

**Families' experiences of providing nutrition to their
child with global developmental delay: A
phenomenological study**

Tania Brown

A thesis presented to Auckland University of Technology in
partial fulfilment of the requirements for the degree of Master of
Health Science

2014

Faculty of Health and Environmental Sciences
School of Sport and Recreation

Table of Contents

CHAPTER ONE: INTRODUCTION	1
1.1 Background to this study	1
1.2 Philosophical approach and research aim	2
1.3 Choosing my study	3
1.4 Significance of the study	4
1.5 Structure of thesis.....	5
CHAPTER TWO: EXPLORING THE LITERATURE.....	7
2.1 Introduction	7
2.2 The prevalence of childhood overweight and obesity	7
2.3 Overweight and obesity in children with global developmental delay.....	9
2.4 Families' experience of having a child with global developmental delay ...	11
2.5 Feeding problems in children with global developmental delay.....	15
2.6 Experiences of families in providing nutrition to their child with global developmental delay.....	19
CHAPTER THREE: THE RESEARCH PROCESS.....	23
3.1 Introduction	23
3.2 Methodology	23
3.2.1 Phenomenological underpinnings of this study	23
3.2.2 Van Manen's life existentials.....	24
3.2.3 Van Manen's structure of phenomenology.....	25
3.2.4 Turning to a phenomenon that seriously interests us and commits us to the world	25
3.2.5 Investigating the experience as it is lived rather than as we conceptualise it	25
3.2.6 Reflecting on essential themes.....	26
3.2.7 The art of writing and re-writing.....	27
3.2.8 Maintaining a strong and orientated relation to the phenomenon.....	28
3.2.9 Balancing the research context by considering the parts and the whole.....	28
3.3 Ethical approval and considerations	28
3.3.1 Informed and voluntary consent	29

3.3.2 Respect for rights of privacy and confidentiality	29
3.3.3 Minimisation of risk	30
3.4 Relevance to the Treaty of Waitangi	30
3.4.1 Participation	30
3.4.2 Partnership	31
3.4.3 Protection	31
3.5 Research design	31
3.5.1 The participants	31
3.5.2 Participant consent	31
3.5.3 Data collection	32
3.5.4 The interview process	32
3.6 Methodological rigour	33
3.6.1 Credibility	33
3.6.2 Transferability	33
3.6.3 Dependability	34
3.6.4 Reflexivity	34
3.7 Conclusion.....	35
CHAPTER FOUR: FINDING THEIR OWN WAY	36
4.1 Introduction – Finding their own way	36
4.2 Seeking help	37
4.3 Feeling let down.....	44
4.4 Taking action	52
4.5 Conclusion – Finding their own way	56
CHAPTER FIVE: REBRANDED WATER.....	57
5.1 Introduction – Rebranded water	57
5.2 Utilising multiple strategies.....	58
5.3 Negotiation and trade-offs.....	64
5.4 Deception/Being caught out.....	68
5.5 Conclusion – Rebranded water.....	72
CHAPTER SIX: JUST GETTING ON WITH IT	73
6.1 Introduction – Just getting on with it.....	73
6.2 The everyday ordinary	74
6.2.1 The ideal versus the reality	77

6.3 Accepting some things	83
6.4 Looking to the future	87
6.5 Conclusion – Just getting on with it	92
CHAPTER SEVEN: DISCUSSION AND RECOMMENDATIONS	94
7.1 Introduction	94
7.2 Discussion.....	94
7.3 Relating the findings to other studies	96
7.4 Study limitations	99
7.5 Recommendations	100
7.6 Suggestions for further research	103
7.7 Closing thoughts.....	104
REFERENCES.....	105
APPENDIX A	117
APPENDIX B	118
APPENDIX C	119
APPENDIX D	122

KEY TO TRANSCRIPTS

In presenting the research findings, the following conventions have been adopted within this thesis:

<i>Italics</i>	Identifies the interview data provided by the families.
Names	With the permission of the families, their individual stories are identified through the use of pseudonyms.
...	Denotes material deleted from the original text.
[]	Indicates insertion of additional material by the researcher to assist with clarity.

THE KEY TERMS USED

Global developmental delay: Is a term used to describe a series of developmental syndromes. It has been published and repeatedly cited in the research literature since the mid-1970s (Wong, 2011). Although it is terminology that is not formally defined by the World Health Organization, it is generally accepted amongst child-health clinicians that global developmental delay can be defined as evidence of significant delay in at least two of the four developmental domains: gross/fine motor; speech/language/cognition; social/personal; or activities of daily living (McDonald, Rennie, Tolmie, Galloway, & McWilliam, 2006; Riou, Ghosh, Francoeur, & Shevell, 2009; Williams, 2010; Wong, 2011). It can include a number of neuro-developmental disorders i.e., autistic disorder, Asperger's syndrome, childhood disintegrative disorder, Retts's disorder, and pervasive developmental disorder not otherwise specified.

ATTESTATION OF AUTHORSHIP

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made.”

Signature:

A handwritten signature in blue ink, consisting of a series of loops and a long horizontal stroke.

Tania Brown

19th December 2014

ACKNOWLEDGEMENTS

I would firstly like to thank my husband Carrick who has been a pillar of support throughout this research journey. Without your love and support Carrick, it would not have been possible for me to undertake this project. I would also like to make special mention of my daughter Axana who was born while I was completing this research. I missed you terribly on the days when I was working Axana, and I am very much looking forward to a lot more visits to the park this summer. A special thank you to my parents Len and Lorraine who allowed me extra time to work by taking care of Axana. Also, thank you to those family members and dear friends who have been there for me throughout this journey and lent me an ear when I needed one.

Thank you to my supervisor Dr Tineke Water. Not only have you been incredibly supportive and encouraging, but you were also there to catch me when I felt like I was falling. I am very grateful for all that you did to make sure I stayed on the right track. Sometimes the path didn't always seem clear to me.

Thank you to Meg Beswick for completing the transcribing of my interviews and also to Helen Borich for editing this work.

Finally, thank you to the mothers who participated in this research. I am forever grateful and humbled that you gave up your time to talk to me and were so open and honest in sharing your stories.

Ethics approval

Date: 28 May 2012

Ethics Application Number: 12/123

ABSTRACT

There is a growing body of research about the feeding challenges that children with global developmental delay can face and the prevalence of obesity; however, there is little research from a family/caregiver's perspective about the difficulties and challenges in providing nutrition to these children. This study aims to partly redress this situation.

The purpose of this study is therefore to investigate the experiences of families in providing nutrition to their child with global developmental delay. Although this study was open to any family member(s) or caregiver(s) of a child with global developmental delay, it was only mothers who participated. Seven mothers were interviewed and shared with me their experiences with their child. Through my interpretation of the mothers' stories combined with my understanding from the literature, I was able to gain a deeper insight into the meaning of their experiences, that is: providing nutrition to a child with global developmental delay. Using the qualitative methodology of phenomenology, I sought to describe and interpret the meaning of the mothers' experiences, and to explore what these meant for the mothers in their everyday lives. The methodological steps proposed by van Manen (1990) were used to analyse, interpret and present the study's findings.

The methodological steps of van Manen (1990) revealed three themes from the mothers' experiences. These three themes are: finding their own way, re-branded water, and just getting on with it. The key findings from these themes suggest that families experience limited practical help and support in addressing their child's feeding challenges. Families must find their own way and create their own communities of support. Finding their own way means developing their own strategies to manage their child's feeding challenges and ways of just getting on with life and dealing with the everyday challenges that can be experienced in raising a child with global developmental delay. The complex nature of the feeding challenges that can be experienced by children with global developmental delay suggests that 'help' for families is not a 'one-size-fits-all' approach. Bearing this in mind, I have provided some recommendations and suggestions for practice, education and future

research that go some way towards looking at ways in which these families could at least be better supported.

CHAPTER ONE: INTRODUCTION

1.1 Background to this study

Obesity has become a significant worldwide health concern and the prevalence of childhood obesity has tripled over the past twenty years (Curtin, Anderson, Must, & Bandini, 2010). Obesity in children and young people can cause premature and chronic health problems such as pulmonary conditions (exercise intolerance); orthopaedic conditions (slipped femoral epiphysis); endocrine conditions (type 2 diabetes); and cardio-vascular conditions (hyperlipidemia and hypertension) and these may go on to become chronic health conditions as an adult (Ebbeling, Pawlak, & Ludwig, 2002). When compared to typically developing children, children with global developmental delay often have one or more predisposing factors for obesity including the coexistence of certain genetic syndromes known to be associated with obesity; reduced levels of physical activity; and the use of centrally acting medications which can cause weight gain (Lobstein, Baur, & Uauy, 2004). Studies have consistently found that children with global developmental delay are more likely to be obese than their typically developing peers (Bandini, Curtin, Hamad, Tybor, & Must, 2005; De, Small, & Baur, 2008; Emerson, 2009; Lin, Yen, Li, & Wu, 2005).

Children with global developmental delay are known to have atypical eating habits with aversions to specific textures, colours, smells, temperatures, and a preference for energy-dense foods which are high in fat and sugar (Ahearn, Castine, Nault, & Green, 2001; Curtin et al., 2010; Schreck, Williams, & Smith, 2004). There is a growing body of research about feeding and eating problems with these children and the prevalence of overweight and obesity; however, there is little research from a family/caregiver perspective of the challenges that can be faced in providing nutrition to such children.

The original proposal for this study had identified potential participants as the families/caregivers of children with global developmental delay where the children were over their healthy weight (overweight or obese). Recruitment for participants proved to be challenging and it was acknowledged that the stigma around childhood obesity was the likely reason for this. There is also the possibility that some children who are overweight may not have been formally diagnosed so families could possibly

be unaware of the extent of their child's weight issue. With the difficulties I experienced in recruiting participants for this study, approval was sought from the Auckland University of Technology (AUT) Ethics Committee to open the study up to *all* families/caregivers of children with global developmental delay, irrespective of weight. Despite opening up the study in this way, the issue of overweight and obesity remained a key one to investigate and of the seven mothers who participated, three had experienced weight issues with their child. One mother had an underweight child and three described their children as being a normal weight. The mothers shared their concerns about overweight and obesity as a potential issue in their child's future, even if they had not experienced weight issues with their child. Their concerns were centred on the future prospects of their child functioning independently away from the family home and whether their child would have the ability to make sensible dietary choices.

1.2 Philosophical approach and research aim

The aim of this research is to investigate the experience of families/caregivers in providing nutrition to a child with global developmental delay. It seeks to provide valuable insights into the challenges these families/caregivers face and how this can impact day-to-day life. The qualitative methodology of phenomenology was identified as the appropriate methodology for this study as it facilitates the in-depth exploration of a particular phenomenon. Phenomenology, which fits within the theoretical perspective of interpretivism, can take various forms and the form appropriate for this research is hermeneutic phenomenology.

Hermeneutic phenomenology is an approach described by van Manen (1990) as descriptive, reflective, and interpretive, and an engaging mode of inquiry from which to derive the essence of an experience. This research seeks to uncover the essence of the families/caregivers' experiences in providing nutrition to their child with global developmental delay. It seeks to describe and interpret what these meanings have to the families and how they impact on the choices and decisions that they make. In this study seven families were interviewed to share their experiences of providing nutrition to their child with global developmental delay. The data was then analysed using the phenomenological approach described by van Manen (1990). This involved

conducting a thematic analysis to determine the themes from the families' descriptions and to reveal the 'things' essential to the phenomenon.

1.3 Choosing my study

I come from a sport and fitness background with a special interest in childhood nutrition. It is my passion for the issues related to childhood nutrition, and specifically the issue of overweight and obesity in children, that was my primary drive for embarking on this master's research project. In 2010 and 2011 whilst I was completing my Postgraduate Diploma in Health Science I was fortunate enough to be given the opportunity to complete two summer studentship projects, both in the area of childhood obesity. I also spent some time working as part of a research team for the AUT Centre for Child Health Research and the AUT School of Sport and Recreation assessing the use of quality of life questionnaires in children with intellectual disabilities and their families. This project was part of a larger project titled SNAP!: Special children, Nutrition, Activity, and Participation for health – an intervention programme that was being developed to run in special needs schools to address the issue of overweight and obesity in this population of children. It was through this work that I first became exposed to the issue of overweight and obesity in children with global developmental delay, and more specifically how they are a population of children who are particularly vulnerable by virtue of the complex behavioural, physical, and psychosocial difficulties that they face.

In looking back at some prior research that the AUT Centre for Child Health Research has been involved in, I came across the evaluation report of an obesity intervention programme MEND (Mind, Exercise, Nutrition, Do it!) which considered obesity management in children with disability, and identification of the lack of lifestyle programmes available for children with intellectual and behavioural disabilities. The AUT Centre for Child Health Research in partnership with the Auckland District Health Board had piloted this intervention programme with children with intellectual and behavioural disabilities. At the end of the pilot, parents of the children were asked to give feedback on what they thought about the programme and what other factors should be considered for any future programmes. Parents in this evaluation highlighted that they thought there needed to be more research carried out on the

feeding and eating issues that they faced with their child and the challenge of providing their child with a healthy diet.

As I started to explore the literature on feeding and eating issues in children with global developmental delay, it became apparent to me that there was a growing body of research looking at the issue from the child's perspective, but comparatively little from a family/caregiver's perspective. The ultimate responsibility of providing nutrition to a child rests with the child's family/caregiver. For the family/caregiver of a child with global developmental delay who has feeding and eating issues, this adds another layer of complexity to providing nutrition to their child. Despite this, there was little in the literature about the experiences of these families/caregivers. Following discussions with my supervisor I decided to focus my master's research on this particular group of children and their families.

1.4 Significance of the study

The issue of overweight and obesity is continuing to gain worldwide media attention as a global epidemic that needs to be addressed. It has been reported that this generation of overweight/obese children will be the first to die (from obesity-related complications) at a younger age than their parents (Grant & Bassin, 2007). The New Zealand government has put in place some initiatives to encourage healthy eating and exercise, with a specific focus on children and young people. The Ministry of Health Food and Nutrition Guidelines for Healthy Children and Young people (aged 2-18) details the recommended intake of food per day and some suggestions on how children and young people can stay physically fit and active (Ministry of Health, 2012). There is mention in these guidelines of strategies to deal with picky eaters and children with allergies; however, there is no mention of strategies for children who suffer from disability (either physical or cognitive).

Funding from the New Zealand government has also recently been given to a new intervention project titled Healthy Families New Zealand (HFNZ). This initiative aims to encourage families to live healthy lives by making good food choices, being physically active, sustaining a healthy weight, not smoking and drinking alcohol only in moderation. Interventions for weight management that are targeted at changing the behaviours of families have proven to be a more successful approach than specific

interventions targeted solely at children. It is possible that the HFNZ project may recruit families who have a child with global developmental delay. There is no mention in the project literature however, of specific interventions for this particular population of children.

Interventions that are targeted at typically developing children are unlikely to be suitable for children with global developmental delay who have feeding/eating issues. The relationship a child with global developmental delay can have with food is vastly more complex than that which a typically developing ‘picky eater’ may have. Without gaining a deeper understanding of some of the issues that families/caregivers face in trying to encourage their child with global developmental delay to maintain a healthy diet and healthy weight, it will be difficult to identify appropriate strategies for this population of children.

1.5 Structure of thesis

The remainder of this thesis is divided into six chapters.

Chapter Two reviews the literature on feeding challenges and the issue of overweight and obesity in children with global developmental delay. The literature is reviewed within five topic areas. Firstly, it reviews literature on the prevalence of childhood overweight and obesity. Secondly, it reviews literature on childhood overweight and obesity as it specifically pertains to children with global developmental delay. Thirdly, it reviews literature on the experiences of families in having a child with global developmental delay. The final two sections explore the literature regarding the feeding challenges that can be experienced by children with global developmental delay and the experiences of families in providing nutrition to their child with global developmental delay.

Chapter Three describes the phenomenological, philosophical and methodological foundations of this research and the methods employed in collecting and analysing the data. It also provides some background on the ethical considerations that guided this research and a discussion of methodological rigour.

Chapters Four, Five and Six present the key findings from the participants' stories including my interpretation of their experiences and some philosophical reflections. I seek to show the meaning and significance of the participants' stories.

Chapter Seven discusses the key findings and how they relate to the established literature on the topic. The implications of the study are discussed and the identified limitations are outlined. Finally, the study proposes recommendations for practice, education and future research.

CHAPTER TWO: EXPLORING THE LITERATURE

2.1 Introduction

This chapter reviews the literature relating to providing nutrition to a child with global developmental delay and the prevalence of overweight and obesity in this population of children. The purpose of a literature review in phenomenological research is to ‘show meaning’ for the research phenomenon in question as it presents itself in the writings of others (Smythe, 2000). This provides the reader with a deeper understanding of what is already known about the research phenomenon in question and what meanings are already ‘out there’ (Smythe, 2000). In the first section of this literature review I take an epistemological view and provide background information on the prevalence of childhood overweight and obesity and the issue as it specifically pertains to children with global developmental delay. I also examine the literature regarding the physiological and behavioural issues that impact on the dietary intake of children with global developmental delay and how this is manifesting in more children becoming overweight/obese. I then follow on with an ontological view and explore in the literature the experiences of families who have a child with global developmental delay and particularly the challenges of providing nutrition to their child who may be overweight or at risk of becoming overweight. Throughout this literature review I identify common themes and examine these in relation to the research question.

2.2 The prevalence of childhood overweight and obesity

Over the past three decades the prevalence of overweight and obesity has increased substantially. According to statistics from the World Health Organization (WHO), obesity rates have nearly doubled since 1980, with 46% of the world’s population now being classified as either overweight or obese (World Health Organization, 2011). Overweight and obesity are a major risk factor for non-communicable diseases such as: cardiovascular disease; diabetes; musculoskeletal disorders; and some cancers (World Health Organization, 2011). Children are also included in this global trend of climbing overweight and obesity rates. The WHO reported that global overweight and obesity rates in preschool children increased from 4.2% in 1990 to

6.7% in 2010, with this trend expected to reach 9.1%, or 60 million children by 2020 (World Health Organization, 2010). Overweight and obesity has been shown to be a trajectory through life meaning that these children who are currently overweight or obese are likely to go on to be overweight or obese adults.

In New Zealand, statistics show that childhood obesity rates are following these global trends. Key findings from the 2012/13 New Zealand Health Survey show that child obesity rates have increased from 8% in 2006/07, to 11% in 2012/13 (in children aged 2-14 years), and that a further 22% (one in five) of New Zealand children are overweight (Ministry of Health, 2013). The prevalence of overweight and obesity has been found to be higher among Maori and Pacific Island children. After adjusting for age and sex differences, Maori children are nearly twice as likely to be obese as non-Maori children, and Pacific children are nearly three times as likely to be obese as non-Pacific children (Ministry of Health, 2013).

In addition to being a risk factor for chronic health conditions, childhood overweight and obesity presents a greater risk for developing secondary conditions associated with the primary disability (Rimmer, Rowland, & Yamaki, 2007). These secondary conditions can include mobility limitations, extreme levels of deconditioning, fatigue, pain, pressure sores, depression, bullying, and social isolation (Liou, Pi-Sunyer, & Laferrere, 2005; Lobstein et al., 2004; Rimmer et al., 2007). Overweight and obesity affects children of all races, ethnicities, and socio-economic status, including children with chronic conditions and developmental disabilities (Bandini et al., 2005; Evans et al., 2012; Ogden, Carroll, & Curtin, 2010). Research is consistently showing that children with disabilities, and in particular with cognitive disabilities (i.e., global developmental delay), are more likely to be obese than their typically developing peers (Bandini et al., 2005; De et al., 2008; Emerson, 2009; Lin et al., 2005).

When compared to typically developing children, children with global developmental delay often have one or more predisposing factors for obesity including the existence of certain genetic syndromes known to be associated with obesity, reduced levels of physical activity, and the use of centrally acting medications that can cause weight gain (Lobstein et al., 2004). Whilst chronic and secondary obesity-related conditions are serious for all children, for those with cognitive disabilities they can further

undermine their already limited independence, and significantly restrict opportunities for work, leisure, physical activity and community engagement (Rimmer et al., 2007; Simeonsson, 2002).

2.3 Overweight and obesity in children with global developmental delay

Global developmental delay encompasses a number of developmental disorders, many of which are characterised by varying levels of deficit in communication, socialisation, and restricted/repetitive or stereotyped patterns of behaviour (Cederlund, Hagberg, & Gillberg, 2010; Eikeseth, 2009; Kozlowski, Matson, Belva, & Rieske, 2012; Matson, Boisjoli, Hess, & Wilkins, 2010; Smith & Matson, 2010). Along with these core features, there is a host of additional associated impairments that are evident in children with global developmental delay such as impulsivity, inflexibility, challenging behaviours, sleep problems, and feeding problems (Gillberg, 2010; Matson, Mahan, Hess, & Fodstad, 2010; Matson, Mahan, Hess, Fodstad, & Neal, 2010; Williams, Field, & Seiverling, 2010). These unusual behaviours can be persistent and can markedly affect social skills and interaction in general (Matson, Carlisle, & Bamburg, 1998; Matson & Fodstad, 2009; Matson, Leblanc, & Weinheimer, 1999; Matson & Wilkins, 2007).

A limited number of studies have examined the prevalence of overweight and obesity among children with developmental disabilities. One of the first was a 1994 study of over 20,000 Japanese students with intellectual disabilities attending special schools. It was reported that the prevalence of obesity was significantly higher among children aged 6-14 years with intellectual disability compared to children the same age without intellectual disability. Bandini, Curtin, Tybor, Hamad, and Must (2003) reviewed data from two nationally representative surveys of the North American population – The Third National Health and Nutrition Examination Survey (NHANES III, 1994-1998) and found that in one of the data sets the prevalence of overweight was higher among children with intellectual disability than those without. The same authors subsequently reviewed the data from another nationally representative US survey, the NHANES 1999-2002, and found that children with health problems that limited their ability to walk, run or play were more likely to be overweight, and that girls with

learning difficulties were more likely to be overweight than typically developing girls (Bandini et al., 2005).

In a Taiwanese study on the prevalence of obesity among children and adolescents with intellectual disability it was reported that the average body mass index of these children was higher than relevant population norms (Lin et al., 2005). De et al. (2008) carried out a retrospective chart review on a group of Australian children with global developmental delay and found that a total of 40% of the children were either overweight or obese. This was found to be significantly higher than the 23% prevalence rate reported in typically developing children (De et al., 2008). Similarly Chen, Kim, Houtrow, and Newacheck (2010) reported significantly higher rates of obesity amongst children with a learning disability when compared to typically developing peers; 19.3% vs. 12.2%; as did Rimmer et al. (2007); 17.5% vs. 13.0%.

For children already faced with many health and social issues, being overweight or obese represents a crucial risk factor for the development and/or deterioration of secondary problems arising from the underlying disability. These include fatigue and pain owing to the strain on joints and muscles – caused by excess weight – which can lead to mobility issues (Reinehr, Dobe, Winkel, Schaefer, & Hoffman, 2010). Further, social isolation, which is common in children with developmental delays, can result in depression (Liou et al., 2005). These secondary sequelae of obesity can lead to a loss of independence and further restrict the child's options for exercise, leisure activities, and later employment (Chen et al., 2010). As a result, quality of life for these children – which is already lower than in their typically developing peers – is reduced even further (Buffart, Berg-Emons, Meeteren, Stam, & Roebroek, 2009; Rimmer et al., 2007). This has the potential to impose a lifetime of personal and economic hardship on both the child and the child's family (Rimmer et al., 2007).

This section of the literature review has provided some background understanding of the issue of overweight and obesity in children with global developmental delay and how the experience for both the child and the child's family might be framed. The issues discussed have pointed to the difficulties that can be experienced if a child with global developmental delay develops a weight problem. The next section of the literature review explores the literature on what everyday life can be like for a family

with a child with global developmental delay, with nutrition and the issue of weight being just one aspect of the parental/caregiver experience.

2.4 Families' experience of having a child with global developmental delay

“My greatest joy and my greatest heartache.”

A parent's own words on how having a child in the autism spectrum has affected their lives and their families' lives. (Myers, Mackintosh, & Goin-Kochel, 2009)

This section of the literature review is dedicated to exploring what everyday life is like for a family with a child with global developmental delay. I decided to focus on parenting as a whole rather than purely on food and nutrition as food and nutrition occurs in the full context of family life. Food and nutrition can be viewed as both a necessity and also a ritual of family life. To consider only the nutritional aspect of parenting a child with global developmental delay would fail to highlight the “whole” experience of what it is like to be a parent/caregiver of a child with global developmental delay. Gaining some understanding of this makes it possible to appreciate the additional challenges that food and nutrition present, and how this may go on to impact family life. Furthermore, because of the numerous physiological, social, and educational demands and stresses that are associated with raising a child with a developmental disorder, it may help to gain an understanding of why weight control may not always be a priority for the families of these children (Bandini et al., 2005). The experience of parenting a child with global developmental delay can be one that is positive but it can also be one that presents additional stressors and challenges to everyday life.

The physical and emotional experience of parenting a child with global developmental delay can be positive (e.g., joyful and happy feelings) or negative (e.g., stress, burden, sorrow, physical exhaustion etc.) or a combination of both, depending on the severity of the case (Nurullah, 2013). Parenting a child with global developmental delay is different in many ways to parenting a typically developing child. A child with global developmental delay requires more attention, care, and patience (Nurullah, 2013). Reichman, Corman, and Noonan (2008) suggested several ways a child with global developmental delay can impact day-to-day family

life: children with developmental delays often require additional primary care as well as more specialised and long-term medical care; functional limitations may necessitate that structural or technical modifications are made to the physical family-home environment; parents may need to seek appropriate educational and recreational facilities to ensure their child has opportunities equal to those of a typically developing child; and finally, as the child ages, specialised rehabilitation programmes may be necessary to ensure a positive transition into adulthood. Therefore for parents who have a child with global developmental delay, everyday life presents circumstances that can at times be both emotionally and physically draining.

