscribed 'in a field of scientifically acceptable observations'. Mothers were not only required to articulate their children's needs and confess their desires for their children, but also provide a history of what they had achieved thus far. Although the goal may have been to offer mothers a means through which they could express themselves and their needs/desires for their child, similar to the analysis by Brich (2008, p.27), regarding the testimonies gathered from prisoners in France by the 'Groupe d'information sur les prisons' (GIP), the methods used and the responses elucidated suggest that statements by mothers were not simply 'set free' but constrained by the NDIS agenda. The confessions of mothers were not spontaneous, rather prompted. Regardless of this prompting, mothers took an active role in the confession. For example, the filling out of the required forms was required to be able to speak from the position of mother of an autistic child and also operated as an acknowledgement of this subject position. Whilst her child was always watched and governed, through the confession mothers took an active role in their own surveillance acting at once as the governor and the governed, the watcher and the watched.

The recorded truth

The incitement to confess brought with it the ability to record (Foucault 1978). The recording of mothers' confessions, however, was not always the 'truthful' confessed desires of the mother. By this, I mean that mothers often had desires for their children that were not heeded, approved or recorded in the outcome of the interview. Mothers were incited to confess so that they and their child might be liberated (transforming an individual burden into a social one) but this confession can only be properly interpreted by the expert authority of the NDIS caseworker (Foucault 1978). The method of interpretation is another means by which the confession has been able to be constituted in scientific discourse and as such, it was not the confessions of mothers that resulted in an outcome, rather it was how the confession was interpreted:

> If one had to confess, this was not merely because the person to whom one confessed had the power to forgive, console, and direct, but because the work of producing truth was obliged to pass through this relationship if it was to be scientifically validated. The truth did not reside solely in the subject who, by confessing, would reveal it wholly formed. It was constituted in two stages: present but incomplete, blind to itself, in the one who spoke, it could only reach completion in the one who assimilated and recorded it (Foucault 1978, p.66).

The knowledge of mothers could only be considered truth once interpreted by the caseworker. It was the function of the caseworker to ‘verify this obscure truth: the revelation of confession had to be coupled with the decipherment of what was said’ (Foucault 1978, p.66). The caseworker was not simply there to listen, judge or condemn, they were the ‘master of truth’ (Foucault 1978, p.67). Theirs was a hermeneutic function. Their power was not only to ‘demand the confession before it was made, or decide what was to follow after, but also to constitute a discourse of truth based on its decipherment’ (Foucault 1978, p.67).

Despite the emancipatory potential the financial resources provided by the NDIS appears to offer, the authority of the mother regarding the needs her child was subject to the knowledge that was produced, controlled and monitored by others. Decisions made by mothers were dependent upon funding given and what this financial resource could be used for:

> **Lauren -** So for kids once they hit nine they’re no longer in a period of early intervention where they qualify, they only qualify for that intensive support early on …. So the things that I needed for him I wasn’t approved on. The things I’ve been approved for I do need them, they’ll help him, but I don’t see them as urgent.

The strategic and rational deployment of funding was determined within expert knowledge. The preferences of the mother were not privileged, they remained invisible and sat at the periphery of the social order. She again had the responsibility but limited authority.

A desire to assist the growth of the child was both experienced by and prescribed to the mother. It was not that the mother was held accountable in a judicial sense for failure to comply, she was rather rewarded by way of financial resources if she complied with the regulative and administrative processes. The choice itself acted as a form of control. A hierarchy was produced where the mother's choices were supervised and her obedient body rewarded.

The money provided by the NDIS was not money that was given directly to the mother. Rather, it was a financial resource based upon how the NDIS professional viewed the needs of her child, placed into an account she could then use to assist the development of her child. The money provided by the NDIS was public money and thus essentially wealth that had been redistributed. This was money that must be used in accordance with, in the words of many mothers spoken to, what a report could measure:

> **Lauren -** So OT, seeing a psychologist and he just doesn't need to see a psychologist … He's tried that it didn't work … but I've got funding for it. I've got funding for things that, I mean the OT guy's lovely, he's got very low muscle tone so that's obviously great, but would I have prioritised that over some of the other things we were doing, no. So, I couldn't get funding for things, that was really frustrating.
>
> **Lauren -** And when they were consulting on that NDIS … they were supposed to consult with leading people and I don't know if they did, in the field. And these people are leading people in the field but it has just been over-ridden by that more important economic need that they can measure. This person doesn't have a qualification where they can provide a written report where it definitively says, your child has improved this amount. We need to know they are going to improve this amount … that can show us and prove to us that he's improved which is just absolutely fucking ridiculous.

Whilst Lauren demonstrates some resistance, she lacked the authority to have her 'truthful' desires implemented. The recorded truth needed to be able to show improvement. The funded therapy required a written report by an NDIS approved expert that demonstrated the improvements and benefits the child had received from the treatment - that their child was transforming into something. Mothers were also required to participate in annual reviews to report their child's progress and what they felt their child needed. However, as stated above, what mothers thought their child needed was not always what was funded. Although the observation of progress and the recording of this progress through the established measurable outcomes (Foucault 1978) of the child saw mothers play a role in the production of knowledge, the recorded outcome lacked the voice of the mother – they didn't have the authority conferred by the relevant expertise. The then recorded truth about what works and what doesn't is then used in the future to further produce the NDIS subject.

Resistance to NDIS and Therapy

Whilst mothers had little authority when it came to the types of therapy funded by the NDIS, they did have the authority to resist the amount suggested:

> **Fiona -** I got a letter from NDIS up here today, and it was hard reading it, … and it's like she will fall behind if she doesn't get this therapy. And I was thinking ... That's why I was going right (laughter) … They just need therapy but there are only so many hours in a day after school … When are these kids allowed to be kids? ... When are they allowed to just be children? … You know, and play and explore, and ... That's how kids learn ... My background's childcare, so I'm big on that learning by [play].

Often mothers felt as though the number of disciplinary practices required robbed their children of childhood. The amount of therapy their kids were supposed to do indicated the amount of fixing their child needed - that they weren't allowed to be children as they had not yet met the appropriate standards of functionality. Consequently, this type of resistance meant mothers such as Fiona would not be the mother whom expert knowledges would view as the mother who 'did everything she could' to correct her child. Rather, mothers such as Fiona would come to understand and act upon their child in a way they felt comfortable by drawing upon the discourse of normative play and childhood development she had been exposed to through her background in childcare.

The practices of the NDIS required mothers to confess the failings of their child. Again, mothers' voices were often unheard and expert authority privileged. Although the NDIS offered some assistance with funding, this funding was to be used in a manner deemed appropriate by the expert authority of the institution. They were the ones who knew how to best fix the delinquent child. Although mothers had little authority to resist, it was evident that mothers did not agree that a government agency knew more than they did about what was best for their child.

Development over Cure - Mother Knows Best

In this final section of the chapter, I examine some of the views expressed by mothers about engaging in therapeutical practices and their views on ‘curing’ their child. I then conclude this section by demonstrating how mothers embodied and reproduced the idea that it is only the mother who can best care for their child.

Aims of therapy

Although mothers often drew upon the medical discourse, in comparison to the narratives that emerged in my media (chapter 6) and website (chapter 7) analysis, there was a far greater focus on development rather than cure. The idea of curing their child was also something mothers resisted:

> **Fiona -** His anxiety ... yes, absolutely, I want to cure that … but the actual autism, how their brain works, I don't think, it's just wired differently, and I think that's just the way it's going to be (laughs) … honestly, I really feel sorry for these mothers looking to cure it, and I just wonder like how they must feel inside. At night, you know, when you're lying in bed and you're thinking about all these things, I think, oh, they must feel so awful all the time.
>
> **Tammy -** … my personal belief is, you don't cure it but you learn to manage it. And- and I'm okay with that. I think, you know, as he gets older and as we get used- more experience with it, we will as a family develop … But I listen to my mom and she still goes, "Oh, I think he's cured." You know? I think he's cured. You know, and I sort of ... I- I love her dearly and I don't want to burst her bubble but I think she's a bit delusional (laughs). And you know, that's her way of coping.

As discussed in chapter eight, mothers resisted the warrior-mother identity. The discourse of the warrior-mother is not simply recovery is possible, but ‘one of recovery at all costs’ (Douglas 2013, p.172). She (the mother) is ‘supposed to be a child-saving hero, expected and encouraged to do anything and everything in pursuit of normalcy’ (Waltz 2015, p. 355). The pursuit of normalcy was again something resisted by mothers. Whilst mothers wanted to assist their children and help them develop particular skills, they did not seek to free their child from autism.

Mother knows best

Further to the evidence provided when dealing with the NDIS, mothers did not expect others to know their children the way they did. For Fiona it was not simply that she was the best person for the role but her physical proximity to her child that enabled her to know them better than others:

> **Fiona -** It's funny. Other people, they can't see those little signs as well. Like, they're missing out on those really early signs … where perhaps you can stop it a bit earlier on … Where you can implement things and … I'm with her all the time, so how can I expect somebody else to know what it was that set her off? Um, and then so she would've, I would've then got a call going, "You need to come pick her up," and you know.

Whilst Fiona drew upon the time spent with her child as a dominant reason for knowing them in a way others weren't able or expected to, it was common for mothers to draw upon dominant gender roles when discussing the role/s they assumed in both the private and public sphere. The discourse of intensive-mothering dictates that children can only be properly cared for by the biological mother (Hays 1996; O'Reilly 2016). In addition, and again consistent with the 'good' mother discourse, when mothers (who were the primary caregiver) spoke of caring work, there was often an assumed undertone of disciplinary acceptance that performing care or dealing with issues related to providing care was the role that was the most important:

> **Liana** – mothering is a bit more like that, fingers in many pies, juggling a lot of things. Probably financially we would have a different life if I worked full time and went back to lecturing and financially we would be in a different position but I think the emotional stuff of dealing with all the teachers and various therapists and all that sort of stuff, Tim (husband) wouldn't be suited to that sort of stuff. It wouldn't be dreadful but it wouldn't happen in the same way.
>
> **Researcher** – the emotional labour?
>
> **Liana -** Yeah! I haven't heard it put that way but that's exactly what it is.

Intensive-mothering separates the mother from paid work in order to best care for her child. Narratives such as Liana's are still consistent with the demand for mothers to 'reproduce socially appropriate neoliberal subjects' (Vandenbeld Giles 2014, p.5). The appropriate neoliberal subject is self-reliant, responsible, manages risk. As discussed in Chapter Two and argued by Vandenbeld Giles (2014, p.5), the focus on the reproduction of socially appropriate neoliberal subjects is ‘consistent with the free-market focus on choice and individual responsibility’, it is, however, an economy that still relies on the free labour and the assumed maternal devotion and desire of the mother.

The emotional labour described by Liana meant that although she recognised the financial sacrifice, she felt she was the one who was best suited to perform the part of the role that required the coordination and mental effort that her husband would not have the ability to do as well as she did. The idea that they (mothers) were better suited to the role was again reflected in my interview with Katie:

> **Katie -** And with, you know, society still so geared towards gender roles … we still say that dads are babysitting their children, and … oh what a wonderful, wonderful dad, he stays at home while that mother goes out to work. If a woman were doing that it's fine, but because it's a man doing it. My husband had long service leave … he stayed home and I went back to work. And you would get all the time, "Oh, well that's pretty cool. How does he feel about that?" … But he never, he couldn't do what I do. He doesn't have the patience to be home all day with Felicity.

Fathers were both excused and excluded from taking up the performance of central caregiver. Whilst two disparate constructs, the excusion and exclusion of fathers were often simultaneously operated and employed. By this I mean; a notable theme was that some mothers would diminish or dismiss the ability of the father to best perform the required caring role – a consistent theme of dominant and expectations of motherhood (where the mother is best suited for the role (Hays 1996; O'Reilly 2016)). Although Katie recognises the social construction of gender roles and how differently she and her husband are treated when they occupy the role of primary caregiver, she simultaneously reproduces this construction by describing him as incapable and herself as capable. Although mothers often felt put-out or frustrated by this responsibility, they themselves reproduced the discourse that children can only be properly cared for by their mother.

Summary

Institutions and techniques of surveillance worked to discipline mothers. The practices of measurement and observation, enabled by the organisation of time, space and structure of disciplinary institutions and constructed standards about what a child should be enabled the categorisation of children as problematic. Furthermore, subjectification effects of this construction produced mothers as a targeted group who were responsible for the assumed ‘problem’ child. With mothers also now viewed as deviant, their knowledge was typically at the periphery. Mothers felt as though their voices and knowledge were often not heard. Or, only heard if they were consistent with what the relevant authority (teachers/principals/case workers) already thought or wanted to hear.

In addition to the subjugation of their knowledge, the effects of examination worked to make the subject position of autism mother, a position they somewhat resisted. For example, although mothers resisted the warrior-mother identity, as evidenced earlier in this chapter, mothers battled and fought with the institutional discourses of schooling and disability (NDIS). Although they did not take up the identity of the warrior-mother they still battled and fought for their child. They became a different kind of warrior-mother. They had to fight for not only their child but for themselves to be heard as mothers. Such effects of surveillance created another discontinuity in the overall discourse from my interviews. Often it was the mothers who felt as though representations of their children as ‘wrong’, were the ones who then felt they had to go into battle - often due to the limited authority and recognition of their position.

