

# **Glimpses of Eternity**

## **Sampled Mormon Understandings of Disability, Genetic Testing, and Reproductive Choice in New Zealand**

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## Abstract

This research explores the narratives of seventeen members of the Church of Jesus Christ of Latter-day Saints (LDS) in Southern New Zealand as they explain the meaning of disability and prenatal genetic testing, and its ethical and spiritual significance within their lives. Qualitative interviews were conducted with participants who were careworkers, parents of children with disabilities, and people with disabilities. This thesis analyses these narratives of life with the experience of one or several impairments, and the LDS doctrine of the spirit's journey explained against Frank's (1995) outline of illness and disability narratives. The narratives related by the participants reveal a spiritual model of disability, which is then compared to Beatson's (2004) models of disability. The faith-based approach to viewing these issues, which the LDS participants describe, reveals a unique disability cosmology. For example, most participants believed that a spirit is autonomous and chooses in the pre-mortal existence to live out life with a disability. Additionally, LDS doctrine teaches that in the resurrection, all bodies will be made whole. Thus, disability is only a temporary condition in the eternal scheme, and this eternal timeframe through which the participants viewed disability is a strong point of contrast with most contemporary models of disability. Furthermore, many participants rejected prenatal genetic testing in their own family life because of their spiritual understanding of disability. However, when speaking to the wider social and regulatory environment surrounding genetic testing, participants expressed a range of ideals displaying varying degrees of opinions from extremely averse to hesitantly supportive of people's rights to engage in prenatal genetic testing.

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## List of Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ICC	International Criminal Court
IVF	In Vitro Fertilization
LDS	Latter-day Saints
NECAHR	National Ethics Committee on Assisted Human Reproduction
PGD	Preimplantation Genetic Diagnosis
PKU	Phenylketonuria

## I. Introduction

Emerging reproductive biomedical technologies form a new world in which every pregnant woman at times becomes a “moral philosopher” (Rapp, 1998). By examining the ways in which some New Zealand Members of the Church of Jesus Christ of Latter-day Saints (more commonly referred to as LDS or Mormons) construct a model of disability through the lenses made available within LDS doctrine and personal life experiences, this thesis explores how participants create ethical conceptions of genetic and reproductive decisions. The thesis also contributes to a larger Marsden-funded research project, “Troubling Choice: exploring and explaining techniques of moral reasoning for people living at the intersection of reproductive technologies, genetics, and disability.” Specifically, this research project considers how Mormonism creates a framework to interpret the spiritual and practical dimensions of disability, and the moral implications surrounding prenatal genetic testing.

Understandings of disability and prenatal genetic technologies are often intrinsically intertwined with spiritual beliefs and religiosity forms one of several possible frameworks to interpret the moral dilemmas surrounding reproductive decision-making. Furthermore, spirituality and religiosity may construct a model of understanding of what it means to be disabled or what it might mean to give birth to a person with an impairment. The decision-making processes associated with these critical life events are often complex and difficult for people when confronted with prenatal genetic testing options such as preimplantation genetic diagnosis (PGD), amniocentesis, or other antenatal diagnostic testings. In these contexts, what are the cognitive processes and situational factors influencing these vital decisions of who is born and who is not?

John Evans suggests that it is critical to consider religious views when it comes to reproductive genetic technology: “To understand the potential of the more public debate, it is important to understand the views of the average member of various religious traditions” (2006:1047). Taking to heart Evans’ suggestion, this ethnography explores the narratives of seventeen Southern New Zealand members of The Church of Jesus Christ of Latter-Day Saints as they explain the meaning and spiritual significance of disability within their lives. Participants include careworkers, parents of children with disabilities, and people with disabilities themselves.

To explore the ‘average’ member’s account should not however imply that there is a homogenizing sameness to every member’s thinking (Hewison et al., 2008). This thesis suggests instead that we need to follow the inventive and strategic ways that ‘average’ members of religious communities draw on doctrinal knowledge to authorise certain and sometimes quite varied uses of genetic and reproductive technologies. This is certainly the case for the people sampled in this study, who although sharing the same religion, had diverse opinions about the ethics of reproductive technologies. This remains true despite the fact that the Church of Jesus Christ of Latter-day Saints is a highly integrated and globalised religion incorporated into almost every aspect of the daily life of its active members. And so this thesis will explore how the seventeen participants utilised Mormonism to create a framework to understand genetic testing and disability through the understanding of doctrine, practical experience of caretaking, and/or through the lived experience of those who needed to make these decisions as parents.

## **Design and Methods**

An anthropology of one’s own people is the most arduous, but also the most valuable achievement of a fieldworker. (Malinowski, 1939:xiii)

Using a mixture of interviews with LDS members who worked extensively with people with special needs, members who have children with disabilities, and members with disabilities, I explored the specifically LDS meaning of disability and perception of genetic testing for participants. Interviews were conducted with open-ended questions allowing participants to engage in a narrative about their experiences, religious beliefs, and attempts to reconcile the two. Some of the interview questions included:

- Could you explain the meaning of disability to you?
- What do you think the purpose of disability is in this life?
- Are there spiritual dimensions of disability?
- How do your religious beliefs shape the way you think about these things?
- Is there anything unique about the way members of the LDS Church think about disability?
- Could you explain the significance of prenatal genetic testing to you?
- Is genetic testing something that you have considered in your life and could you explain your reasons for whether or not to use it personally or for a family member?
- How have your beliefs influenced your opinions about genetic testing?