In general, research focusing on the experiences of parents of children with global developmental delay has been dominated by a medical model of disability which views disability from an individual and tragic perspective (Kearney & Griffin, 2001). As such, it is well documented in the scholarly literature that raising a child with a developmental disability is stressful for parents and families (Duarte, Bordin, Yazigi, & Mooney, 2005; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings & Johnson, 2001; Koegel et al., 1992; Konstantareas & Homatidis, 1989; Montes & Halterman, 2007; Yamada et al., 2007). Mothers in particular have repeatedly been found to have poorer mental health, poorer physical health, and lower quality of life when they are parenting a child with a developmental delay as compared to mothers raising typically developing children (Allik, Larsson, & Smedje, 2006; Bromley, Hare, Davison, & Emerson, 2004; Hastings et al., 2005; Herring et al., 2006; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Olsson & Hwang, 2001; Schwichtenberg & Poehlmann, 2007).

There is comparatively less research on parental qualitative experiences of raising a child with global developmental delay, negotiating as Nurullah (2013) describes; “the burden and joys of parenting a child with developmental delay” (p. 437). In Myers et al. (2009) parents were asked the simple question “How has having a child in the autism spectrum affected your life and your family’s life?” (p. 673). Their attempt was to listen to parents’ own words on how raising a child with autism affected their lives and the lives of their families. Parents spoke at one moment of their unspeakable depression and despair, and in the next moment celebrated how wonderful their child was. Larson (1998) interprets this as “embracing the paradox”

(p. 29). The paradox was the tension between the child's current circumstances and their hopes and desires for a better future. The mix of negative and positive themes from this research was interpreted as a dialectical viewpoint of finding positive meaning to life even while acknowledging the stresses and difficulties of having a child with autism. Meaning-making is a central aspect to coping with adversity (Frankl, 2006). A search for meaning has been found to aid the coping of families faced with medical challenges and disabilities of various kinds (Huws, Jones, & Ingledew, 2001; Myers et al., 2009).

Kearney and Griffin (2001) took a phenomenological approach to explore both the 'sorrow' and the 'joy' of parenting a developmentally delayed child, the "other reality" as they referred to it (p. 583). Parents reported experiencing much anguish and sorrow, but they also spoke of hope, love, strength and joy. Huws et al. (2001) using a grounded theory approach analysed messages sent to an email group by parents of children with autism. They found there was a high level of uncertainty and anxiety amongst parents. A feeling that everyday life previously taken for granted had become disrupted, and that the future appeared ambiguous. For some parents there was a paradoxical striving for normality: wanting other people to accept their child as they are, but other people endeavouring to enforce their own models of normality upon their children. This could result in the parents feeling frustrated about the lack of understanding and sometimes isolating themselves further as a way of protecting both themselves and their child.

Fleischmann (2004) in his research to understand the adjustment process parents go through in caring for an autistic child utilised stories found on the internet. He used conventional 'data mining' by searching the keywords: *autism* and *stories*. He found that the parents' narratives all had a certain degree of similarity in the core story presented and described the way the parents had coped with autism. He concluded that the parents' exchange of narratives and correspondence via the internet was part of the process of learning to cope with the challenges that they faced. By documenting their struggles in the public domain, parents were forging ties with others in similar circumstances – creating virtual support groups (Fleischmann, 2004). Huws et al. (2001) describe parents' stories published on the internet as "postmodern diaries whereby on first glance they appear as calls for communal support, but on

closer inspection they are actually soliloquies” (p. 580). Parents appear to be motivated by the need to share their story, or to utter their thoughts aloud without addressing any person in particular (Huws et al., 2001).

I was interested in uncovering some stories first-hand of parents’ everyday experiences with a child with global developmental delay so I embarked on my own internet search using a simple data-mining approach similar to Fleischmann (2004). I found many stories where parents documented their struggles, stressors, joy, hope, and sometimes despair. One mother of a little boy who was diagnosed with global developmental delay at the age of one after failing to reach any of his infant-development milestones described her experience:

Parenthood in and of itself is challenging but when you have a child with developmental delays, it’s even more challenging. The world looks at you and your child with a different set of eyes because they can’t figure out why your child isn’t doing what other children his or her age are doing. This can be extremely frustrating and you find yourself constantly defending your child and explaining why your child does what he or she does, or does not do. I say this because this has been my life for the past seven years (Aminah, 2012, “I’ve realised I’ll never be used to this”).

The mother of a five-year old girl diagnosed with global developmental delay titles her blog A lifestyle that cannot be changed. She writes:

As a mother with a child who has a disability, I have to say it’s hardest to accept that fact, sometimes I feel like I have fully accepted her condition, then there are days where I break down and feel so depressed, feel so overwhelmed, and just very weak. But tears still flow down my cheeks like a daily routine; it’s just something I can’t help. Depression comes and goes, but life still goes on for myself and for my lovely daughter who has to live with this condition for the rest of her life. And she is the one who has to face the challenges her condition and this cruel world has to offer. But without challenges there is no growth (Abbyjan, 2013, “A lifestyle that cannot be changed”).

Similarly, as has been documented in the scholarly literature, parents also posted stories on the internet about how proud they were of their child, and the joy they were bringing to their life. This gives a sense of “embracing the paradox”. A mother writes about her son in a blog titled From one parent to another:

Raising a child is never easy, let alone one with special needs. As a parent of a child that experienced developmental delays, I have a new appreciation of what it means to be a parent. I don't take anything for granted and I am delighted when my son learns something new or has achieved something, no matter how small it may be. I know that I have done my job when my son looks at me as says “Mommy I did it!” and to see his face light up when I say “Proud of you!” is absolutely priceless (Faith, 2014, “Two years after my son’s diagnosis of colpocephaly”).

The experience of parenting a child with global developmental delay shows that everyday life presents challenges that can have an impact on both the emotional and physical state of parents. The experience for parents is one that despite the difficulties that they have encountered is also one of celebrating the positives. Although parents experience feelings of uncertainty for the future they also have feelings of hope.

2.5 Feeding problems in children with global developmental delay

For parents the overall experience of parenting a child with global developmental delay encompasses many areas – one of significance is that of nutrition. For new parents the first indication of the importance of nutrition and society’s preoccupation with weight becomes evident in the reporting of their new baby’s measurements. For new parents the weight and height of their baby is often the first information that is relayed to relatives. From then on at each check-up on progress, the child’s weight and height are tracked along the growth charts and recorded. This information is used to identify children that may not be progressing as expected. When issues with nutrition first become apparent it is usually through these measurements of a child’s growth. Bearing this in mind, it is no wonder that parents/caregivers view feeding their child as one of their most important responsibilities (Schreck & Williams, 2006). As children are weaned from a diet primarily milk-based onto a diet of solid foods, it is not uncommon for them to enter a stage of picky eating and fear of new foods as

they gain independence from their parents (Carruth, Ziegler, Gordon, & Barr, 2004). Feeding challenges are reported in 25-35% of typically developing young children (Dunn et al., 2001; Hastings & Johnson, 2001; Rogers, Magill-Evans, & Rempel, 2011). This stage of picky eating can often include food refusal, difficulty accepting new foods, behavioural feeding problems, tantrums and slow eating (Rogers et al., 2011). Determining if and when children's feeding challenges are beyond the level of picky eating is difficult, even more so for children with global developmental delay.

Children with global developmental delay often have repetitive or stereotyped patterns of behaviour that can include a preoccupation of interests that are abnormal in intensity or a focus on strict adherence to specific routines or rituals (Gabriels et al., 2008; Kozlowski et al., 2012). Some researchers have asserted that feeding problems in children with global developmental delay could be related to these restricted/repetitive patterns of behaviour (Matson, Fodstad, & Dempsey, 2009). Children with global developmental delay are known to have aversions to specific food textures, colours, smells, temperatures, and a preference for energy-dense foods that are high in fat and sugar (Ahearn et al., 2001; Curtin et al., 2010; Schreck et al., 2004). Research has shown that up to 80% of children with global developmental delay exhibit some form of feeding or eating problem (Manikam & Perman, 2000).

Feeding and eating problems in children with global developmental delay are often multi-factorial (Twachtman-Reilly, Amaral, & Zebrowski, 2008). Burklow, Phelps, Schultz, McConnell, and Rudolph (1998) found that the majority of children with a broad range of developmental etiologies demonstrated both physiological and behavioural factors in their feeding problems. It can sometimes be difficult to pinpoint the physiological basis for feeding problems in children with global developmental delay but two that have been researched in some detail are: sensory processing issues; and gastrointestinal (GI) issues (Twachtman-Reilly et al., 2008). Sensory modulation allows an individual to appropriately filter the multitude of sensory information that constantly bombards the nervous system (Twachtman-Reilly et al., 2008). For several decades sensory processing issues have been acknowledged to be part of the diagnostic picture for global developmental delay (Iarocci & McDonald, 2006; Twachtman-Reilly et al., 2008). Twachtman-Reilly et al. (2008) describe what might occur when a child has distortions in his/her sensory processing:

for example, within a cafeteria setting, a multitude of sensory experiences occurs that would not be noticed by the typical student: the smell of food cooking in the kitchen, the visual flickering from fluorescent lights, the constant movement of students within the lunchroom, and the noise of conversations reverberating from the cafeteria walls. The student with global developmental delay may have difficulty filtering out all of this input, experiencing it as a sensory onslaught to the nervous system. Behavioural responses to this experience may be that of *fight* (e.g., screaming or becoming aggressive), *flight* (e.g., fleeing the environment), or *fright* (e.g., shutting down and not being able to socialise with peers). The impact this may have on the child's feeding can be pervasive.

There is speculation around the prevalence of gastrointestinal disorders (GI) disorders in children with developmental delay and to explore this in great detail is outside the scope of this literature review. Some studies have reported that children with global developmental delay were no more likely than their typically developing peers to experience GI disorders (Black, Kaye, & Jick, 2002), whilst others have reported a much higher incidence in children with global developmental delay (Horvath, Papadimitriou, Rabsztyrn, Drachenberg, & Tildon, 1999). What is known about children with global developmental delay who experience GI disorders is that they often have difficulty expressing their discomfort and/or correctly identifying its source (Twachtman-Reilly et al., 2008). This affects the child's ability to obtain relief or prevent the discomfort from recurring and in some cases may lead to the refusal of larger categories of food rather than just the particular one causing the discomfort (Twachtman-Reilly et al., 2008). All of these factors – physical discomfort, communication limitations, hunger, and so on – can cause a high level of frustration which may manifest as undesirable mealtime behaviour (Twachtman-Reilly et al., 2008).

Disruptive mealtime behaviours such as crying, screaming, or otherwise agitated behaviour, aggressive and self-injurious or disruptive behaviour (e.g., spitting out food, leaving the table, knocking food off the table) can also interfere with food consumption and adequate nutritional intake (Ahearn et al., 2001; Lukens & Linscheid, 2008). Children with global developmental delay may be unable to adequately communicate their nutritional wants and needs such as hunger, fullness,

food likes and dislikes, or discomfort around eating, or they may not be influenced by their caregivers/families' attitudes toward healthy eating in the same way as children without such communication deficits (Lukens & Linscheid, 2008). In addition, rigid and repetitive behaviour patterns that are characteristic of children with global developmental delay often extend to other aspects of mealtimes, including insistence on specific methods of preparation, food types, and mealtime rules (Schreck & Williams, 2006). The negative behaviours that are frequently observed in children with global developmental delay have the potential to lead to a significant detrimental impact on the feeding experience (Twachtman-Reilly et al., 2008).

Much of the research to date regarding feeding issues in children with global developmental delay has examined the eating differences of children with global developmental delay vs. their typically developing peers. Schreck et al. (2004) compared the eating habits of children with autistic disorder to typically developing children and found that children with autistic disorder have significantly greater feeding problems, and eat a significantly narrower range of food. The parent of one of the autistic children included in this study by Schreck et al. (2004) reported that her child would only eat food that had been presented in a certain manner (e.g., on a Thomas the Tank Engine plate with no foods touching and only sitting at his picnic table). A further example from this study was children who would only consume a limited number of food types, mostly yellow-coloured, high-calorie foods (i.e., French fries, chicken nuggets) (Schreck et al., 2004).

Schmitt, Heiss, and Campbell (2008) further explored this topic by examining a three-day food record of boys with autistic disorder in comparison to typically developing boys. These authors discovered that the restrictive nature of the diet of children with autistic disorder was based primarily around the texture of food. In a comparison study by Johnson, Handen, Mayer-Costa, and Sacco (2008), it was concluded that there were significantly more mealtime behavioural differences in their group of autistic children vs. typically developing children, and that this may pose significant hardship for families in coping with mealtimes and other family activities. Matson et al. (2009) found that 76% of children with an autism spectrum disorder (ASD) in their sample would only eat certain foods (i.e., were food selective), and 76% preferred foods of a certain texture and/or smell. In examining feeding difficulties in toddlers

with ASD, Kozlowski et al. (2012) concluded that feeding difficulties often lead to other difficulties such as caregivers allocating more time to feeding rituals as opposed to other important activities.

The authors of a 2010 study which examined the eating patterns of fussy-eating children (both with and without developmental delay) were surprised to discover that only 26.4% of the children in the study sample were found to be underweight (Hendy, Williams, Riegel, & Paul, 2010). Research had previously suggested that fussy-eating children are often underweight (Carruth et al., 2004; Dovey, Staples, Gibson, & Halford, 2008); however, more research is now showing that due to the fact that fussy-eating children often have a preference for starchy, high-calorie foods, this is often leading to weight gain in these children (Lockner, Crowe, & Skipper, 2008; Schreck et al., 2004).

2.6 Experiences of families in providing nutrition to their child with global developmental delay

Eating difficulties have been observed in children with global developmental delay since the earliest diagnostic descriptions of the disorder (Twachtman-Reilly et al., 2008). Whilst this body of empirical research continues to grow, there is still little experiential research about the challenges families/caregivers face in providing nutrition to their child with global developmental delay. One of the few studies that has provided a family/caregiver perspective on some of these challenges is a study by Williams, Gibbons, & Schreck (2005). The authors of this study interviewed families/caregivers of children diagnosed with autism spectrum disorders about the issue of food selectivity, and compared this to the data from a control group of families/caregivers of typically developing children. They found that the families/caregivers of children with autism were frequently concerned about their child's food intake and that they often prepared new foods if their child would not eat the foods presented at a meal. Many of these families/caregivers also reported that they presented only the child's preferred foods in order to ensure that their child ate. This highlights the level of concern of families/caregivers in feeding a child with developmental delay. Such was their desire to ensure their child ate something; they would resort to multiple strategies to make this happen.

Rogers et al. (2011) specifically focussed on mothers' perspectives in the process of addressing feeding challenges of children with ASD. They asked: "What is the process of mothers feeding their children with ASD who have feeding challenges, and specifically what is the nature of these challenges?" Mothers described a tumultuous and confusing process of trying to feed children with severe reactions to foods. Some of the mothers recognised their child's feeding challenges from birth, as one mother reported:

*Breastfeeding was horrible, wouldn't work. He didn't suck very well.
We went around the block on the formulas (Rogers et al., 2011, p. 6).*

Another mother described how her child appeared to be progressing typically until around 12-24 months, when the number of foods gradually diminished to a limited repertoire:

*He's a dream baby. He's eating everything. Then, I can remember the day – it's imprinted, tattooed on my mind and he hadn't eaten his lasagne. He's always enjoyed it. For some reason that day...things started changing with his eating. He was a kid who ate everything....
Then more food started dropping off the list (Rogers et al., 2011, p. 6).*

Some mothers talked about trying to get food into their child in any way possible, even if that meant catering to their child's food preferences. By the time most of the children in this study were aged three to four years they were down to eating only between three and five different foods. A nutritionally sound diet was no longer of concern to many of the mothers; their primary concern was just making sure their child ate *something*. These feeding challenges significantly affected the mothers' home life, family mealtimes and eating in other environments. Mothers described the dilemma of meeting their child's needs or the expectations of relatives at family gatherings and how trying to feed their child on family vacations affected the whole family (Rogers et al., 2011).

Many autobiographical books have been written by parents telling their story of caring for their developmentally delayed child, often with a particular emphasis on the difficulties they face in providing their child with a healthy diet. Legge (2002), a mother of a son with Asperger's syndrome wrote: "When your child eats, say, only

four foods, it would be nice if you could announce that these four were fresh vegetables, fresh fruit, brown rice and wholemeal bread. In reality, their staple diet is more likely to consist of French fries, chopped and reformulated chicken pieces coated in batter or breadcrumbs, chocolate biscuits, and bucketloads of juice sweetened with aspartame” (p. 190). Jackson (2004), likened family mealtimes to “mayhem” and due to the rigidity in her child’s eating habits and aversions to many foods talked about how “potentially explosive any mealtime can be” (p. 141). Moore (2005), a mother of two autistic boys, in talking about her intentions of raising her children on a healthy diet explains: “I would have been astonished and horrified if I could have seen into their nutritional future” (p. 159).

A news segment on Television New Zealand’s *Close Up* (Janes & Valintine, 2011) programme highlighted the plight of the parents of a boy with cerebral palsy, and autistic-like traits, who would eat nothing except KFC™ chicken skins, and more recently fish batter. This had been going on for some 12 years, since the boy was eight-years old. His family had unsuccessfully sought help from various health professionals over the years. They explained that they had decided to take their story to the press in the hope that another family in a similar situation could offer advice, or that some other health professional may have some new advice. It was a cry for help.

This literature review has shown that children with global developmental delay experience feeding challenges that can often be complex and multifactorial in nature. It has pointed to how these feeding challenges can often lead to children with global developmental delay becoming overweight. Research has shown that children with global developmental delay are more likely to be overweight or obese than their typically developing peers. The consequences of this are significant as children with global developmental delay often already experience other health and social issues that can impair their development. Raising a child with global developmental delay presents significant challenges in the everyday lives of parents. In the parenting experience, providing food and nutrition is just one important aspect in the overall context of parenting. The parenting experience for parents of a child with global developmental delay – where feeding challenges need to be managed and the potential issue of overweight and obesity addressed – adds another layer of complexity to day-to-day life. The stress and uncertainty that these parents

experience in day-to-day life has been shown to negatively impact on both their physical and emotional health and their well-being.

CHAPTER THREE: THE RESEARCH PROCESS

3.1 Introduction

This chapter explains the methodological underpinnings, design and methods of this study. It provides a rationale for the choice of hermeneutic phenomenology as the appropriate methodology for exploring the meaning and significance of the experiences of the mothers. To clarify why this study only presents the stories and experiences of mothers when the title of the study incitates ‘families’ is simply because it was only mothers who responded to the study invitation. The study invitation clearly stated that the study was open to *any* family member(s) or caregiver(s) of a child with global developmental delay. The reason why it was only mothers who responded to the study invitation is perhaps indicative of the traditional role mothers often assume in taking primary responsibility for their child’s nutrition.

Interpretation of the mothers’ experiences was carried out following the methodological steps proposed by van Manen (1990), and this chapter will outline the process of phenomenological reflection, interpretation, writing and re-writing that was followed. This chapter will also describe the methods used to collect and analyse the research data, and how ethical principles were upheld throughout the course of this research. In addition, this chapter will outline the steps taken to ensure the trustworthiness of the research.

3.2 Methodology

3.2.1 Phenomenological underpinnings of this study

Phenomenology is a research philosophy that attempts to understand, or grasp, the essence of how people attend to their everyday world. It is about wanting to understand the world as it is experienced. What differentiates phenomenology from other social sciences is the focus on describing and interpreting existential meanings as we live them in our everyday world (van Manen, 1990). It does not attempt to explicate meanings specific to certain cultures (ethnography) or to certain social groups (sociology), or from particular historical periods (biography). Rather it attempts to understand, or grasp, the essence of how people attend to their everyday

world. Van Manen (1990) refers to a person's description as a perception, a form of interpretation. The foundations of phenomenology are rooted in the work of the philosopher Husserl, and later Heidegger, who described the basic structure of the lifeworld, focusing on the lived experience. Our everyday lives are filled with meaning and the aim of phenomenology is to 'lay open and let be seen' that 'which is taken for granted' (Heidegger, 1962). This allows understandings and meanings to emerge from our human experiences.

Hermeneutic phenomenology fits within the theoretical perspective of interpretivism. According to Crotty (1998) interpretivism is linked to the work of Max Weber (1864-1920) who suggested that human sciences are concerned with understanding. Crotty explains that interpretivism takes the epistemological viewpoint of constructionism, which suggests that "we do not create meaning, we construct meaning" (Crotty, 1998 p. 43-44). Meaning is constructed through the experiences we have in our engagement with the world in which we are interpreting (Crotty, 1998). The ontological position of this paradigm is therefore one in which there is no 'one reality' but rather reality is 'multiple and subjective' (Crotty, 1998). This means that different people may construct different meanings about the same phenomenon. Or, as van Manen (1990) describes it, "A phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description" (p. 31). This methodology thus challenges the positivist scientific notion of an objective reality.

3.2.2 Van Manen's life existentials

For van Manen (1990) there are four essential contexts of the lifeworld to consider when studying the lived experience. These are known as "existentials". As a guide for reflection in the phenomenological research process, he proposes that these four existentials provide the structure of meaning of the lifeworld, and pervade all human beings regardless of their historical, cultural or social situatedness. The first existential is lived space (spatiality) or being a body in a space. The space in which we find ourselves, in some way, always affects the way we feel. The second – lived body (corporeality) – refers to the fact that we are always bodily in the world through our physical or bodily presence. This physical or bodily presence may both reveal

and/or conceal something about ourselves. The third – lived time (temporality) – is subjective time rather than ticking time and refers to how the temporal dimensions of past, present, and future influence our understanding of the world. What we encounter in the past leaves traces on our being and thus how we carry ourselves into the future. The fourth – lived other (relationality) – is about sharing bodily space with others and the lived relationship that we therefore share.

3.2.3 Van Manen's structure of phenomenology

There is no one method by which phenomenological researchers can carry out their research. I have chosen to utilise the methodological guidelines proposed by van Manen (1990) for this study. The following is an overview of what these guidelines suggest and how I put them into practice in my study.

3.2.4 Turning to a phenomenon that seriously interests us and commits us to the world

Phenomenological researchers must have an interest in the aspect of human experience from which they seek to gain an understanding (van Manen, 1990). My interest in seeking understanding of the experience of families in providing nutrition to a child with global developmental delay stems from my previous childhood obesity research with the AUT Centre for Child Health Research, and my particular interest in research focussed on children who, by nature of their behavioural, physical, and/or psychosocial difficulties, are particularly vulnerable to the development of overweight and obesity.

3.2.5 Investigating the experience as it is lived rather than as we conceptualise it

Van Manen (1990) describes that the 'point' of phenomenological research is to "borrow other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience" (p. 62). The researcher's role is to capture and record how the study phenomenon is experienced. To do this it is imperative that one stays as close as possible to the actual experience as lived (van Manen, 1990).

I was mindful of this as I began interviewing, and was conscious of saying enough, but not too much, so that I was able to encourage the mothers to explore their experiences to the fullest. I did this by asking questions when it felt necessary as they were talking about a particular experience, such as: “And then what happened?” or “What was that like for you?” and “How did you feel about that?” There were a number of times in the interviews where the mothers would tell me about some other aspect of their child’s development (outside of nutrition), and I came to accept that this was actually an important aspect of me gaining an insight into their day-to-day lives. I was always mindful of returning the conversation back to their experiences with nutrition, but I felt it was important to also hear about these other incredibly important aspects of their child’s life and the journey with their child thus far.

According to van Manen (1990) our past experiences and pre-understandings predispose us to interpret the nature of the phenomenon perhaps before we have even come to fully comprehend the meaning of what the phenomenological question is that we are seeking to uncover. Because it is not possible for one to simply ignore or forget these past experiences, van Manen (1990) believes that it is better to make explicit these prior understandings, beliefs, biases, assumptions, presuppositions, and theories. “We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay, and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character” (van Manen, 1990, p. 47). Because I have previously been involved in research with families of children with developmental delay, I have already formed my own understandings of the phenomenon in question for this study. In order to become more fully aware of the ways my assumptions may influence the research process, I documented in my research journal what these assumptions were. It was helpful for me to go back and reflect on these as new understandings and meanings emerged from the mothers’ stories.

3.2.6 Reflecting on essential themes

According to van Manen (1990), a true reflection on the lived experience of a phenomenon requires the researcher to thoughtfully reflect on “what it is that renders this or that particular experience its significance” (p. 32). In other words, it is about reflectively “bringing into nearness that which tends to be obscure” (van Manen,

1990, p. 32). It is the researcher's role at this point to uncover the essential themes from within the data. I began this process by re-listening to the taped interviews with the typed transcripts in front of me. I then re-read the transcripts several times highlighting the essential or revealing statements about the phenomenon. As I re-read the mothers' stories I kept asking myself "What is this story telling me?" or "What does it reveal about the phenomenon?" and "What does this mean?" The emergence of the key themes was a slow process and it helped immensely to keep talking with my supervisor about the stories that were really resonating with me, and which I could see were essential to the phenomenon. I found at times that I had to take a break from writing and take some time to reflect on the mothers' stories and their experiences without thinking about themes. This helped me to think more clearly and often I found myself searching for some paper and a pen so I could jot down some thoughts that had been so elusive but were now suddenly there.

I was reminded as I was re-reading the transcripts that the mothers were often very expressive with their body language and showed a lot of emotion when talking about some of their more difficult experiences. I wanted to somehow link the transcripts to what I had witnessed while interviewing them. I made notes on the transcripts of what I had observed with the mothers' body language and their emotions so that I could bring the two together and truly gain an appreciation for the essence of their experiences.