Whilst resistance was evident, it is impossible to know bodies outside of power relations (they are fundamentally entangled in these practices) (Foucault 1978). Furthermore, we no longer see the power/knowledge relations that enabled them. For example, if mothers remove their child from school or if they resist the types, or amount, of therapy they were told to place upon their child, by resisting expert knowledge they risk being a mother who did not do everything they could for their child. Not doing everything you can for your child not only violates the current ‘good’ mother discourse, that of intensive-mothering, it also opens further avenues of mother-blame.

Although mothers practiced intensive-mothering they did this from a deviant position. Intensive-mothering was assumed, even intensified, even though there was little certainty of status safeguarding or upward progression. Mothers often became the docile bodies their children weren’t able to be.

This is not to say mothers did not seek out or listen to expert knowledge. Whether it was the internet, a novel, a therapist, or a support group, mothers turned towards information that they would not have sought if their child had not been diagnosed as autistic. Making sense of the information available to and imposed upon them led to mothers often questioning this knowledge (the abilities of their child, the therapy needed), but rarely did they question or resist the dominant constructions of motherhood.

CHAPTER 10: CONCLUSION – JANUS FACED MOTHERING

The previous four chapters (six to nine) presented the findings from the data collected across my study. This final chapter explains how my research furthers understandings about how mothers of autistic children are represented, the effects of this representation, and how, by my own interpretation (within the range of possible interpretations) the subject position of 'autism mother' was negotiated. Moreover, bringing together the data examined enabled me to identify something I have named *Janus-faced mothering* – a state of having two faces.

I begin this chapter by addressing the three research questions my study examined. The dominant themes across each data set were those of mother-blame and responsibility. Mothering discourses, whether they be that of the 'good', 'bad' or 'intensive' mother, were evident throughout. As was the medical discourse of autism. An important finding was that medical discourse set the standard for the child, discourses of motherhood set the standard for the mother. It was evident that we blame the mother for 'this' child. And we shouldn't. Blame was evident from my genealogy chapter right through my interviews. This blame is cruel to mothers and it is cruel to the child.

Research Questions

RQ: 1) How is autism and how are mothers of autistic children represented within public sources of information and data?

Both sources of public data examined – newspapers and *Generation Rescue* - represented the autistic child as less than human. Autism was presented as undesirable, unwanted, to be avoided and something that could eventually be eradicated by science and medicine. Autism was something that had happened to the child. As a consequence, the notion of mother blame was evident throughout the public discourses examined. Blame was placed upon the failings of the mother in a variety of ways: Mothers were blamed for creating the autistic child; blamed for their failure to acknowledge and avoid risk, and blamed for failing to rear a docile child who could be governed in a manner deemed acceptable to set societal norms and standards. Furthermore, with autism being represented as something that happened to the child and autistic children represented as taken children who are now trapped, mothers could be blamed for failing to recover their true child. This not only represented mothers of autistic children as being responsible for having lost their true child but also as responsible for bringing them back. The lack of success mothers exhibit in ‘bringing their child back’ then leads to further confirmation of the inherent ‘truth’ of the social institutions of science and medicine, institutions represented as those that will save the population from the devastating version of the failed and incomplete human that is the autistic child. You as a mother have failed: ‘we’ as dominant discourses of truth will correct or, at a bare minimum, point out your failure.

Both sources of public data focused on the rate at which autism is said to be increasing. This rate of increase was used to highlight the importance of, or strengthen, the agenda of the knowledge being discussed. Autism was represented as no longer rare or the concern of only a few. Again, the representation of autism as a problem made the growing rate of autism something that is a concern for all. Furthermore, both public data sources suggested links between autism and everyday experiences, such as food and environmental toxins (i.e., paint and traffic fumes), again reducing the distance between autism and the wider community. As noted in chapter six, and again in chapter seven, the manner in which the discourse of autism was propagated was through tropes of fear, tragedy and urgency.

Public discourses examined positioned mothers of autistic children as devastated, grieving, their lives and families destroyed. Mothering an autistic child was predominantly represented as a burden, not an experience to be celebrated. If mothers were to be celebrated, it was for their extraordinary efforts. Whether that be the burdened life she must now lead, her efforts in making hers and other autistic children’s lives better, her heroic, tireless, never-ending efforts to seek answers, or standing up against the medical community (as per Jenny McCarthy), the mother was only celebrated through self-sacrifice, devoting her life towards addressing the problem of autism.

Whilst there were similarities across the two sites of public data examined, there were also differences. Whilst both data sets were dominated by autism being something that had happened to the child, there were competing claims about when this ‘happening’ occurs. Newspaper data was dominated by suggestions that autism was something that occurred during pregnancy (when within the mother’s body: her breathing of traffic fumes, her stress levels or thyroid function), *Generation Rescue* was dominated by narratives that claimed autism as something that happened to the child post-pregnancy (vaccinations and other toxins) or a combination of toxins and a genetic defect. Never was it purely genetic. Newspaper data presented mothers as responsible for causing their child's autism, *Generation Rescue* as responsible for curing it.

RQ: 2) What are some of the discursive and subjectification impacts produced by the representation of autism and mothers of autistic children?

Regarding the impacts of representations, my study focused on two key effects: discursive - effects that follow from the limits imposed on what can be thought and said and how this closes off other solutions, and subjectification effects - the ways in which subjects and subjectivities are constituted in discourse (Bacchi 2009).

An important discursive effect identified was the limits imposed on the way both autistic children and their mothers could be thought of. For example, neither the mother nor the child could be referred to as normal. For autistic children, what was constituted as normal was used to compare, contrast, test and ultimately categorise the child as abnormal. Moreover, their perceived abnormality provided a measure of health. As highlighted by Foucault (Droit 2004, p.95):

> if you are not like everybody else, then you are abnormal, if you are abnormal, then you are sick. These three categories, not being like everybody else, not being normal and being sick are in fact very different but have been reduced to the same thing.

The reduction of difference, abnormality and health to a single category was evident throughout the data analysed. Whether it be the use of terms such as autism as a disorder, or the use of 'normal children', or 'healthy children' as a control measure, the representation of autism reduced autistic individuals to those who were abnormal. Moreover, rarely was not being like everyone else thought of in any other way other than as a problem.

Similarly, mothers of autistic children could not be thought of as normal. They could be devastated or heroic, Train A or Train B, but never normal. The representation of mothers of autistic children as devastated simultaneously represented and imposed limits on what mothers should expect, or deserve, from motherhood. There was an assumption that a mother should have a certain type of child, and in this case, that child should not be autistic. Furthermore, the devastation that comes with an autism diagnosis meant that they could never be 'good' mothers. As demonstrated in this thesis, a 'good' mother is a happy mother and mothers of children who have 'gone wrong' cannot be happy, they can only be 'bad' (Ladd-Taylor & Umansky 1998, p.3).

Moving on to the subjectification effects identified in my study, representations of autism and assumptions around motherhood resulted in numerous subjectification effects regarding the way mothers of autistic children were thought and spoken of. Representations of why children were autistic made mothers individual subjects responsible for this production. With their children represented as a version of an undesired human, their real child taken and being held hostage by the villain that is autism, subjectification effects of the textual (public) data constituted mothers of autistic children as those who needed to fight. The 'autism mother' subjectivities (i.e., the feminine-warrior, hero-warrior) were "reinventions" and intensifications of neoliberal and postfeminist discourses of the empowered feminine (Ringrose & Walkerdine 2008). These subjectivities were also individualising – a neo-liberal doctrine that represented mothers as having the personal and moral responsibility to control the outcome of their children. This mother must avoid risky behaviours before and during pregnancy. She should follow the advice given to her, make sense of it all, consume it, enact it and remain hopeful that she either hasn't tried the right course of action or that the right course of action will soon exist.

Bringing together representation and effects of this representation I identified nine interrelated frames of 'autism mothering' evident in the public data:

1) Mothers of autistic children can never be happy.
2) The 'good' mother has a child who develops by normative, pre-established standards.
3) Mothers of autistic children do not have their true child nor the child a 'good' mother deserves.
4) Science and medicine hold the key to rescuing her child, but this can only happen if she loves her child enough to dedicate herself to doing everything she can.
5) Whilst science and medicine hold the key to rescuing their child, the 'bad' and 'good' mother discourse are dominant when it comes to blame.
6) Her child is vulnerable. She is raising a child vulnerable to violent attacks and a likely perpetrator of criminal behaviour.
7) She must keep trying; even if the attachment to such possibility may be cruel, it is not seen as such.
8) Whilst she is blameworthy, she deserves our pity and condolences.
9) She cannot be fully satisfied in the role she is performing.

Individually, each theme is negative. When brought together it presents a bleak picture of how we think of mothering an autistic child and the mother herself.

RQ: 3) How do mothers of autistic children negotiate the subject position of mother of an autistic child and what are some of the lived effects of this subject position?

Whilst acknowledging that researchers have created the category of autism mother and that participant's response to my invitation operates as acknowledgement of belonging to this subject position, the final research question of my study examined the ways mothers took up the subject position of 'autism mother' and also some of the lived effects of this position. In addition to having to negotiate the nine themes of 'autism mothering' outlined above, the findings of my research indicate that mothers were also disciplined to perform intensive-mothering practices. Whilst intensive-motherhood is the dominant discourse of motherhood in Western society, mothers of autistic children were disciplined to engage in intensive-mothering practices from an "abnormal" position. Furthermore, whilst the overarching categories of intensive-mothering remained the same, the specific requirements differed. For example, the expectation of mothers to adhere to traditional mothering roles and responsibilities dictates that mothers spend copious amounts of time and energy in rearing their children. It is not simply proximity that intensive-mothering demands, rather "quality time" (O'Reilly 2016, p.49). Whilst this demand is true of all mothers, rather than classes (such as learning French or being taught karate), the "quality time" and energy of mothers of autistic children were to be spent engaging in therapy. Essentially, rather than trying to make their child better than other children, they needed to make them like other children.

The standards set by intensive-motherhood are virtually impossible for any mother to meet (Hays 1996; O'Reilly 2016). For 'autism mothers', the abyss between what was dictated and what mothers felt as possible, meant mothers often resisted these demands and the pressure to meet them. Part of mothers' resistance in attempting to meet the expectations of therapy was the idea of 'when did their children just get to be kids?' It was not simply their own time and energy: they saw these demands being placed also upon their child. This form of resistance created dissonance for mothers. On the one hand, they were protecting their child, as 'good' mothers should. On the other hand, they were no longer mothers who did everything they could for their child. Whilst mothers often viewed these expectations as unrealistic and these unrealistic expectations made resistance possible, these expectations were also another example of how the impossible ideals set for mothers make possible feelings of inadequacy and self-doubt.

Mothers were subjected to the role of producer and carer, the person who could be blamed and deemed responsible for the child. In contrast to the public representations of mother blame, mothers interviewed felt it was their mothering that was blamed rather than any failure to adhere to medical discourse. Chapter six (media chapter) demonstrated that if one wants to avoid having an autistic child (and according to the themes identified, one should), the medical discourse demanded mothers avoid traffic fumes and understand the impact being abused as a child will have. In chapter seven (Jenny McCarthy and *Generation Rescue*) science and medicine were to blame for the autistic child (vaccines in particular). In contrast, in my interview chapter, whilst self-blame was made possible by what medical discourses dictate mothers should do to achieve the perfect pregnancy, it was evident that the discourses of the 'good' and bad' mother outweighed the medical discourse and the individual characteristics of the mother (marriage status, native language) were the target of blame.

The failures of the child to meet the standardised constructions of development and social conformity made the mother highly visible. This was particularly evident within the education system. That their child stood-out meant they also stood-out as mothers. They were visible to the teachers, principals and also other mothers. Mothers' visibility meant that their failure to possess any or all of, the dictated attributes that the 'good' mother should have were also visible. Returning again to Ladd-Taylor and Umansky's (1998, p.3) description of the 'bad' mother, bad mothers are 'those who d[o] not live in a "traditional" nuclear family'. Failure to have the appropriate nuclear setup and role models were viewed by others as the reason for their child's lack of conformity to socially required standards.

Although medical and schooling discourses were evident throughout, overall, when it came to my interviews, the discursive, subjective and lived experiences examined were dominated by the mothering discourse. Mothers often became the docile bodies their children couldn't be. The docility of mothers 'joined the analysable body' (capable of being understood) 'to the manipulable body' (a useful body) (Foucault 1984, p.180). The docility of mothers made them productive. Productive in the child they were constructing and productive in contributing to statistical records of the measurement of success for programs such as the NDIS.