Membership within the Church of Jesus Christ of Latter-day Saints was thus a critical component of this project to gain entrée and rapport with the subjects and was the basis for a reflexive analytical approach. Researching Mormons in New Zealand exposed me to a different perspective of the religion in which I was raised (I was born and have lived most of my life in the United States) and allowed me to assess the role of local cultures in shaping the experiences of other Mormons. However, because of my divided identity, I found myself in a position similar to what Lila Abu-Lughod (1991) described as being a “halfie” anthropologist. Abu-Lughod found herself in a complex situation conducting anthropology among Arabian women, being a half-Arabian woman herself. While my juxtaposition of being an anthropological researcher and being Mormon provided me with both etic and emic perspectives on this topic, I was forced to mediate an asymmetrical relationship within myself. The participants were aware that I was raised LDS, therefore I had roots of entry and access to the communal knowledge that others would not. Participants perhaps spoke more freely with the language and jargon because they knew I would understand. They also took some risks by openly sharing opinions that sometimes went against doctrines of the Church even though they knew that I was aware of the doctrines as well. Medical anthropologists and disability scholars, Kasnitz and Shuttleworth (2001) suggest, “Anthropologists seek the other to find themselves” (2001:2) however, I found the relationship between self/other was ambiguous throughout my research journey.

As a basis for conducting and analysing fieldwork, I applied principles outlined in Emerson, Fretz, and Shaw’s (1995) manual, *Writing Ethnographic Fieldnotes*. To find themes within the transcripts of the interviews, I also used the method of open-coding that Strauss and Corbin advocate in their manual, *Basics of Qualitative Research*: “Data are broken down into discrete parts, closely examined and compared for similarities and differences” (1998:102). I chose to use grounded theory as my main method because it worked well with the qualitative nature of this ethnography. Using the interviews as empirical data, I analysed the data without a preconceived theory in mind. I transcribed the interviews, printed them out, and re-read them several times to pick out themes that emerged repeatedly. I then pulled all of the most prominent themes from the interviews and discuss them in this thesis. My analytic approach derived from grounded theory and textual deconstruction to create a critical account of the meaning and management of genetic testing and disability in New Zealand Mormon society. The prominent themes emerging from the interviews that will be discussed throughout the thesis were:

- Purpose of disabilities
- Plan of Salvation
- Spirits volunteering to have this body
- Special spirits
- Being Mormon and being disabled
- Genetic testing
- Termination
- Choosing not to have more children
- Strength from gospel faith

The participants were offered anonymity but most chose to use their first names—some of the names used are aliases. Ethical approval for this research was obtained as part of the Marsden-funded research project, “Troubling Choice” and was granted by the University of Otago Human Ethics Committee Category A (reference number 10/110).

I originally planned to site my study in various cities throughout the North and South Island of New Zealand, but after becoming involved with the LDS community in Dunedin, I found that Dunedin and its surrounding areas had a rich pool of people from which to draw participants. Initially, I found participants through some previously established contacts I had made when I came to New Zealand in 2010 to conduct research with Fitzgerald and Nuckolls. From that point onward, I used the social networking site, Facebook, to stay in contact with members of the LDS community. When I began my fieldwork, I posted an inquiry on the LDS Young Single Adult Facebook group page (Dunedin LDS, 2012) describing my research and asking if anybody knew of someone willing to participate. I informed the Branch President (the congregation leader) of my intent to conduct research with members in the LDS community. He told me that he was enthusiastic about research but because of some regulations outlined in the Priesthood Handbook of Instructions (LDS Church 2006), he advised that I should use discretion when recruiting members at the church building specifically. Being limited in searching for participants at church, I had the opportunity of attending the branch picnic, which was held in the Botanic Gardens, to approach members to find possible interviewees. A few more participants were acquired using the snowball technique, where I asked my informants if they knew of anyone else that I could interview—and this was my most fruitful method for recruiting.

The interviews took place either in the participants’ homes, or in one of the study rooms in the Central Library at the University of Otago. All interviews consisted of open-ended questions that allowed participants to engage in narratives about their beliefs and

experiences around disability and genetic testing. Interviews lasted between 45 minutes to two and a half hours. I interviewed seventeen people in total. All of the participants were members of the Church of Jesus Christ of Latter-day Saints. At least two participants had been inactive for a while but had since come back to full activity within the Church. One participant is currently inactive but still upholds many of the teachings and traditions of the Church. Three of the interviews were conducted with couples who were parents of children with disabilities. At least five people I interviewed were special needs educators or careworkers, but I also found that several people who had children with disabilities also worked in special needs education or care. I interviewed three people with impairments themselves. However, while interviewing careworkers, educators, or parents, I found that people brought personal problems up in the context of disability with their own chronic illnesses, behavioural problems, or disorders—so there was much overlapping between categories of participants, as one would expect in a study that explored disability. The intersecting categories of participants are representative of the dynamic and complex quality of disability according to Peter Beatson (2004), a New Zealand disability scholar and sociologist, who is also blind. Beatson's models of disability, which will be used as a framework throughout this thesis, will be further discussed in Chapter Two.