3.2.7 The art of writing and re-writing

Van Manen (1990) describes the act of writing and re-writing as an essential part of reflecting on essential themes. Writing and rewriting enables interpretation to unfold. I began writing once I had come to some consensus on how to group the mothers' stories. Writing then became a way for me to start bringing the mothers' stories together and doing so allowed my interpretation of their experiences of the phenomenon to emerge. I learnt very quickly that this is not a process that can be rushed and taking the time for thought and reflection is essential to this writing process. I was conscious of maintaining focus on the mothers' 'lived experience' and while immersing myself in the mothers' stories facilitated my emerging interpretation, it could at times feel overwhelming. Pausing and reflecting thus became an important

aspect of the writing and re-writing element of my phenomenological research process.

3.2.8 Maintaining a strong and orientated relation to the phenomenon

Van Manen (1990) stresses the importance of the researcher staying oriented to his or her research question so as not to get side-tracked and stray away from the phenomenon of interest. Not settling for what van Manen (1990) describes as “superficialities” or “falsities” (p. 33). When I first started writing I found myself writing mostly about ‘what’ was happening and it took some re-writing for me to really settle into writing about the mothers’ experiences and uncovering the meaning in these experiences. I found it helpful to keep reminding myself of the phenomenon and the understanding I was seeking to gain.

3.2.9 Balancing the research context by considering the parts and the whole

An important component of van Manen’s (1990) methodological process involves balancing the research context by considering the parts and the whole. He suggests that at several points the researcher needs to take a step back and look at the ‘total’, at the contextual givens, and then reflect on how each of the parts contributes towards the whole. As I read through the mothers’ transcripts I listed the emergent themes and considered the commonalities in the mothers’ experiences and the differences. This opened up the hermeneutic circle of interpretation where I could see the parts making sense of the whole text and the whole text being understood by its parts.

3.3 Ethical approval and considerations

Ethical approval for the original study: *Families’ experiences of providing nutrition to their child with global developmental delay who is overweight/obese: A phenomenological study*, was sought from the Auckland University of Technology Ethics Committee (AUTEC) and considered at their meeting on the 28th May 2012. Approval was granted (ethics application number 12/123) subject to the provision of a letter from AUT Counselling, and that the information sheets and consent forms be amended to ensure consistent use of terminology, either ‘global developmental delay’ or ‘intellectual disability’. It was also suggested that the title of the research be reworded to read as follows: *Families’ experiences of providing nutrition to their*

overweight/obese child with global developmental delay: A phenomenological study. Final ethical approval was granted on the 9th May 2013 (APPENDIX A). Following the difficulties I experienced in attempting to recruit participants for this study, approval was sought from ATEC to remove the weight aspect and open the study up to *all* families of children with developmental delay, irrespective of weight status. ATEC approved this amendment on the 12th March 2014 (APPENDIX B). The title of the research was revised to read as follows: *Families' experiences of providing nutrition to their child with global developmental delay: A phenomenological study.* To give some context to the long time frame between ethical approval, recruitment and the completion of this study, it may be worth noting that from June 2012 to June 2013 I was on maternity leave following the arrival of my baby daughter. Taking maternity leave, combined with the difficulties I experienced in recruitment, extended the time frame for this research further than I had initially planned.

3.3.1 Informed and voluntary consent

All research requires that participation is voluntary and based on understanding adequate or appropriate information about what such participation will involve. Participants for this study were provided with an information sheet with sufficient information about the purpose of the study to enable them to give informed consent (APPENDIX C). Most of the participants had read the information sheet prior to contacting me to express their interest in participating. The participants were asked to sign a consent form prior to the interview which informed them of their right to withdraw from the study at any time with the assurance that any information provided by them in the course of the research would be destroyed in accordance with their wishes (APPENDIX D).

3.3.2 Respect for rights of privacy and confidentiality

It is important that participants' privacy and confidentiality is respected at all stages of a research project. Participants were given a pseudonym that was used in all transcripts throughout this study. To ensure the on-going protection of participants' identities all material arising from this study that is published will use these pseudonyms. The digitally recorded interviews were saved onto a memory stick and stored in a secure place throughout the study. All interviews were deleted from the digital Dictaphone as soon as the files had been saved to a memory stick. All original

data from this study will be stored securely at AUT for six years, after which time it will be destroyed.

3.3.3 Minimisation of risk

Researchers should make every attempt to identify, disclose and minimise any risks that may be involved for individuals or certain groups in a research project. It was not anticipated that there would be any risks to participants in this research project; however, due to the research exploring sensitive human experiences it was acknowledged that some participants might experience strong emotions. The participant information sheet provided details of participants' rights to seek three free counselling sessions from AUT Health and Counselling in the event that the research caused them distress. Participants were also told that they could withdraw from the research at any time during the data collection phase. None of the participants chose to do this.

3.4 Relevance to the Treaty of Waitangi

Central to health research in Aotearoa/New Zealand is adherence to the principles of participation, partnership and protection as outlined by the Treaty of Waitangi. I was not contacted by any Maori families or caregivers to participate in this study; however, the principles of the Treaty of Waitangi were integrated into my study in the following way.

3.4.1 Participation

In recruiting for this study I did not target any particular cultural or ethnic group. The invitation to participate was via organisations that work with developmentally delayed children and their families, of which there are a diverse range of cultures and ethnicities represented. There was also no coercion to participate in this research. Participants were invited to contact either myself, or my supervisor – Dr Tineke Water, if they had an interest in participating. Some participants contacted me via email and others through a phone call.

3.4.2 Partnership

During the interview process I endeavoured to create a supportive and open environment. I listened respectfully and made no judgements about the experiences the participants shared with me.

3.4.3 Protection

I protected the participants in this research by adhering to the ethical guidelines as outlined by AUTECH. In addition, respect for the participants was an underpinning core value and key-contributing factor to ensuring they were protected from any potential harm throughout the research process.

3.5 Research design

3.5.1 The participants

To obtain a rich description of providing nutrition to a child with global developmental delay, I sought participants who were knowledgeable about the subject matter so as to provide the in-depth data required to understand the phenomenon being studied (Field & Morse, 1985). I therefore specifically sought families and caregivers of children with global developmental delay with feeding and eating issues. Following approval from AUTECH I contacted two organisations actively involved in working with children with developmental delay and their families: The Wilson Trust, and Autism New Zealand. The Wilson Trust advertised my study in their monthly e-newsletter, and Autism New Zealand posted my invitation on their research website page, and also on their Facebook page. In phenomenological research there is no 'right' number of participants, so I continued interviewing until I felt that I had sufficiently rich data to begin analysis. This occurred after I had interviewed seven mothers. As outlined previously I didn't specifically target mothers as participants. Fathers, extended family members, caregivers or family groups were all welcome to participate; however, it was only mothers who made contact with me.

3.5.2 Participant consent

Prior to each interview the mothers were asked to provide written consent that they were fully informed about the study and willing to participate. The consent form

detailed their right to withdraw at any point during the interview process without being disadvantaged in any way.

3.5.3 Data collection

Data collection was undertaken through face-to-face interviews, and Skype interviews with the participants. The interviews lasted between 45 and 120 minutes and took place over a seven-week period. The interviews were digitally recorded and transcribed verbatim by a professional transcriptionist. I had originally planned to transcribe the interviews myself as a way of getting as close as possible to the mothers' stories. Due to time constraints I ended up engaging the expertise of a professional transcriptionist. My typing ability, whilst competent, is certainly not at the level of a professional transcriptionist, and I acknowledged that my time would be better spent reading the transcripts and re-listening to the interviews. Upon receiving the transcripts I listened to the interviews at the same time as reading line by line through the transcripts to ensure the accuracy of what had been transcribed.

3.5.4 The interview process

The mothers were offered the choice of being interviewed either in their own home, at the AUT Akoranga campus, or via Skype. Interview times were discussed either via telephone or email and were arranged for a time that was most convenient to the mothers. Five of the mothers chose to be interviewed in their own home and two chose to be interviewed via Skype. Interviewing via Skype, as a researcher, was not something I had previously experienced and I found these interviews to be more challenging than the face-to-face interviews. There was the time-delay issue in the video display to adapt to and also some technical difficulties with the sound. While these issues did not in any way affect the actual interview itself – in terms of the data that was captured – they did however prove to be an annoyance at times.

Before I started the interviews I had a little chat with the mothers about 'life in general' – how their morning had been, how cold the past few days had been etc. – general 'chit-chat' just to break the ice. I wanted the mothers to feel comfortable in my company and comfortable with sharing their experiences with me particularly as these experiences could spark memories of some very deep and personal emotions. The mothers were very open and honest in their interviews and while I felt humbled

that they had chosen to share their stories with me, I also sensed from them a feeling of relief that somebody was actually listening.

3.6 Methodological rigour

3.6.1 Credibility

Montes and Halterman (2007) claim that a study is credible when it presents faithful descriptions and when co-researchers or readers confronted with the experience can recognise it. There are several ways in which to improve credibility of qualitative research and Montes and Halterman (2007) suggest that prolonged involvement is one such method. Prolonged involvement requires the researcher to invest sufficient time in the data collection process to build trust and rapport with the interviewee, facilitating the increased scope and depth of the interview data. Duarte et al. (2005) suggest that sufficient time must also be spent in the analysis of the data such that the researcher is able to gain a deep understanding and interpretation of the phenomenon under investigation.

To enhance the credibility of this study I was mindful of investing sufficient time both in interviewing the participants and time in understanding and interpreting the meanings that emerged from their stories. I also found it helpful to consider the participant's non-verbal forms of communication such as their facial expressions, the tone of their voice, and their body language, as a means of revealing their unspoken words. This helped me to gain a deeper understanding and interpretation of the phenomenon.

3.6.2 Transferability

Montes and Halterman (2007) suggest that transferability is dependent upon the degree of similarity between two contexts with the original context described adequately enough that readers are able to make a judgement of transferability. This is also referred to as 'thick description' – where extensive details about both the context and the participants are included (Yamada et al., 2007). There is no intention for the findings of this study to be generalised to the wider population; however, it should be possible that a reader who has had a similar experience can relate to the findings, or at least to certain aspects of the findings. Allik et al. (2006) use the term

“fittingness” for evaluation and describe a study meeting the criteria of fittingness when its findings can “fit” into contexts outside the study situation and when its audience views the findings as meaningful and applicable in terms of their own experiences.

3.6.3 Dependability

Allik et al. (2006) proposes that a study and its findings are auditable when another researcher can clearly follow the decision trail and could arrive at the same, or comparable but not contradictory conclusions, given the researcher’s data, perspective and situation. In my research journal I have detailed all of my decision-making processes regarding theoretical, methodological and analytical aspects of this research. This should provide the transparency needed to ensure the findings from this study can be viewed as dependable.

3.6.4 Reflexivity

Reflexivity involves the researcher critically reflecting on themselves and considering their own prejudices and pre-understandings (Lavery, 2003). Acknowledging that what they may already know about the research phenomenon may colour their interpretation. Koch and Harrington (1998) explain that researchers bring to the final research product the following: data generated; a range of literature; a positioning of this literature; a positioning of oneself; and moral and socio-political contexts. Incorporating a reflexive approach requires the researcher to signpost to readers ‘what is going on’ throughout the research process so that readers will be able to “travel easily through the worlds of the participants and makers of the text (the researchers) and decide for themselves whether the text is believable or plausible” (Koch & Harrington, 1998, p. 887).

Throughout this research journey I was consciously aware of the impact my own prejudices and pre-understandings may have on my emerging understandings and interpretations of the phenomenon. I gained a deeper awareness of my own understandings and positioning in regard to my experience of the phenomenon through my journal writing and conversations with my supervisor. This emerging awareness enabled me to be clearer in my thinking and more open to new insights and understandings.

3.7 Conclusion

This chapter has outlined the philosophical underpinnings of this study and the reasons for choosing phenomenology as my research methodology. This chapter has also outlined the research design for this study and discussed the ethical considerations and methodological rigour that have guided this study.

Having explained the research methodology and research design for this study I will now in the following four chapters share the findings and discuss these as they relate to the research methodology and to previous literature. Finally some recommendations for practice and future research will be provided.

CHAPTER FOUR: FINDING THEIR OWN WAY

The next three chapters of this thesis uncover the themes that have been identified as describing the phenomenon that is the lived experience of providing nutrition to a child with global developmental delay. Seven mothers were interviewed for this study and three essential themes have emerged that capture the essence of the mothers' experiences: 'finding their own way', 're-branded water' and 'just getting on with it'. Within these three themes several sub-themes have been identified which help reveal the meaning of the mothers' experiences. The mothers' stories are shown and interpreted using van Manen's (1990) four existentials: lived space (spatiality), lived body (corporeality), lived time (temporality), and lived other (relationality). Van Manen (1990) suggests that these four existentials describe the fundamental nature of being human. While these existentials can be distinguished and separated in writing, in everyday life they overlap and cannot be separated. "They all form an intricate unity which we call the lifeworld – our lived world" (van Manen, 1990, p. 105).

Van Manen's work, as discussed in Chapter Three, is drawn from Martin Heidegger (1889-1976) and his study of the origins and dimensions of existence in the human world (Crotty, 1998). Heidegger describes our existence as being embedded in a meaningful world of particular relationships, practices, language and culture and he called this existence 'being-in-the-world' (Leonard, 1989). 'Being' is fundamentally 'being-in-the-world' where everything encountered in our everyday experiences has an implicit meaning. Extracting meaning from the mothers' everyday experiences of providing nutrition to their child requires an appreciation of what it might be like to *be* the mother of a child with global developmental delay; an appreciation of what 'being-in-the-world' is like for these mothers. The first theme 'finding their own way' uncovers the experiences of the mothers in looking for help in addressing their child's feeding challenges.

4.1 Introduction – Finding their own way

The theme of 'finding their own way' uncovers the 'journey' the mothers found themselves on; a journey that would see them 'seeking help' with their child's feeding

challenges; a journey that would see them ‘feeling let down’; and a journey that would see them realising they had to ‘own this’, ‘take action’ and start searching for their own answers. The mothers have had to navigate an unfamiliar path with no signposts, no guides and no map; they have had to ‘find their own way’.

The mothers had started out their ‘journey’ with an underlying expectation that they would get the help they needed with their child’s feeding challenges through the health professionals involved in their child’s care. They weren’t necessarily expecting a significant amount of practical help, but they were expecting some guidance, at least, about what they should do. Without guidance the mothers have experienced feelings of being ‘lost’ and ‘alone’ in their journey. A bit like the feeling you might experience if you were to suddenly find yourself in a foreign city with no guide or no map. How do you navigate where you are going in the absence of a guide or a map? Which way should you turn? Should you stay away from the side streets? Will the main streets be safer and perhaps provide some familiarity? What should you pack for a journey where you have no clue where you may end up? As you wander around feeling ‘lost’ and ‘alone’ might you stumble across a signpost that provides some direction? Will the path eventually become a bit clearer? The mothers could not have known at the start of their journey just how much their path would end up being shaped by their own personal efforts: ‘finding their own way’. In this theme of ‘finding their own way’ there are three parts: seeking help, feeling let down and taking action.

4.2 Seeking help

Sarah was the first mother I interviewed for this study and she asked me at the start of the interview if I wanted her to begin by telling me about her experiences with her son right from when he was a newborn baby. For Sarah, this is where the journey with her son’s feeding challenges had begun. This was not the case for all of the mothers. For some, the journey didn’t begin until later on when feeding problems became apparent as they weaned their child onto solids. For others, their child had some additional complex medical conditions that contributed to difficulties with their feeding. This meant the mothers sought help with their child’s feeding issues at different stages of development and from different areas of expertise within the health

profession. For the mothers 'seeking help' became a path in their journey as they developed a growing awareness that all was not well with their child. They had a sense of unease about their child and a feeling that circumstances had gone beyond what they could manage themselves. Their path was becoming unfamiliar and not well signposted; they were struggling to 'find their way'.

Sarah sought help from a breastfeeding consultant when she began experiencing difficulties with her newborn son who had trouble breastfeeding and regurgitated and vomited after every feed. The breastfeeding consultant suggested that Sarah feed her son expressed breast milk from a cup rather than from her breast, which for a period of time Sarah did, later moving him onto a bottle. She was however determined to establish breastfeeding so persevered with this while her son continued to suffer with the regurgitation and vomiting. Eventually, not feeling like she was making progress, Sarah talked to her general practitioner (GP) to see if there was anything that could be done to help her son. Her GP advised her that there was nothing that could be done and that she should just continue on with what she was doing. Sarah recalled how she was feeling:

So I just thought okay, I'll take this health practitioner's advice and I'll just get on with it. Still being a first-time parent, not really understanding that my child was abnormal in any way; I thought that parenting was just quite a lot harder than I was expecting it was going to be.

As a first-time mother Sarah had no practical way of knowing what was *normal* and what was *not normal*. She talked of finding parenting quite a lot harder than she was expecting which suggests that Sarah had some basic understanding of what caring for an infant would be like. Heidegger (1962) argues that we always begin with some kind of understanding of the world and how to go about things, even if it is not well worked out and even if we are presented with things that we do not understand. We may not always know what to make of certain circumstances that are presented to us; however, it is our encounters with these things or behaviours that lead to further understanding. Understanding therefore, has what Heidegger (1962) calls a 'fore-structure'. That is to say, we have some understanding to begin with and that *opens*

the way to better understanding (Greaves, 2010). As Sarah was a first-time mother her fore-structure of parenting was most likely based on her experiences and encounters with other parents and mothers, perhaps family and friends in her life whom she had witnessed becoming parents. Her fore-structure was most likely based on what it might be like to raise and care for a typically developing child. Her fore-structures of feeding an infant, again, may have been based on her experiences and encounters with friends and family whom had become parents. Sarah found herself questioning why her experiences with her newborn son were not in keeping with her fore-structure of understanding. But then how could Sarah have possibly had any foreknowledge of what feeding an infant with the feeding challenges typical of a child with global developmental delay would be like? Sarah didn't even know – to use her words – “*that her child was abnormal in any way*”. Also, in Sarah's fore-structure of parenting, how could she have had any foreknowledge of what support and advice she should expect to receive from health professionals in relation to her newborn son? Sarah's circumstances were *opening up the way* to a greater understanding of what parenting and feeding an infant could be like, or for Sarah – was like. This challenged her perception of motherhood – her fore-structure of understanding. She questioned whether her perceptions of motherhood had just been distorted and she now had to face up to the harsh reality of what the experience of parenting an infant was really like. Despite this call to reality, Sarah couldn't help but feel that her son's constant regurgitation and vomiting surely mustn't be *normal*. Her knowledge of the problem at this point however, was limited to the information she was being provided by her son's health professionals. Sarah's GP had reassured her that there wasn't anything that could be done to help her son, so Sarah had little choice other than to accept his advice and ‘just continue on’. Despite ‘seeking help’, Sarah's path was still unfamiliar and not well signposted. She felt like she had turned down a side street, still without a map, still without a guide and with no clue about where she should turn next. ‘Just continuing on’ took on a whole new meaning for Sarah as she became more tired and exhausted as the days and weeks went by. She explained:

Along with feeding him from a bottle I was very keen to be able to breastfeed him, as you try to do. So each feed I would first try to breastfeed him because I hoped he would learn and when he was unable

to do that I would give him a bottle and then after that I would express my own milk for the next feed. So every feed for this little baby actually for me was three feeds – trying to breastfeed, bottle feed and then expressing my own milk for the next feed. So as you can imagine I was pretty exhausted by this whole situation and I also had a child who was vomiting up every meal. So it wasn't so good. Experience as a first-time mum was pretty tough.

Rather than *enjoying* motherhood, Sarah felt it was something to be *endured*. The days felt endless and the weeks monotonous. Van Manen (1990) talks about time appearing to speed up when we are enjoying ourselves, or slowing down when we feel bored or anxious about something. According to van Manen (1990) “lived time” is “our temporal way of being in the world” (p. 104) which means it is related to our inner perception of time in contrast to actual time. Within this concept of “lived time”, Sarah’s experience of being-in-the-world of early motherhood was one of time seemingly slowing down and the days and weeks growing longer and longer. ‘Seeking help’ for Sarah was an experience of still *not knowing*. There were no signposts on her path; she had no guide and no map; she must ‘continue on’ and see if she could ‘find her own way’.

Moira’s experience of early motherhood was similar to Sarah’s. Moira joked that she used more nappies on the top half of her daughter, for her daughter’s reflux and vomiting, than she did on the bottom. One day her daughter refused to eat and Moira, not knowing if there was something medically wrong with her, sought help from her GP and Plunket¹ nurse. Moira was told not to worry about things and that her daughter would eat when she was hungry. Moira reflected that she now believed this was when her daughter’s autism set in. A diagnosis of autism was a relatively rare phenomenon at the time Moira’s daughter was growing up and she wondered if it might now be picked up earlier in children exhibiting eating behaviours such as her daughter’s. She explained:

¹ Plunket is a New Zealand not-for-profit, community-owned and governed organisation that provides free parenting information, support and developmental assessments for children under the age of five.

Yeah she just stopped and I often wonder whether because she's autistic as well as having a global delay, I wonder whether that was when it kicked in. I don't know. Nobody seemed to know very much about autism or anything; when she was diagnosed that was kind of the beginning in New Zealand of autism awareness. Because we're like two decades behind Australia and also being a girl, they never used to think it could be autistic related.

Like Sarah, Moira's fore-structure of understanding of what parenting an infant would be like was very much called into question as she struggled with her daughter's feeding challenges. Without *knowing* that something was wrong with her daughter Moira had little choice other than to 'just continue on'. Her daughter's eventual diagnosis of autism finally opened up some new understandings for Moira. She now had something to relate her past experiences to, and some explanation for the difficulties she had experienced with feeding her daughter. Although it perhaps felt somewhat a little too late for Moira, it was helpful to finally have a diagnosis for her daughter and a greater understanding of her feeding challenges. Finally *knowing* what she had been dealing with.

Unlike Moira, some of the mothers had a diagnosis of their child's primary condition shortly after birth and were in a different realm of 'seeking help' for feeding difficulties. They had some foreknowledge of the lay of the land – so to speak – albeit still tempered with much uncertainty. Robyn was one such mother. She was facing great difficulties feeding her son through his mouth and for infants in this predicament a decision has to be made about when to move forward with assisted feeding. For Robyn this decision was made when her son was ten-days old, and so began her journey of feeding her son initially via a nasal gastric tube and then via a mickey button. At the age of four Robyn's son was still unable to orally take food and Robyn was receiving in-home care to encourage her son to develop an interest in food and eating. She recalled her experience with her son's speech-language therapist who used many different approaches to try and help her son overcome his feeding challenges:

So things are not getting any better and he's not eating and we've got this speech-language therapist who is trying her best but kind of chucking everything at him. It felt like every week we were trying a new approach and it's really hard to have someone come into your home every two weeks and say "Try this" and it just doesn't work and she comes in all bright and bushy eyed and goes "How did it go?" I carried a bowl of pumpkin across the room towards him to try and entice him and he looked at it and it got him gagging and heaving at the look of a bowl of food and it's an appalling thing...I'm really, really fond of this speech-language therapist that's coming but she's lost. She's not succeeding, he's beginning to resent her now ... she was a lovely woman but in all fairness she didn't make a jot of difference despite all her best efforts. She didn't make a jot of difference to his life and that's really hard to say because I know she tried so hard.

While Robyn acknowledged that although her son's speech-language therapist was doing everything within her professional capabilities to try to help her son, she was feeling frustrated that nothing seemed to be working. She was frustrated at *not knowing* what she, or anyone else, could do to help her son. Was her son's speech-language therapist also feeling frustrated *not knowing* what to try next? Equally, were the other health professionals involved in her son's care frustrated that they also *did not know* what else to try next? Even with a diagnosis of her son's primary condition there remained so much uncertainty and almost a lack of knowledge on how to proceed. Robyn had asked for help and along with that had expected some answers – a solution to her problem. She had maintained a confident expectation of a positive outcome. When this positive outcome didn't eventuate, Robyn tried to make sense of why this was so. Part of expecting a solution is being offered information and explanations and there didn't seem to be any explanations. Robyn, feeling that things were not progressing as they should, began to ask questions of her son's health professionals regarding certain aspects of his care. One issue she was particularly frustrated about was that, without any explanation, her son was not being provided with the feeding equipment supplies that were recommended in the manufacturer's guidelines. She explained:

So we were at loggerheads because I was saying to them “You know the manufacturer’s guidelines are a fresh bottle every day,” and they would give us the tubing and the tubing is impossible to clean out but you know you just felt like the supplies were being eeked out and that you were a troublemaker. You were very clearly a troublemaker to ask for a fresh bottle for my child every day. I was a real nuisance and you know it was all like, “Where are you going to store all this stuff when we bring it around?” There was just a real edge to everything. In all of my dealings with the nurses because whenever you question people in authority... “Why can’t we have a bottle each day when the manufacturer’s guidelines state that?” Then you are putting those guys up against their bosses and their budgets and their way of doing things and it just creates tension, and you are not supposed to answer back. So there is this constant thing about how these people have to be in your life, they have to come into your home when you don’t want them...

Robyn talked about there being a “real edge” to everything. What did this mean for Robyn? An ‘edge’ can be described as an area next to a steep drop such as ‘the cliff edge’, or the point immediately before something unpleasant or momentous occurs (Oxford English Dictionary, 2011). Did this ‘edge’ to everything make Robyn feel like she was perhaps standing at the cliff edge? Was Robyn starting to feel unsure about what was going to happen next? Perhaps she was feeling unsafe being so close to the edge; unsafe because at any given point something unpleasant or momentous could occur; unsafe in having to trust these health professionals who were essentially strangers coming into her home and telling her how best to manage her son’s care. Baier (1986) describes trust as letting other persons take care of something the truster cares about, where such “caring for” involves some exercise of discretionary power. Robyn had little choice other than to invite these health professionals into her home with the expectation upon her that she would accept their decisions, follow their advice and ‘not answer back’. Perhaps ‘not answering back’ would have made Robyn feel safe for a period of time but would she have inevitably been driven by her instinct as a mother to raise questions of her son’s care?