On the other hand, the productivity required from mothers made them docile. For example, the authority of the mother to decide what therapy to engage in was limited. Part of the intensive-mothering discourse requires mothers to turn to experts for advice. It was the experts who had the authority to originally diagnose their child and it was the experts who had the authority to dictate how they should correct their child. Furthermore, the expert authority of science and medicine was also part of the web of technologies that made mother blame possible. In turn, mothers were also viewed as deviant and their knowledge was typically at the periphery. That their voices were not heard meant that they had to conform to the power of disciplinary institutions, in particular, the NDIS, and behave in the ways those with the authority wished them to. Making the body of the mother docile to particular types of disciplinary power.

Conversely, that their child was deemed to not be developing according to dictated measurements meant they had knowledge other mothers do not have. They had to deal with situations, learn skills and ways of thinking that other mothers do not. For example, one important decision mothers had to make was whether or not to place the subject position of autism onto their child. For some mothers, this was something they were hesitant to do. The decision to not impose the subject position of autism was often done for their own child's self-esteem or the way they would then be treated by others. This type of knowledge was knowledge the "good" mother doesn't need to have.

Of importance, however, was that mothers were often docile up until the point they felt repressive power was being enacted. By this, I mean power that through its influence sought to repress who their child was, rather than power that helped their child develop. It was often when repressive power was enacted, such as the expectation of the school to drug the child, that mothers demonstrated their strongest form of resistance. Efforts, in particular by schools and teachers, to constrain, regulate and dominate saw mothers resist with their focus being on development over recovery. Thereby refusing the recovery discourse evident on *Generation Rescue* and evident in the newspaper data. Although there was self-doubt, they often thought they were doing their best. That they were trying to be good mothers.

Resistance by mothers was evident throughout my interviews but this was mainly directed toward expert authority and disciplinary institutions such as schools, the NDIS and the dictated requirements of the amount and type of therapy their child engaged in. There was minimal resistance of the institution of motherhood (as responsible and intensive). Rather than question the intensive-mothering discourse, mothers tried to find a place within it. Although resistance to the schooling discourse embedded mothers further in intensive-motherhood, intensifying the intensive-mother discourse enabled them to challenge the competing school discourse. This strategy of carving out a space for themselves and their child/ren in some ways worked for them. They noticed a positive change in their children and an increase in happiness in their performance as a mother.

In comparison to public representations of autism, mothers held a stronger attachment and focus on autism as part of who their child was and focused more on development than cure. Potential cures for autism, although not as dominant as causes, were evident throughout the newspaper data. Recovery from autism was the slogan of *Generation Rescue* and the platform on which McCarthy's narrative was built. In contrast, mothers interviewed focused more on development and progress - the learning of new skills. Even though these skills were driven by what they wanted or hoped their child would be able to do, they did not seek the eradication of autism from their child.

There was both acceptance and refusal of the subject position of autism mother. Mothers interviewed all took up the subject position of autism mother but navigated what *type* of 'autism mother' they would be. After turning towards information or resources they felt might have been useful to help understand their new subject position, mothers often then 'turned away' from what they found. After taking up the subject position of autism mother and seeing the world from that vantage point, mothers navigated their way through the various options and expectations of this new identity.

By bringing together the data analysed in my study I was able to gather a more complete understanding of the representations of mothers of autistic children, some of their experiences and knowledges and some of the effects of the power/knowledge relations that produce mothers of autistic children. From this, I was able to identify some of the complexities of this subject position, in particular, some of the contractions it produces. I have categorised this subject position as Janus-faced mothering. as

Janus-faced mothering:

Described as having two faces, Janus was the Roman god of beginnings, gates, transitions, time, duality and doorways (Ostberg, Barth & Frelinger 1998). The duality of many of the experiences and representations of mothers of autistic children created identities and positions that were often contradictory. Whilst, not each duality discussed below applies to all data sets, the overall representation presents an often uncomfortable, frustrating and demanding position.

She must protect yet fight:

Mothers were found to provide the feminine quality of nurturer, shielding their child from the demands of the normalised world. They would also go out and fight for their child's world to be more normal. For example, fighting for resources such as education saw mothers enter the political arena – an area where the ‘good’ mother does not engage (O’Reilly 2016). As argued by Douglas (2013, p.174), identities such as the warrior-mother must abandon their “natural” place as proximate to their own child in order to perform the role.

Whilst mothers across each data set fought for their children, the manner in which they did so differed. In the newspaper data analysed, mothers fought to open schools’, mothers on *Generation Rescue* fought to rescue their ‘true child’, and in my interviews, mothers fought with schools and NDIS dictations of what their child needed.

Even within the way mothers fought there was contrast. Mothers on *Generation Rescue* embodied the warrior-mother identity. Recovery from autism was not only possible, it was expected that mothers would invest copious amounts of time, money and energy until this was achieved. In contrast with the warrior-mother discourse, mothers interviewed fought against this label and felt sorry for those hoping for a cure.

Although there were differences in the way mothers fought, what was consistent was that mothers on *Generation Rescue* and in my interviews fought to be heard. In both data sets, it emerged that mothers felt they were not heard. That what they felt to be true and necessary for their child was minimised and the voice of authority was given to those who drew upon the dominant discourses of science, medicine and schooling and disability.

In addition to mothers fighting for their children, mothers also strove to protect them. On *Generation Rescue*, mothers sought to protect their children from the dangers of vaccines and other toxins in their environment (paint, carpets). In my interviews, mothers wanted to protect their children from the expectations of expert knowledge of the schooling discourse and therapeutical practices. Mothers interviewed wanted to protect their children from many of the expectations of normalcy whilst mothers on *Generation Rescue* fought for their child to be normal.

This is not to say that all mothers interviewed protected their children in the same ways. For example, the theme of protection ranged from removing their children from the public school system and home-schooling them, to hesitation to impose the subject position of autism onto their child.

She is the docile battler

The docility of mothers was apparent on both *Generation Rescue* and within my interviews. A docile body is described by Foucault (1977, p.136) as ‘one that may be subjected, used, transformed, and improved’. For McCarthy, this was particularly evident in the transformation of her physical appearance and how she took up various categories of attractiveness (i.e., classic beauty, sex-kitten) depending on the target audience. For mothers in my interviews, their docility was particularly evident when discussing the NDIS. Whilst the core aim of the NDIS was to transform the child, the desirable behaviour of the mother was promoted by disciplinary power that organised mothers in a manner that made them docile and obedient. With the reward of financial assistance only available if certain therapies were accessed and measurable development goals identified and demonstrated, the actions of the mother were directed towards that which the governing body deemed reasonable and appropriate.

Whilst there were differences in the ways mothers were docile, there was consistency in the fact that mothers were docile up until a point. This point tended to be that where mothers felt repressive power was being enacted upon their child - power they felt limiting their child. In the newspaper data, the act of bullying was a driving force behind a mother opening a new school for special needs kids. On *Generation Rescue*, mothers resisted the demands for vaccinations. In my interviews, mothers resisted the repressive power of schools or therapists (i.e., the need to medicate or engage in ABA) when they felt that power was having detrimental effects on their child and on their happiness as a mother.

She is often ignored but highly visible

Having a child who was different made mothers highly visible – they stood out from other mothers due to their difference. But although visible, they lacked authority. The newspaper data represented McCarthy as a mother who should be ignored but due to her celebrity status, has visibility. McCarthy represented herself as someone who was ignored by the medical community but made herself visible through appearances on talk shows and books about autism featuring her image. Mothers interviewed felt as though they were ignored by those with authority (within schools and the NDIS) but were highly visible in their performance of motherhood – particularly at school where the deviance of their child made them stand-out.

Mothers were not ignorant of the structures they were immersed within. This was particularly evident on *Generation Rescue* and in my interviews. On *Generation Rescue,* McCarthy was particularly vocal about how she (and mothers who supported her narrative) were made out to be anti-vax and how the medical community was trying to silence their claims. In my interviews, mothers recognised some of the structural challenges they faced when dealing with the schooling system and NDIS.

Whilst the motherhood discourse was powerful enough to override the medical discourse when it came to mother-blame, the discourse of biological mothers being the only ones who can properly care for their children does not extend to being listened to when deciding what is best for children or what children should be doing. This finding is consistent with the intensive-mother discourse as mothers often have limited or no authority from which to mother but have full responsibility (O'Reilly 2016).

She can be extraordinary yet still pitied.

Within the newspaper data, mothers who had articles written about them were celebrated for their efforts, yet still pitied for the situation they were in. Mothers were represented as having their lives and their families devastated by autism. It is not often that someone we think of as extraordinary is someone that we pity. Extraordinary achievements are usually admired. The fact that mothers who can be perceived as extraordinary are also pitied demonstrates the authority of both the autism discourse (autism as a way of being that should be avoided) and the discourse of motherhood (what we expect of motherhood).

For McCarthy, the warrior-mother was an identity mothers of autistic children should be. In contrast, mothers interviewed did not see the warrior-mother as something to be admired but rather viewed the warrior-mother as a selfish identity and pitied the warrior-mother trying to cure her child. Whilst this is an example of there being more than one way to negotiate the subject position of autism mother, it is also an example of the conflict that multiple subject positions can produce. The data examined did not show an internal conflict but a negative attitude towards mothers who took up the alternate identity.

She relies on yet questions her instincts

On the one hand, mothers interviewed felt they were the ones who knew their child the best and were the best person to perform the role of primary caregiver. On the other hand, mothers often turned towards expert knowledge to help guide them. Mothers interviewed spoke about how they felt reassurance when told they were doing a good job. Moreover, mothers often doubted themselves and the decisions they made.

Doubt ranged from concerns about their actions during pregnancy to decisions made about obtaining a diagnosis, to decisions made about their own methods of practicing motherhood. Although this doubt was often resisted by turning away from discourses that made them feel uneasy (such as ABA and mother's groups) they were still doubts that existed and had to be negotiated.

She loves as is yet tries to transform

That a mother loves her child was never in question. No data examined questioned the assumed love of a mother. Which child a mother should love or hope for however was debated. Autism was not something mothers interviewed sought to remove from their child. Whilst they questioned why their child was different, mothers interviewed accepted the child they had as their true child. But although they accepted the child they had as their true child, they could never escape the uniform standards of what is normal. What is considered normal and what a child should be able to do were standards that kept mothers engaged in practices to assist with their children's development.

Development was something mothers were supposed to make happen. The 'failure' of their child to develop naturally placed the responsibility on the mother. Although mothers interviewed did not seek to eradicate the child in front of them, they engaged in intensive-mothering practices as that was what they felt their child needed and deserved. This desire for development links heavily with the intensive-mothering discourse, in particular, that of independence and anxiety for the future. This was an uncomfortable place for mothers to inhabit and an area for further research.

Concluding summary

In furthering my understanding of non-normative motherhood, specifically that of mothers of autistic children, it became evident how dominant certain constructions of motherhood are. There is a preconceived idea of what motherhood should be, and having an autistic child was not it. In the public data examined and for mothers interviewed, the baseline for the 'good' mother was normative development of the child.

As discussed earlier, my findings were that the medical discourse set the standard for the individual child and discourses of motherhood set the standard for the individual mother. That the mothering discourse was at times powerful enough to override the medical discourse of autism is an area that warrants further research. Moreover, the characteristics of the mother emerged as an important component of how mothers were viewed. These findings suggest that further research that critically examines issues of class, race and culture and the role they play in the surveillance and construction of mothering an autistic child is needed.

Although fathers/parents were not within the scope of my study, two important themes emerged within the data collected. Consistent across all three data sets was the idea that fathers were secondary caregivers and exempt from blame. Chapter six (media analysis) identified that when understanding was given, the term ‘parents’ was used. When blame was placed, the term ‘mother’ was used. Chapter seven (Jenny McCarthy and *Generation Rescue*) identified that although the term ‘parents’ was used across the website, when it came to responsibility and who was represented on the website, it was mothers. Chapters eight and nine (interview chapters) revealed that an absentee father could result in the mother being blamed for her autistic child. Secondly, mothers interviewed were both critical of the construction of gender roles in parenting, yet simultaneously produced and reproduced the idea that mothers were the only ones who could properly care for the child. This is of particular importance from a gendered perspective as not only does the introduction of children encourage the ‘resurgence of traditional gender roles’ (Crittenden 2002, p. 25), when that child has a disability, these roles are often amplified further.

Whilst there was a discontinuity in the way mothers took up the subject position of mother of an autistic child there was consistency in what remained largely unchallenged, the assumptions of the overarching expectations of motherhood (i.e., central giver, requires copious amounts of time and energy). Whilst many mothers questioned the additional expectations and imposed knowledge specific to their child’s diagnosis, the absence of questioning or criticism of dominant constructions of motherhood shows how powerful these discourses are.

APPENDICES

Appendix 1: Participant information sheet

THE UNIVERSITY of ADELAIDE

PARTICIPANT INFORMATION SHEET

Interview and Focus Groups

PROJECT TITLE:

The experiences of motherhood for mothers of autistic children

PRINCIPAL INVESTIGATOR:

Anna Szorenyi

STUDENT RESEARCHER:

Karen Williams

STUDENT'S DEGREE:

PhD Student (Gender Studies and Social Analysis)

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

We are interested in talking to mothers of autistic children regarding their everyday experiences, views on motherhood and life as a woman.