In this next section of the chapter I would like to spend some time introducing the participants in this study in some more detail. First, although my focus has been on New Zealanders particularly, it is important to note the transnational identity of some of my participants. Writing on transnationalism and globalisation, Rapport and Dawson (1998:23) address the fluid concept of “cultural worlds and boundaries” resulting from the increasing relative ease of travel. For example, two participants to whom I refer as Steve and Vivian were from Utah but they have lived in Dunedin every summer since the 1980s while Steve teaches a course at the University of Otago. They used to bring their thirty-eight-year-old son, Jacob, who has Down syndrome, but since he started working in a mailroom in the United States, they leave him behind while they come to New Zealand. Jacob is self-sufficient and Steve and Vivian think he is quite possibly a savant when it comes to movies.

Another participating couple whom I have termed John and Beverly have a grown son, Robert, who is deaf. Robert grew up in Dunedin but now teaches mathematics at a school for children who are deaf in the United States. His parents still live in Dunedin but Skype with Robert and his family frequently. I interviewed Robert via email correspondence and I was fortunate enough to get to meet him when I returned to the United States for a brief period during 2012.

Another participant, identified as Carol, teaches drama for a living and publishes children's literature. She has a twenty-nine-year-old son with cerebral palsy and epilepsy. She has Obsessive Compulsive Disorder (OCD) herself. Nicola is a lecturer who lives in Christchurch and has a twenty-one-year-old son, Jonathan, who is blind and autistic. Jonathan is a gifted pianist and organist. He appeared on the television show *New Zealand's Got Talent*, and also on *Sesame Street*. Jonathan is going to be the keynote speaker at an autism conference this year in Australia. Dave is a New Zealand man who married a woman from Fiji, Nirmala. They have a three-year-old son with Down syndrome, Edward, who loves to sing, dance, and play games.

Another person with whom I spoke was Jennifer, who has an intellectual disability. She likes to play touch rugby and is learning how to play the guitar. Fay worked with special needs children, has chronic fatigue, and has a twenty-four-year-old son, Ben, who has ADD and Asperger's. Sam currently works in a residential home taking care of men with special needs. Michael previously worked in a care home. Shona worked with children with special needs in daycare and high school and has sons with ADD and depression. Diane currently works with high schoolers with special needs. Ace's mother was a matron at a mental hospital in the Pacific Islands and she grew up on the mental hospital grounds. She now studies psychology at the University of Otago and plans to go back one day to help decrease the stigma of mental illnesses in the Pacific Islands. As demonstrated, participants come from a diverse range of backgrounds, ages, and interests.

Another person who is not a participant but who is mentioned throughout the thesis is author and editor Kathryn Soper. Soper is most well known for compiling and editing *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* (2007) a book that is utilised by New Zealand's Saving Down's Group to substantiate their opinions about prenatal genetic testing. She stated in her memoir *The Year My Son and I were Born* (2009) that her drive to gather essays for the book *Gifts* compelled her because, as she stated, "I was horrified to read about obstetricians and perinatologists giving subtle or not-so-subtle pressure to terminate pregnancy. And I was even more horrified when I learned the abortion rate for fetuses prenatally diagnosed with Down syndrome: 90 percent<sup>1</sup>" (2009:285). Her son Thomas was born with Down syndrome. She is also a Mormon. Even though she does not reside in New Zealand, her memoir complements the narratives I gathered from New Zealand Mormon participants.

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<sup>1</sup> This figure is from the United Kingdom (Morris, 2010). It is not a New Zealand figure.

## Narratives

Narrative ethics is complete, within its sphere. This sphere is not clinical adjudication but personal becoming. Narrative ethics is an ethics of commitment to shaping oneself as a human being. Specific stories are the media of this shaping, and the shaping itself is the story of a life...Thinking *with* stories is the basis of narrative ethics. (Frank 1995:158)

Eliciting narratives from participants is a crucial component of the interview method. Participants in this study produced rich narratives that provided insight into their lives and beliefs. Medical anthropology recognizes the increasing significance of narratives as empirical data as well as “the centrality of narratives to the life worlds of informants” (Young, 2010). Not only do narratives have value as data but they also wield influence as a source of experiential knowledge that others can turn to. France, Wyke, Ziebland, Entwistle, and Hunt (2011) examined thirty-seven qualitative interviews with women from the UK and their perceptions of diagnostic testing from 55 pregnancies. When it comes to genetic testing, France et al. purport that women facing life-altering decisions about prenatal diagnostic testing more often turn to others’ personal experiences and narratives as a source for information about how to proceed. France et al. affirm, “The concept of ‘experiential knowledge’ recognises the kinds of knowing that arise from everyday interactions and interpersonal experiences, and through which everyday life events are interpreted” (2011:755). Similarly, this thesis examines disability and genetic testing through the window that narratives provide into the everyday ‘experiential knowledge’ gained in the lives and experiences of the participants.