Robyn also spoke of feeling resentful at having to have these health professionals in her home and her 'space'. Van Manen (1990) speaks of home as a place reserving a very special space experience. Our experience of our home space is linked to the fundamental sense of our 'being'. "Home is where we can *be* what *we are*" (van Manen, 1990, p. 102). Heidegger (1971) describes home as that secure inner sanctum where we can feel protected and 'by ourselves'. What had the feeling of 'home' come to mean to Robyn? It was no longer a place where she could be sure of being 'by herself'. Her 'space' was now being shared with the comings and goings of these people – health professionals – whom she would have much preferred were not in her life. Perhaps if some progress were being made with her son's feeding challenges Robyn may not have developed this deep resentment of the invasion of her space. With her growing disappointment Robyn was heading towards the 'edge'. She was losing faith in her son's health professionals. Robyn experienced this as 'feeling let down' or perhaps as being about to 'fall over the edge'.

This feeling of being 'let down', which will be discussed as the next sub-theme, was a pivotal point in the journey of the mothers. The mothers had started out with an underlying expectation that they would get the help they needed for their child through the health professionals responsible for managing their care. This included help with their child's feeding challenges. When the mothers did receive advice they trusted not only in the accuracy of that advice but also in the health professional delivering it. It was frustrating for the mothers when they continued to see a lack of progress being made with their child, and when the advice or help offered to them was inappropriate or ineffective.

4.3 Feeling let down

As time went on the mothers began to recognise more and more issues with their child's diet and eating. Most of the children went on to have extremely limited diets with aversions to certain tastes, temperatures, smells and textures of foods. Krista recalled that it took her some time to realise that her son wouldn't eat any food that had been touching another food, and even longer to realise that the only foods that he was eating were white in colour. The mothers spoke about their experiences in looking for help with their child's eating and their subsequent disappointment at the

lack of practical advice and support that was available to them. Judy talked about her experience with her son's paediatrician and how she had come to only expect a script for his attention deficit hyperactivity disorder (ADHD) medication and no practical advice about how she might improve his extremely limited diet. She explained:

They can only prescribe ADHD medication and ask me to get him to eat healthy food. They wouldn't emphasise too much on alternative medicine or gluten, casein free or any other kind of diet. If I talk about it she says, "Yes you can try it". It works for some people; it doesn't work for some people. So she's quite good but she wouldn't suggest it if I hadn't brought it up. Really fast with five or ten minutes with her appointment. "Anything else?" I don't know if there's anything else so I say, "Nothing else." And that's it. And they say give me a call. Once a year we get this. There's really nothing else actually.

Judy had started out her journey with her son with an expectation that her son's paediatrician would be in a position to offer practical advice and support as to how she might go about making changes to her son's diet. She had trust that her son's paediatrician was capable and motivated to help her. Govier (1992) talks about having trust in another person as being an attitude based on beliefs and expectations about what others are likely to do. "When we trust others, we expect them to act in ways that are helpful, or at least not harmful to us. We have a sense that they are persons of integrity, persons capable of reliable action, persons well motivated, with proper concern and respect for others" (p. 17). The somewhat dismissive experience that Judy talks about with her son's paediatrician led her to the realisation that she really was 'on her own'. There was a realisation that if she wanted answers, she would need to find them for herself.

Sarah also talked about the lack of practical advice and support she received from her son's paediatrician with regards to her son's diet. She talked about her frustration that despite seeing this paediatrician for a number of years, he never mentioned anything to her about some children responding well to a gluten-casein-free diet. Sarah had gone to great lengths to educate herself about the gluten-casein-free diet and had successfully managed to transition her son onto the diet. When Sarah told the

paediatrician about the positive impact the diet had had on her son's development he commented that if all parents of the children under his care gave their child a diet such as Sarah was giving her son, then he wouldn't need to see some 40% – 60% of them. Sarah was at a loss as to why her son's paediatrician had not shared this information with her sooner, particularly given the time and effort she had put in to educating herself about the diet. She explains:

So I found that quite astounding that he knew this information but he had never passed it on to me and I could have chosen to get very cross about that because we'd been coming to see him for a number of years for help with our son and it took me finding the information for myself and telling him about it for him to say, "Yeah, yeah, yeah, yeah, yeah. That's great." So I don't know how I feel about that.

Sarah struggled to find the words to verbalise how she felt about her son's paediatrician having not shared this information with her. She initially talked of finding it 'astounding' which the Oxford English Dictionary (2011) describes as synonymous with: astonishing, shocking, bewildering, disturbing and unbelievable. When someone is 'shocked' it can be difficult to find the right words to express how that feels. Sarah had always found her son's paediatrician to be helpful and supportive and over the years she had come to trust and rely on his expertise and advice. What Sarah had not expected was for him to have information that might help her son but completely neglect to pass it on. For her, this was 'astounding'. Why had he not shared this information? Was it because she had never specifically asked for dietary-related advice for her son? Was it because, as a health professional, he was only concerned with evidence-based interventions as opposed to anecdotal interventions, such as special diets? Was it because he felt that nutrition was outside his realm of professional expertise? Irrespective of the specific reason *why*, Sarah had trusted her son's paediatrician and thought that any information he had that may have been of help to her would have been shared with her. She had been under the belief that he was as committed to finding ways to help her son as she was. The collaborative relationship she thought she shared with her son's paediatrician had been tarnished and Sarah felt more 'on her own' than she had perhaps ever felt before. I wonder whether this experience made Sarah more consciously aware of the

possibility of being ‘let down’ or ‘unsupported’ by someone whom she trusted. Has the notion of trust taken on a whole new meaning for Sarah?

Like Sarah, Krista’s story was also one of feeling unsupported and not knowing whom she can trust. Krista had the double task of not only trying to improve her son’s diet, but also the need to help him lose some weight. She approached her son’s GP to ask if it would be possible to enlist the help of a dietician. She explains:

I did ask my GP about seeing a dietician and he did say he’d put me on the hospital waiting list but...it was about 18 months long, but I still haven’t heard back from that and eventually you just get sick of chasing it up, like it took us 18 months to get a diagnosis then it took us 18 months to get Ministry of Ed help for school and you’ve only got so much time and energy and you just get sick of chasing up everything, so I haven’t chased that up to try and get more help for him.

Subsequently, in an appointment with her son’s paediatrician, a diagnosis was made based on her son’s body mass index that he was overweight. The paediatrician prescribed a Green Prescription² to her son in an effort to get him eating better and exercising. Krista initially felt grateful that her son was at last getting some much-needed support; however, things didn’t quite work out as she had hoped. The nutritionist who was assigned to address her son’s diet had no prior experience of the feeding challenges experienced by children with global developmental delay. Krista’s son had significant aversions to the smell and texture of food, and anxiety issues around food and eating. The nutritionist gave Krista a meal plan for a typically developing child and suggested she make adjustments as she saw fit. Krista did not find this particularly helpful. She also felt frustrated and ‘let down’ by the lack of follow-up on her son’s progress. She explained:

Apart from the two meetings I’d had with the guy where he’s spoken to me a bit about nutrition, according to him with the Green [Prescription], we’re meant to have half a dozen meetings over the six months and there

² A Green Prescription is a New Zealand health professional’s written advice to a patient to be physically active, as part of the patient’s health management. The Green Prescription programme is a nationwide partnership between general practitioner groups and the New Zealand Ministry of Health.

were quite a few things he was going to post to me and I've rung three or four times, I've emailed and I haven't followed up because I never heard back about the booklet he was going to send out and the links for the food and exercise and stuff.

Krista felt like she was continually being 'let down'. She wondered why it was so hard to try and get help for her son. She was doing everything within her power to access the services she felt her son needed in order to help him with his weight but felt like she was hitting a dead end at every turn. Krista perceived this as a lack of concern from health professionals that her son was overweight and perhaps also felt a lack of respect for her efforts as a mother in trying to seek help. She was tired of being placed in the position of having to constantly ask for things and chase everything up. Nobody seemed to care, or even listened. Despite all her efforts in trying to get help for her son, Krista was left once again feeling 'unsupported' and 'on her own'.

In contrast to Krista's situation with a seeming lack of concern or help for her overweight son – the situation can be quite the opposite for parents of a child who has been diagnosed as failing to thrive. Parents can be subjected to considerable pressure from health professionals to ensure their child gains weight. This experience was part of Robyn's journey. The health professionals monitoring her son's progress had advised Robyn that she needed to increase the number of feeds and also increase the amount of food she was feeding her son via his mickey button. Robyn initially went along with this advice but as time went on she started to feel more and more uncomfortable with this forced rapid weight gain. She felt that it was not helping her son developmentally, particularly as he had poor muscle tone and was having difficulty supporting the additional weight he was gaining. She explained what happened when she made the decision to cut down her son's feeds and let him progress at what she felt, as his mother, was a more natural rate:

So I decided that we ought to cut his feeds down and we got into a lot of aggravation with the dietician over this but I say, look at my daughter, look at the pictures of her when she was a baby and look at Toby and I find it actually distressing to look at baby photos. He just looks like

these big, fat, rolls of fat baby with big pouchy cheeks.... So we started feeding him according to his own desires. He did lose weight, which everyone kicked off about, but he looked normal... his energy levels went up and he could move better, but it was amazing how much of a struggle it was to be trusted as a mother. Not a first-time mother. To say that this is what's right for my child when we've got a nutritionist and dietician who most of the time are doing this over the phone and going via the [children's community nursing service] weighing records. So I found that I was becoming really distrustful of the medical profession.

There was an underlying expectation that Robyn would trust the professional advice that was given to her, but there was no reciprocal trust in her instincts as a mother, bearing in mind also that Robyn was not a first-time mother. She was not comfortable with this force-feeding approach and also felt it was time to consider weaning her son off the elemental formula. She consulted an overseas expert on weaning tube-fed children onto 'real' food and made the decision to try this approach with her son. She explained how she started including some 'real' food in her son's formula:

We started putting a tablespoon of puréed apple in or baby rice. All these things; watching very carefully; recording the whole thing because I knew I would be under scrutiny for doing this.

I asked Robyn if she had informed her son's dietician of her decision to do this. She explained what happened next:

Yeah, and then she told [the children's community nursing service] and they withdrew all of our supplies, everything. So we had nothing to feed him with. So we had to import stuff from Europe... The dietician had said to the [children's community nursing service] deliberately not to support me, that she wasn't going to support me, but at the same time she wanted to know what I was doing.

Robyn did not toe the party line. Her actions in standing up for her beliefs and instincts as a mother had essentially resulted in all support being withdrawn. If Robyn hadn't already realised it, she realised it now that she was 'on her own'. I

wonder how Robyn must have felt to not only have her son's feeding supplies taken away but also her entire support network; simply because she had chosen to start feeding her son some 'real' food – an approach she had researched extensively and consulted overseas feeding experts on. I wonder if Robyn experienced this as a lack of respect for an intelligent, informed individual and mother who knew the risks and benefits of what she was doing but was prepared to try something new to help her son? It appears Robyn's expertise as an informed individual and an experienced mother was neither heard nor supported. The consequences of seeking help from other sources and implementing an intervention that was beyond the realm of knowledge of the current service was for support to be withdrawn. The paradox here is that although the dietician refused to support Robyn she still wanted to maintain a high level of surveillance on her.

Maxine also spoke of feeling disappointed in her experiences with her son's health professionals. She talked about how for her, it was the 'village approach' – family and friends – that filled this gap:

Not practical support, no. Not people that actually come in and are effective and do it and they're professional and follow through. It's all fragmented. Everything we've had, we've had to fight for....A lot of it is around just sharing, speaking with girlfriends that have got disabled kids. Just networking really, and trial and error and gradually introducing change. Just doing it sensibly. It's our friends mostly that make it. They're just really good friends. I think that makes a difference because they've always helped as well, and supported, but it's a village. It's not the government that is doing it; it's the locals and the parents of other kids. They're the ones that muck in and support you and share information.

There is an African proverb that is commonly used to highlight what it *is* to raise a child: "it takes a village to raise a child". Parenting is not something one can easily tackle alone and parenting a child with global developmental delay comes with significant challenges. The mothers had to find out where they could go to get some

much-needed help and support with their child. The mothers had to create their own ‘villages’.

The feeling of ‘being let down’ was something the mothers often became emotional about. Robyn talked about *“hitting a brick wall with people not willing to help”* and described some of her experiences as the *“battles I have been through”*. Maxine summed up her journey of trying to get help with her son by saying *“everything we’ve had, we’ve had to fight for”*. The mothers’ expectations about the level of care they would receive for their child and their confidence in a positive outcome had left them disappointed and frustrated. For some of the mothers this had led to a distrust of the medical profession. Coming to the realisation that they were essentially ‘on their own’ was not something that happened overnight. It was rather an on-going experience of having asked for help but not receiving it, or having asked for help and the help offered being inappropriate or ineffective. The experience of the mothers in ‘feeling let down’ was the catalyst for them in ‘taking action’ and looking for their *own* answers to try and help their child.

4.4 Taking action

“When you walk to the edge of all light you have and take that first step into the darkness of the unknown, you must believe that one of two things will happen. There will be something solid for you to stand upon or you will be taught to fly.”

(Overton, 1975, p. 85)

The mothers had reached the ‘edge’. They had asked for help, they had fought for help, they had held out hope, they had trusted and they had been let down. Now it was time for them to take a leap of faith, forget all that had gone before, and start looking for their *own* answers. The mothers had realised they needed to ‘own this’ for themselves. They could have chosen to just continue on as they were but their overwhelming desire to help their child didn’t make this an option. As time went on the mothers came to be well educated about their child’s feeding challenges, constantly searching for new information. One mother had put so much time and effort into searching for answers that she made the comment *“there isn’t much I don’t know about autism now”* (Moir). Personal time and effort was one aspect of searching for answers, another was the financial cost in doing so. Some of the mothers and their families had faced a considerable financial burden in trying out interventions with their child.

Sarah’s search for answers led her to anecdotal evidence that suggested a gluten-casein-free diet could be beneficial for some children with global developmental delay. With much perseverance she went through the difficult process of transitioning her son onto this new diet. She managed this transition with very little support apart from some limited input from a naturopath that she and her husband privately funded. Her frustration at having to go to such great personal lengths to find something that would help her son was still evident:

I don’t have to get emotional and upset about this anymore because I’ve talked about it so much and I’ve got past this. If you’d talked to me a couple of years ago I would have been a mess telling you about these things. I feel happy now because we’ve found our own way through the difficulties that we had.... It’s been a very bumpy journey, yeah. Very, very bumpy but I’m really pleased at the point that we’ve got ourselves to

now and the point that we've got ourselves to now has been through absolute dogged determination on my and my husband's part to find out how we can help our child. And we have just refused to give up, and thank goodness for our family, we have managed to find some really good answers along the way.

Despite Sarah saying “*she doesn't have to get emotional about this anymore*”, her experience of having to essentially ‘go it alone’ and ‘find her own answers’ is something she can never forget. Sarah may have *chosen* not to dwell on her experience, or get emotional about it anymore, but this past experience will always be there in the back of her mind. Van Manen (1990) talks about how whatever we have encountered in our past sticks with us as memories that somehow leave traces on our being. Or, as described by Large (2008) in his interpretation of Heidegger's work in *Being and Time* (1962): “Our past is not external to our present, but belongs intimately to it. We live the past through the present, and the present through the past” (p. 12).

In reflecting on her journey Sarah talked about how she realises that not every family is in the position to go to the lengths that she and her husband did looking for ways to help their child, and how she hoped that medical professionals may at some point be in a position to take a more proactive role in offering support to families:

I feel grateful that I am a person who was able to do a lot of research and pull a lot of information together from a lot of different places in order to come to the conclusions that I've come to about the diet that we've implemented. I don't want to blow my own trumpet too much but there would be a lot of parents who wouldn't be able to bring that information together for themselves and I would hope that, I would love to see, that trusted medical professionals would be able to bring that information together for them and make those types of recommendations for just your normal everyday parent who is struggling like I was.

For parents who feel like they ‘do it alone’ and ‘find their own way’ there is a question mark over whether other parents would be able to take on this challenge. Part of ‘finding their own way’ was through knowledge. Like Sarah, Judy was

constantly searching for ways to try and help her son. She talked about how she keeps attending courses, sometimes on a weekly basis, in the hope that she might come across something that could be helpful. She explained:

I just keep attending courses. I attended a course last week. It's run by a Chinese doctor; I didn't get much out of it because it's all spoken in Mandarin and they had all the organs pronounced in Mandarin. That is the worst; I can have a normal conversation but then the nouns and the jargon – that's like what is that? What do you call that in English? Is that the liver? I don't know but I just try to put things together. That's what she talked about a lot; meat is difficult for them to digest because they have weak guts. Vegetables are better. What kind of vegetables are they looking into? They are talking about fish as well, whether it has a lot of mercury. I'm pretty sure it's mercury because I've heard about that. They call it another Chinese word. Mercury and something else, is it lead?

Although Judy attended these courses in the hope of gaining new knowledge, she still had to make sense of it all. With more knowledge and information often came more questions rather than answers. The search for answers can begin to feel like a 'journey' that might never end. Robyn's search for answers to help her son had her at the computer in the early hours of the morning, trawling through the Internet, unable to sleep. She had reached a point where she felt she had exhausted all her options with the health profession in New Zealand – nothing seemed to be working – so she had started to look abroad for information on how she could help her son with his eating. She explained:

I had virtually stood on my head; I'd argued with them [health professionals]; I'd done all of the things you aren't supposed to do; I'd done all of the things that you are supposed to do. You can't really guilt trip a child with Down's syndrome if he's two-years old but I mean if I could have done I would have done. I would have done anything and I wasn't used to not being able to get things right, you know? It was

hideous, it was really hideous. And then at three o'clock in the morning, this is how obsessed I was, I was trawling through the Internet.

Robyn's trawl through the Internet led her to a blog written by the mother of a child with a similar condition to her son's. This mother had successfully sought help for her son's feeding issues from a specialised feeding clinic in Austria. Over the following months Robyn and her family undertook the difficult task of raising the funds required to travel to Austria, such was their motivation and determination to try and help their child. It was a difficult journey but they finally received the help they needed and their son began eating.

Motivation and determination were two key attributes that seemed to be at the core of everything the mothers did and every decision they made. They demonstrated determination beyond persistence in looking for ways to address their child's feeding challenges. They were driven by their overwhelming desire to make positive improvements in their child's diet and health. Sarah spoke of her motivation for never giving up on looking for answers. She talked about how improving her son's life also improved the lives of the whole family:

Motivation came from the fact that our life was really difficult with our son. It was really, really difficult right from when he was born and I wanted to try and find out if I could help him and by doing that help all of us. So my motivation came from the fact that our family life was so tough and I wanted to change that. And I suppose I also dreamed of more for my son. I dream of a normal life for my son and I suppose it's only a parent that can feel that and feel the motivation that that gives you. Your child's future is worth whatever you are able to give and for us we'll do anything to have a healthy family. Our son's difficulties have cost us very, very, dearly emotionally and financially and that's just how it has turned out.

In the parental experience of raising a child van Manen (1990) talks of the sense of "lived time" in the modality of hope which a parent cherishes for their child's happiness and becoming. "And we experience a sense of lived time in the child's desire to become someone himself or herself, to live for something and to create

personal meaning in life” (van Manen, 1990, p. 105). Sarah dreamed of a *better* life for her son; a life that was more *normal*; a life where he might have the opportunity to make *something* of himself. This motivated her to do whatever she possibly could to support her son towards a better future. In doing so she knew that life would be better for the whole family.

4.5 Conclusion – Finding their own way

This theme of ‘finding their own way’ uncovered the lengths the mothers would go to in their search for answers. Their desire to find something that might help with their child’s feeding challenges motivated them to continue on with what was sometimes, a very difficult journey. The mothers wanted and dreamed of more for their child and strived for any positive change, no matter how small. This next theme ‘rebranded water’ continues to show how determined and motivated the mothers were to make changes to their child’s diet and to manage their feeding challenges.

CHAPTER FIVE: REBRANDED WATER

5.1 Introduction – Rebranded water

The title of this theme came from Maxine, a mother who was desperately trying to find a way to get her daughter to drink water. A commonality that a number of the mothers talked about was their child's reluctance to drink water, or as one mother described it, "*she just doesn't do the thirst thing*" (Moir). Maxine's 'rebranding' of water involved presenting water to her daughter in miniature glass milk bottles, with a sprig of mint. Prior to doing this Maxine had struggled to get her daughter to drink water. Maxine described this new approach as a "trick": "*You use every trick you're told. That's one of them – presentation of drinking water*" (Maxine). Similarly many of the mothers spoke of their child's reluctance to try new foods and the resistance they faced when encouraging their child to accept food with different textures or a different colour. Their children's food aversions, intolerances and sensory processing issues meant that the 'rebranding' of food was often a very difficult and delicate process.

The mothers found themselves having to constantly look for ways to work around their child's feeding challenges. Their efforts were concerned with changing the focus or direction of particular aspects of their child's eating or eating behaviours, in order to make some improvement to the child's diet and health. The general approach the mothers took when it came to 'rebranding' food was to take an already accepted food, add to it nutritionally, and hope that their child would accept this new improved, rebranded alternative. This rebranding usually involved the mothers adding in nutrient-dense foods such as fruit and vegetables. The risk the mothers were taking with this approach was that their child would detect the difference in the food. This could result in the non-acceptance of the original food and in some cases non-acceptance of an entire food group. The mothers' experience of 'rebranding' is just one example of the tensions and trade-offs that became part of the mothers' everyday lives – their everyday world. This led to the theme of 'rebranded water' which is made up of three parts: utilising multiple strategies, negotiation and trade-offs, and deception/being caught out.

5.2 Utilising multiple strategies

The mothers' initial feeding efforts when their child was very young were simply focused on finding ways to provide adequate food intake. When their child was an infant they were concerned with making sure that he/she had an adequate intake of milk and was meeting growth milestones. The mothers' care and concern for their child's growth and development was a fundamental aspect of their role as a mother and nurturer. Nurturer or nurturing comes from the Latin word *nu tri tura* that means to nurse, to nourish and to promote growth. Growth and development are viewed as key indicators or milestones for a child who has been adequately nurtured or nourished. Perhaps this explains the fixation on a child's weight from the very day they are born. As the mothers weaned their child on to solid foods they became more focused on trying to understand their child's feeding challenges and identifying ways in which to include as many nutritious foods in their child's diet as possible. The mothers often made the comment that they were trying to achieve a 'well-balanced' diet for their child. What constitutes a 'well-balanced' diet can mean different things to different people. When considering what this means in the context of parenting, it is perhaps tied up with what it is to be considered a 'good parent', providing healthy nutritious food to your child in order to nurture their growth and development. For the mothers in this study, it was about including as many nutrient-dense foods in their child's diet as possible such as: fruit, vegetables, and good quality protein; and limiting processed foods high in fat, salt and sugar. This was often difficult for the mothers as their child's food preferences, aversions and intolerances came into play. Some of the mothers talked about how they found themselves manipulated by the foods their child *would* eat just to ensure that they ate *something*.

The mothers were intentional and purposeful in seeking positive improvements in their child's feeding habits, repertoire of foods and abilities over time. They made statements such as, "*I'm trying to just make sure I get enough nutrition into him as I can*" (Maxine), and "*we were kind of determined and just refused to give up*" (Sarah). These comments re-iterate the fundamental role the mothers played in the nurturing or nourishing of their child; wanting to make sure that they were providing their child with the best diet possible and their constant concern for their child's growth and development. Having experimented with some common approaches to

encourage a child to eat better, the mothers recognised that approaches and strategies that might be effective in encouraging a typically developing child to eat more healthily were unlikely to be successful with their child. The feeding challenges their child experienced in day-to-day life went far beyond that of a picky eating child. With this in mind the mothers experimented with their own approaches and strategies over time. When deciding what approaches and strategies to use, the mothers were mindful of their child's food preferences, aversions and intolerances and were guided by the adaptability they perceived they were able to achieve with their child. They had an intimate awareness and deep sense of what might work with their child and likewise what would be unlikely to work.

Maxine was experimenting with different strategies in an attempt to expand her son's repertoire of food, particularly fruit and vegetables. She talked about constantly looking for opportunities to get what she called "good fodder" into her son, and to find ways to encourage him to accept new foods. She explained:

Nutritionists come and observe what I'm doing. They've basically said you're doing all the right stuff. You are introducing new food, whether it be disguised in the old food. Just gradually try to get them to eat a whole apple. Like he'll eat apple purée now so I can get apple into him, because it's puréed so it's just looking at getting that food into him in a different form. So he gets meat, he gets iron, but it's in a soft form.

Maxine was well aware of what constitutes a healthy, well-balanced diet, or as she describes it "good fodder". Maxine's son has significant texture intolerances so Maxine had to find creative ways to cater for these. She explained:

We make a batch which is basically food cooked for hours. So it's a sloppy texture. His diet is so limited it's not funny. That's the main way we can get any food with nutritional value into him. So we put all veges, all manner of veges, you know onions, passata and olive oil and mince, a whole lot of mince... carrots, anything I've got, celery, potatoes, onions, pumpkins, baked beans, tomato sauce, mustard, Worcestershire. Just put a little bit of seasoning in it, pepper, and cook it for hours and hours and hours, until it's just mush. If the texture is hard he won't eat it. Like he's

never had a bit of steak or a bit of chicken apart from a chicken tender or a chicken nugget.... His dietary habits are really restricted and really limited and he just gags all the time, even with a batch he will gag every night.