Given the ever-changing and individual approaches to motherhood and the complexities of debate that surround autism, the construction of contemporary motherhood this research aims to identify the ways in which autism and mothers of autistic children are represented, and give voice to mothers who are caring for autistic children.

Who is undertaking the project?
This project is being conducted by Karen Williams. Karen herself is the mother of an autistic child

This research will form the basis for the degree of PhD in Gender Studies and Social Analysis at the University of Adelaide under the supervision of Dr Anna Szorenyi.

Why am I being invited to participate?
You have been asked to participate as a mother of an autistic child aged between 18 months and 18 years and are a registered member of Autism SA.

By being involved you will assist us in learning more about the factors that influence the choices of mothers of autistic children. Your participation will also ensure that your views are represented in research that is being undertaken regarding the representation and understanding of mothers of autistic children.

What will I be asked to do?
If you agree to participate in this study you will be asked to participate in your choice of an interview or focus group with Karen Williams who is a PhD student at the University of Adelaide. Focus groups will be conducted on-site at the Adelaide Universities North Terrace campus and will involve 6-12 other mothers of autistic children. Interviews will be conducted at the preferred location of the participant. Karen can come to your home or the interview can be conducted at the university. Alternatively, you can choose an alternative location that is preferable for you. Scheduled focus groups time can be found at the end of this letter.

How much time will the project take?
Interviews are expected to last between 60-90 minutes and focus groups 90-120 minutes with tea, coffee and biscuits provided.

There will be no follow up interviews required however a copy of your transcript will be provided to participants for you to view and identify any information you do not want to be quoted when published.

Are there any risks associated with participating in this project?
Participants will be asked to discuss their lives as the mother of an autistic child openly and honestly. The other members of the focus group (if applicable) will also be mothers of autistic children as is the primary researcher of the study. Mothers will not be pushed to answer any questions they are not comfortable with and if a participant experiences emotional distress or discomfort they will be within a supportive environment, are free to leave at any time and relevant counselling or support service contact information will be made available to them.

What are the benefits of the research project?

Participation may not provide any direct benefits to you personally, however, your contribution will help to give a personalised voice to mothers caring for an autistic child, the multiple roles they assume and the expectations placed on them.

The study also aims to develop an understanding of policy and promotion of autism and both the direct or indirect benefits this can have for the mother. This may in the future help practitioners to better help mothers in your situation.

Can I withdraw from the project?
Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time and this will have no negative impact on you or your family in the future.

What will happen to my information?
All information collected in the study will be kept strictly confidential. Karen will transcribe the conversations that take place during the interview/focus group however a coding system will be used rather than your name on all research documents. The transcripts will be stored in both digital and written form. The digital versions will be kept on a personal password-protected computer and the written versions stored in a locked filing cabinet. After the conclusion of the study data will be kept on a USB in a locked storage facility by the University of Adelaide for five years in accordance with The Australian Code for the Responsible Conduct of Research.

Results of the study will be published however no identifying information will be used. Karen will send you a copy of your transcript. You will have the opportunity to view your transcript and identify any quotes you do not want to be used when the research is published.

Who do I contact if I have questions about the project?
This study has been approved by the Human Ethics Research Committee If you would like to speak to a person not directly involved in the study, particularly in relation to your rights as a participant or to make a complaint, please refer to the attached form.

What if I have a complaint or any concerns?
The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2014-xxx). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. Contact the Human Research Ethics Committee's Secretariat on phone (08) 8313 6028 or by email to hrec@adelaide.edu.au. if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant. Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you would like to be involved in the study please contact Karen Williams to arrange an interview or selected focus group. Karen can be contacted on 04 02 045 759 or via email at Karen.Williams@adelaide.edu.au.

Yours sincerely,

Karen Williams, Ms

Appendix 2: Consent Form

Human Research Ethics Committee (HREC)

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	**The experiences of motherhood for mothers of autistic children**
Ethics Approval Number:	**H-2014-216**

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand the purpose of the research project it has also been explained that involvement may not be of any benefit to me.

5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

6. I agree to the interview being audio/video recorded. Yes ☐ No ☐

7. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ______________________ Signature:________________________ Date: ____________________________

Researcher/Witness to complete:

I have described the nature of the research to

____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: ___________________ Position: _________________________ Date: ____________________________

Appendix 3: Contacts and independent complaints procedure:

The University of Adelaide
Human Research Ethics Committee (HREC)

This document is for people who are participants in a research project.

CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

Project Title:	**The experiences of motherhood for mothers of autistic children**
Approval Number:	**H-2014-216**

The Human Research Ethics Committee monitors all the research projects which it has approved. The committee considers it important that people participating in approved projects have an independent and confidential reporting mechanism which they can use if they have any worries or complaints about that research.

This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research (see http://www.nhmrc.gov.au/publications/synopses/e72syn.htm)

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinator:

Name:	**Dr Anna Szorenyi**
Phone:	**08 8313 3736**

2. If you wish to discuss with an independent person matters related to:
    - making a complaint, or
    - raising concerns on the conduct of the project, or
    - the University policy on research involving human participants, or
    - your rights as a participant,

   contact the Human Research Ethics Committee's Secretariat on phone (08) 8313 6028 or by email to hrec@adelaide.edu.au

Appendix 4: Interview protocol

Interview/focus group schedule for mothers with autistic children

Interview Schedule

Thank the participant/s

Consent form – Provide each participant with two copies of the consent form (one for their own records and one for mine) and ask that they read the form and if they have any questions. Inform the participant that consent forms are a requirement of the University of Adelaide Human Research Committee but no one other than myself will view the details on the form. If the participant agrees they will be asked to sign the form after which I will sign in the witness section and seal my copy in an envelope with only the participant's code number on it.

During the interview, I will guide you with some questions but please feel free to also raise any issues that are important to you as we go along.

Digital recording – The participant will be asked if they mind the interview be recorded, informing them that no one besides myself will hear the recording and that it can be turned off at any point if the participant wishes.

If the participant agrees, begin recording. If the participant does not agree, prepare to take notes instead.

Commence interview

So you have a child named ….. and he/she is [age], is that right?

As you know my research is exploring the lives of mothers of autistic children, particularly surrounding the way we think and talk about motherhood and the way we think and talk about autism.

So could we just start with a little about your everyday life?

What's a normal day like for you?
Does this change much?

Are there things you would like to be doing but can't/don't?

What stops you from doing these things?
Do you think this is the same for men [why/why not]?

How was the experience of diagnosis for you?

What did you think when you were told your child was autistic?

How did others [friends/family] react to the news?
Was anyone with you at the time?
What did you do then [carry on as normal, begin frantically reading, cry]?

How do you feel about the way autism is represented in the general public?

What issues do you see discussed the most?
How does this affect your life?
Does this affect the way you parent?
Is there anything you like to see less of?
Is there anything you would like to see more of?

How do you feel about how motherhood is represented in the general public?

How does this affect your life?
Does this affect the way you parent?
Is there anything you like to see less of?
Is there anything you would like to see more of?

How do feel about how mothers of autistic children are represented in the general public?

How does this affect your life?
Does this affect the way you parent?
Is there anything you like to see less of?
Is there anything you would like to see more of?

Do you feel there are any specific pressures placed on you to do certain things?

These may be therapy
Be constantly available to schools, doctors, ...
Do you think this is your responsibility as his mother?

How do you feel about the services available to you?

Where did you hear about these from?
Are there any you would avoid using?
Are there any you would like to see?

Whose advice do you listen to?

What about it makes you trust it or believe it?
Do you feel like your own opinion is heard?

Can you separate your child from autism?

How do you see the role of therapy?
What types of therapy (if any) have you used?

How do you feel about work opportunities?

What assets do you think having an autistic child provides or would provide you within the workplace?
What aspects do you think restrict your ability?

What are your views of the future?

Whose responsibility do you see it as being to ensure he is cared for?
Do you know of any other mums whose child is older and what their life is like?
Do you know of services available to you in the future?
What would you like to be doing in 5-10 years time?

Have you heard about the possibility of prenatal testing for autism?

How do you feel about this?

Have you heard about the possible cuts to family payments once your child turns six?

How do you feel about this?
How do you think it will affect you?

What do you do when needs are not met?

Do you think this is something you should have to do?
Do you feel any guilt?

What are some of the enjoyable aspects of your life with [child's name]?

How do you feel listening to others talk about mothering a non-autistic child?

Do you think your voice is heard?
Do you think there are additional pressures on you to perform your role?
How do you see your role as a mother?

What do you think having an autistic child has taught you about motherhood that you may not have otherwise known?

Is mothering different from you thought it would be?
Do you think there are knowledge's you share with other mothers of autistic children?

If there was one thing you could say about mothering an autistic child what would it be?

Thanks, that has been really useful. I'm just going to take a few moments to look at the topics I wanted to cover. While I'm doing that can you have a think about whether there is anything else you would like to talk about>

Fill in answers to demographic questions

Thank you, for your time.

REFERENCE LIST

Aapola, S, Gonick, M, Harris, A & Campling, J 2005, *Young femininity: girlhood, power and social change*, New York: Palgrave Macmillan.

Afflerback, S, Carter, SK, Anthony, AK & Grauerholz, L 2013, 'Infant-feeding consumerism in the age of intensive mothering and risk society', *Journal of Consumer Culture*, vol. 13, no. 3, pp. 387-405.

Aguilar, J 1981, ‘Insider research: an ethnography of a debate’, in DA. Messerschmidt (ed.) *Anthropologists at home in North America: methods and issues in the study of one’s own society,* Cambridge: Cambridge University Press, pp.15–26

Ahmed, S 2007, ‘A phenomenology of whiteness’, *Feminist Theory*, vol. 8, no. 2, pp.149-168.

Altheide, DL 2002, *Creating fear: news and the construction of crisis*, Hawthorne, NY: Aldine de Gruyter

Althusser, L 1971, ‘On ideology and ideological state apparatuses. Notes towards an investigation’, in *Lenin and philosophy and other essays*, London: New Left Books, pp. 121–173.

American Psychiatric Association 1980, *Diagnostic and statistical manual of mental disorders (DSM-3)*, American Psychiatric Pub.

American Psychiatric Association 1987, *Diagnostic and statistical manual of mental disorders (DSM-3®)*, American Psychiatric Pub.

American Psychiatric Association 2013, *Diagnostic and statistical manual of mental disorders (DSM-5®)*, American Psychiatric Pub.

Anderson, JH & Damarin, S. K 1996, ‘Poststructural feminism and research in educational communications and technology’, in DH. Jonassen (ed.), *Handbook of research for educational communications and technology,* New York: Simon & Schuster Macmillan, pp. 269-275.

Anti-Defamation League 2005, *‘A brief history of the disability rights movement’,* viewed 5 July 2017, Anti-Defamation League, <https://www.adl.org/education/resources/backgrounders/disability-rights-movement>.

Apple, RD 2006, *Perfect motherhood: science and childrearing in America*, New Jersey: Rutgers University Press.

Arendell, T 1999, *'Hegemonic motherhood: deviancy discourses and employed mothers’ accounts of out-of-school time issues'*, (Center for Working Families Working Paper No. 9), Berkeley: University of California

Ashmore, RD, Solomon, MR & Longo, LC 1996, 'Thinking about fashion models' looks: a multidimensional approach to the structure of perceived physical attractiveness', *Personality and Social Psychology Bulletin*, vol. 22, no. 11, pp. 1083-1104.

Australian Department of Human Services (2019), *Supports funded by the NDIS*, viewed 6 June 2018, <https://www.ndis.gov.au/participants/reasonable-and-necessary-supports>.

Avdi, E, Griffin, C & Brough, S 2000, 'Parents' constructions of the ‘problem’ during assessment and diagnosis of their child for an autistic spectrum disorder', *Journal of Health Psychology*, vol.5, no.2, pp.241-254.

Azzarito, L 2009, 'The panopticon of physical education: pretty, active and ideally white', *Physical Education and Sport Pedagogy*, vol. 14, no. 1, pp. 19-39.

Bacchi, C 1999, *Women, policy and politics: the construction of policy problems*, London: Sage.

Bacchi, C 2009, *Analysing policy*, Frenchs Forest, NSW: Pearson Education.

Bacchi, C & Bonham, J 2014, 'Reclaiming discursive practices as an analytic focus: political implications', *Foucault Studies*, no. 17, pp. 179-192.

Bailey, M 2011, ‘‘‘The illest’’: disability as metaphor in hip hop music’, in CM. Bell (ed.), *Blackness and disability: critical examinations and cultural interventions,* East Lansing, MI: Michigan State University Press, pp. 141–148.

Baird, G, Cass, H & Slonims, V 2003, ‘Diagnosis of autism’, *British Medical Journal*, vol. 327, no. 7413, pp.488-493.

Baker, SE, Edwards, R & Doidge, M 2012, *'How many qualitative interviews is enough?: Expert voices and early career reflections on sampling and cases in qualitative research'*, National Centre for Research Methods (NCRM): University of Southampton.

Ball, SJ 2013, *Foucault and education*: d*isciplines and knowledge*, London: Routledge.