France et al. reference Abby Lippman, a medical anthropologist who focuses on reproduction and biotechnology. Lippman notes that women utilise “various transformative, interpretive and integrative processes...to refashion ‘received’ biomedical information, taking ownership of it and weaving it together with their own experiences and understandings and with ‘inside’ information, their feelings and beliefs” (Lippman, 1999:259). Women thus use stories as a way to process information and make decisions about prenatal testing. Both male and female participants in this study provided stories of what life is like to have a disability, or to care for people with disabilities. These narratives can contribute to the sources of information that people use to make decisions about diagnostic testing.

The influence of stories in how we view the world and make decisions, is why I chose to analyse my data drawing from the works of Arthur Frank (1995), who wrote *The Wounded Storyteller*, in which he outlines three schemas of illness and disability narratives—Restitution, Chaos, and Quest. Frank observes from a collection of works and life experiences that ill or impaired people are not only patients of medicine or victims of circumstance but they are storytellers—the stories they tell become a fundamental aspect of identity and help make sense of suffering. The restitution narrative suggests that illness is only temporary and finds hope in medical or technological healing. The chaos narrative is one that is trapped in the thick of the relentless struggle with illness. The quest narrative accepts illness as a transformative experience for wisdom and personal growth. Within this thesis, I will compare these three schemas to fundamental LDS doctrinal teachings that participants referenced while expressing opinions about disability and genetic testing. Because of this affinity between the illness narratives and the theological narratives the participants related, the comparisons will be highlighted as “interludes” woven throughout the thesis. I chose this unconventional layout to develop a narrative within the thesis itself. Such an arrangement serves two purposes. I hope to be an ethical witness to the participants’ stories with an analysis that in turn draws on the richness and depth of narrative to create shared meaning. I also intend to use these interludes to convey to readers less familiar with the Mormon faith, some of the lyricism and beauty of its core doctrinal beliefs and narrative interludes suit such a purpose admirably. This unorthodox style of laying out the thesis also symbolises and encompasses the interspersed of eternal memories throughout life.

## **Some Notes on Terminology**

Before moving on, it is necessary to make some clarifications on terminology and phrases used throughout the thesis. In the first place, I would like to define the difference between spirituality and religion, given the prominent role of religious faith for most of my participants’ lives. Often, participants divided their metaphysical reflections on the ethical dilemmas of genetic testing into the realms of spirituality and religiosity and assigned different meanings to these terms. A useful definitional statement on these terms comes from Selway and Ashman (1998) who explored the literature involving disability, religion, and health. They referred to a conference held in the United States that defined the term “‘spirituality’ as being ‘related to perceptions of the transcendent’ and ‘religiosity’ as being ‘related to the group behaviours and social institutions that arise around those perceptions’”

(Selway and Ashman, 1998:430). For the participants in this study both religion and spirituality are integral aspects of being a dedicated member. Whether formally structured or a more individualistic approach, spirituality and religiosity both provide lenses to view and make sense of life and its unforeseeable circumstances. However, I found that (true to Selway and Ashman's [1998] definition) my participants dichotomized their experiences of the Church and the gospel. When mentioning the formal institution of the Church, members illustrated some concerns with the organisation—this will be discussed further in Chapter Four. But, as discussed in Chapter Nine, when referencing the gospel, members expressed the strength they gained from their faith.

When referring to the members of the Church of Jesus Christ of Latter-day Saints, for ease and sake of space I will call them by their colloquial nickname, Mormons or LDS members. When referring to the Church of Jesus Christ of Latter-day Saints, I generally use the phrase “the Church.” There has always been debate around the nickname, “Mormon,” given to the Church. Recently, in an LDS General Conference, the apostle, Elder M. Russell Ballard addressed this issue:

While *Mormon* is not the full and correct name of the Church, and even though it was originally given by our detractors during our early years of persecution, it has become an acceptable nickname when applied to members rather than the institution. We do not need to stop using the name *Mormon* when appropriate, but we should continue to give emphasis to the full and correct name of the Church itself. In other words, we should avoid and discourage the term ‘Mormon Church.’ (LDS.org, 2011: Ballard)

The political correctness of certain phrases is constantly changing. At the time I am writing my thesis, it is more correct to use the term “people with disabilities” rather than “disabled people.” But even that phrase is in debate. Shuttleworth and Kasnitz argue, “We use disabled people in preference to people with disabilities to reflect that disability is not a part of the impaired person but is a social process that disables.” (Shuttleworth & Kasnitz 2004:141). In a later section I will explore further the difference between impairment and disability, and readers will note that I use the terms sometimes interchangeably. However, since it is more widely accepted to use the term “people with disabilities,” that is the phrase I will use in this thesis. This phrase, I believe, encapsulates both the personal physical impairment and the external societal barriers that disable a person. In a few years' time, however, like the word “handicap,” this phrase will most likely become superseded by a new phrase that will come into vogue.