Maxine's experience of feeding her son was one of constantly looking for 'opportunities'. She viewed the 'batch' dinner as an opportunity to at least get food of some nutritional value into her son even though with the hours and hours of cooking it ended up resembling 'mush'. Maxine described this 'mush' as having a 'sloppy' texture. It barely resembled food and might have looked more like the kind of puréed food that would be fed to an infant rather than food for a growing teenager. But what choice did Maxine have? If this was the only way that she could get food of some nutritional value into her son, then quite simply there was no alternative to 'sloppy mush'. Maxine, at one point, referred to the 'batch' dinner as a 'thing' when talking about how she tried to introduce new foods into the 'batch': *"Yeah, for instance I'll put peas in his thing instead of carrots, but they are so mushed. I mean he's never had peas, yeah"*. The 'batch' bore so little resemblance to what Maxine considered 'real' food that she could not help but think of the 'batch' as his 'thing'.

Maxine knew that due to the significant aversions and intolerances her son experiences, her options, or 'opportunities' were limited. Maxine was, in a sense, just dealing with the hand that she had been dealt and making the most of the opportunities that she had. Providing her son with some healthy food or *"good fodder"* was more important to Maxine than worrying about the fact that it resembled 'sloppy mush'. While Maxine felt constrained by the extremely limited nature of her son's diet, she found it reassuring that nutritionists had told her she was *"doing all the right stuff"*. In an everyday world filled with so much uncertainty some reassurance provided Maxine with a sense of confidence and purpose in her role as a mother. She was reminded of the tensions and trade-offs that were inherent in her mothering role and took comfort that she was at least getting something right.

In contrast to Maxine, Sarah did not feel like she was *"doing all the right stuff"*. She found herself manipulated by the foods her son *would* eat just to ensure he ate

something. Sarah was becoming concerned that her son's predominantly wheat and dairy-based diet was having an impact on his development. She explained:

So as time continued I suppose I found myself manipulated by things he would eat. So he really enjoyed, again his pasta and his bread, his sandwiches, his drinks of milk, his yoghurt, his custard, macaroni cheese, these types of food and they were smooth and easy for him to eat without choking. So they continued to be a large part of his diet and he continued to be more and more different than his peers – developmentally, not developing, as he should, delayed by more and more and more.

Sarah made the tough decision to embark on a complete 'rebranding' of her son's diet to a gluten-casein-free diet. As she gradually transitioned her son away from all his favourite foods she explained to him that the food and diet he was now eating were to make him "strong and healthy". She explained:

So we implemented this diet. So we cut out all these favourite foods, the sandwiches and the macaroni cheese and all these things and kids get a bit cross about that, but we were kind of determined.... so what we've really just called it is we say his name, you have healthy choices for your food and your food is gluten free. So we do keep it simple, we don't say gluten free, dairy free, sugar free, blah, blah, blah, blah, blah, blah. That's too hard so we just say you have a gluten-free diet and that makes you strong and healthy.... When he goes to a birthday party he will take his own food. I never imagined that I would be the parent doing that but it's fine. He's always happy with the options that I provide and he understands that that's just how it is.

Sarah never imagined being *that* parent that has to take along 'special' food for her child. Her concern for her son's health however, meant she would have done absolutely *anything* to help him. Knowing this diet was improving her son's development enabled Sarah to accept that she had to be *that* parent. Although this wasn't something she had ever expected in her role as a mother, it was now something she simply acknowledged she must do. Part of changing how she

‘rebranded’ her son’s nutrition was to strategise on how best to make the transition. She talked of ‘easing things out’ and ‘easing things in’:

I kind of eased it. I eased things out and eased things in. So just quietly over time I might serve less macaroni cheese and then all of a sudden it was gone. Then quietly over time I served less milk and then quietly it was gone and then quietly over time I would find a gluten-free loaf and offer that instead of a normal bread and sort of yeah. That’s what I’ve done all the way along. Just eased things out and eased things in and that has seemed to work really, really well.

Sarah’s experience of ‘rebranding’ her son’s diet was that of a gradual almost methodical process one of ‘easing things out’ and ‘easing things in’. To ‘ease’ is to make something (unpleasant or intense) less serious or severe (Oxford English Dictionary, 2011). Sarah was guided by her instincts as a mother to take this gentle approach of ‘easing things out’ and ‘easing things in’. She was aware that her son sought comfort in his favourite foods so she chose not to suddenly take these foods away from him. As Sarah was primarily responsible for her son’s day-to-day care, it is reasonable to assume that her son’s view of food and nourishment would be something he associated as coming from his mother. The notion of ‘food is love’ comes into play here – as a sign of her love, a mother feeds her child. This creates a deep bond between a mother and her child. Van Manen (1990) talks about the parent-child relationship as “a special lived relation to the other”, which is “highly personal and charged with interpersonal significance” (p. 106). If Sarah had not taken this gentle approach with her son she may have risked exposing him to a stressful and confusing experience where suddenly his mother was no longer providing him with that which gave him comfort – his favourite foods. Perhaps he may have experienced this as feeling unloved and this would have undoubtedly had a damaging effect on the special relationship Sarah shared with her son.

Sarah was not the only mother to talk about the comfort that her child got from food. Krista talked about the comfort that her son got from his favourite foods as possibly *the* most important thing for him: “*he doesn’t have much else in his life that gives him comfort.*” Her son’s comfort foods were energy-dense, carbohydrate-based foods:

food types not particularly suitable for a child who had been diagnosed as overweight. This placed Krista in a conflicting position as a mother. She found herself having to work amongst the tension between her desire to nurture and love: provide her son with his comfort foods, and the necessity to act in the best interests of her son's health and try to help him lose weight. Like Sarah, Krista devised a gentle strategy. She had heard that eating fruit before a main meal can aid with digestion and can also reduce the amount of food that is consumed. She explained:

What I do which is a bit sneaky, while he's engaged in an activity, I cut up his apple and give him his apple and I do that 20 – 30 minutes before dinner time because I was told that it was beneficial to try and get something into him before he ate his carbs. For some reason that helps with digestion or something. So while he's busy doing something I try to give him the apple or pear, or a piece of fruit... and anyway I will serve up his dinner when he has already had his fruit.

Krista felt that she was being “a bit sneaky” in what she was doing. Being ‘sneaky’ is synonymous with being sly, crafty, cunning, scheming, devious, conniving, deceitful, dishonest, or underhand (Oxford English Dictionary, 2011). These are strong words, and not the kind of words one would ordinarily expect to see in relation to the experience of a mother feeding her child. Krista's ‘sneakiness’ was fuelled by her desire to help her son lose weight. She was so determined to help him that if underhand tactics were required; she would happily oblige. Being ‘sneaky’ is now part of Krista's everyday experience of being-in-the-world. It is her nightly ritual. She cuts up her son's fruit and places it in a bowl and then she watches and waits. Watches and waits for the right moment. The moment when she can see her son is engaged in an activity and distracted. She knows if she gets the timing right her son will be so distracted that he will barely think twice before eating the bowl of fruit she has placed in front of him. Krista's approach to helping her son, like Sarah's, was one that was thoughtful and respectful; a nurturing but ‘sneaky’ approach that avoided unnecessary stress and pressure being placed on her son.

Both Sarah's and Krista's stories highlight the significance of the mother's role in providing nutrition to her child with global developmental delay. This showed itself

as a fundamental aspect of their mothering, or motherhood experience. The mothers had to work within the constraints of their child's specific food aversions and intolerances when deciding which strategies they were prepared to try. 'Rebranding' took on many different forms and along with 'utilising multiple strategies' the mothers also attempted to negotiate with their child in an effort to improve their nutrition. This is explored throughout the next sub-theme – 'negotiation and trade-offs'.

5.3 Negotiation and trade-offs

Negotiation occurs in many aspects of life: in business, government, among nations and in everyday personal circumstances such as marriage, divorce and parenting. Utilising negotiation as a parenting tool can come with its challenges. There are books and websites proposing to teach parents the skills to successfully negotiate with their child. Scott Brown, author of the book titled *How to negotiate with kids... even if you think you shouldn't: 7 essential skills to end conflict and bring more joy to your family*, is a founding member of the world-famous Harvard Negotiation Project (Brown, 2003). As an expert negotiator and father of four, he wrote this book because he believes parents face the same dilemmas as negotiators everywhere and he felt compelled to share some effective negotiation techniques with parents. Negotiation can be difficult for any parent, but for the parent of a child with global developmental delay it can come with another whole set of challenges. Language and behavioural difficulties can further complicate what can already be a complicated process. The mothers in this study talked about using negotiation in dealing with their child's feeding and eating challenges. More often than not it was an attempt to get their child to try some new foods or encourage them to eat more healthy foods. With negotiation came the necessity that the mothers also had to accept some trade-offs. The mothers were often tasked with the challenge of deciding when, or if, the trade-off was too great to accept.

Krista utilised the negotiation/trade-off strategies recommended by her son's Green Prescription nutritionist. One strategy he suggested was for Krista to start offering her son rewards – in the form of his favourite foods – for trying new healthy foods.

Krista started out offering her son frozen peas in return for his favourite food – pizza. She explained:

I got Liam to the point where he would eat a teaspoon of frozen peas but it took a lot of bribery and the nutritionist said, “Initially let him have his favourite food”, which is Hell’s pizza, which he is never ever allowed. He said “Let him have a slice of that as a reward for trying the frozen peas.” So for one pea he got a piece of pizza and we sort of built up to the whole teaspoonful. So eventually he would eat just an ice block or a thing of jelly for the frozen peas or computer time or an extra TV programme but that’s as far as I’ve got it to and it’s still a battle. The idea is that from there we should be able to generalise into trying other new foods, but that hasn’t been quite as successful. I think I used all my strategies and now he’s weary of them and he’s not so interested. The bribes have to keep increasing for him to try new things.

The irony was not lost on Krista that she was essentially reinforcing a *bad* food choice to her son in order to introduce a *good* food choice. Krista initially felt uncomfortable with this strategy, but at the same time held out hope that this could at last be the answer she had been looking for in getting her son to eat better, and as a result, lose some weight. Despite her perseverance Krista felt it was somewhat of a conundrum that she was managing to get her son to eat a teaspoon of peas followed by a whole slice of pizza. As time went on she soon came to realise that the bribes would have to keep increasing with the trade-off in this situation being that her son would potentially gain more weight. This was completely counter-intuitive to what Krista was trying to achieve and again the irony of this was not lost on her. Successful negotiation and trade-off situations require that the parties concerned intend to reach some understanding or resolve some points of difference. Can this be possible when one of the parties to the negotiation is a child with global developmental delay? When negotiation between parent and child is around the issue of food, can this be possible with a child with global developmental delay experiencing feeding challenges? Krista’s experience with her son highlights the tricky nature of negotiation and trade-off and what can happen when one does not have the right cards to play.

Another strategy recommended by her son's Green Prescription nutritionist was that Krista offers her son the same evening meal as the rest of the family, rather than creating special meals to cater to his aversions and intolerances. The idea being that if he didn't like what was being offered to the family then he could go to bed hungry. Krista talked about what happened if her son was hungry in the night:

If I don't feed him he'll get up in the night and steal food. He will get up. If he's hungry in the night he will go eat frozen bread out of the freezer and you know when he was little I had stuff in high cupboards but now he can reach everything. I've tried putting kiddy locks but of course he's a big boy he can get through kiddy locks. Short of buying a big locking cabinet you can't actually withhold food from a kid of his age.

The 'trade-off' for Krista in this strategy was that her son would get up in the night and steal food to satisfy his hunger. Krista realised that short of hiding all the family's food in lockable cabinets, this strategy was never going to be effective. Krista's experience of adopting the nutritionist's negotiation and trade-off tactics was one of disappointment, frustration, and once again feeling 'let down' and 'on her own'. She had begun to worry that if a qualified nutritionist couldn't help her son, then who could? Or was it that her son needed a nutritionist who had an understanding of the complex feeding challenges characteristic of children with global developmental delay? Did her son just not have the *right* nutritionist? Krista did not know the answer to these questions. She just knew that everyday life for her, battling with her son's feeding challenges, would just continue on, unchanged, the same. Her experience of the Green Prescription intervention was summed up in one word – "*ineffective*". There was no win-win situation here for Krista; she had reached a 'stalemate'.

Judy spoke of her son having similar food aversions to that experienced by Krista's son. Such was his texture and taste sensitivity that he would often reach the point where he would gag and vomit during mealtimes. Judy was concerned about the lack of nutrients in her son's diet and engaged in a nightly ritual of 'negotiation' and 'trade-off' to get him to eat his vegetables. She explained:

He really doesn't want to eat the vegetables. I still give him vegetables. He'll eat around it. Every grain of rice he'll sweep it on. I say you have to eat the vegetable, you know that, otherwise you can't go. You can't leave the table. If worse comes to worse I tell him to vomit. If you have to vomit, just vomit back into the bowl not everywhere, because we do a lot of cleaning up. So if worse comes to worse, he vomits up and I think I learned from somewhere as food goes down, the body is busy absorbing the nutrients as much as it can, so if he was to vomit up half an hour later at least some of it has already been absorbed. It's fine, I'm happy I think.

Judy's son knew he couldn't leave the table until he had eaten his vegetables. He also knew that he could vomit them back up if he had to, and commonly did. What must this nightly mealtime experience be like for him? Does he comprehend that his mother has his best interests at heart as he physically tries to keep the vegetables down? Equally, what is this experience like for Judy, as a mother? Having to watch her son go through the distress of gagging and vomiting up his food most nights, unable to do anything to help him, and with the knowledge that it is through her doing that he must endure this nightly ritual. Judy talked about how she had struggled to find ways to include healthy foods in her son's diet and was worried about the amount of unhealthy food he eats. Van Manen (2002) talks about how *worry* is "the active ingredient of parental attentiveness" (p. 264). "Worry – rather than duty or obligation – keeps us in touch with the one for whom we care" (van Manen, 2002, p. 264). He suggests that caring concern or worry is borne out of our responsibility for the other. "The more we care for a person, the more we worry and the more we worry, the stronger our desire to care. Why? Because care is worry" (van Manen, 2002, p. 270). Judy's *worry* for her son guided her as a mother to make the tough decision to endure this nightly ritual. Negotiation and trade-off had come to be part of Judy's being-in-the-world and to sustain this she had to find a way to de-sensitise herself to the negative emotions she experienced in relation to her son's mealtimes. She tried hard to accept the trade-off – "*It's fine, I'm happy I think*" – and consoled herself with the knowledge that, whatever the outcome, her son may at least have absorbed some nutrients. Judy was rationalising with herself as part of her own internal negotiation.

She knew the situation was not ideal and she wished things could be different; however, given the circumstances, she felt she was doing the ‘right thing’ as a mother.

Mothers – or parents for that matter – are not always inherently sure what the ‘right thing’ to do is, although there seems to be a societal expectation that parents should always know what is *best*, or *right*, for their child. How can it be that parents are equipped with the ability to always know what is best or right for their child? The parenting experience can be challenging, with parents having to navigate their way through a multitude of decisions on a daily basis. Can it be humanly possible to always get things *right*? I am reminded here of a quote I have seen many times: in parenting literature, on Facebook feeds and even hanging on a wall as a piece of inspirational ‘art’. This quote is about what it is to be a mother – although it can also describe the experience of parenting whether from a mother or a father: *“Motherhood is a choice you make every day to put someone else’s happiness and wellbeing ahead of your own, to teach the hard lessons, to do the right thing, even when you’re not sure what the right thing is, and to forgive yourself over and over again for doing everything wrong”* (Author unknown).

The mothers in this study had all chosen to put their child’s health and wellbeing at the forefront of their everyday life. This guided them in making decisions for their child about what they felt the ‘right thing’ to do was. The mothers found that using negotiation as a tool in trying to make positive changes to their child’s diet came with significant challenges. Things did not always work out as the mothers planned but despite the setbacks they picked themselves up and continued to look for new ways to try to help their child. Their determination was so great that they were prepared to resort to deceptive tactics if they deemed that necessary. The mothers had to live with the risk of their deceptive tactics not working out and the consequence of picking up the pieces when it all went wrong. The following sub-theme shares what this experience was like for the mothers.

5.4 Deception/Being caught out

In looking for ways to include more nutrient-dense foods in their child’s diet, the mothers talked about how they experimented with ‘hiding’ foods, such as fruit and vegetables, in foods already accepted in their child’s food repertoire. They hoped that

the fruit or vegetables would be ‘disguised’ enough that their child would not notice they were there. To ‘disguise’ something is to give it a different appearance, camouflage it, or make it unrecognisable (Oxford English Dictionary, 2011). Disguising food became a creative form of deception for the mothers. Coming from the Latin word for deceive, deception is said to occur when one deceives another. Deceive: Latin *de* – meaning “from” and *capre* – meaning “to take” – “to take from” (Ayto, 2011, p. 159). A common phrase often used to describe deception is ‘to take someone for a ride’. The deception in what the mothers were doing was not how you would view deception in its literal sense. The mothers were not trying ‘to take from’, or ‘take their child for a ride’, but rather were engaging in deception as a ‘rebranding’ tactic. They viewed it as another ‘opportunity’ to make some positive changes to their child’s diet. For this approach to work it was important that the mothers were ‘inconspicuously deceptive’. The consequences of ‘getting caught out’ could result in their child losing trust in them and the loss of foods from their child’s already limited food repertoire.

Moira’s motivation to employ deceptive tactics was to help her daughter lose weight. Moira knew this would be difficult and came up with the strategy of telling her daughter she was allergic to sugar and that it was causing the eczema on her hands to flare up. Moira explained:

The way I got around it with Megan, I told her she was allergic to sugar because she has a little patch of eczema that when she eats too much sugar, it’s like an alarm bell and it flares up. So that’s actually something that she can recognise and now if she’s sitting there going like this [scratching] I just have to go like this at her now [points her finger] and she’s like, “Oh yeah, I’ve been eating too much sugar.” It was quite deceitful but it was something tangible that she could see.

To help her daughter with her weight loss whilst still satisfying her sweet tooth, Moira offered ‘re-branded’ alternatives:

I make things like the rolled oat cookies with things like honey in them and that sort of thing and she quite likes that sort of thing, and they’re

sweet but they're not that exciting that she will eat the whole container full.

Moira acknowledged that she was being deceitful but at the same time she felt comfortable in her approach because she knew that she was doing this purely to help her daughter. Her 'rebranding' of cookies has been a successful tactic and provides Moira with a sense of satisfaction. Satisfaction that she does not have to deny her daughter the comfort and pleasure she gets from eating sweet-tasting foods. Moira has been 'inconspicuously deceptive'. Her strategy has been so successful that she no longer needs to verbally remind her daughter of the association between her eczema and sugar, she just has to point a finger at her. Although Moira knows she has not been honest with her daughter, she feels justified in her actions. All she was trying to do was help. Moira knows however, that she must always keep this little secret to herself. For the sake of her relationship with her daughter it must never be revealed.

In contrast to Moira's experience, Krista's experience of utilising deceptive tactics was not so successful. Krista had been looking for ways to include more vegetables in her son's diet and had started hiding grated vegetables in her baking. She talked about 'getting sprung' and the repercussions of her son losing trust in her:

Actually he catches me out, like I tried grating vegetables, like you know you can put beetroot into your chocolate cake, zucchini in your cakes and things, but of course one day he sprung me putting vegetables in the cake, so then he wouldn't eat my home baking anymore so that's a drama and then it takes a long time to rebuild the trust. He's always very suspicious and he did actually, when he was younger, he did actually used to eat mince and I tried very, very finely putting through the blender vegetables and stirring it through the mince and either the taste of that or the change to the texture, either way it turned him off and it's taken years. I can now get him to eat mince again but I daren't risk slipping vegetables into it again.

When I think of the parent-child relationship and the words 'getting caught out' or 'sprung', my thoughts immediately turn to a child having done something he/she shouldn't and hoping not to get found out by his/her parents. Thoughts of a mother

trying to provide a healthy diet to her child certainly don't spring to mind. For Krista 'getting caught out' or 'sprung' by her son was something she must accept in her mothering role as part of her efforts to get her son eating more healthy food. The implications of being 'caught out' or 'sprung' were significant for Krista and not something she took lightly.

Krista went on to talk about how she had successfully managed to get her son to drink fruit smoothies but made the mistake of preparing him a smoothie with a particular fruit he disliked. She explained:

The smoothies were one thing that was quite successful briefly. I was able to switch him to, but again I stuffed up. There was one fruit or flavour that he didn't like and that put him off, so now he will only have banana and Milo in his smoothies with his yoghurt.

Krista's experience of deception and getting caught out was one of feeling like a failure. She felt like she had 'stuffed up'. Of course her plan was never to actually 'get caught out,' so I wonder how Krista felt at that moment when she realised she had 'been sprung'; knowing that it could possibly take her *years* to rebuild her son's trust. Trust, or distrust, is something that can alter ways of 'being together' or 'being with'. This is particularly pertinent in the relationship between a mother and her child where 'being together' or 'being with' is such an integral part of everyday life. Mothers are faced with making decisions for their child on a daily basis but rarely do these decisions come with such repercussions. Did losing her son's trust also serve as a reminder of the fragility of her circumstances? The repercussions from something so minor being something that she must now battle to overcome; a battle that may take her *years*. Does Krista sometimes wonder whether her efforts are really worth it? Is the trade-off of getting caught out and having to battle years to re-build trust a fair exchange?

Van Manen (1990) explains how our past experiences leave traces on our being and can impact the way we carry ourselves – "hopeful or confident, defeated or worn-out" (p. 104). Does Krista experience both of these emotions I wonder? At times having the confidence and hope that something will work only to have these hopes crushed and having to accept defeat; a defeat that may take *years* to overcome. Krista was

trying to help her son lose weight and I wonder if she would have felt as motivated to continually place herself in these circumstances if it weren't for her son's weight issue. Deceptive tactics had become somewhat of a last-resort strategy for Krista and her experiences highlight the fine line that exists between deception and the consequences of getting caught out.

This sub-theme of deception and getting caught out was an emotive one for the mothers. The experience of 'getting caught out' and losing their child's trust was a difficult burden to bear. Rebuilding trust is never easy and is particularly challenging in the parenting relationship with a child with global developmental delay. The consequences of 'getting caught out' must have surely called into question whether the risk involved was really worth it. That the mothers were prepared to take this risk reveals their determination in never giving up, and always looking for opportunities to try to help their child.

5.5 Conclusion – Rebranded water

This theme of 'rebranded water' has shown itself as having different meanings to the mothers; different meanings in the sense that the mothers were guided by their child's specific feeding challenges when deciding what rebranding approaches and strategies to use. The mothers experimented with different approaches and strategies over time and were motivated by their desire to make a positive difference to their child's diet and health. Providing nutrition to a child is undeniably an important and essential component of mothering, or parenting. This theme has shown how the mothers were often torn between their desire to nurture their child and the need to make dietary decisions in the best interests of their child's health. The mothers expended considerable time and energy in meal preparation for their child and managing their child's difficult eating behaviours and this next theme will explore how the mothers, in their day-to-day lives of being-in-this-world, 'just got on with things'.

CHAPTER SIX: JUST GETTING ON WITH IT

“Parenthood in itself is a journey but when you throw a few more odd balls into the mix, it just makes it a bit more challenging. But what do you do? You just do it don’t you?” - Moira

6.1 Introduction – Just getting on with it

The mothers’ journey down a path that not was well signposted and in the absence of a map had left them with little choice other than to ‘just get on with things’ – navigating their own path, finding their own way and at the same time trying to make some sense of their everyday world and their everyday circumstances. Everyday circumstances, which to some people would appear extraordinary – for the mothers – had become their ‘everyday ordinary’. This ‘everyday ordinary’ was mostly hidden from the view of others as the mothers tried to achieve some sense of normality in their day-to-day lives. The mothers’ circumstances were anything *but* normal and they often spoke of how exhausting it could be trying to manage their child’s feeding challenges. Despite the time and effort that was required however, they were dedicated and committed to making improvements in their child’s diet and health. Diet and health being just one aspect of the mothers’ parenting role. In the wider context of parenting they had other aspects of their child’s wellbeing to consider such as the development of social skills and supporting their child’s academic achievements.

In addition to parenting their child with global developmental delay, many of the mothers had other responsibilities and commitments, including the care of other children, and in some cases employment outside of the family home. The mothers talked about the effect their child’s feeding challenges had had on their home life, family mealtimes and the ability of the family to engage in social activities. They acknowledged and accepted that there were some things in their ‘everyday ordinary’ that, despite their best efforts, they were unable to change. Accepting some things enabled the mothers to hold onto hope for the future, even when at times their fears and concerns could be overwhelming. There are three parts to this theme: the everyday ordinary, accepting some things and looking to the future. Within the first

theme of ‘the everyday ordinary’ there emerged a sub-theme that reflected how, despite the mothers doing their very best, they still had to reconcile their ‘ideal’ with their ‘reality’ in terms of their mothering role. This is explored in the sub-theme ‘the ideal versus the reality’.

6.2 The everyday ordinary

From the moment of a child’s birth, a mother begins the often-delicate task of responding to her child’s feeding needs. As her child grows and develops, she must learn the child’s feeding cues and provide food that meets his/her nutritional needs and supports his/her development. Feeding is often considered as one of the most important everyday responsibilities of parents (Schreck et al., 2004). It is also a basic fundamental of life. If we don’t eat, we will not survive. While the responsibility for feeding and nurturing a child does not solely rest with the mother, it is most often the mother who assumes this responsibility. The mothers in this study had all assumed primary responsibility for providing nutrition to their child and preparing meals for their family. Many of the mothers spoke of the time and energy that was required to prepare food for their child, often preparing special meals to cater to their child’s specific food aversions and intolerances. The added complication for many of the mothers was that their child’s feeding challenges did not stay static, a particular food or a strategy to deal with challenging feeding behaviours that might be accepted or work one week, might perhaps be rejected the next, or in Maxine’s words: *“things can constantly change”*. The mothers found themselves often wanting to do more to improve their child’s nutrition but also having to balance their time and energy and consider the needs of other family members. Here the ‘everyday ordinary’ is about trying to achieve some sense of day-to-day normality in a life that is far from ordinary.