Barnes, RE & McCabe, H 2012, ‘Should we welcome a cure for autism? A survey of the arguments’, *Medicine, Health Care and Philosophy*, vol. 15 no. 3, pp. 255–269.

Barriball, KL & While, A 1994, 'Collecting data using a semi-structured interview: a discussion paper', *Journal of Advanced Nursing*, vol. 19, no. 2, pp. 328-335.

Barry, A, Osborne, T & Rose, N 1996, *Foucault and political reason: liberalism, neo-liberalism and the rationalities of government*, London: UCL Press.

Bartky S 1988, ‘Foucault, feminism, and patriarchal power’, in *Feminism and Foucault: reflections on resistance*, I. Diamond & L. Quinby (eds.), Boston, MA: Northeastern University Press, pp. 61-86.

Bartlett, A 2004, 'Black breasts, white milk? Ways of constructing breastfeeding and race in Australia', *Australian Feminist Studies*, vol. 19, no. 45, pp. 341-355.

Bassin, D, Honey, M & Kaplan, MM 1996, *Representations of motherhood*, New Haven, CT: Yale University Press.

Beck, U 1992, *Risk society: towards a new modernity*, vol. 17, London: Sage.

Bell, J 2005, *Doing your research project* (4th ed.), Maidenhead, England: Open University Press.

Bender, L 1959, 'Autism in children with mental deficiency', *American Journal of Mental Deficiency*, vol. 64, no. 1, pp. 81-86.

Berger, MT & Guidroz, K 2010, *The intersectional approach: transforming the academy through race, class, and gender*, Chapel Hill: University of North Carolina Press.

Berlant, L 2006, 'Cruel optimism', *Differences*, vol. 17, no. 3, pp. 20–36.

Bettelheim, B 1967, *The empty fortress: infantile autism and the birth of the self*, New York: The Free Press.

Bie, B & Tang, L 2015, 'Representation of autism in leading newspapers in China: a content analysis', *Health Communication*, vol. 30, no. 9, pp. 884-893.

Billawala, A & Wolbring, G 2014, 'Analyzing the discourse surrounding autism in the New York Times using an ableism lens', *Disability Studies Quarterly*, vol. 34, no. 1, viewed 30n March 2018, <http://www.dsq-sds.org/article/view/3348/3524>.

Bloch-Elkon, Y 2007, 'Studying the media, public opinion, and foreign policy in international crises: the United States and the Bosnian crisis', 1992—1995', *The Harvard International Journal of Press/Politics*, vol. 12, no. 4, pp. 20-51.

Blum, LM 2007, 'Mother-blame in the Prozac nation raising kids with invisible disabilities', *Gender & Society*, vol. 21, no. 2, pp. 202-226.

Blum, NS 1991, 'The management of stigma by Alzheimer family caregivers', *Journal of Contemporary Ethnography*, vol. 20, no. 3, pp. 263-284.

Bordo, S 1993, 'Feminism, Foucault, and the politics of the body', in *Up against Foucault*, C. Ramazanoglu (ed.), New York: Routledge, pp. 170–202.

Bordo, S 2003, 'The empire of images in our world of bodies', *Chronicle of Higher Education*, vol. 50, no. 17, pp. B6-B9.

Bourke-Taylor, H, Howie, L & Law, M 2010, 'Impact of caring for a school-aged child with a disability: understanding mothers' perspectives', *Australian Occupational Therapy Journal*, vol. 57, no. 2, pp. 127-136.

Bowlby, J 1951, *Maternal care and mental health*, Geneva: World Health Organization.

Brich, C 2008, 'The Groupe d'information sur les prisons: the voice of prisoners? Or Foucault's?', *Foucault Studies*, vol. 4, iss. 5, pp.26-47.

Broderick, AA 2009, 'Autism,"recovery (to normalcy)," and the politics of hope', *Intellectual and Developmental Disabilities*, vol. 47, no. 4, pp. 263-281.

Bueskens, P 2017, *Modern motherhood and women's dual identities: rewriting the sexual contract*, London: Routledge.

Butler, J 1993, *Bodies that matter: on the discursive limits of "sex.",* New York and London: Routledge.

Buckley, B 2012, *Autism Spectrum Disorders and Mental Health in Australia: perception, administration, challenges and outcomes*, viewed 6/11/2017: http://www.a4.org.au/sites/default/files/20120104%20Mental%20Health%20Report.pdf

Caplan, P 2013, 'Don't blame mother: then and now', in M. Hobbs & C. Rice (eds.) *Gender and women's studies in Canada: critical terrain*, pp. 99-106.

Carabine, J 2001, 'Unmarried motherhood 1830-1990: a genealogical analysis', in M. Wetherell, S. Taylor & S. Yates (eds.), *Discourse as data: a guide for analysis*, London: Sage Publications, pp. 267-310.

Carers Australia 2018, *What is he NDIS*, viewed 6 June 2018, <http://www.carersaustralia.com.au/ndis-and-carers/what-is-the-ndis/>

Chance, P 1974. 'After you hit a child, you can't just get up and leave him; you are hooked to that kid' O. Ivar Lovaas Interview'. *Psychology Today*, vol. *7*, no. 8, pp.76-84.

Chavez, C 2008, 'Conceptualizing from the inside: advantages, complications, and demands on insider positionality', *The Qualitative Report*, vol. 13, no. 3, pp. 474-494.

Chivers Yochim, E & Silva, VT 2013, 'Everyday expertise, autism, and "good" mothering in the media discourse of Jenny McCarthy', *Communication and Critical/Cultural Studies*, vol. 10, no. 4, pp. 406-426.

Cipani, E (ed.) 2008, 'Autism: the early years', in *Triumphs in early autism treatment,* New York: Springer Publishing, pp.141-150.

Clarke, JN 2012, 'Representations of autism in US magazines for women in comparison to the general audience: 2000–2009 US english language publications', *Journal of Children and Media*, vol. 6, no. 2, pp. 182-197.

Clarke, J & Van Amerom, G 2008, 'Asperger's syndrome: differences between parents' understanding and those diagnosed', *Social Work in Health Care*, vol. 46, no. 3, pp. 85-106.

Colaizzi, PF 1978, 'Psychological research as the phenomenologist views it', in R. Valle & M. King (eds.), *Existential phenomenological alternatives for psychology*, New York: Oxford University Press, pp. 48–71.

Collett, JL 2005, 'What kind of mother am I? Impression management and the social construction of motherhood', *Symbolic Interaction*, vol. 28, no. 3, pp.327-347.

Collins, PH 1991, *Black feminist thought: knowledge, consciousness and the politics of empowerment*, Boston: Unwin Hyman,

Conn, R & Bhugra, D 2012, 'The portrayal of autism in Hollywood films', *International Journal of Culture and Mental Health*, vol. 5, no. 1, pp. 54-62.

Cortese, AJ 1999, *Provocateur: images of women and minorities in advertising*, Lanham, MD: Rowman & Littlefield.

Creswell, JW 2003, *Research design: qualitative, quantitative, and mixed methods approaches*, (2nd ed.), Thousand Oaks, CA: Sage.

Creswell, JW 2014, *Research design: qualitative, quantitative, and mixed methods approaches*, Thousand Oaks, CA: Sage.

Creswell, JW, Hanson, WE, Clark Plano, VL & Morales, A 2007, 'Qualitative research designs: selection and implementation', *The Counseling Psychologist*, vol. 35, no. 2, pp. 236-264.

Crittenden, A 2002, *The price of motherhood: why the most important job in the world is still the least valued*, New York: Henry Holt

Cummins, R, Hughes, J, Tomyn, A, Gibson, A, Woerner, J & Lai, L 2007, 'Australian unity wellbeing Index: report 17.1', *The wellbeing of Australians-carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, School of Psychology, Deakin University.

Danaher, G, Schirato, T & Webb, J 2000, *Understanding Foucault*, London: Sage.

Danforth, S 1997, 'On what basis hope? Modern progress and postmodern possibilities', *Mental Retardation*, vol. 35, no. 2, pp. 93-106.

Daniels, C 2001, 'Between fathers and fetuses: the social construction of male reproduction and the politics of fetal harm', in M. Wyer, M. Barbercheck, D. Geisman, H. Ozturk & M. Wayne (eds.), *Women, science and technology: a reader in feminist science studies*, London: Routledge, pp. 312-331.

Davidson, A (ed.) 1997, 'Structures and strategies of discourse', *Foucault and his interlocutors*, Chicago: University of Chicago Press, pp. 1-17.

Dean, M 1999, *Governmentality power and rule in modern society*, London: Sage.

de Souza, R 2013, 'Who is a 'good' mother?: moving beyond individual mothering to examine how mothers are produced historically and socially', *Australian Journal of Child and Family Health Nursing*, vol. 10, no. 2, p. 15.

Demaine, L 2009, 'Navigating policy by the stars: the influence of celebrity entertainers on federal lawmaking', *The Journal of Law and Politics*, vol. 25, no. 2, pp. 83-143.

Dent, C 2008, 'Journalists are the confessors of the public, says one Foucaultian', *Journalism*, vol. 9, no.2, pp. 200-219.

Diamond, I & Quinby, L 1988, *Foucault and feminism: reflections on resistance*, Boston: Northeastern University Press.

Dietz, MG 1985, 'Citizenship with a feminist face: the problem with maternal thinking', *Political Theory*, vol. 13, no. 1, pp. 19-37.

Disability Investment Group 2009, *The way forward: a new disability policy framework for Australia*, Canberra, viewed 24 April 2015, viewed at: http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/disability-investment-group/the-way-forward-a-new-disability-policy-framework-for-australia

Douglas, P 2013, 'As if you have a choice: autism mothers and the remaking of the human', *Health, Culture and Society*, vol. 5, no. 1, pp. 167-181.

Douglas, S & Michaels, M 2004, *The mommy myth: the idealization of motherhood and how it has undermined women,* New York: Simon and Schuster.

Doyle, A 2011, ‘Revisiting the synopticon: reconsidering Mathiesen's ‘the viewer society’ in the age of web 2.0’. *Theoretical Criminology*, vol. 15, no. 3, pp.283-299.

Draaisma, D 2009, 'Stereotypes of autism', *Philosophical Transactions of the Royal Society of London B: Biological Sciences*, vol. 364, no. 1522, pp. 1475-1480.

Draper, A & Swift, JA 2011, 'Qualitative research in nutrition and dietetics: data collection issues', *Journal of Human Nutrition and Dietetics*, vol. 24, no. 1, pp. 3-12.

Dreyfus, H & Rabinow, P 1982, *Michel Foucault: beyond hermeneutics and structuralism*, Brighton: Harvester.

Droit, RP 2004, *Michel Foucault, entretiens*. Paris: Odile Jacob.

Drisko, JW & Maschi, T 2015, *Content analysis*, New York: Oxford University Press.

Duncan, MC 1994, 'The politics of women's body images and practices: Foucault, the panopticon, and shape magazine', *Journal of Sport & Social Issues*, vol. 18, no. 1, pp. 48-65.

Dwyer, SC & Buckle, JL 2009, 'The space between: on being an insider-outsider in qualitative research', *International Journal of Qualitative Methods*, vol. 8, no. 1, pp. 54-63.

Dziobek, I, Rogers, K, Fleck, S, Bahnemann, M, Heekeren, HR, Wolf, OT & Convit, A 2008, 'Dissociation of cognitive and emotional empathy in adults with Asperger syndrome using the multifaceted empathy test (MET)', *Journal of Autism and Developmental Disorders*, vol. 38, no. 3, pp. 464-473.

Eggertson, L 2010, ‘Lancet retracts 12-year-old article linking autism to MMR vaccines’, *Canadian Medical Association. Journal*, vol. 184, no. 4, pp.199-200.

Ells, C 2003, 'Foucault, feminism, and informed choice', *Journal of Medical Humanities*, vol. 24, no. 3, pp. 213-228.

Evans, B 2013, 'How autism became autism: the radical transformation of a central concept of child development in Britain', *History of the Human Sciences*, vol. 26, no. 3, pp. 3-31.

Eyal, G, Hart, B, Onculer, E, Oren, N & Rossi, N 2010, *The autism matrix: the social origins of the autism epidemic,* Malden, MA: Polity Press.

Eyer, D 1996, *Mother guilt: how our culture blames mothers for what’s wrong with society*, New York, NY: Random House.

Factor, DC, Freeman, NL & Kardash, A 1989, 'Brief report: a comparison of DSM-III and DSM-III-R criteria for autism', *Journal of Autism and Developmental Disorders*, vol. 19, no. 4, pp. 637-640.

Farrant, W 1985, ‘Who’s for amniocentesis?’ in H. Homans (ed.) *The sexual politics of reproduction,* London: Gower Publishing Comp. Ltd., Hants, pp. 198596-198122.

Feinstein, A 2011, *A history of autism: conversations with the pioneers*, Chichester, UK: Wiley Blackwell.

Foucault, Michel. 1971. Nietzsche, la généalogie, l'histoire in *Hommage à Jean Hyppolite*. Paris: P.U.F., pp. 145–72, English Transl (1977): Nietzsche, Genealogy, History, in DF. Bouchard (ed.), *Language, Counter-Memory, Practice*, Ithaca: Cornell University Press.