My colleague, who works in a high school with students with special needs, advised me that it is important to not refer to a person by their disability first. For example, it is more

sensitive to say “the boy, who has Down syndrome” rather than “the Down syndrome boy.”

One of my participants, who is deaf, explained to me:

It is always polite to address the person’s name first before stating his or her nature of disability. For example, ‘Jane who is blind’ is better than ‘A blind woman named Jane’ In Deaf culture, it is inappropriate to use ‘Hearing Impairment’ even though it is considered politically correct. Relevant terms are ‘Deaf’ and ‘hard of hearing.’ (Robert)

I will attempt to be as politically correct as possible, however, I am sure that I will not always be consistent. But please know that I intend no offense. Additionally, some of my participants are older and come from generations where certain phrases like “retarded” did not carry the same negative connotations as they do now when it has come to be understood as so highly prejudicial that many now speak of it as the “r word.” I am sure that these participants also did not intend to offend while using such phrases.

## **Background on Prenatal Diagnostic Testing in New Zealand**

To set the stage of current affairs related to this study in New Zealand, Mike Sullivan and an organisation of parents of children with Down syndrome, called the Saving Downs group, are taking the Ministry of Health to the International Criminal Court (ICC) contending that the Ministry of Health’s antenatal screening programme introduced in 2007 is “akin to genocide and a crime against humanity” (northernadvocate.co.nz, 2011). As I am writing this, *3 News* reported that the ICC decided to move forward with the preliminary investigation into this case, making it one of eight cases worldwide (3news.co.nz, 2012).

To give a brief history of the Ministry of Health’s antenatal screening programme, in 2005 the Ministry of Health appointed Professor Stone and Professor Austen to assess antenatal screening nationally because safety requirements were not being met and there was a lack of consistency in prenatal diagnostic screening in New Zealand (Johnston, 2006). As a result, the National Screening Unit (NSU) assembled the Antenatal Down syndrome screening advisory group, who provided advice on how to improve access, safety and quality of antenatal screening (Ministry of Health, 2007). Screening is available to all pregnant women in New Zealand. Screening involves first trimester maternal serum testing, nuchal translucency scan, or second trimester maternal serum screening. If the antenatal screening indicates that there is an increased risk of the fetus having a genetic condition, diagnostic testing is offered (National Screening Unit, 2009).

In addition to amniocentesis and the other forms of genetic testing (see glossary) that were discussed with the participants, preimplantation genetic diagnosis (PGD) is a different form of diagnostic testing which uses cells from preimplantation embryos created by in vitro fertilization (IVF). The use of PGD was approved in New Zealand in June 2003. The National Ethics Committee on Assisted Human Reproduction (NECAHR) with the Minister of Health produced guidelines for the use of PGD. PGD for sex selection is illegal in New Zealand. It is also illegal to use PGD to replicate in the offspring, an impairment that is present in the parents. New Zealand government funding is provided for PGD for up to 40 cycles annually nationwide for couples who have a severe inherited condition (NECAHR, 2005).

If not funded, PGD is expensive and not very accessible to most couples. Many couples are not even aware of whether or not they carry potential genetic risks and so would not consider IVF/PGD in the first place. Moreover, if prenatal genetic testing is offered in the early stages of pregnancy, some would think it would seem wise to know the genetic status of the fetus—as discussed in Chapter Two, genetic testing is seen as a part of good parenting (Remennick, 2006). But, the risk of miscarriage makes this option less appealing to some. However, recent improvements in antenatal testing<sup>2</sup> are currently underway and becoming more widespread and administered as part of best practice. As technology becomes more advanced and routinely used, the way people think about the genetic makeup of their unborn child is becoming increasingly complex. The opinions of the LDS community explored here will hopefully further enlighten medical practitioners, careworkers, and genetic counsellors of the various ways lay people interpret genetics and disabilities through the perspective of LDS religiosity.

## Structure

To explore the complex ways people conceptualise disability and genetic testing this thesis will first overview in chapter two, the relevant literature on models of disability, spirituality, and genetic testing, using New Zealand material wherever possible. As mentioned previously, woven throughout the thesis there are three interludes (Chapters Three, Five, and Eight) discussing Frank's illness and disability narratives and comparing them to participants'

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<sup>2</sup> For example, in October of 2011 Sequenom, Inc., a biotech company in the United States, began offering a more reliable maternal blood test that does not involve invasive procedures to the womb, eliminating the risk of miscarriage. The test is called MaterniT21 or SafeT21. It detects trisomies 13, 18, and 21 from circulating cell free DNA taken from the mother's blood (Palomaki et al., 2012).

understanding and narratives around the LDS doctrine of the Plan of Salvation. Chapter Four surveys what life is like to be a disabled Mormon in New Zealand for participants. Chapter Six explores participants' different conceptions of disability. Chapter Seven delves into informants' opinions on genetic testing and how they make sense of it within their framework of religion. Chapter Nine explores testimonies from participants' narratives. And lastly, Chapter Ten concludes an overall discussion of perceptions of disability and genetic testing.