Judy talked about how she would try to introduce new foods to her son but it was dependent upon whether she had the energy and was prepared for the added frustration that he possibly wouldn’t eat it anyway. She talked of the difficulties she faced trying to get her son to accept new foods and her awareness that his diet lacked nutrients and included too many processed foods. This clearly bothered Judy but at

the same time she acknowledged that she also had a responsibility towards her daughter and was mindful of considering her needs as well. She explained:

I would like to but just the thought that he wouldn't take it and then having cooked it, just puts me off sometimes. But once in a while I have the energy and say let's go for this and I would... It's too much effort to put into it. I have another child as well so I have to make sure I'm not doing too much for my son, very obviously in front of her, because sometimes she will say something and I know that she felt left out.

Judy was conscious about trying to balance her time between her son and her daughter. She tried not to fall into the trap of spending so much time preparing meals for her son and managing his difficult feeding behaviours that she had no time left to focus on her daughter. Her day-to-day life was a 'juggling act' as she provided her son with the support he needed but equally tried to ensure that her daughter didn't feel left out. I wonder if this experience for Judy is one of 'feeling caught'. Caught between knowing she could possibly do more to get her son eating better but this would be at the expense of spending time with her daughter. Judy talked about how she felt like she was "always in ready mode", anticipating, planning and preparing. As one day ended, Judy was planning and preparing for the next. Judy finds herself in the challenging position of trying to find her 'middle ground'. Her middle ground where she feels she has balanced her time as best as she possibly can. The 'everyday ordinary' here is about acknowledging that sometimes it is simply not possible to 'do it all'.

Robyn also talked about the amount of time that she expends on food preparation, not just for her son but also for the rest of the family. Robyn's son isn't able to tolerate lumpy textured food so Robyn prepared puréed food for him. She explained:

I spend three hours making three weeks' worth of those [puréed fruit pouches] for the freezer for his morning tea alone. Just trying to make them all different. So some have got mango in them and some have got berries in them and it's all got to be just the right consistency. So I spend a lot of time, not just making food for the family, but making food that's

just for Toby alone. That's one of the biggest things we have on a time level. I spend so much time making food for Toby.

Robyn went on to talk about also having to prepare food for her daughter who also has some dietary restrictions:

Yeah, it's tough. My daughter has got some dietary restrictions as well. She's on a gluten-free diet. So it's actually a bloody nightmare, a complete nightmare.

Robyn was clearly feeling frustrated about the 'nightmare' of having to spend so much of her time preparing food to cater to her children's food intolerances and dietary restrictions. She found it consuming and relentless, and like Judy experienced her day-to-day life as a bit of a 'juggling act'. Robyn also had a part-time job outside the family home and so juggled her role as a mother with that of provider/employee. Van Manen (1990) talks about the multiple lifeworlds that humans can experience in their everyday lives and that each of us may be seen to inhabit different lifeworlds at different times of the day, such as the lived world of work and the lived world of the home. The mothers inhabited multiple lifeworlds on a daily basis. Their lifeworld of the home and parenting was dominated by caring for their child with global developmental delay and this could at times raise conflicts with their other lifeworlds. The saying 'there are only so many hours in the day' aptly describes how the mothers felt when it comes to 'balancing' or 'juggling' their multiple lifeworlds. What the mothers must strive to achieve on a day-to-day basis in 'balancing' and 'juggling' these multiple lifeworlds – their 'everyday ordinary' – is quite extraordinary.

Within this theme of the 'everyday ordinary' there emerged a sub-theme that showed itself in how the mothers were always doing their very best but were often reconciling their 'ideal' with their 'reality'. This 'ideal' and 'reality' related to many different aspects of their motherhood experience and their experiences in having a child with global developmental delay. Their 'ideal' of what it is to be a mother and the 'reality' of the circumstances they found themselves in were often in stark contrast. This next sub-theme 'the ideal versus the reality' will explore the mothers' experiences in having to find some way to reconcile their 'ideal' with their 'real'.

6.2.1 The ideal versus the reality

Hannah's story showed that despite having so much going on in her multiple lifeworlds, she still struggled with feelings of not being the 'ideal' mother. She questioned whether she could and should be doing more. Her circumstances pointed to a 'reality' where Hannah *was* doing everything she could. This reality just didn't match up to Hannah's perceptions of the 'ideal'. Hannah had returned to part-time work to provide the means to privately fund cognitive therapy for her daughter. She talked about how she struggled to find the time to provide her daughter with the kind of diet she would ideally like to. Hannah compared herself to her own mother and how her view of a good mother was of one who does good nutritional things for their child. She acknowledged that she just didn't have the energy with all that she had to deal with in her day-to-day life:

I don't have the energy for the fabulous nutrition that I would love to give her. It requires too much thought, it requires too much effort and it's probably not.... There's probably not a lot more effort that goes into pre-soaking millet the night before, adding a few dried fruit and linseeds. That's actually not a lot of effort but somehow it feels like it... And in part I feel like a bad mother, but that's just down to the fact that mum used to do everything nutritionally for me, so I've been raised that when you're a good mother you do these good nutritional things but you know what, I've got so much going on.

Hannah feels worried she is not doing enough for her daughter. Her role as a mother is 24-7 and she constantly lives with this worrying kind of mindfulness. Life for any parent is 24-7, however life for Hannah not only includes raising her daughter with global developmental delay; it also includes employment outside the family home, and parenting another child. Hannah's circumstances in raising her children could be described as extraordinary. Yet, despite these extraordinary circumstances Hannah's 'ideal' of what a 'good' mother does, or should do, is still based on her experiences of what her mother did for her. Hannah sometimes feels she is doing her *best* but she also feels it isn't as *good* as her past experiences of being mothered. Her memories of how much her mother did for her as a child had created in her mind her 'ideal' of what a 'good' mother does. I wonder how realistic this 'ideal' is for Hannah given

what her day-to-day life entails. If Hannah were able to find the time to do more for her daughter would she ever feel she was doing enough? Would her 'ideal' about what a mother should nutritionally do for her child ever become a 'reality'? Despite Hannah feeling that she was not doing enough, she acknowledged that all a mother can do is her best:

So I think you just have to do the best you can really. You can't look after everything; you can't do better than that.

The role of a mother and the day-to-day care that she provides her children is often the glue that sticks a family together. Mothers often assume responsibility for the needs and wellbeing of other family members and prioritise this responsibility over and above everything else. For the mother who organises and prepares meals for her family, a further responsibility can become inherent in her 'mothering' role – that of family mealtimes. For the mother of a child with global developmental delay family mealtimes can present an additional burden as she must find ways to deal with her child's difficult eating behaviours and food aversions and intolerances. In researching the literature for this study I read stories from mothers of children with global developmental delay sharing their experiences of family mealtimes. They often spoke of the tension that family mealtimes could create and their experiences often not living up to the 'ideal' of what they thought family mealtimes should be like. I asked the mothers in this study to share their experiences of family mealtimes and for some of them their experiences were a deviation from that mostly presented in the literature. They talked about having reached a point where family mealtimes, for the most part, were a positive experience for the family members involved. The family was able to come together and enjoy the social aspect of eating together. For other families this was not the case. The sensory aversions of some of the children made it difficult for them to tolerate being around food that other family members were eating. Some of the mothers talked about mealtimes taking a considerable period of time with one mother experiencing mealtimes with her son that took upwards of an hour and a half. Krista talked about how she tried to include her son in family mealtimes but he usually preferred to eat alone:

His father gets home from work, around 8.30, 9 o'clock most nights. So he doesn't eat with them; it's usually just the two kids and I and often [my son] just wants to eat on a tray, alone in his room. He doesn't want to eat with the family. Sometimes I can get him to eat with us but that can be a bit of a battle, but if I give him a tray he will lie on the floor and eat.

Krista's experience of family mealtimes was one of just making sure everyone gets fed. Krista's 'ideal' would be that her family all eat together at the dinner table. In the 'ideal' world is this not what families do? Krista's reality however was not the 'ideal' world. She knew that if she pushed hard enough she may be able to convince her son to eat with the family but she had to weigh up whether the battle was worth it. She reconciled her 'ideal' with her 'reality' and accepted that if he was happier to eat alone then perhaps for everyone's sake it was better to keep the peace.

In contrast to Krista's experience, Maxine's experience of mealtimes with her son was one that involved a considerable amount of participation on her part. Maxine needs to hand feed her son as he lacks the coordination required to feed himself. She also had to find ways to alleviate her son's anxiety around food and eating. Despite her son's difficult eating behaviours, Maxine made every effort to try and turn mealtimes into a positive experience for her son and she acknowledged that there was no point getting worked up about things. She explained:

Yeah, he pokes, covers his ears and rocks. That's his anxiety; he screws his face up and gets in your face. You've just got to jolly him on, sing his favourite song. Just kind of ignore that. Just try to de-escalate that behaviour. You know? Jolly him a bit. Once he's distracted by a song or whatever he tends to relax.... Yeah, there's no point getting worked up, you know? That doesn't help.

The mealtime experience for Maxine was one of trying to reframe what was a somewhat stressful experience for her son into something positive. Despite Maxine working so hard to create this positive experience, she was unable to escape the emotional toll of what had become her 'everyday ordinary':

No, no, no, no. I really don't want to talk about this because I'll get emotional, but it has, it still is. It's quite soul destroying. When you set out to have kids you don't see this coming, but you don't expect to be feeding your 13-year-old son, you know? He's got hairy armpits, you know, his food and singing him nursery rhymes...

Maxine's experience of everyday life was at times – as she described it – “*soul destroying*”. Soul destroying not only in the sense of the time and energy that was involved in her son's day-to-day care, but soul destroying in the realisation that she was having to feed an almost grown man, and sing him nursery rhymes. Maxine's ‘reality’ of motherhood couldn't be further from her ‘ideal’. At times she struggled to hold on to hope in the face of her ‘ideals’ being so dashed. Are Maxine's past and present experiences with her son providing her with reminders of what their possible future together may be? Van Manen (1990) suggests that knowledge from our past can trigger positive feelings of hope but it can also engender feelings of fear and hopelessness. Heidegger (1962) talks about the feeling of hopelessness as an awareness of something that is ‘still outstanding’, that has not yet become actual. Maxine maintained a confident demeanour in her positive approach to her son's feeding challenges but at times she couldn't help but feel defeated and hopeless. What is ‘still outstanding’ for Maxine? In reflecting on her past and present experiences with her son she cannot help but wonder what their future together holds; that which is ‘still outstanding’. Twentieth century philosopher Henri-Louis Bergson, whose work is said to have influenced Heidegger, describes human experiences involving the past, present and future as a ‘flow’. In ‘flow’ an experience in time becomes a past experience: it becomes a memory. Future experiences, the ‘not-yet’ exist differently: they are imaginations or ‘projections’ (Bergson, 2008). Maxine's daily mealtime experience with her son paints a picture or a ‘projection’ of what their future together may hold. For Maxine, time becomes a point of reconciling the ‘ideal’ with the ‘real’ whilst trying to maintain hope for the future. Her everyday experiences serve as a reminder of this ‘not-yet’ future and she cannot escape thinking about it. Maxine finds it difficult at times to stay there ‘in the moment’ as her ‘projections’ of future possibilities take over her consciousness.

While the future was something the mothers often spoke about, some also reflected on their yearning for the simplicity of their past life. Life – as they knew it – before their child with global developmental delay came into their lives. They talked about the difficulties they now faced in socialising and participating in events outside of their home environment. For some of the mothers, their child's challenging eating behaviours and food intolerances had taken a toll on their ability to do every day, taken-for-granted things such as enjoying a meal at a café or restaurant, or catching up with a friend for coffee. Robyn described her experience with her son as “*social death*” which left her “*feeling really isolated*”. She spoke of losing the ability to be spontaneous and the impossibility of trying to enjoy a family meal at a restaurant:

So taking him to a restaurant is not possible because although you could say yes to some soup but you don't know what the consistency of the soup is and if it's too runny he can't eat it and then you've got to take something to thicken it up. So it's a constant thing, so you always have to take food wherever you go and so you know I started keeping baby jars in the car, in the glove compartment, because there's no spontaneity if you go and visit a friend – “Oh do you want to stay for lunch?” “Yeah but then what are we going to feed Toby”. So you know there is always that problem and travelling is always going to be a problem.

Eating at family or social gatherings presented a whole other set of challenges for the mothers. Not only could there be issues with their child being overwhelmed by the number of people, the noise level, and changes from the home environment, but there were also the expectations of family and friends to be managed. Krista spoke about feeling frustrated with the lack of understanding from family and friends about her wish not to give her son sugary drinks. She explained:

If anybody is drinking fizzy drinks he will want it and I can't get friends and family at picnics and barbeques, they can't get like why I'm a bit hard on him for only having water. He gets so many bad calories, he just can't afford to have them and they're like “All the other kids are having it” and they'll bring lemonade and Fanta and Coke and all the other kids

who go run around and exercise and eat better, will have it. I find that a bit frustrating.

Krista experienced this lack of respect for her wishes as being unsupported. Unsupported by the very people whom she expected should be there for her no matter what – her family and friends. Having to justify why her son couldn't have a sugary drink left Krista feeling 'caught'; caught between the expectations of her family and friends and her personal choice as a mother. Krista would have loved for her son to be included and treated like all the other kids but her son was *not* like the other kids. This left Krista feeling frustrated, frustrated that she had to explain herself and frustrated that these family members and friends seemed to lack some basic understanding and empathy for her circumstances and what she must deal with in her day-to-day life with her son. Krista's 'everyday ordinary' became about reconciling the life she once had with the life she was now faced with. Experiences like this become part of her 'everyday ordinary' and she must find a way to carry on regardless.

Hannah also spoke about sometimes feeling a lack of understanding from family and friends of the challenges that come with having a child with global developmental delay. She described how she felt like she had gone from being a regular person in society to feeling that she had become "*marginalised*" and "*like an invisible part of society*". She had found herself largely homebound with her daughter and described her experience of second-time motherhood as having her life "*hijacked*": "*I think it's blissful ignorance when you are a regular part of society, you don't realise you're part of society. You just take for granted at the point of which your life gets hijacked by something significant like this*". Everyday life changes for any woman who becomes a mother, but for the mother of a child with global developmental delay, it can mean changes that are significantly more far-reaching and challenging. The concept of 'thrownness' proposed by Heidegger (1962) describes how the mothers felt in this 'new life' they found themselves in. Heidegger (1962) describes 'thrownness' as a mode of being in the world and suggests that we are constantly being "delivered over to the world" (p. 174). The world we find ourselves in may be a world that we did not choose and a life that we did not ask for. 'Thrownness' is being thrown into a world that is outside our control – like saying, "to be thrown into

despair”. Hannah found herself thrown into a life she had neither chosen nor asked for. This ‘new life’ is her ‘new reality’ – her ‘everyday ordinary’.

This theme of ‘the everyday ordinary’ in this ‘new life’ the mothers find themselves in, uncovers the time and effort that is required of the mothers in managing their child’s feeding challenges. This ‘everyday ordinary’ that is mostly hidden from the view of others sees the mothers striving to achieve some sense of normality in their day-to-day lives; day-to-day lives that are anything *but* ordinary. They have had to find a way to ‘juggle’ and ‘balance’ their multiple lifeworlds. The ‘everyday ordinary’ for other family members is also altered as feeding challenges impact on family life and the family’s ability to engage in social activities outside of the home. Over time the mothers’ *everyday* life has become their new *ordinary*. Despite this new *ordinary* the mothers often struggle with reconciling their ‘ideal’ of motherhood versus their ‘reality’. The sub-theme ‘the ideal versus the reality’ has uncovered how the mothers have had to try and make some sense of their ‘reality’ in order to keep going in their everyday lives. Coping with the challenges that are now part of the mothers’ everyday lives requires the acceptance of some things. The following theme will explore what ‘acceptance’ means for the mothers and how ‘accepting some things’ has enabled the mothers to reconcile their ‘ideal’ with their ‘real’.

6.3 Accepting some things

Dealing with the feeding challenges that can be experienced by a child with global developmental delay can have a significant impact on day-to-day life. The mothers spent a considerable amount of time and effort focused on providing nutrition to their child, often having to find a balance between ‘good nutrition’: providing healthy nutrient-dense food; and catering to their child’s specific aversions and intolerances. In listening to the mothers’ stories, there is evidence that over time they have become somewhat accustomed to what is now their ‘everyday ordinary’. They made comments about “*just getting used to things*”, and when speaking of the time and effort they expended made comments such as “*it’s just part and parcel*” and “*it’s what you do*”. It seems that they have reached a certain level of acceptance – a reconciliation of their ‘ideal’ with their ‘real’; an acceptance of the things they have come to realise, despite their best efforts, they cannot change. In some cases they

acknowledged how they wished things could be different but in the end ‘just getting on with it’.

Judy had experienced difficulties with her son’s eating right from birth. He had significant aversions to certain textures and tastes. When talking about her experiences with her son’s nutrition she often spoke about how she and her husband were just “*so used to things*”. She acknowledged however that despite reaching this level of acceptance she still found dealing with her son’s feeding challenges stressful:

*Quite stressful sometimes but it’s something we’re used to already...
We’ve been doing that for a long time.... I take it a day at a time... You
just have to get used to it.... Tell yourself to get used to it.*

Judy wasn’t just telling herself to “*get used to it*” in her head, she was actually verbally saying it out loud to herself: “*I tell myself, actually say it out, where I can hear and carry on*”. Is this part of Judy’s process in learning to accept some things? Does hearing herself actually *say* the words make it easier for her to change her mindset from one of feeling stressed and frustrated to one of acceptance? Acceptance can be described as a ‘willingness to tolerate a difficult situation’ (Oxford English Dictionary, 2011). Judy is telling herself to “*get used to it*” and learn to tolerate what is, at times, a difficult situation for her.

Like Judy, Krista also spoke about ‘just getting used to things’. When talking about the time and effort that she put into her son’s nutrition she admitted to finding it difficult but then described it as just being “*part and parcel*” and “*what you do*”:

*Yeah it is sometimes, most of the time it’s just part and parcel. It’s what
you do, but every now and then you just go, it would be nice to just do a
normal meal and not have to think so hard.*

Krista fantasied about what her everyday world could be like if she was able to prepare normal meals and not always have to think so hard. She appeared to have accepted that this is simply not her reality by saying it’s just “*part and parcel*” and “*what you do*”, but I wonder if this was perhaps more a feeling of resignation rather than acceptance. Resignation is described as ‘the acceptance of something undesirable but inevitable’ (Oxford English Dictionary, 2011). Krista had come to

accept that the time and energy she put into her son's nutrition was "*part and parcel*" and "*what you do*". At the same time she found her situation undesirable and wished for things to be different. Krista's expectation of having to go to so much effort points to how Krista viewed herself as a mother, and what her 'mothering' role entailed. She viewed her 'mothering' role as being responsible for providing good nutrition to her son – "*part and parcel*" and "*what you do*". In this 'mothering' role Krista placed considerable importance on her son being able to participate in family time. She spoke of the progress her son had made and how pleased she was that the family was now able to eat out together. Her son's participation however came at a cost for Krista. Krista has had to accept that her son may not eat a particularly healthy meal if it was a meal outside the family home. She explained:

So like he'll go to a café and sit with the family but all he'll eat will be the fries or if they'll do chicken and chips and he's got now that he asks the waitress. He'll look at the menu and he'll say, "I'll have this meal, but leave out the spinach, leave out the greens, leave out the tomato. I don't want the dressing. Have the sauce...." So in the end, by the time he's removed everything he doesn't want, all he is actually asking for is meat and potato. The chip or whatever with the meal... But it's been a huge progress in the last few years, that he can now come to a café or restaurant with us and it's really nice to be able to do that as a family. Even though it's a very limited diet, that is less frustrating for me than it was not having him participate and not being able to have a family activity.

In parental experience van Manen (1990) talks about the time a child and a parent spend together as creating a history of family time. "Especially meaningful are the lived time experiences of the special days and times of the year when significant events are celebrated in the family and in the school or the community. And then there are of course the mealtimes, the evenings together, the outings and the weekends when time acquires qualities that turn eventually into positive or negative memories of childhood" (van Manen, 1990, pp. 105-106). In 'accepting some things' Krista is helping her son build some positive memories of outings with his family and the sharing of a family mealtime.

For Moira, ‘acceptance of some things’ with regard to her autistic daughter was almost a conscious decision. Following many years of trying to find ways to help her daughter, Moira had ‘accepted’ there was only so much she could do. Over time she had found some information and advice that had worked well for her daughter but in the end, she had come to the conclusion that realistically there would always be limitations to what change could be achieved when dealing with the complex nature of a developmental delay such as autism. Rather than continually search for answers Moira had decided it was time to ‘just get on with it’. She explained:

I’ve read so much about disability and autism and I have moments where I’m really interested in it and want to learn more, but honestly, you know, I could read every book and every printed article about it and learn all about it, but I still, I don’t understand it. I don’t think anybody does. All that tells me is that we’re never going to understand it so we may as well just accept it. Work with what you can and get on with it you know.

With much of Moira’s *past* having been devoted to searching for answers she was now choosing to ‘accept some things’ and focus instead on the *future*. She wasn’t forever banishing to her past all interest in learning new things that could help her daughter, but rather acknowledging the enigma that autism can be. She was accepting that there was still much that was not understood, even by esteemed professionals, and was focussing instead on working with the knowledge she already possessed, or in her words: “*work with what you can*”.

‘Acceptance of some things’ appears to be somewhat of a coping mechanism for the mothers. This is an important aspect of the mothers’ journey as it enables them to focus on the things that they can change rather than constantly feeling burdened by the things they cannot. The mothers are always looking for ways to improve their child’s diet and challenging eating behaviours but had come to the realisation that it is alright to accept that some things are beyond their control. This acceptance had enabled some of the mothers to enjoy other aspects of the parental and family experience such as enjoying mealtimes and family outings together. Accepting the ‘everyday ordinary’ is also something that is apparent with the mothers. Their

comments about ‘just getting used to it’ and ‘just doing it’ normalised their everyday circumstances that to others might be viewed as extraordinary. The mothers’ ‘everyday ordinary’ is often filled with thoughts about what the future might hold for their child. This next sub-theme uncovers the mothers’ hopes and concerns for their child’s future and explores how food and nutrition is just one important aspect amongst many others in the parenting experience.

6.4 Looking to the future

“The past changes itself, because we live toward a future which we already see taking shape, or the shape of which we suspect as a yet secret mystery of experiences that lie in store for us.”

(Linschoten, 1953, p. 245)

In the parenting experience it is only natural for a parent to consider what their child’s future holds. This consideration for the future, while filled with hope, will undoubtedly be influenced by what has transpired in the past. For the parents of a child with global developmental delay another layer of complexity is added when considering this future outlook, both for the parent and for the child. The mothers in this study were devoting a significant part of their lives to providing nutrition to their child and looking for ways to improve their child’s diet and manage their child’s feeding challenges. When considering their child’s future, it was therefore only natural that the mothers would think about what might unfold as their child grew in independence and became capable of making their own dietary decisions. In the wider context of the mothers’ parenting role there were many other aspects of their child’s future that caused them concern. These included their child’s social and academic abilities and whether their child would ever develop the necessary skills to function independently in the community. While the mothers were very focused on day-to-day life they spoke of their hopes and concerns for the future.

Krista’s concerns for her son’s future were heightened by the fact that her son was overweight and she was finding it increasingly difficult to manage his weight. Her son’s food aversions and intolerances were so severe that it left Krista with limited options in terms of offering him a healthy nutritious diet. She talked about how she

wished he had a healthier body shape and a healthier diet but her biggest concerns were centred on his difficult behaviour and limited social skills. She explained:

In the scheme of things, behaviour and social are probably more likely to cause me concern on a day-to-day basis but probably at least half a dozen times a day it [his weight] does concern me because the half a dozen times I'm either dressing him or bathing him or preparing food for him, it does cause me some concern. He hasn't got a healthy body shape at the moment and sometimes when I look at his legs I just think oh, yeah it would be lovely if he ate differently, yeah, but I mean despite being as fussy as he is I know he is not going to starve and I know if I can find a whitish looking wholemeal bread I can always give him something that's not too awful to eat, like not too unhealthy that he will eat. Yeah....

Krista talked about how she feared her son's current weight issue and poor diet could mean he will face obesity as an adult:

I'm concerned that having such a bad diet now could have long-term implications for him. He's more inclined to obesity as an adult. It's going to be harder for him to lose weight and then having had this bad diet now could mean it's harder for him to eat healthy, if and when he ever gets to the point as an adult that he is concerned, you know looking at that element of his health.

In Krista's everyday experience of 'mothering' her son, bathing and dressing him, and preparing his meals, she was constantly reminded that he did not have a healthy body shape or a healthy diet. Van Manen (1990) talks about the physical closeness that is shared between a parent and child in the things that a parent does for their child as part of their day-to-day care. He refers to it as "the lived bodily encounter" (van Manen, 1990, p. 105). "We also sense in the lived bodily encounter a primordial sense of security for the child" (van Manen, 1990, p. 105). Krista sensed this feeling of security for her son. She could see that her son was not healthy but at the same time she felt somewhat helpless in not being able to do more to help him. In the 'scheme of things' it was just one thing that Krista must deal with. One thing in amongst the many challenges she must face in parenting her son.