Foucault, M 1972, *The archaeology of knowledge* London:Tavistock Publications Ltd

Foucault, M 1977, *Discipline and punish: the birth of the prison*, trans. Sheridan A, Penguin Books. London.

Foucault, M 1978, *The history of sexuality, volume I*, New York: Vintage.

Foucault, M 1980, 'Truth and power in Gordon', trans Marshall, L, Mepham J & Soper, K (eds.) in *Power/Knowledge: selected interviews and other writings 1972-77.* New York: Pantheon.

Foucault, M 1981, 'Practicing criticism', in *Politics, philosophy, culture: interviews and other writings, 1977-1984*, New York: Routledge.

Foucault, M 1982, 'The subject and power', *Critical Inquiry*, vol. 8, no. 4, pp. 777-795.

Foucault, M 1984, 'Space knowledge and power', in P. Rainbow (ed.), *The Foucault reader*. New York: Pantheon Books, pp. 239-257.

Foucault, M 1991, 'Governmentality', in *The Foucault effect: studies in governmentality*, G. Burchell, C. Gordon & P. Miller (eds.), London: Harvester Wheatsheaf, pp. 53–72.

Foucault, M 2000a, *Ethics: essential works of Foucault 1954-1984*, London: Penguin.

Foucault M 2000b, *Power. essential works of Foucault, 1954–1984*, vol. 3, JD Faubion (ed.). New York: New Press.

Foucault, M 2001, 'Power/knowledge', in S. Seidman & JC. Alexander (eds.), *The new social theory reader: contemporary debates*, New York: Routledge, pp. 69–76.

Foucault, M 2003, *The essential Foucault: selections from essential works of Foucault, 1954–1984*, P. Rabinow & N. Rose (eds.), New York and London: New Press.

Foucault, M 2005, *The hermeneutics of the subject: lectures at the Collège de France 1981–1982*. Translated by G. Burchell. New York: Palgrave-Macmillan.

Foucault, M 2007, *Security, territory and population. lectures at the College de France 1977–1978*, London: Palgrave.

Fox, B 2006, Motherhood as a class act: the many ways in which 'intensive mothering' is entangled with social class, in K. Bezanson & M. Luxtion, *Social reproduction: feminist political economy challenges neo-liberalism*, pp.231-262.

Francis, A 2012, 'Stigma in an era of medicalisation and anxious parenting: how proximity and culpability shape middle-class parents' experiences of disgrace', *Sociology of Health & Illness*, vol. 34, no. 6, pp. 927-942.

Frith, K, Shaw, P & Cheng, H 2005, 'The construction of beauty: a cross-cultural analysis of women's magazine advertising', *Journal of Communication*, vol. 55, no. 1, pp. 56-70.

Fromm-Reichmann, F 1948, 'Notes on the development of treatment of schizophrenics by psychoanalytic psychotherapy', *Psychiatry*, vol. 11, no. 3, pp. 263-273.

Fusar-Poli, P & Politi, P 2008, 'Paul Eugen Bleuler and the birth of schizophrenia (1908)', *American Journal of Psychiatry*, vol. 165, no. 11, pp. 1407-1407.

Gane, N 2012, 'The governmentalities of neoliberalism: panopticism, post-panopticism and beyond', *The Sociological Review*, vol. 60, no. 4, pp. 611-634.

Garner, A, Jones, S & Harwood, V 2015, 'Authentic representations or stereotyped ‘outliers’: using the CARS2 to assess film portrayals of autism spectrum disorders', *International Journal of Culture and Mental Health*, vol. 8, no. 4, pp. 414-425.

Gill, J & Liamputtong, P 2011, ‘Being the mother of a child with Asperger's syndrome: women's experiences of stigma’, *Health Care for Women International*, vol. 32, no. 8, pp.708-722.

Goffman, E 1963, *Stigma*, Englewood Cliffs, NJ. Prentice-Hall.

Goodwin, S & Huppatz, K 2010, *The good mother: contemporary motherhoods in Australia*, Sydney: Sydney University Press.

Graham, H 1983, 'Caring; a labour of love', in J. Finch & D. Groves (eds.) *A labour of love: women, work and caring*, London: Routledge and Kegan Paul.

Gray D 1993, ‘Perceptions of stigma: the parents of autistic children’, *Sociology of Health and Illness*, vol. 15, no. 1, pp.102–119.

Gray, DE 2002, ‘Ten years on: a longitudinal study of families of children with autism’, *Journal of Intellectual and Developmental Disability*, vol. 27, no. 3, pp.215-222.

Green, SE 2003a, ‘They are beautiful and they are ours: swapping tales of mothering children with disabilities through interactive interviews’, *Journal of Loss &Trauma*, vol. 8, no.1, pp.1-13.

Green, SE 2003b, '“What do you mean ‘what's wrong with her?”: stigma and the lives of families of children with disabilities', *Social Science & Medicine*, vol. 57, no. 8, pp. 1361-1374.

Green, S 2007,‘“We’re tired, not sad”: benefits and burdens of mothering a child with a disability’, *Social Science & Medicine*, vol. 64, no. 1, pp. 150-163.

Greene, MJ 2014, 'On the inside looking in: methodological insights and challenges in conducting qualitative insider research', *The Qualitative Report*, vol. 19, no. 29, pp. 1-13.

Greenspan, M 1998, ‘’Exceptional’ mothering in a “normal” world', in K. Weingarten (ed.), *Mothering against the odds: diverse voices of contemporary mothers,* London: Guildford Press, pp. 37-60.

Gregory, S 1991, ‘Mother’s and their deaf children’, in *Motherhood: meanings, practices and ideologies,* E. Lloyd (ed.), London: Sage, pp. 123-142.

Guest, G, Bunce, A & Johnson, L 2006, 'How many interviews are enough? An experiment with data saturation and variability', *Field Methods*, vol. 18, no. 1, pp. 59-82.

Hall, S1977, ‘Culture, the Media and the “Ideological Effect”’, in J. Curran, M. Gurevitch & J. Woollacott (eds.), *Mass communication and society,* London: Arnold, pp. 315–348.

Hanbury, M 2005, *Educating pupils with autistic spectrum disorders: a practical guide*, London: Sage.

Harrison, D & Freinberg, T 2005, 'Autistic liberation front fights the ‘oppressors searching for a cure.’', *Daily Telegraph*, 9 January 2005, p. 3.

Hays, S 1996, *The cultural contradictions of motherhood*, New Haven:Yale University Press.

Hellawell, D 2006, ‘Inside-out: analysis of the insider-outsider concept as a heuristic device to develop reflexivity in students doing qualitative research’, *Teaching in Higher Education*, vol. 11, no. 4, pp. 483-494.

Henderson, AC, Harmon, SM & Houser, J 2010, 'A new state of surveillance? Applying Michel Foucault to modern motherhood', *Surveillance & Society*, vol. 7, no. 3/4, pp. 231-247.

Herring, S, Gray, K, Taffe, J, Tonge, B, Sweeney, D & Einfeld, S 2006, 'Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning', *Journal of Intellectual Disability Research*, vol. 50, no. 12, pp. 874-882.

Hesse-Biber, S 1996, *Am I thin enough yet?: the cult of thinness and the commercialization of identity*, New York: Oxford University Press.

Hesse-Biber, S 2013, *Feminist research practice: a primer*, London: Sage.

Hesse-Biber, S & Leavy, P. 2007, *Feminist research practice*, Thousand Oaks, California: Sage.

Hesse-Biber, S & Leckenby, D 2003, ‘Applications and methods: how feminists practice social research', in SN. Hesse-Biber & ML. Yaiser (eds.), *Perspectives in social research*, New York: Oxford University Press, pp. 209-226.

Hochschild, AR 1983, *The managed heart*, Berkeley, CA: University of California Press.

Hodge*, N 2005, 'Reflections on diagnosing autism spectrum disorders', *Disability & Society*, vol. 20, no. 3, pp. 345-349.

Holton, AE, Farrell, LC & Fudge, JL 2014, 'A threatening space? Stigmatization and the framing of autism in the news', *Communication Studies*, vol. 65, no. 2, pp. 189-207.

Hornby, G & Seligman, M 1991, ‘Disability and the family: current status and future developments,’ *Counseling Psychology Quarterly*, vol. 4, pp.267-271.

Howell, P 2015, ‘From rain man to Sherlock: theological reflections on metaphor and ASD,’ *Practical Theology*, vol. 8, no. 2, pp.143-153.

Hughes, B, McKie, L, Hopkins, D & Watson, N 2005, 'Love’s labours lost? Feminism, the disabled people’s movement and an ethic of care', *Sociology*, vol. 39, no. 2, pp. 259-275.

Hughes, N, Locock, L & Ziebland, S 2013, 'Personal identity and the role of ‘carer’ among relatives and friends of people with multiple sclerosis', *Social Science & Medicine*, vol. 96, pp. 78-85.

Inzlicht, M & Good, C 2006, ‘How environments threaten academic performance, self-knowledge, and sense of belonging’, in S. Levin & C. van Laar (eds.), *Stigma and group inequality: social psychological approaches,* Mahwah, NJ: Erlbaum, pp. 129–150.

Jack, J 2014, *Autism and gender: from refrigerator mothers to computer geeks*, Urbana, Chicago, and Springfield: University of Illinois Press.

Jermyn, D 2008, 'Still something else besides a mother? Negotiating celebrity motherhood in Sarah Jessica Parker's star story', *Social Semiotics*, vol. 18, no. 2, pp. 163-176.

Jick, TD 1979, 'Mixing qualitative and quantitative methods: triangulation in action', *Administrative Science Quarterly*, vol. 24, no. 4, pp. 602-611.

Johnston, D 1991, ‘Constructing the periphery in modern global politics’, in CN. Murphy & R. Tooze (eds.), *The new international political economy*, Colorado, CO: Lynne Rienner, pp.149–169.

Johnston, DD & Swanson, DH 2003, 'Invisible mothers: a content analysis of motherhood ideologies and myths in magazines', *Sex Roles*, vol. 49, no. 1-2, pp. 21-33.

Jones, SC & Harwood, V 2009, 'Representations of autism in Australian print media', *Disability & Society*, vol. 24, no. 1, pp. 5-18.

Judd, CM, Smith, ER & Kidder, LH 1991, *Research methods in social relations* (6th ed), Fort Worth, TX: Holt, Rinehart, and Winston, Inc.

Kagan, J 1989. *Unstable ideas: temperament, cognition, and self*, Cambridge: Harvard University Press.

Kang, S 2013, 'Coverage of autism spectrum disorder in the US television news: an analysis of framing', *Disability & Society*, vol. 28, no. 2, pp. 245-259.

Kanner, L 1943, 'Autistic disturbances of affective contact', *Nervous Child*, vol. 2, no. 3, pp. 217-250.

Kanner, L 1949, 'Problems of nosology and psychodynamics of early infantile autism', *American Journal of Orthopsychiatry*, vol. 19, no. 3, pp. 416.

Kanner, L 1965, 'Infantile autism and the schizophrenias', *Systems Research and Behavioral Science*, vol. 10, no. 4, pp. 412-420.

Kanner, L 1973, 'The birth of early infantile autism', *Journal of Autism and Developmental Disorders*, vol. 3, no. 2, pp. 93-95.

Keller, R 2006, ‘Analysing discourse. An approach from the sociology of knowledge’, *Historical Social Research/Historische Sozialforschung*, vol. 6, no. 3, pp.223-242.

Kelly, MG 2013, ‘Foucault, subjectivity, and technologies of the self’, in C. Falzon, T. O'Leary, & J. Sawicki (eds.), *A companion to Foucault*, pp. 510-525.

Kirk, SA & Kutchins, H 1992, *The selling of DSM: the rhetoric of science in psychiatry,* New York: Aldine de Gruyter.

King, A 2004, ‘The prisoner of gender: Foucault and the disciplining of the female body’, *Journal of International Women's Studies,* vol. *5* no. 2, pp.29-39.

Klein, SM & McCabe, H 2007, ‘From mother to disability professional: role change, resilience, and rewards’, *Journal of Early Intervention*, vol. 29, no.4, pp.306-319.

Knaak, SJ 2010, 'Contextualising risk, constructing choice: breastfeeding and good mothering in risk society', *Health, Risk & Society*, vol. 12, no. 4, pp. 345-355.

Krane, J & Davies, L 2007, 'Mothering under difficult circumstances: challenges to working with battered women', *Affilia*, vol. 22, no. 1, pp. 23-38.

Kwan, S & Trautner, MN 2009, 'Beauty work: individual and institutional rewards, the reproduction of gender, and questions of agency', *Sociology Compass*, vol. 3, no. 1, pp. 49-71.

Ladd-Taylor, M & Umansky, L 1998, *" Bad" mothers: the politics of blame in twentieth-century America*, New York: NYU Press.

Landsman, GH 1998, 'Reconstructing motherhood in the age of" perfect" babies: mothers of infants and toddlers with disabilities', *Signs: Journal of Women in Culture and Society*, vol. 24, no. 1, pp. 69-99.