## **II. Disability Models, Spirituality, and Studies of Choices in Genetics**

This chapter provides an overview of some of the arguments surrounding the topics of disability studies, and spirituality in the context of prenatal testing. I will begin with a brief background of the involvement of anthropology in disabilities studies. Then, I will discuss the theoretical conceptions of disability that are referenced throughout the thesis. After that, I will survey some key and recent work on genetic testing and spirituality. The literature discussed in this chapter demonstrates how complex conceptions of disability and genetic decision-making can be. Although focusing on a small and well read portion of the works and research on this topic, the aim of this chapter is to provide a context to inform the reader and to help locate the research in this project.

### **Anthropology and Disability Studies**

Anthropology promotes the idea that culture influences the way people experience disability. Disability can be viewed and defined in myriad ways of which an anthropological approach provides one unique perspective. Even before disability became a pertinent area of study among anthropologists, topics explored in the field of anthropology seemed to be already suited for its study. Previously established anthropological areas of interest such as notions of ‘the other’, deviance, difference, stigma, liminality, personhood, and power-relations are often used to approach the study of disability and impairment (Rogers and Swadner, 2001; Reid-Cunningham 2009). It may seem insensitive to state that people with disabilities are viewed as “the deviant other,” but when observing definitions of disability or impairment, one finds that alterity is often a constituent. Beatson, for example, defines impairment as such:

An impairment is a bodily or psychological loss or abnormality which may cause suffering and which makes it difficult, dangerous or impossible to perform tasks, to participate in community life and to play social roles in the ways taken for granted by non-impaired people. (2000:23)

Beatson dichotomizes disability and impairment by stating that impairment is essentially corporal while the term disability is the interaction of impairment with “physical barriers, institutional structures, social policies and cultural attitudes...” (2000:42). In other

words, disability is the interplay of difference and culture. Ingstad and Whyte, who researched disability within various cultures, have observed that impairments and biological defects are universal, “But the significance of a deficit always depends on more than its biological nature; it is shaped by the human circumstances in which it exists” (1995:ix). The anthropological method of examining the situational contexts that cultivate difference have helped to promote the model of viewing disability as a social construct.

Disability awareness and activism became recognised on the worldwide stage in 1981, which was declared The International Year of Disabled Persons by the United Nations, and then was followed by the declaration in 1983 of the United Nations Decade for Disabled Persons. Disability studies then became a prevalent subject of interest in many academic disciplines. This is not to suggest that disability had not been an object of enquiry prior to these dates, it was rather that the 1980s marked the development of critical models of disability, which purposefully interrogated prior medical-based models of disability as deficit or personal tragedy. Anthropology entered the scene later than others but made significant contributions to the disability movement (Ingstad & Whyte, 1995) including a few quite early works. These earlier studies of disability in anthropology include Ruth Benedict’s “Anthropology and the Abnormal” (1934), a study of psychological definitions of “normal” and “abnormal” in cross-cultural contexts, and Jane and Lucien Hanks’ work “The physically handicapped in certain non-occidental cultures” (1948) which provided one of the earliest frameworks of disability as a social construction (Switzer & Vaughn 2003; Reid-Cunningham, 2009).

Despite anthropology’s interest in “the other,” disability did not become a major topic of interest among anthropologists (in the United States at least) until the mid 1980s with the publication of Louise Duval’s newsletter, *Disability and Culture* (Kasnitz and Shuttleworth, 2001:26). Duval went on to found and chair the Disability Research Interest Group of the Society for Medical Anthropology. This spurred several other anthropologists to become involved by producing ethnographies and publishing works about people with disabilities and their culture (Shuttleworth & Kasnitz 2004, Ingstad & Whyte, 1995). But the anthropological approach most often taken is one that focuses on disease and cure—Shuttleworth and Kasnitz state, “Anthropology and specifically medical anthropology has not ignored impairment-disability, but impairment-disability is still situated peripherally to the core research issues of illness and healing” (2004:142).

Joan Ablon was one of the first medical anthropologists to focus on bodily difference and social exclusion as opposed to mainly concentrating on the aspects of sickness and healing. Ablon’s theoretical approach draws from Erving Goffman (1963) who utilised

examples of people with disabilities to illustrate the social construction of stigma caused by difference. Ablon's works contributed to the disability movement and further supported the anthropological study of disabilities (Ablon, 1981).