Like Krista, Maxine and her husband were also concerned about their son's weight. They were trying to remain positive about their son's future and acknowledged that due to his intellectual disability being so severe, all they could really do was try and equip him with the life skills that would enable him to go out into the community independently. They recognised that their 'journey' with their son was going to continue for some time because he would always need some form of secure care. Maxine explained:

He's got many redeeming features. He's so delightful. We thought he was, what's it called? Bipolar? Because when he's happy he's like Stevie Wonder. He dances with his head and just wants you to dance and he laughs his head off.... He's a bit manic but we really relish those times because he's so engaged and he's so social. Whereas when he's the other way he is so self-destructive...It is hard for us but I always think it must be a lot harder for Michael, because he's the one that is locked inside himself... it must be very, very frustrating not to understand how the world works. We've often been quite heartened over the years at his progression but then his regression always goes way, way back. We want to balance realism, you know we want to be realistic but um...it's just he's so severely disabled intellectually. We don't worry about the academic stuff with him. We worry about whether he can go out into the community. Go to a dairy and you know, buy a pint of milk or go to someone else's house without trashing it. I mean they're the life skills that he is going to need to get on in the world, because otherwise kids like that can't live in community homes. They need to be in secure care. So that's why we try so hard with him, even his self-help skills.

Van Manen (1990) talks about how in the special relationship between parent and child the child experiences the support and security from his/her parents to allow him/her to mature as an independent person. Maxine and her husband were offering their son the support and security he needed to help develop his social skills and become more independent. They had recognised and accepted what they could, and could not change, in terms of their son's development. They recognised and accepted there was little value in placing importance on academic achievement so instead had

made it their priority to help their son gain the necessary life skills that might enable him to gain independence. Their profound love and commitment to their son meant that they would do anything they possibly could to help him develop into a mature and independent man.

Moira also spoke of the importance she placed on her daughter gaining independence, although for Moira it was important this independence was within certain boundaries. Moira's daughter had developed the skills necessary to leave the family home and go on outings with friends and relatives. Despite this growing independence, Moira was reluctant however, to take the next step and allow her daughter to progress into a supported-living environment. In addition to her autism Moira's daughter has some metabolic and endocrine disorders that make her susceptible to weight gain. Moira had been strictly managing her daughter's diet for a number of years and felt it was important that she continued to provide her full-time care. Moira spoke of how she had observed some of her daughter's friends struggling with the lack of support moving from the school environment into the community and how most of them are now overweight. She explained:

Once she left the school environment there was nothing really; nothing for her as a young adult to do. I got her into a day programme because how it used to be was unless you were in residential living – living in a supported living environment, you couldn't go to the day programmes. Now there are three [in our area] but that depends on funding – the Ministry of Social Development – and a lot of the kids that were at school with Megan didn't have all this funding. They didn't have all this high level of funding that was needed to support them at school. So I don't know what they do now. Sit at home watching TV and getting fat probably, because most of the kids that she knew.... they are all pretty big, even the ones that are out in supported living are quite big... You know? But it must be a big contributor to diabetes and I would say that there are a lot of people with disabilities where, if they are not diagnosed, I think they must be borderline.

Moira's experience with her daughter and what she had witnessed with her daughter's peers going out into the community independently highlights both the positive and negative aspects with regards to her daughter gaining independence. While Moira would have liked to see her daughter gain more independence from the family home she equally wanted to continue to have some input and control over the direction of her daughter's life and the decisions that she made. Control over her daughter's diet and managing her weight being just one aspect for Moira in the wider context of parenting, but one very important aspect when one gives consideration to the consequences.

Like Moira, Robyn also expressed her concerns about her son gaining independence and her fear that he will lack the ability to make sensible food choices. She was aware of the prevalence of overweight and obesity in adults with Down's syndrome. She explained:

So it's still a journey and I just think it's always going to be because I can see the day when he goes off independently. What I've noticed about anything that I read in a magazine about children with Down's syndrome, they're off on an outing, they're going to stop at McDonald's on the way back or something. You know? And what I notice about adults with Down's syndrome, they're always overweight and have very poor diets; and institutions, people who live in group homes and have to have food cooked for them. So I can see this is going to be a battle that we've got for a really long time.... it's always going to be difficult....

Robyn acknowledged that the 'journey' with her son continues and that the future will undoubtedly present new challenges as her son gains independence. For now however, she felt that she needed to take a step back and just *be* in the present. Robyn's 'journey' in trying to find help for her son had consumed her life for a number of years. She explained:

There is not much I don't know about it now and I have a life now. I'm back at work. I have to do something else now. I think it's going to be for Toby now as he gets older, if he wants to be like his mates, he is going to have to put some effort in there and try and taste and do some other

things... Yeah I've got a life now, so I feel that I've been plugging away at this so long. Maybe I'll find some information or find some way that will help him get over this but we have tried.

Robyn was trying to find some much-needed *balance* in her life. Thoughts of her son's future were never far from her mind and her 'mothering' role meant that while she was placing less emphasis on trying to find practical ways to help him, she was still committed to finding answers. Choosing to find more *balance* in her life, I imagine, must have been a difficult decision for Robyn. For so many years her search for answers and fight to try and find help for her son had been something she was intently focussed on. She had lived and breathed it. To think now about what might happen if her son is eventually able to go off into the community independently and suddenly have the autonomy to make his own food choices – and most likely poor food choices – must have felt very real and very concerning for Robyn. With uncertainty comes fear and Robyn tried hard not to dwell on these fears but rather focused on the positives – the things she could change and the progress she had, and continues to make with her son:

Toby has a phenomenal diet now. He just eats amazing food now. He can't bite or chew still. He can't bite or chew and it took us another two years to teach him to drink... [So he has been on this journey] from having this really unhealthy diet to the diet that he has now which is exemplary... I think it's been an amazing journey... but I have to have a life now...

6.5 Conclusion – Just getting on with it

This theme of 'just getting on with it' has uncovered that everyday life for the mothers is about trying to find as much normality as possible in a world that is filled with uncertainty. The mothers sometimes struggle with 'juggling' and 'balancing' their multiple lifeworlds and talk of how their child's feeding challenges have impacted their family and their ability to engage in activities outside the family home. The mothers have come to recognise that in order to achieve some balance in their lives they need to 'accept some things'. Accept that there are some things that are beyond their control and that despite their best efforts might never change.

Acceptance has enabled the mothers to cope with the uncertainties that life has thrown at them. With knowledge that the incidence of overweight and obesity is exponentially increasing, it is unsurprising that the mothers feel particularly worried for their child's nutritional future and their risk of becoming overweight or obese as an adult. All they can do at this point however, is remain focussed on the here and now and provide their child with the support and security that they need to help them mature as an independent person. While holding *fears* for their child's future the mothers also hold on to *hope*.

Chapters Four, Five and Six have presented the findings of this study under specific themes: 'finding their own way', 'rebranded water' and 'just getting on with it'. Utilising van Manen's (1990) lifeworld existentials has enabled me to provide a deeper insight into the phenomenon that is: the experience of providing nutrition to a child with global developmental delay.

In the following chapter I will discuss these findings in relation to current literature and make recommendations for practice, education and suggestions for further research.

CHAPTER SEVEN: DISCUSSION AND RECOMMENDATIONS

7.1 Introduction

This aim of this thesis has been to explore the meaning of mothers' experiences in providing nutrition to their child with global developmental delay. Utilising the qualitative methodology of phenomenology has enabled me to reveal a deeper understanding of what these experiences mean to the mothers. This chapter examines the key findings of this research in the themes that were uncovered from the mothers' stories. I will discuss how the findings relate to other studies in the literature, and the limitations of this study. Finally, I will provide some recommendations and identify some further areas for research.

7.2 Discussion

This thesis has uncovered that the experience of mothers in providing nutrition to their child with global developmental delay reveals a world that is uncertain, where the mothers find themselves in circumstances that are often beyond their control. There is a sense that they have been 'thrown' into these circumstances, into a world they could never have anticipated or imagined. The mothers are 'caught' in having to be there, in these circumstances, which are now part of their everyday life. What has become their 'everyday ordinary' encompasses circumstances and challenges that to others might be considered extraordinary. The mothers 'ideal' of motherhood is far from their 'reality' and they must try to reconcile and make some sense of this in order to find the courage and determination to carry on with day-to-day life.

The findings of this study show that the experience of the mothers in 'seeking help' for their child's feeding challenges is one of often 'feeling let down'. This experience of 'feeling let down' is the precursor to the mothers' losing faith and developing feelings of distrust towards the health professionals whom they had entrusted with their child's care. Their experiences left them feeling disappointed, frustrated and 'on their own'. In their everyday 'taken-for-granted' world the mothers expected knowledge and support would be forthcoming from the health professionals that came into their lives. The mothers' experiences disrupt this 'taken-for-granted' view of the world and instead show a different world. A world that leaves the mothers feeling

they are on this journey alone – ‘on their own’. This feeling of being ‘let down’ and ‘on their own’ impacts on the mothers’ ‘being’ and what it means for them to ‘be-in-this-world’. They try to remain positive but at times struggle to feel optimistic as they travel without a map on a path that is not well signposted; they hold onto hope for the future but it is often tempered with feelings of hopelessness and uncertainty for the ‘not yet’ and the ‘still outstanding’ – the *not knowing* what is yet to come. How the mothers now view the world stems from their past experiences. These past experiences paint a picture or a ‘projection’ of what the future may hold. Although the mothers would prefer to cast aside some of these negative memories of the past, they are unable to do so. These past experiences shape their future and, perhaps unknowingly, influence the decisions and choices that the mothers make in their everyday lives. The mothers have come to the realisation that they have to ‘own things’ for themselves, ‘find their own way’, look for their own answers, and create their own communities of support.

What is hidden and what this study reveals, is the time and energy that is required in parenting a child with global developmental delay, particularly in managing the day-to-day feeding challenges that are characteristic of such children. In the parenting experience, providing nutrition to one’s child is a fundamental aspect of what it is to be a parent. In this special parent-child relationship providing nutrition is about nurturing, sustaining life, providing nutrients and ties in with the concept of ‘food as love’. As a sign of love a parent nourishes their child in the hope that they may continue to grow and develop into a healthy human being. The mothers in this study are all primarily responsible for providing nutrition to their child and while this highlights the traditional roles of parenting, it is also testament to how the mothers view their role as a mother and nurturer. Being a mother is *one* of their lifeworlds amongst *many* other lifeworlds.

In exploring the multiple lifeworlds the mothers have come to inhabit, this study has shown that the mothers have had to work amongst the tension of wanting to do everything possible to help their child but having to balance this with the needs of other family members, and with their commitments outside the family home. Their willingness to try anything possible reveals itself when the mothers resort to deceptive tactics in a bid to improve their child’s nutrition. The mothers find themselves in a

conflicting position with the risk of ‘getting caught out’ weighing heavily against the chance of success. The angst of ‘getting caught out’ and the repercussions they could face in doing so always loom over them.

Without *knowing* the mothers’ stories, at first glance it might appear that the mothers are resilient, that they have ‘found their own way’ to manage their child’s feeding challenges and appear to ‘just be getting on with things’ coping with the circumstances in which they find themselves, and to the outsider, appearing completely in control of their everyday lives. Uncovering their stories however paints a very different picture. The mothers spoke of their ‘battles’ and ‘having to fight for everything’, and it is through these words that one comes to realise that this is not resilience, this is courage. The mothers’ lives are filled with uncertainty and they have to endeavour to overcome this uncertainty by ‘accepting some things’. Acceptance has made it possible for the mothers to continue living with uncertainty. Acceptance is a courageous way of ‘*being*’ where the mothers acknowledge the things that are beyond their control, which in turn enables them to carry on with everyday life. Acceptance also enables the mothers to hold on to hope for their child’s future.

Hope

Knows no fear

Hope dares to blossom

Even inside the abysmal abyss

Hope secretly feeds

And strengthens

Promise

- Sri Chinmoy

7.3 Relating the findings to other studies

The literature reviewed in Chapter Two provided a comprehensive overview of the feeding challenges that can be experienced by children with global developmental delay, and the experience of parents in managing their child’s nutrition.

This study has revealed that feeding challenges for children with global developmental delay are multi-factorial. The mothers reported many different issues that impacted on their child's nutrition including: sensory aversions – to smell, texture, temperature and taste; anxiety issues; behavioural issues; and physiological issues such as difficulty in chewing. This supports the work of Twachtman-Reilly et al. (2008) and Burklow et al. (1998) who found that the majority of children with a broad range of developmental etiologies demonstrated both physiological and behavioural factors in their feeding problems.

The mothers in this study spoke of the difficulties they faced in trying to provide their child with a healthy diet. Due to their child's specific food aversions, intolerances and sensory processing issues, the mothers faced many setbacks in their attempts to get their child to accept new foods, in particular healthy foods such as fruit and vegetables. Often their child's preferences were for starchy, sugary and salty foods, and often for foods of only a certain colour or texture. These findings are consistent with those in the literature with Ahearn et al. (2001), Curtin et al. (2010) and Schreck et al. (2004) reporting that children with global developmental delay often exhibit a preference for energy-dense foods that are high in fat, salt and sugar.

This study has highlighted that difficult mealtime behaviours and anxiety issues around food and eating can have a significant detrimental impact both on the mealtime experience and the nutritional intake of the child. This claim is supported by the work of Schreck and Williams (2006) who reported on the negative impacts of rigid and repetitive mealtime behaviours, and Twachtman-Reilly et al. (2008) who observed how negative behaviours in children frequently had detrimental effects on the feeding experience.

The literature suggests that mealtimes for families with a child with global developmental delay were mostly difficult and often chaotic; however, some of the mothers in this study talked about how they had reached a point with their child where family mealtimes were, for the most part, a positive experience. This research provides another perspective and I would argue that this disparity may be because families who are experiencing *positive* encounters with their child's mealtimes are less likely to participate in research that is focussed on the *difficulties* at mealtimes.

Additionally, with limited academic research focussing on the *experiences of families* with a child with global developmental delay, I turned to books that had been written by mothers wishing to share the difficulties they faced in raising their child with global developmental delay. Feeding challenges and difficult mealtime behaviours were common themes in these mothers' books.

One of the few studies in the literature that has provided a family/caregiver perspective on the feeding challenges that can be experienced by children with global developmental delay found that families and caregivers were often so concerned about their child's food intake that they often prepared special meals for their child and only offered their child the foods they were known to prefer (Williams et al., 2005). The findings of this study support this claim with the mothers often expressing their concerns about their child just eating *something*. One mother talked of how she had felt "*manipulated*" by the foods her son would eat. The efforts the mothers went to in utilising multiple strategies to try and improve their child's nutrition further highlights their high level of concern for their child's diet and health.

The mothers in this study often paused to reflect on their *old* life and how different things were for them in this new 'reality' they found themselves in. They talked of how their child had come to affect many aspects of their life and their family's lives. One mother talked of her life having been "*hijacked*" and how she now felt like a "*marginalised member of society*". These findings are consistent with a study by Huws et al. (2001), which found that parents of children with global developmental delay experienced a feeling that everyday life previously taken for granted had become disrupted, and the future now appeared ambiguous. The mothers in this study experienced a feeling of anxiety around the uncertainties that their future presented. Everyday life for them has forever changed.

For some mothers there is a paradoxical striving for normality and this shows itself in how the mothers' 'everyday ordinary' is mostly hidden from the view of others. The mothers just 'got on with things' and have come to 'accept' the impact their child's feeding challenges has on their home life, family mealtimes and their ability to engage in social activities outside the family home. They often experienced encounters where they were reminded of their 'reality' and this could engender

feelings of frustration at the apparent lack of understanding and empathy towards what they are dealing with as mothers in their day-to-day lives. This is consistent with the findings of a study by Rogers et al. (2011) where mothers described the dilemma of meeting their child's needs and the expectations of relatives at family gatherings and how trying to feed their child on family holidays came to have an effect on the whole family.

While this study has been focused on uncovering the experiences of providing nutrition to a child with global developmental delay, it has also provided some insight into what it is to *be* the parent or mother of a child with global developmental delay. The mothers often talked about the difficulties and struggles they faced but contrasted these with the feelings of love and hope they had for their child. This is in keeping with Kearney and Griffin (2001) where the 'sorrow' and 'joy' of parenting a child with global developmental delay was explored. Parents reported experiencing much anguish and sorrow, but they also spoke of hope, love, strength and joy. Larson (1998) interpreted this as "embracing the paradox" (p. 29). The paradox was the tension between the child's current circumstances and their hope and desire for a better future for their child. The mothers in this study talked of their hope and desire for a better future for their child while acknowledging the stresses and difficulties that everyday life presented to them.

In the absence of notable research that focuses specifically on the *experiences of families* in providing nutrition to their child with global developmental delay, this study provides valuable insight into what this experience is like, in this case specifically for mothers. The findings of this study related to the mothers' experiences appear to resonate and go beyond what has previously been described in the literature. This study has revealed some 'rich descriptions' of what the experience is like for the mothers and what it has meant for them in their everyday lives.

7.4 Study limitations

This study was carried out for a dissertation as part of a Master of Health Science; consequently it draws insights from a small number of participants. This is however in keeping with the philosophy of phenomenology; in seeking to uncover deep

understanding of a particular phenomenon, it is the richness of the data rather than the number of participants that matters most.

A further limitation of the study relates to the participants' lack of cultural, geographic and gender diversity. All of the seven participants were mothers living in Auckland with only one mother identifying herself as not being of European descent. From a cultural perspective, we know from research here in New Zealand that Maori and Pacific children are disproportionately affected in the rates of overweight and obesity and I had hoped to include some Maori and Pacific families in this study. Unfortunately I did not get any response to my study invitation from Maori and Pacific families who were willing to participate.

A further limitation of this study is that the mothers' experiences of providing nutrition to their child appeared, in some cases, to be dependent on the level of functioning of their child and whether their child also experienced some other co-morbidities in addition to their diagnosis of global developmental delay. I cannot therefore claim that the findings of this research are/or would be transferable to every family with a child with global developmental delay who is experiencing feeding challenges.

7.5 Recommendations

The mothers' experiences with seeking help for their child's feeding challenges were varied; varied in the sense that the mothers sought help at different stages of their child's development and from health professionals in different areas of expertise. One of the themes however that seemed to be common amongst the mothers was that their experience of seeking help was, as one mother described it: *"fragmented"*. Another talked about how *"everything we've had, we've had to fight for"*. Having no personal experience myself of the support that is available to families of a child with global developmental delay experiencing feeding challenges, I cannot personally provide any insight as to how things might be done differently in this regard. This study highlights that families do not appear to be getting appropriate support in addressing their child's feeding challenges and that the 'journey' for these families is being made all the more difficult in having to essentially fight to try and get some help.

Findings from this study have therefore illuminated that there is a ‘gap’ between expectation and experience when it comes to receiving help with the feeding challenges parents (or in this case – mothers) face with a child with global developmental delay. What seemed most upsetting, and sometimes distressing, for the mothers was that they had expected they would get the help they needed from the health professionals managing their child’s care, but that help never materialised. It appears there is still much that is not understood about how and why children with global developmental delay experience the feeding challenges that they do. I wonder whether the complexities of these feeding challenges contribute to health professionals feeling reluctant to offer advice or intervene in any way. It could perhaps feel ‘too hard’ to consider offering advice, and may also be viewed as something which falls outside the particular area of expertise of many health professionals. I believe the mothers in this study would have benefited from being informed that there would be limited, if any, help from within the health profession in addressing their child’s feeding challenges. Having this prior knowledge would have set the mothers on a path to looking for help either privately or, depending upon their beliefs, via alternative medicine. Perhaps this advice could be given to parents upon diagnosis of their child.

One mother in this study had experience of the Green Prescription programme as an intervention to try and get her son eating better and lose weight. She summed this intervention up in one word: “*ineffective*”. It appeared that the ‘ineffectiveness’ of this intervention was largely due to the lack of consideration the Green Prescription programme had in respect of feeding challenges in children with global developmental delay. While the nutritionist who worked with this family had prior experience working with children, his experience was limited to typically developing children and he was unable to offer a specialised plan for a child experiencing feeding challenges. The Green Prescription programme is a way for health professionals to provide patients with resources to enable them to make healthy lifestyle changes. I wonder if the health professional that wrote this script, while doing something positive to try and help this family, was aware that there was no specialised support within the Green Prescription programme for children with global developmental delay. A further recommendation from this study would therefore be that if

interventions are offered to children with global developmental delay, they are offered in such a way that takes into account the feeding challenges that these children experience, and that interventions are supported by professionals who have an understanding of what these feeding challenges entail.

This study has provided an insight into the lengths mothers will go to in order to achieve basic nutrition with their child, often with their child still having an extremely restricted repertoire of foods. Feeding goes beyond nutrition. The mothers in this study wanted to change feeding behaviours. They wanted to expand their child's repertoire of food. They wanted to expand their child's nutrition to be healthier. They wanted their child to have the ability to eat meals outside the family home. What the mothers essentially wanted was for feeding to be easier for their child and their family. Children with global developmental delay can experience a wide range of food aversions, intolerances and sensory processing issues and the mothers in this study highlighted the multi-factorial nature of their child's feeding challenges, and how things could, and often did, change. What all of this points to is that any potential interventions for feeding challenges for children with global developmental delay are never going to be a 'one-size-fits-all' approach. Appropriate interventions will need to account for all the factors that contribute to the challenges faced by the child and family at a given point in time. Additionally, interventions would need to be sensitive to the family's beliefs and take into consideration the family's situation, environmental factors and other stressors in the child or family's life. Finally, interventions would need to be offered within a trusting, mutually respectful parent-professional relationship. The health professionals involved in any potential interventions would need to have the appropriate background knowledge of the complex nature of the feeding challenges children with global developmental delay can experience. Additionally, knowledge and awareness of what families must deal with in trying to address their child's feeding challenges would place health professionals in a better position in terms of offering practical advice and support and this would in turn foster a collaborative parent-professional relationship.

My final recommendation, outside of any potential specialised interventions, is around the sharing of information. I believe there could be great benefit to families if health professionals were to share information about what approaches or strategies for

addressing feeding challenges have been successful for other families in similar circumstances. Many families (like the mothers in this study) are doing their own research and trialling interventions and strategies for themselves. With regards to the sharing of information, I am not suggesting that health professionals should be advocating certain dietary approaches or strategies, as I understand for many health professionals this may be outside their particular area of expertise and not an area they may be knowledgeable about. What I am suggesting is the sharing of success stories and offering the possibility of a new direction for families to explore when they are struggling to ‘find their own answers’. Sarah was one such mother and she summed up how she would like to see things for other families, like her own, in the future:

I feel grateful that I am a person who was able to do a lot of research and pull a lot of information together from a lot of different places in order to come to the conclusions that I've come to about the diet that we've implemented. I don't want to blow my own trumpet too much but there would be a lot of parents who wouldn't be able to bring that information together for themselves and I would hope that, I would love to see that, trusted medical professionals would be able to bring that information together for them and make those types of recommendations for just your normal everyday parent who is struggling like I was.

7.6 Suggestions for further research

This research has explored the experiences of families in providing nutrition to their child with global developmental delay. It has highlighted the lack of practical help and support that is available to families in managing their child's feeding challenges. My suggestion for further research would be to uncover what exactly ‘help’ would mean to families. What is it that would provide families with the ability to make positive changes to their child's nutrition and prevent the possible issue of overweight and/or obesity with their child? What are the needs of families in getting ‘help’ with their child's feeding challenges? In what form could or should ‘help’ be offered?

Another complementary piece of research could look at how health professionals view feeding challenges in children with global developmental delay. Should ‘help’ be expected to come from health professionals? If so, what would be the appropriate avenue for ‘help’, and what other opportunities might there be in offering support to families and to the children themselves?

7.7 Closing thoughts

This study has provided a window from which to view the phenomenon that is the experience of a mother providing nutrition to her child with global developmental delay. To truly understand this phenomenon I believe one would have to actually *be* the mother (or parent) of a child with global developmental delay who is experiencing feeding challenges. This study can only provide readers with some insight into the meaning of what this experience might be like.

The mothers chose to participate in this study because they wanted to be ‘heard’. They wanted to ‘speak up’ and give a voice to their experience. They wanted to share their ‘journey’. They hoped that sharing their journey would highlight the struggles they face and that some appreciation would be gained of what it is like to be on such a journey with very limited help and support. This study has revealed the courage of these mothers in living in a world filled with uncertainty. Despite all they must deal with in the day-to-day circumstances they find themselves in, they remain positive, they ‘own it’, and admirably, they ‘just get on with it’.