Langan, M 2011, 'Parental voices and controversies in autism', *Disability & Society,* vol. 26, no. 2, pp. 193-205.

Lareau, A 2003, *Unequal childhoods: race, class, and family life*, Berkeley: University of California Press.

Larson, E 1998, 'Reframing the meaning of disability to families: the embrace of paradox', *Social Science & Medicine*, vol. 47, no. 7, pp. 865-875.

Lasser J & Corley K 2008, ‘Constructing normalcy: a qualitative study of parenting children with Asperger’s disorder’, *Educational Psychology in Practice*, vol. 24, no. 4, pp. 335–346.

Lee, EJ 2008, 'Living with risk in the age of ‘intensive motherhood’: maternal identity and infant feeding', *Health, Risk & Society*, vol. 10, no. 5, pp. 467-477.

Lee, E, Macvarish, J & Bristow, J 2010, 'Risk, health and parenting culture', *Health, Risk & Society*, vol. 12, no. 4, pp. 293-300.

Lemke, T 2001, 'The birth of bio-politics': Michel Foucault's lecture at the Collège de France on neo-liberal governmentality, *Economy and Society*, vol. 30, no.2, pp.190-207.

Liamputtong, P 2006, 'Motherhood and “moral career”: discourses of good motherhood among Southeast Asian immigrant women in Australia', *Qualitative Sociology*, vol. 29, no. 1, pp. 25-53.

Lilja, M & Vinthagen, S 2014, ‘Sovereign power, disciplinary power and biopower: resisting what power with what resistance?’, *Journal of Political Power*, vol. *7,* no. 1, pp.107-126.

Lilley, R 2011, 'The ABCs of autism: aspects of maternal pedagogy in Australia', *Social Analysis*, vol. 55, no. 1, pp. 134-159.

Littler, J 2013 ‘The rise of the “yummy mummy”: popular conservatism and the neoliberal maternal in contemporary British culture’, *Communication, Culture & Critique*, vol. *6*, no. 2, pp.227-243.

Lovaas, OI 1987, 'Behavioral treatment and normal educational and intellectual functioning in young autistic children', *Journal of Consulting and Clinical Psychology*, vol. 55, no. 1, pp. 3-9.

Loxley, A & Seery, A 2008, ‘Some philosophical and other related issues in insider research’, in P. Sikes & A. Potts (eds.), *Researching education from the inside: investigations from within,* London: Routledge, pp.15-32.

Lutz, HR, Patterson, BJ & Klein, J 2012, ‘Coping with autism: a journey toward adaptation, *Journal of Pediatric Nursing*, vol. 27, no. 3, pp.206-213.

Mak, WW & Cheung, RY 2008, 'Affiliate stigma among caregivers of people with intellectual disability or mental illness', *Journal of Applied Research in Intellectual Disabilities,* vol. 21, no. 6, pp. 532-545.

Malacrida, C 2009, 'Performing motherhood in a disablist world: dilemmas of motherhood, femininity and disability', *International Journal of Qualitative Studies in Education,* vol. 22, no. 1, pp. 99-117.

Mallett, R & K Runswick-Cole 2012, ‘Commodifying autism: the cultural contexts of 'disability' in the academy’, in D. Goodley, B. Hughes & L. Davis (eds.) *Disability and social theory: new developments and directions.* UK: Palgrave MacMillan.

Marshall, JD 1989, 'Foucault and education', *Australian Journal of Education*, vol.33, no.2, pp.99-113.

Marshall, NL, Barnett, RC, & Sayer, A 1998, ‘The changing workforce, job stress, and psychological distress’, in NL, Marshall (ed.), *Work and family today: recent research at the Center for Research on Women,* Wellesley, MA: Center for Research on Women, pp. 1-15.

Marshall, C & Rossman, GB 1999, *Designing qualitative research*, Thousand Oaks, CA, US: Sage Publications inc.

Martinez, E & Gracia, A 2000, *What is "neo-liberalism?” a brief definition*, New York: The New Press.

Mason, J 2002, *Qualitative researching*, London: Sage.

Mays, N & Pope, C 1995, 'Rigour and qualitative research', *BMJ: British Medical Journal*, vol. 311, no. 6997, p. 109.

McGovern, CM 1985, *Masters of madness: social origins of the American psychiatric profession*, Vermont Books: Publishers.

McHoul, A & Grace, W 1993, 'A Foucault primer: discourse', *Power and the subject,* London: Routledge.

McLaren, MA 1997, 'Foucault and the subject of feminism', *Social Theory and Practice*, vol. 23, no. 1, pp. 109-128.

McLaughlin, J 2003, *Feminist social and political theory: contemporary debates and dialogues*, New York: Palgrave Macmillan.

McNay, L 2013, *Foucault and feminism: power, gender and the self*, Cambridge: Polity Press.

McRobbie, A 2007, 'TOP GIRLS? Young women and the post-feminist sexual contract 1', *Cultural Studies*, vol. 21, no. 4-5, pp. 718-737.

McRobbie, A 2009, *The aftermath of feminism: gender, culture and social change*, London: Sage.

McVilly, KR & Rawlinson, RB 1998, 'Quality of life issues in the development and evaluation of services for people with intellectual disability', *Journal of Intellectual and Developmental Disability*, vol. 23, no. 3, pp. 199-218.

Merriam, SB, Johnson-Bailey, J, Lee, M-Y, Kee, Y, Ntseane, G & Muhamad, M 2001, 'Power and positionality: negotiating insider/outsider status within and across cultures', *International Journal of Lifelong Education*, vol. 20, no. 5, pp. 405-416.

Middleton, L 1999, *Disabled children: challenging social exclusion*, Oxford, UK: Blackwell.

Milkie, MA & Warner, CH 2014, 'Status safeguarding: mothers’ work to secure children’s place in the social hierarchy', *Intensive mothering: the cultural contradictions of modern motherhood*, Branford, ON: Demeter.

Miller, P & Rose, N 1993, 'Governing economic life', *Economy & Society*, vol. 19, no. 1, pp. 1-31.

Miller, T 2005, *Making sense of motherhood: a narrative approach*, Cambridge: Cambridge University Press.

Miller, YD & Brown, WJ 2005, 'Determinants of active leisure for women with young children - an “ethic of care” prevails', *Leisure Sciences*, vol. 27, no. 5, pp. 405-420.

Mills, R 1995, ‘Confession as a practice of freedom: feminism, Foucault and elsewhere truths’, *Law Text Culture*, vol. 2, iss. 1, pp.100-117.

Molloy, H & Vasil, L 2002, 'The social construction of Asperger syndrome: the pathologising of difference?', *Disability & Society*, vol. 17, no. 6, pp. 659-669.

Morris, J 1992, 'Personal and political: a feminist perspective on researching physical disability', *Disability, Handicap & Society*, vol. 7, no. 2, pp. 157-166.

Moskowitz, A & Heim, G 2011, 'Eugen Bleuler's dementia praecox or the group of schizophrenias (1911): a centenary appreciation and reconsideration', *Schizophrenia Bulletin*, vol. 37, no. 3, pp. 471-479.

Moustakas, C 1994, *Phenomenological research methods*, Thousand Oaks, CA: Sage.

Murphy, E 2004, ‘Risk, maternal ideologies and infant feeding’, in J. Germov & L. Williams (eds.), *A sociology of food and nutrition: the social appetite*, Melbourne: Oxford University Press, pp. 200-219.

Nadesan, MH 2013, *Constructing autism: unravelling the 'truth' and understanding the social*, London: Routledge.

Naples, NA 2003, *Feminism and method: ethnography, discourse analysis, and activist research*, London: Routledge.

Neill, J 1990, 'Whatever became of the schizophrenogenic mother?', *American Journal of Psychotherapy*, vol. 44, pp. 499-505.

Nelson, MK 2010, *Parenting out of control: anxious parents in uncertain times*, New York: NYU Press.

Nettleton, S & Gustafsson, U (eds.) 2002, *The sociology of health and illness reader*, Cambridge: Polity.

Neuman, W 2011, *Social research methods: quantitative and qualitative approaches* (7th ed.), MA, Pearson Education, Boston.

Novas, C & Rose, N 2000, 'Genetic risk and the birth of the somatic individual', *Economy and Society*, vol.29, no.4, pp.485-513.

O'Brien, M 2007, 'Ambiguous loss in families of children with autism spectrum disorders', *Family Relations*, vol. 56, no. 2, pp.135-146.

O'Brien Hallstein, DL 2011, 'She gives birth, she's wearing a bikini: mobilizing the post-pregnant celebrity mom body to manage the post-second wave crisis in femininity', *Women's Studies in Communication*, vol. 34, no. 2, pp. 111-138.

Ohanian, R 1990, 'Construction and validation of a scale to measure celebrity endorsers' perceived expertise, trustworthiness, and attractiveness', *Journal of Advertising*, vol. 19, no. 3, pp. 39-52.

Oliver, M 1990, *The individual and social models of disability*, Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, Thames, UK.

O'Neil, S 2008, 'The meaning of autism: beyond disorder', *Disability & Society*, vol. 23, no. 7, pp. 787-799.

Ong, A 1999, *Flexible citizenship: the cultural logics of transnationality*, Durham, NC: Duke University Press.

Ong-Dean, C 2009, *Distinguishing disability: parents, privilege, and special education*, Chicago, IL: University of Chicago Press.

O'Reilly, A (ed.) 2008, *Feminist mothering*, Albany, NY: SUNY Press.

O'Reilly, A 2014, *Ain't I a feminist?: matricentric feminism, feminist mamas, and why mothers need a feminist movement/theory of their own*, Keynote speech and induction into the Motherhood Hall of Fame at the Museum of Motherhood in NYC (2014), Retrieved from: https://mommuseum.org/aint-i-a-feminist-matricentric-feminism-feminist-mamas-and-why-mothers-need-a-feminist-movementtheory-of-their-own/

O'Reilly, A 2016, *Matricentric feminism: theory, activism, and practice*, Branford, ON: Demeter Press.

Ortlipp, M, Arthur, L & Woodrow, C 2011, ‘Discourses of the early years learning framework: constructing the early childhood professional’, *Contemporary Issues in Early Childhood*, vol.12, no.1, pp.56-70.

Ostberg, JR, Barth, RK & Frelinger, JG 1998, ‘The Roman god Janus: a paradigm for the function of CD43’, *Immunology Today*, vol. 19, no. 12, pp. 546-550.

Parker, R 1997, ‘The production and purposes of maternal ambivalence’, in W. Hollway and B. Featherstone (eds.) *Mothering and ambivalence,* London: Routledge, pp. 17–37.

Patel, DR & Greydanus, DE 2012, *Autism spectrum disorders: practical overview for paediatricians,* Philadelphia, PA: W.B. Saunders Co.

Patton, MQ 1990, *Qualitative evaluation and research methods*, Newbury Park, CA: Sage.

Pearce JMS 2005, Kanner’s infantile autism and Asperger’s syndrome, *Journal of Neurology, Neurosurgery & Psychiatry,* vol 76, pp.205.

Persson, A & Richards, W 2008, 'From closet to heterotopia: a conceptual exploration of disclosure and ‘passing’ among heterosexuals living with HIV', *Culture, Health & Sexuality,* vol.10, no.1, pp.73-86.

Phillips, MJ 1990, 'Damaged goods: oral narratives of the experience of disability in American culture', *Social Science & Medicine*, vol. 30, no. 8, pp. 849-857.

Pitt, NA 2008, "Yummy Mummies": Angelina Jolie and early 21st century representations of motherhood, in T. Majoribanks, J. Barraket, JS. Chang, A. Dawson, M. Guillemin, M. Henry-Waring, A. Kenyon, R. Kokanovic, J. Lewis, D. Lusher, D. Nolan, P. Pyett, R. Robins, D. Warr & J. Wyn (eds.), *The annual conference of The Australian Sociological Association 2008. Re-imagining sociology: conference publication proceedings.* The Australian Sociological Association (TASA), Australia, pp. 1 - 13, Australian Sociological Association Annual Conference 2008, Melbourne, Australia, 2/12/08.

Popay, J, Rogers, A & Williams, G 1998, 'Rationale and standards for the systematic review of qualitative literature in health services research', *Qualitative Health Research*, vol. 8, no. 3, pp. 341-351.

Rabinow, P (ed.)1991, *The Foucault reader: an introduction to Foucault’s thought,* London: Penguin.

Rao TSS & Andrade C 2011, ‘The MMR vaccine and autism: sensation, refutation, retraction, and fraud’, *Indian Journal of Psychiatry*, vol. 53, no.2, pp.95–96

Reich, JA 2014, 'Neoliberal mothering and vaccine refusal: imagined gated communities and the privilege of choice', *Gender & Society,* vol. 28, no. 5, pp. 679-704.

Reimer, V & Sahagian, S 2015, *The mother-blame game*, Branford, ON: Demeter Press.

Rich, A 1976, *Of woman born: motherhood as experience and institution*, New York: Norton.