The ethnographic method of approaching impairment-disabilities (which highlights its culturally constructed nature) further probes the topic with questions such as, "How are deficits of the body and mind understood and dealt with in different societies? How is an individual's culturally defined identity as a person affected by disability? What processes of cultural change shape local perceptions of disability?" (Ingstad & Whyte, 1995:3). Ethnography offers a lens for investigating the personal, lived aspects of disability as well as how culture and society construct meanings of disability. Reid-Cunningham asserts, "An ethnographic lens continues to provide a valuable perspective for understanding disability, especially the experiences of people who are different from the researcher" (2009:108). Davis (2000) (a disabilities scholar who promotes emancipatory research) suggests that researchers can contribute to processes of change by incorporating and legitimising individual experiences through ethnography. By doing ethnography with an emic approach, Davis states that, "all respondents are viewed as possessing the potential to contribute to the improvement of disabled peoples' life experience" (2000:200). By sharing participants' stories, this thesis strives to achieve this potential.

A further inspirational analysis of the meaning of disability/impairment and one on which this thesis draws is the work of the disability activist and bioethicist, Dr Tom Shakespeare, who defines disability as, "an interaction between someone with an impairment, and their wider physical, social, cultural, political environment" (Shakespeare, 2009). Because anthropology studies this interaction, especially in a sociocultural context, it provides an ideal framework to understand disability. Furthermore, anthropology explores how disability is viewed within different aspects of culture. These varying components of culture involve many different frames of reference to understand disability: "Religious teaching, laws, customs, and 'media portrayals also reflect, define, or perpetuate' how people approach disability" (Susman, 1994 cited in Reid-Cunningham, 2009:107). Such a statement is highly relevant to this thesis which explores how religiosity and spirituality "reflect, define, and perpetuate' how participants approach disability. However it is also appropriate to understand how a researcher approaches the topic of disability and so the next section of this chapter discusses some theoretical models of disability which resonate with my own approach to understanding this taken-for-granted aspect of human living.

## Models of disability

In examining disability from an academic perspective, I have chosen to consider the current conceptualisations of disability and the different models of disability through the perspectives of internationally known scholars as well as local New Zealand scholars, such as Beatson (2004) and Sullivan (2001). Beatson refers to different spheres of disability: the social, the medical, the identity, and the political. The medical model views disability as a “deficit”—something that needs to be fixed or cured. As discussed in the previous section, the social model of disability contends that society is disabling. The lack of access and support for people is disabling, for example, having no wheelchair ramps into buildings for people who use wheelchairs. Additionally, as Beatson describes, “community attitudes” can further be disabling (2004:35). To understand the social model of disability, it is necessary to reiterate the difference between disability and impairment. Impairment is a physical lack of something, or as Shakespeare defines it—the “medical condition of the body.” While disability is, “discrimination and prejudice in society” (1998:665).

The social model of disability contends that disability is inflicted *upon* people with impairments—they are excluded from society. Disability activists maintain that the elimination of imposed social barriers, not medical cure or rehabilitation, will alleviate this oppression (Shakespeare and Watson 2001:10-11). This activist movement began in the 1970s and was spearheaded by the Union of the Physically Impaired Against Segregation (UPIAS) (*ibid.*:9). In New Zealand, the social model was taken up and branches of the Coordinating Councils for the Disabled combined in 1978 and became the New Zealand Coordinating Council for the Disabled (NZCD) (Sullivan 2001:97).

Shakespeare and Watson (2001), moreover, point out several flaws in the social model of disability. They argued that “the very success of the social model is now its main weakness,” (2001:11) and they criticised that it had become a “rigid shibboleth,” concluding that the social model has “outlived its usefulness” (*ibid.*:13). The problem with the social model of disability, they suggested, was that it did not give individual impairments enough consideration and left little room for difference. They advocated for an understanding of disability and impairment that saw the two not as “dichotomous” but as “different places on a continuum, or different aspects of a single experience” (*ibid.*:22).

Beatson (2004) is somewhat in agreement although his work is expressed slightly differently. Moving on from the social model, Beatson argues that because disability is permanent, it is inherently a characteristic of identity. The problem with seeing disability

from the medical perspective—as a deficit—is that it disregards that a person with a disability could “lead contented, fulfilled and creative existences...” and many “take an active pride in their disabled identity” (2004:41). Totalling some of the different aspects of disability Beatson defines disability as such:

Disability is a characteristic of social identity, similar to ethnicity, gender, class and sexual preference. It is based on the presence of a permanent or intermittent impairment, and may be associated with structural inequalities or discriminatory attitudes in the social environment, but is not in itself a cause for negative self-image. (2004:41)

Beatson reiterates, however, that this definition only sums up “what disability is, but not what it means” (2004:44). Disability for Beatson is a multifaceted phenomenon and he stresses the intricate and fluctuating nature of disability. People with impairments weave in and out different aspects of disability throughout their lifetimes. To discover what disability means we must explore the varied ways individuals personally conceive it. As will be discussed in Chapter Six, LDS participants maintain complex conceptions of disability involving the medical, identity, political, and social models of disability that Beatson illustrates. For the next section, however, I will move on to discuss the ways in which notions of disability combine in complex ways with the issues of choice and of spirituality when difference or ‘the other’ is created from genetic diagnoses.