REFERENCES

- Abbyjan. (2013, February 3). A lifestyle that cannot be changed. [Web blog post]. Retrieved from <https://www.inspire.com/groups/my-child-without-limits/journal/a-lifestyle-that-cannot-be-changed/>
- Ahearn, W. H., Castine, T., Nault, K., & Green, G. (2001). An assessment of food acceptance in children with autism or pervasive developmental disorder-not otherwise specified. *Journal of Autism and Developmental Disorders*, 31(5), 505-511. doi:10.1023/a:1012221026124
- Allik, H., Larsson, J.-O., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health and Quality of Life Outcomes*, 4(1), 1.
- Aminah. (2012, May 21). I've realized I'll never be used to this. [Web blog post]. Retrieved from <https://www.inspire.com/groups/my-child-without-limits/journal/ive-realized-ill-never-be-used-to-this/>
- Ayto, J. (2011). *Dictionary of word origins*. New York, NY: Arcade Publishing.
- Baier, A. (1986). Trust and antitrust. *Ethics*, 96(2). doi:doi:10.2307/2381376
- Bandini, L., Curtin, C., Hamad, C., Tybor, D., & Must, A. (2005). Prevalence of overweight in children with developmental disorders in the continuous National Health and Nutrition Examination Survey (NHANES) 1999-2002. *The Journal of Pediatrics*, 146(6), 738-743. doi:10.1016/j.jpeds.2005.01.049
- Bandini, L., Curtin, C., Tybor, D., Hamad, C., & Must, A. (2003). Prevalence of overweight among children with mental retardation based on nationally representative surveys. *Obesity Research*, 11s(A120).
- Bergson, H. (2008). *Time and free will: An essay on the immediate data of consciousness*. New York: NY: Cosmio Books. (Original work published 1910)

- Black, C., Kaye, J. A., & Jick, H. (2002). Relation of childhood gastrointestinal disorders to autism: Nested case-control study using data from the UK General Practice Research Database. *British Medical Journal*, 325, 419-421.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), 409-423.
doi:10.1177/1362361304047224
- Brown, S. (2003). *How to negotiate with kids even when you think you shouldn't: 7 essential skills to end conflict and bring more joy into your family*. New York: NY: Viking.
- Buffart, L. M., Berg-Emons, R. J., Meeteren, J. V., Stam, H. J., & Roebroek, M. E. (2009). Lifestyle, participation, and health-related quality of life in adolescents and young adults with myelomeningocele. *Developmental Medicine & Child Neurology*, 51(11), 886-894. doi:10.1111/j.1469-8749.2009.03293.x
- Burklow, K. A., Phelps, A. N., Schultz, J. R., McConnell, K., & Rudolph, C. (1998). Classifying complex feeding disorders. *Journal of Pediatric Gastroenterology and Nutrition*, 27, 143-147.
- Carruth, B. R., Ziegler, P. J., Gordon, A., & Barr, S. I. (2004). Prevalance of "picky/fussy" eaters among infants and toddlers and their caregivers' decision about offering new food. *Journal of the American Dietetic Association*, 104, S57-S64.
- Cederlund, M., Hagberg, B., & Gillberg, C. (2010). Asperger syndrome in adolescent and young adult males. Interview, self - and parent assessment of social, emotional, and cognitive problems. *Research in Developmental Disabilities*, 31(2), 287-298. doi:http://dx.doi.org/10.1016/j.ridd.2009.09.006
- Chen, A. Y., Kim, S. E., Houtrow, A. J., & Newacheck, P. W. (2010). Prevalence of Obesity Among Children With Chronic Conditions. *Obesity*, 18(1), 210-213.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. St Leonards, Australia: Allen & Unwin.

- Curtin, C., Anderson, S. E., Must, A., & Bandini, L. (2010). The prevalence of obesity in children with autism: A secondary data analysis using nationally representative data from the National Survey of Children's Health. *BMC Pediatrics*, 10(11), 1-5.
- De, S., Small, J., & Baur, L. A. (2008). Overweight and obesity among children with developmental disabilities. *Journal of Intellectual & Developmental Disability*, 33(1), 43-47. doi:10.1080/13668250701875137
- Dovey, T. M., Staples, P. A., Gibson, E. L., & Halford, J. C. G. (2008). Food neophobia in childhood affects dietary variety. *Appetite*, 50, 181-193.
- Duarte, C. S., Bordin, I. A., Yazigi, L., & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, 9(4), 416-427. doi:10.1177/1362361305056081
- Dunn, M., Burbine, T., Bowers, C., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52. doi:10.1023/A:1026592305436
- Ebbeling, C. B., Pawlak, D. B., & Ludwig, D. S. (2002). Childhood obesity: Public-health crisis, common sense cure. *The Lancet*, 360(9331), 473-482. doi:http://dx.doi.org/10.1016/S0140-6736(02)09678-2
- Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities*, 30(1), 158-178. doi:http://dx.doi.org/10.1016/j.ridd.2008.02.003
- Emerson, E. (2009). Overweight and obesity in 3- and 5-year-old children with and without developmental delay. *Public Health*, 123(2), 130-133. doi:10.1016/j.puhe.2008.10.020
- Evans, E. W., Must, A., Anderson, S. E., Curtin, C., Scampini, R., Maslin, M., & Bandini, L. (2012). Dietary patterns and body mass index in children with autism and typically developing children. *Research in Autism Spectrum Disorders*, 6(1), 399-405. doi:http://dx.doi.org/10.1016/j.rasd.2011.06.014

- Faith. (2014, January 22). Two years after my son's diagnosis of colpocephaly. [Web blog post]. Retrieved from <http://www.inspire.com/groups/my-child-without-limits/journal/2-years-after-my-sons-diagnosis-of-colpocephaly/>
- Field, P. A., & Morse, J. M. (1985). *Nursing research: The application of qualitative approaches*. Maryland, Aspen: Rockwell.
- Fleischmann, A. (2004). Narratives published on the internet by parents of children with autism: What Do They Reveal and Why Is It Important? *Focus on Autism & Other Developmental Disabilities*, 19(1), 35-43.
- Frankl, V. (2006). *Man's search for meaning*. Boston, MA: Beacon Press.
- Gabriels, R. L., Agnew, J. A., Miller, L. J., Gralla, J., Pan, Z., Goldson, E., (. . .) Hooks, E. (2008). Is there a relationship between restricted, repetitive, stereotyped behaviors and interests and abnormal sensory response in children with autism spectrum disorders? *Research in Autism Spectrum Disorders*, 2(4), 660-670. doi:<http://dx.doi.org/10.1016/j.rasd.2008.02.002>
- Gillberg, C. (2010). The ESSENCE in child psychiatry: Early symptomatic syndromes eliciting neurodevelopmental clinical examinations. *Research in Developmental Disabilities*, 31(6), 1543-1551. doi:<http://dx.doi.org/10.1016/j.ridd.2010.06.002>
- Govier, T. (1992). Trust, distrust, and feminist theory. *Hypatia*, 7(1), 16-33. doi:10.2307/3810131
- Grant, B. C., & Bassin, S. (2007). The challenge of paediatric obesity: More rhetoric than action. *The New Zealand Medical Journal (Online)*, 120(1260), U2684.
- Greaves, T. (2010). *Starting with Heidegger*. New York, NY: Continuum.
- Hastings, R., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders*, 31(3), 327-336. doi:10.1023/A:1010799320795

- Hastings, R., Kovshoff, H., Ward, N., Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644. doi:10.1007/s10803-005-0007-8
- Heidegger, M. (1962). *Being and time* (J. McQuarrie & E. Robinson, Trans.). Oxford: Blackwell Publishing Ltd.
- Heidegger, M. (1971). *Poetry, language, thought*. New York, NY: Harper and Row.
- Hendy, H., Williams, K., Riegel, K., & Paul, C. (2010). Parent mealtime actions that mediate associations between children's fussy-eating and their weight and diet. *Appetite*, 54(1), 191-195. doi:http://dx.doi.org/10.1016/j.appet.2009.10.006
- 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*, 50(12), 874-882. doi:10.1111/j.1365-2788.2006.00904.x
- Horvath, K., Papadimitriou, J. C., Rabsztyrn, A., Drachenberg, C., & Tildon, J. T. (1999). Gastrointestinal abnormalities in children with autistic disorder. *The Journal of Pediatrics*, 135(5), 559-563. doi:http://dx.doi.org/10.1016/S0022-3476(99)70052-1
- Huws, J. C., Jones, R. S., & Ingledew, D. K. (2001). Parents of children with autism using an email group: A grounded theory study. *Journal of Health Psychology*, 6(5), 569-584. doi:10.1177/135910530100600509
- Iarocci, G., & McDonald, J. (2006). Sensory integration and the perceptual experience of persons with autism. *Journal of Autism and Developmental Disorders*, 36(1), 77-90. doi:10.1007/s10803-005-0044-3
- Jackson, J. (2004). *Multicoloured mayhem: Parenting the many shades of adolescents and children with autism, asperger syndrome and AD/HD*. London, United Kingdom: Jessica Kingsley.

- Janes, R., & Valintine, M. (2011). *Boy eats nothing but chicken skins for 12 years* [Close up]. Auckland, New Zealand: Television New Zealand.
- Johnson, C., Handen, B., Mayer-Costa, M., & Sacco, K. (2008). Eating habits and dietary status in young children with autism. *Journal of Developmental and Physical Disabilities*, 20(5), 437-448. doi:10.1007/s10882-008-9111-y
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-592. doi:10.1046/j.1365-2648.2001.01787.x
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: The case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890. doi:10.1046/j.1365-2648.1998.00725.x
- Koegel, R., Schreibman, L., Loos, L., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F., & Plienis, A. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22(2), 205-216. doi:10.1007/BF01058151
- Konstantareas, M. M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, 30(3), 459-470. doi:10.1111/j.1469-7610.1989.tb00259.x
- Kozlowski, A. M., Matson, J. L., Belva, B., & Rieske, R. (2012). Feeding and sleep difficulties in toddlers with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 6(1), 385-390. doi:http://dx.doi.org/10.1016/j.rasd.2011.06.012
- Large, W. (2008). *Heidegger's being and time*. Indiana, USA: Indiana University Press.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science & Medicine*, 47(7), 865-875. doi:http://dx.doi.org/10.1016/S0277-9536(98)00113-0

- Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 1-29.
- Legge, B. (2002). *Can't eat, won't eat: Dietary difficulties and autism spectrum disorders*. London, United Kingdom: Jessica Kingsley.
- Leonard, V. W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. *Advances in Nursing Science*, 11(4), 40-55.
- Lin, J.-D., Yen, C.-F., Li, C.-W., & Wu, J.-L. (2005). Patterns of obesity among children and adolescents with intellectual disabilities in Taiwan. *Journal of Applied Research in Intellectual Disabilities*, 18(2), 123-129.
doi:10.1111/j.1468-3148.2005.00241.x
- Linschoten, J. (1953). *Nawoord. Persoon en wereld. J.H van den Berg and J. Linschoten (eds)*. Utrecht: Erven J. Bijleveld.
- Liou, T.-H., Pi-Sunyer, F. X., & Laferrere, B. (2005). Physical disability and obesity. *Nutrition Reviews*, 63(10), 321-331. doi:10.1111/j.1753-4887.2005.tb00110.x
- Lobstein, T., Baur, L., & Uauy, R. (2004). Obesity in children and young people: A crisis in public health. *Obesity Reviews*, 5, 4-85. doi:10.1111/j.1467-789X.2004.00133.x
- Lockner, D. W., Crowe, T. K., & Skipper, B. J. (2008). Dietary intake and parents' perception of mealtime behaviors in preschool-age children with autism spectrum disorder and in typically developing children. *Journal of the American Dietetic Association*, 108(8), 1360-1363.
doi:10.1016/j.jada.2008.05.003
- Lukens, C., & Linscheid, T. (2008). Development and validation of an inventory to assess mealtime behavior problems in children with autism. *Journal of Autism and Developmental Disorders*, 38(2), 342-352. doi:10.1007/s10803-007-0401-5
- Manikam, S., & Perman, J., A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, 30, 34-36.

- Matson, J. L., Boisjoli, J. A., Hess, J. A., & Wilkins, J. (2010). Factor structure and diagnostic fidelity of the baby and infant screen for children with autism. *Developmental Neurorehabilitation, 13*(2), 72-79.
doi:doi:10.3109/17518420903213576
- Matson, J. L., Carlisle, C. B., & Bamburg, J. W. (1998). The convergent validity of the Matson Evaluation of Social Skills for individuals with severe retardation (MESSIER). *Research in Developmental Disabilities, 19*(6), 493-500.
doi:http://dx.doi.org/10.1016/S0891-4222(98)00020-1
- Matson, J. L., & Fodstad, J. C. (2009). The treatment of food selectivity and other feeding problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*(2), 455-461. doi:10.1016/j.rasd.2008.09.005
- Matson, J. L., Fodstad, J. C., & Dempsey, T. (2009). The relationship of children's feeding problems to core symptoms of autism and PDD-NOS. *Research in Autism Spectrum Disorders, 3*(3), 759-766.
doi:http://dx.doi.org/10.1016/j.rasd.2009.02.005
- Matson, J. L., Leblanc, L. A., & Weinheimer, B. (1999). Reliability of the Matson Evaluation of Social Skills in individuals with severe retardation (MESSIER). *Behavior Modification, 23*(4), 647-661. doi:10.1177/0145445599234008
- Matson, J. L., Mahan, S., Hess, J. A., & Fodstad, J. C. (2010). Effect of developmental quotient on symptoms of inattention and impulsivity among toddlers with autism spectrum disorders. *Research in Developmental Disabilities, 31*(2), 464-469. doi:http://dx.doi.org/10.1016/j.ridd.2009.10.014
- Matson, J. L., Mahan, S., Hess, J. A., Fodstad, J. C., & Neal, D. (2010). Progression of challenging behaviors in children and adolescents with autism spectrum disorders as measured by the Autism Spectrum Disorders-Problem Behaviors for Children (ASD-PBC). *Research in Autism Spectrum Disorders, 4*(3), 400-404. doi:http://dx.doi.org/10.1016/j.rasd.2009.10.010
- Matson, J. L., & Wilkins, J. (2007). A critical review of assessment targets and methods for social skills excesses and deficits for children with autism

- spectrum disorders. *Research in Autism Spectrum Disorders*, 1(1), 28-37.
doi:<http://dx.doi.org/10.1016/j.rasd.2006.07.003>
- McDonald, L., Rennie, A., Tolmie, J., Galloway, P., & McWilliam, R. (2006). Investigation of global developmental delay. *Archives of the Disabled Child*, 91, 701-705. doi:10.1136/ad.2005.078147
- Ministry of Health. (2012). *Food and nutrition guidelines for healthy children and young people (aged 2-18). A background paper*. Wellington: Ministry of Health.
- Ministry of Health. (2013). *New Zealand Health Survey: Annual update of key findings 2012/13*. Wellington: Ministry of Health.
- Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics*, 119(5), e1040-e1046. doi:10.1542/peds.2006-2819
- Moore, C. (2005). *George and Sam*. New York, NY: Penguin Books.
- Mugno, D., Ruta, L., D'Arrigo, V., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, 5(1), 22.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). My greatest joy and my greatest heart ache: Parents own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670-684. doi:10.1016/j.rasd.2009.01.004
- Nurullah, A. S. (2013). "It's really a roller coaster": Experience of parenting children with developmental disabilities. *Marriage & Family Review*, 49(5), 412-445. doi:10.1080/01494929.2013.768320
- Ogden, C. L., Carroll, M. D., & Curtin, L. R. (2010). Prevalence of high body mass index in US children and adolescents in the United States. *The Journal of American Medical Association*, 303(3), 242-249.

- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45(6), 535-543. doi:10.1046/j.1365-2788.2001.00372.x
- Overton, P. (1975). *The leaning tree*. St Louis, MO: Bethany Press.
- Oxford English Dictionary. (2011). (12th ed.). Oxford, United Kingdom: Oxford University Press.
- Reichman, N., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal*, 12(6), 679-683. doi:10.1007/s10995-007-0307-z
- Reinehr, T., Dobe, M., Winkel, K., Schaefer, A., & Hoffman, D. (2010). Obesity in disabled children: An overlooked group of patients [Review Article]. *Deutsches Arzteblatt International*, 107(15), 268-275. doi:10.3238/arztebl.2010.0268
- Rimmer, J. H., Rowland, J. L., & Yamaki, K. (2007). Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health*, 41(3), 224-229. doi:http://dx.doi.org/10.1016/j.jadohealth.2007.05.005
- Riou, E. M., Ghosh, S., Francoeur, E., & Shevell, M. I. (2009). Global developmental delay and its relationship to cognitive skills. *Developmental Medicine and Child Neurology*, 51(8), 600-606.
- Rogers, L., Magill-Evans, J., & Rempel, G. (2011). Mother's challenges in feeding their children with autism spectrum disorder - managing more than just picky eating. *Journal of Developmental and Physical Disabilities*, 1-15. doi:10.1007/s10882-011-9252-2
- Schmitt, L., Heiss, C. J., & Campbell, E. E. (2008). A comparison of nutrient intake and eating behaviors of boys with and without autism. *Topics in Clinical Nutrition*, 23, 23-31.
- Schreck, K., & Williams, K. (2006). Food preferences and factors influencing food selectivity for children with autism spectrum disorders. *Research in Developmental Disabilities*, 27(4), 353-363. doi:10.1016/j.ridd.2005.03.005

- Schreck, K., Williams, K., & Smith, A. (2004). A comparison of eating behaviors between children with and without autism. *Journal of Autism and Developmental Disorders*, 34(4), 433-438.
doi:10.1023/b:jadd.0000037419.78531.86
- Schwichtenberg, A., & Poehlmann, J. (2007). Applied behaviour analysis: Does intervention intensity relate to family stressors and maternal well-being? *Journal of Intellectual Disability Research*, 51(8), 598-605.
doi:10.1111/j.1365-2788.2006.00940.x
- Simeonsson, R. J. (2002). Secondary conditions in children with disabilities: Spina bifida as a case example. *Mental Retardation & Developmental Disabilities Research Reviews*, 8(3), 198-205.
- Smith, K. R. M., & Matson, J. L. (2010). Social skills: Differences among adults with intellectual disabilities, co-morbid autism spectrum disorders and epilepsy. *Research in Developmental Disabilities*, 31(6), 1366-1372.
doi:http://dx.doi.org/10.1016/j.ridd.2010.07.002
- Smythe, E. (2000). *The structure of a phenomenological/hermeneutic thesis*. Unpublished paper, Auckland University of Technology. pp 1-9.
- Twachtman-Reilly, J., Amaral, S. C., & Zebrowski, P. P. (2008). Addressing feeding disorders in children on the autism spectrum in school-based settings: Physiological and behavioral issues. *Lang Speech Hear Serv Sch*, 39(2), 261-272. doi:10.1044/0161-1461(2008/025)
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. New York, NY: State University of New York Press.
- Van Manen, M. (2002). Care as worry, or "Don't worry be happy". *Qualitative Health Research*, 12, 262-278.
- Williams, J. (2010). Global developmental delay - globally helpful? *Developmental Medicine and Child Neurology*, 52(3), 227-227.

- Williams, K., Field, D., & Seiverling, L. (2010). Food refusal in children: A review of the literature. *Research in Developmental Disabilities*, 31(3), 625-633. doi:<http://dx.doi.org/10.1016/j.ridd.2010.01.001>
- Williams, K., Gibbons, B., & Schreck, K. (2005). Comparing selective eaters with and without developmental disabilities. *Journal of Developmental and Physical Disabilities*, 17(3), 299-309. doi:10.1007/s10882-005-4387-7
- Wong, V. C. N. (2011). Global developmental delay – a delay in development of terminology. *Developmental Medicine & Child Neurology*, 53(7), 585-585. doi:10.1111/j.1469-8749.2011.03986.
- World Health Organization. (2010). *Global prevalence and trends of overweight and obesity among school children*. Retrieved 28th May, 2012, from http://www.who.int/entity/nutgrowthdb/publications/overweight_obesity/en/
- World Health Organization. (2011). *Obesity and overweight*. Retrieved 19th April, 2012, from <http://www.who.int/mediacentre/factsheets/fs311/en/index.html>
- Yamada, A., Suzuki, M., Kato, M., Suzuki, M. I. E., Tanaka, S., Shindo, T., (. . .) Furukawa, T. A. (2007). Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry and Clinical Neurosciences*, 61(6), 651-657. doi:10.1111/j.1440-1819.2007.01736.x

APPENDIX A



A U T E C
S E C R E T A R I A T

9 May 2013

Tineke Water
Faculty of Health and Environmental Sciences

Dear Tineke

Re Ethics Application: **12/123 Families' experience of providing nutrition to their overweight/obese child with global developmental delay: A phenomenological study.**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 8 May 2016.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 8 May 2016.
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 8 May 2016 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Madeline Banda
Acting Executive Secretary
Auckland University of Technology Ethics Committee

APPENDIX B



A U T E C
S E C R E T A R I A T

12 March 2014

Tineke Water
Faculty of Health and Environmental Sciences

Dear Tineke

Re: Ethics Application: **12/123 Families' experiences of providing nutrition to their child with global developmental delay.**

Thank you for your request for approval of amendments to your ethics application.

I have approved minor amendments to your ethics application allowing changes to the recruitment protocol and a change in the title.

I remind you that as part of the ethics approval process, you are required to submit the following to AUTEK:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 8 May 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 8 May 2016 or on completion of the project.

It is a condition of approval that AUTEK is notified of any adverse events or if the research does not commence. AUTEK approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEK grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

APPENDIX C

Participant Information Sheet



Date Information Sheet Produced:

24th February 2014

Project Title

Families' experiences of providing nutrition to their child with global developmental delay.

An Invitation

Hello. My name is Tania Brown and I am embarking on this research project as part of my master's thesis. Children who are globally developmentally delayed are known to have difficult eating behaviours and food preferences, and I want to gain an understanding of some of the challenges that can be faced in providing nutrition to these children. As a family with a globally developmentally delayed child, I would like to invite you to take part in this research. Your participation in this research project is entirely voluntary. If for any reason prior to the completion of data collection, you decide you no longer wish to participate, you may withdraw at any time without any adverse consequences.

What is the purpose of this research?

The purpose of this research is to explore and describe the experience of families in providing nutrition to their globally developmentally delayed child. This study is being carried out as part of my Master of Health Science Degree at Auckland University of Technology (AUT). In addition to the publication of a master's thesis, the findings of this study will be shared with a wider group of health and educational professionals and other interested individuals. Findings may be published in professional child health journals and presented at professional child health conferences.

How was I identified and why am I being invited to participate in this research?

You may have been invited to this study either through your child's school or through the Autism Society of New Zealand. Alternatively, it is possible a friend or colleague may have asked whether you would be happy for me to contact you. You have been invited to participate in this study because you have a developmentally delayed child in your family, and as a family, have experienced challenges around nutrition.

What will happen in this research?

I would like to interview you and ask you to tell me your story of the experience of providing nutrition to your child. The interview will last between 60-90 minutes and will be

more like an informal discussion. The interview will take place at a time and place that is convenient to you, and with your consent, will be audiotaped. I may need to contact you again after the interview to clarify some points raised in the interview. Prior to completion of the study, the data I have gathered from you will be returned to you to enable you to make changes as you see fit and/or to request the withdrawal of anything you do not wish to be made public.

What are the discomforts and risks?

It is possible that some of the experiences you share about providing nutrition to your child may evoke strong emotions. I will, at all times, be sensitive to your feelings and discontinue taping the interview should you request me to do so.

How will these discomforts and risks be alleviated?

You may choose not to talk about particular experiences, or choose not to answer any questions that you find distressing or uncomfortable. You may also choose to withdraw from the interview and/or the study at any time. Additionally, should you feel emotionally distressed as a result of the interview, I can refer you to a counsellor from the AUT Counselling Service for three counselling sessions which will be provided at no financial cost to yourself.

What are the benefits?

Although there may not be any immediate benefits of your participation in this research, the stories you share will be contributing to the body of knowledge about the challenges of providing nutrition to a child with global developmental delay. This may contribute to a better understanding by professionals and individuals who are involved in some aspect of the health, nutrition, and educational care of your child. It may also contribute to the development of more appropriate interventions for you and your child that take into account some of these challenges.

How will my privacy be protected?

To ensure your privacy and confidentiality is maintained, I will take the following steps:

1. I will not divulge your true identity to anyone other than my supervisor, Dr. Tineke Water
2. Your name will be substituted with a pseudonym (false name) in all reporting of the study findings
3. All identifying information that I gather will be kept in a secure place that is only accessible to myself and my supervisor, Dr. Tineke Water
4. Upon completion of the study all the data collected will be stored securely on AUT premises for six years. The audiotape of your interview will be offered back to you once the work is completed, or you may request that it be destroyed.

What are the costs of participating in this research?

The main cost of participating in this study is your personal time for the interview (60-90 minutes) and possibly a follow-up telephone call (20 minutes). If you choose to take part, the interview will be held at a place that is convenient to you. Any travel costs that you incur will be reimbursed in the form of taxi costs or petrol vouchers.

What opportunity do I have to consider this invitation?

You have two weeks to consider this invitation. It would be appreciated if you could advise of your intended participation in this study within two weeks of receiving this information sheet.

How do I agree to participate in this research?

If you decide you would like to participate in this study please contact my supervisor, Dr. Tineke Water, or myself by telephone or e-mail. You will be asked to sign a consent form prior to being interviewed. We will send this form out to you when you advise us of your intended participation.

Will I receive feedback on the results of this research?

You will have the opportunity to view and approve the data I gather from you prior to the completion of the study. You will have access to my completed thesis and any research journal article(s) that are sent for publication. If you indicate on the consent form that you wish to receive a copy of the summary research report then this will be sent to you on completion of my thesis. On completion of the study, I will be more than happy to discuss the findings with you and answer any questions you may have. You will also be welcome to attend any public presentations where the findings of the study are discussed.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr. Tineke Water, tineke.water@aut.ac.nz, 921 9999 extn 7335.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details:

Tania Brown, tanbro01@aut.ac.nz, 021 0272 1932

Project Supervisor Contact Details:

Dr. Tineke Water, tineke.water@aut.ac.nz, 921 9999 extn 7335

Approved by the Auckland University of Technology Ethics Committee on 9th May 2013, AUTC Reference number 12/123.

APPENDIX D

Consent Form



Project title: **Families' experiences of providing nutrition to their child with global developmental delay.**

Project Supervisor: **Dr. Tineke Water**

Researcher: **Tania Brown**

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 24th February 2014.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one):
Yes ☐ No ☐

Participant's signature:

Participant's name:

Participant's Contact Details (if appropriate):

.....

.....

.....

.....

Date:

Approved by the Auckland University of Technology Ethics Committee on 9th May 2013, AUTEK Reference number 12/123