Richardson, L 1994 'Writing: a method of inquiry',\. In N. K. Denzin & YS. Lincoln (eds.), *Handbook of qualitative research*, Thousand Oaks: Sage, pp. 923-94.

Richardson, N 2016, *Transgressive bodies: representations in film and popular culture*, Burlington, VT: Ashgate.

Rimland, B 1964, *Infantile autism: the syndrome and its implications for a neural theory of behavior*, London: Methuen & Company.

Ringrose, J & Walkerdine, V 2008, 'Regulating the abject: the TV make-over as site of neo-liberal reinvention toward bourgeois femininity', *Feminist Media Studies*, vol. 8, no. 3, pp. 227-246.

Rocco, T 1997, ‘Hesitating to disclose: adult students with invisible disabilities and their experiences with understanding and articulating disability’, in SJ. Levine (ed.), *Proceedings of the 16h annual midwest research-to-practice conference in adult, continuing, and community education,* Lansing: Michigan State University, pp.157-163.

Romano, J 1975, ‘American psychiatry: past, present, and future’, in *American psychiatry: past, present, and future*, Charlottesville, VA: University Press of Virginia, pp. 28-43.

Rose, N 1990, *Governing the soul: the shaping of the private self*, London: Routledge.

Rose, N 1999, *Governing the soul of the private self*', London: Free Association Books.

Rose, N, O'Malley, P & Valverde, M 2006, 'Governmentality', *Annual. Review of Law & Social. Science*, vol. 2, pp. 83-104.

Rothbaum, F, Martland, N & Jannsen, JB 2008, 'Parents' reliance on the Web to find information about children and families: socio-economic differences in use, skills and satisfaction', *Journal of Applied Developmental Psychology*, vol. 29, no. 2, pp. 118-128.

Ross, EK 1969, *On death and dying*, London: Tavistock.

Roxburgh, S 1997, ‘The effect of children on the mental health of women in the paid labor force’, *Journal of Family Issues*, vol 18, pp. 270-289.

Ruddick, S 1980, *'Maternal thinking: towards a politics of peace*, London: The Women’s Press.

Russell, GM & Kelly, NH 2002, ‘Research as interacting dialogic processes: implications for reflectivity’, *Forum Qualitative Sozialforschung*, vol. 3, no. 3, Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/831/1807

Ryan, S & Runswick-Cole, K 2008, 'Repositioning mothers: mothers, disabled children and disability studies', *Disability & Society*, vol. 23, no. 3, pp. 199-210.

Ryan, S & Runswick-Cole, KR 2009, 'From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum', *Journal of Applied Research in Intellectual Disabilities*, vol. 22, no. 1, pp. 43-53.

Salganicoff, A, Ranji, UR & Wyn, R 2005, *Women and health care: a national profile*, Menlo Park, CA: Kaiser Family Foundation.

Sanders, JL 2011, 'A distinct language and a historic pendulum: the evolution of the diagnostic and statistical manual of mental disorders', *Archives of Psychiatric Nursing*, vol. 25, no. 6, pp. 394-403.

Sarrett, JC 2011, 'Trapped children: popular images of children with autism in the 1960s and 2000s', *Journal of Medical Humanities*, vol. 32, no. 2, pp. 141-153.

Sawchuk, D & Clarke, J 2015, 'Representations of autism and autism spectrum disorder (ASD) in the North American Roman Catholic print media, 1990–2013', *Journal of Disability & Religion*, vol. 19, no. 2, pp. 146-167.

Sawicki, J 1991, *Disciplining Foucault: feminism, power, and the body*, New York: Routledge.

Sawyer, RK 2002, 'A discourse on discourse: an archeological history of an intellectual concept', *Cultural studies*, vol. 16, no. 3, pp. 433-456.

Schall, C 2000, ‘Family perspectives on raising a child with autism’, *Journal of Child and Family Studies*, vol. 9, no. 4, pp.409-423.

Schermerhorn, J, Davidson, P, Poole, D, Woods, P, Simon, A & McBarron, E 2014, *Management: foundations and applications* (2nd Asia-Pacific ed.), Australia: Wiley & Sons.

Seccombe, K, James, D & Walters, KB 1998, '"They think you ain't much of nothing": the social construction of the welfare mother', *Journal of Marriage and the Family*, vol. 60, pp. 849-865.

Severson, KD, Aune, JA & Jodlowski, D 2008, ‘Bruno Bettelheim, autism, and the rhetoric of scientific authority’, in M. Osteen (ed.) *Autism and representation*, New York: Routledge, pp. 65–77.

Shakespeare, T 1998, 'Choices and rights: eugenics, genetics and disability equality', *Disability & Society*, vol. 13, no. 5, pp. 665-681.

Sharp, L & Richardson, T 2001, 'Reflections on Foucauldian discourse analysis in planning and environmental policy research', *Journal of Environmental Policy and Planning*, vol. 3, no. 3, pp. 193-209.

Shearn, J & Todd, S 2000, 'Maternal employment and family responsibilities: the perspectives of mothers of children with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, vol. 13, no. 3, pp. 109-131.

Sheridan, A 2003, *Michel Foucault: the will to truth*, New York: Tavistock Publications Ltd.

Showalter E 1997, *Hystories*, New York: Columbia University Press.

Shuntermann P 2002, ‘Pervasive developmental disorder and parental adaptation: previewing and reviewing atypical development with parents in child psychiatric consultation’, *Harvard Psychiatry*, vol. 10, pp.16–27.

Simpson, RL 2001, 'ABA and students with autism spectrum disorders issues and considerations for effective practice', *Focus on Autism and Other Developmental Disabilities*, vol. 16, no. 2, pp. 68-71.

Skubby, D 2012, *A history of medical practices in the case of autism: a Foucauldian analysis using archaeology and genealogy*, (PhD thesis), The University of Akron: Akron, USA.

Smart, B 2002, *Michel Foucault* (rev. ed.), London: Routledge.

Smart, C 1996, ‘Deconstructing motherhood’, in EB. Silva (ed.) *Good enough mothering: feminist perspectives on lone motherhood*. London: Routledge, pp. 37-57.

Smith, B, Surrey, J & Watkins, M 1998, ‘Adoptive mothers: real mothers in resistance’, in SJ. Weingarten, & C. Garcia-Coll (eds.), *Mothering against the odds: diverse voices of contemporary motherhood*, New York: Guilford Press.

Smyth, L 2012, *The Demands of motherhood: agents, roles and recognition*, Basingstoke, UK: Palgrave Macmillan.

Sofaer, S 1999, 'Qualitative methods: what are they and why use them?', *Health Services Research*, vol. 34, no. 5, pp. 1101-1118.

Sousa, AC 2011, 'From refrigerator mothers to warrior-heroes: the cultural identity transformation of mothers raising children with intellectual disabilities', *Symbolic Interaction*, vol. 34, no. 2, pp. 220-243.

Spitzack, C 1997, *Confessing excess: women and the politics of body reduction*, Albany, NY: State University of New York Press.

St. Pierre, EA 2000, 'Poststructural feminism in education: an overview', *International Journal of Qualitative Studies in Education*, vol. 13, no. 5, pp. 477-515.

Stevenson, C & Cutcliffe, J 2006, 'Problematizing special observation in psychiatry: Foucault, archaeology, genealogy, discourse and power/knowledge', *Journal of Psychiatric and Mental Health Nursing*, vol. 13, no. 6, pp. 713-721.

Stevenson, JL, Harp, B & Gernsbacher, MA 2011, 'Infantilizing autism', *Disability Studies Quarterly*, vol. 31, no. 3. Retrieved from http://dsq-sds.org/article/view/1675/1596

Stevenson, S 2007, '(M)Othering and autism', in M. Osteen (ed.) *Autism and representation*, New York: Routledge, pp. 197-212.

Stotz-Ingenlath, G 2000, 'Epistemological aspects of Eugen Bleuler's conception of schizophrenia in 1911', *Medicine, Health Care and Philosophy*, vol. 3, no. 2, pp. 153-159.

Stronach, I, Corbin, B, McNamara, O, Stark, S & Warne, T 2002, ‘Towards an uncertain politics of professionalism: teacher and nurse identities in flux’, *Journal of Education Policy*, vol.12, no.1, pp.109-138.

Svendsen, L 2016, *Work* (2nd ed.), Abingdon, UK: Routledge, …

Tang, L & Bie, B 2016, 'The stigma of autism in China: an analysis of newspaper portrayals of autism between 2003 and 2012', *Health Communication*, vol. 31, no. 4, pp. 445-452.

Thurer, S 1994, *The myths of motherhood: how culture reinvents the good mother*, Houghton Mifflin Harcourt.

Todd, S & Jones, S 2003, '‘Mum's the word!': maternal accounts of dealings with the professional world', *Journal of Applied Research in Intellectual Disabilities*, vol. 16, no. 3, pp. 229-244.

Turner, BS, 1984, *The body and society*, Oxford: Basil Blackwell

Turner, BS 2006, *The Cambridge dictionary of sociology*, Cambridge: Cambridge university press.

Vakirtzi, E 2010, *The archaeology of autism and the emergence of the autistic subject*, (PhD thesis), Exeter: University of Exeter.

Vandenbeld Giles, M 2014, ‘Introduction’, in M. Vandenbeld Giles (eds.), *Mothering in the age of neoliberalism*, Bradford: Demeter Press, pp. 1-34.

Van den Hoonaard, WC 2002, *Walking the tightrope: ethical issues for qualitative researchers*, Toronto: University of Toronto Press.

Veal, AJ 2006, *Research methods for leisure and tourism: a practical guide*, London: Pitman.

Veck, W 2002, 'Completing the story: connecting relational and psychological processes of exclusion', *Disability & Society*, vol. 17, no. 5, pp. 529-540.

Verhoeff, B 2013, 'Autism in flux: a history of the concept from Leo Kanner to DSM-5', *History of Psychiatry*, vol. 24, no. 4, pp. 442-458.

Veyne, P 1997, ‘Foucault revolutionizes history’, in AI. Davidson (ed.) *Foucault and his interlocutors*, Chicago, IL: University of Chicago Press, pp. 146–82.

Vitello, SJ & Soskin, RM 1985, *Mental retardation: its social and legal context*, Englewood CIiffs, NJ: Prentice-Hall.

Wakefield, AJ, Murch, SH, Anthony, A, Linnell, J, Casson, D, Malik, M, Berelowitz, M, Dhillon, AP, Thomson, MA & Harvey, P 1998, 'RETRACTED: Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children', *The Lancet*, vol 351, no. 9103, pp.637-641.

Walkerdine, V 1987, ‘No laughing matter: girlís comics and the preparation for adolescent sexuality’, in JM. Broughton (ed.), *Critical theories of developmental psychology*, New York: Plenum Press.

Waltz, MM 2015, 'Mothers and autism: the evolution of a discourse of blame', *AMA Journal of Ethics*, vol. 17, no. 4, p. 353-358.

Weedon, C 1987, 'Principles of poststructuralism', in *Feminist practice and poststructuralist theory*, Blackwell: Oxford, pp. 12-19.

Wetherell, MT, Taylor, S & Yates, S 2001, *Discourse theory and practice: a reader*, London: Sage.

White, SK 1986, 'Foucault's challenge to critical theory', *American Political Science Review*, vol. 80, no. 2, pp. 419-432.

Whitmarsh, J 2008, 'Mums, dummies and ‘dirty dids’: the dummy as a symbolic representation of mothering?', *Children & Society*, vol. 22, no. 4, pp. 278-290.

Wickham, G & Kendall, G 1999, *Using Foucault’s methods*, London, UK: Sage.

Williams, KJ & Murray, DW 2015, 'Negotiating the normative: the other normal for mothers of disabled children', *Journal of Family Studies*, vol. 21, no. 3, pp. 324-340.

Wing, L 1986, ‘Letter: clarification on Asperger's syndrome’, *Journal of Autism and Developmental Disorders*, vol. 16, pp. 513-515.

Wing, L 1981, 'Asperger's syndrome: a clinical account', *Psychological Medicine*, vol. 11, no. 1, pp. 115-129.

Wolfensberger, W 2011, ‘Social role valorization: a proposed new term for the principle of normalization’, *Intellectual and Developmental Disabilities*, vol. 49, no. 6, pp. 435-40.

Wolff, S 2004, 'The history of autism', *European Child & Adolescent Psychiatry*, vol. 13, no. 4, pp. 201-208.

Wood, J 1999, *Communication, gender and culture* (3rd ed.), Belmont, CA: Wadsworth.

Woodward, K 1997, ‘Motherhood: identities, meanings and myths’, in K. Woodward (ed.) *Identity and difference*, London: Sage/Open University Press.

Yates, S 2005, *Truth, power, and ethics in care services for people with learning difficulties*, Detroit: University of Michigan Press.

Young, IM 1980, ‘Throwing like a girl: a phenomenology of feminine body comportment motility and spatiality, *Human Studies*, vol. 3, pp. 137-56.

Zembylas, M 2005, ‘Discursive practices, genealogies, and emotional rules: a poststructuralist view on emotion and identity in teaching’, *Teaching and Teacher Education*, vol.21, no.8, pp. 935-948.