## **Spirituality and Choices in Genetics**

Members of the disabled community have for some time now expressed concerns that advances in genetic technologies will bring about greater prejudices towards differences and anomalies (Scully, 2008). For example, rates of termination of affected pregnancies after prenatal diagnosis for Down syndrome may likely increase in New Zealand with the Ministry of Health’s Antenatal Screening Programme introduced in 2007 that made quality testing for Down syndrome more readily available to all women. And in a United States context, more than twenty years ago, in *Women and Prenatal Testing: Facing the Challenges of Genetic Technology* (1994) Rothenberg and Thompson raised the question: “Is a life with a disability worse than no life at all?” (1994:8).

While it is tempting to polarize antenatal screening and outright reject genetic testing, the use of such technologies provides benefits besides just forewarning. Shakespeare and Watson (2001) elaborate, “While we would oppose blanket selective screening of all impairments, there are times where it seems appropriate and desirable to take advantage of

genetic technologies” (2001:16). Shakespeare and Watson bring up genetic conditions such as Tay-Sachs disease and anencephaly, both of these conditions are fatal and “most people would want to avoid them if at all possible” (*ibid.*:16). There are also certain disorders, such as phenylketonuria (PKU) where early detection can help prepare parents for the metabolic treatments involved with the successful treatment of such a disease.

Furthermore, Shakespeare exposes the scarcity of disabled voices contributing to genetic policy (1998). He argues, “if we are to understand the implications of impairment, and make appropriate decisions about individual and societal screening options, then we need to listen to those people directly affected by genetic conditions” (1998:673). Shakespeare argues that if people with disabilities are not included in the discussions of the ethics of genetics then when such a high percentage of a certain population are being targeted and terminated, the issue of eugenics arises. In Shakespeare’s view, “While the clinical establishment may promote a rhetoric of salvation from genetic disease, the disability rights movement is inclined to equate new genetics with Nazi eugenics” (1998:666). This is exactly what Mike Sullivan and the very recently formed New Zealand-based activist group Saving Down’s are contending. However, the rhetoric of choice also surfaces in considering how to respond at an individual level to the information of a genetic diagnosis:

At the heart of the debate around pre-natal genetic testing are contested choices and rights: a woman’s right to choose, the civil rights of disabled people, the postulated rights of the unborn child, the rights of the individual versus the rights of the collective. (Shakespeare, 1998:665)

With the increasing availability and routinisation of prenatal screening and genetic testing, the onus of choice is placed on parents. For example, Scully, Banks, and Shakespeare (2006) conducted a study examining the lay discussion on social sex selection using group discussions based in England. Their participants felt that the burden of choice placed on people is sometimes too much:

Several participants suggested that offering a choice might place an unfair burden on ordinary people. They agreed that, in principle, people are or should be responsible for their own choices, but questioned whether most lay people would genuinely have the ability to make them. (2006:24)

However, if people cannot make choices for themselves, who will decide on their behalf? Scully et al.’s participants further expressed concerns that even if people can make choices for themselves, they cannot truly make a best choice unless all of the relevant information is disseminated: “Many participants seemed to hold the view that an offer of choice is meaningless unless people have the level of information about the choice, its consequences and their own desires, which allows them to make wise decisions” (*ibid.*:25). Moreover, there

are other questions that need to be considered: What are the consequences of the choices we make? What messages do our choices send? (Considerations of these consequences and messages will be further discussed in Chapter Seven.) Scully et al. contend:

The expressivist argument, developed within the disability critique of prenatal testing, says that offering testing and possibly termination of an affected pregnancy ‘sends out a message’ to living disabled people and to society in general that people with certain impairments would be better off dead. (*ibid.*:25)

Regardless of the inadvertent messages sent, the choice that couples or an individual make whether or not to bring a child with disabilities into the world depends on several factors, one of which is prior experience with disabilities. Rapp (1999) a pioneer researcher in this area in the United States during the 1980s/90s elaborates,

Thus, the ‘choice’ any pregnant woman makes to take or reject the test, and to keep or end any specific pregnancy, flows from the way that both pregnancy and disability are embedded in personal and collective values and judgments within which her own life has developed. (1999:91)

Previous experience and understandings of disability influence the interpretation of prenatal testing and ultimately may guide a woman’s pathway to decision.

In addition to previous experience with disabilities, how parents perceive society will accept a child with a disability is another critical dimension of prenatal decision-making. In societies that do not provide adequate support, or where stigma against people with disabilities is strong, terminations of affected pregnancies will most likely be high. For example, elective antenatal testing in Israel has become increasingly more prevalent since the mid-1990s (Remennick, 2006). Remennick interviewed Israeli women who chose to have testing as well as women that chose not to have the testing in order to determine the key social factors that influenced this growth. Remennick found that one of the social factors that influenced women’s decisions was fear of having a child with disabilities in an “unsupportive environment” (2006:21). In New Zealand, however, government programmes such as the New Zealand Disability Strategy were instituted to guide government action to provide a more supportive and inclusive society to those with disabilities (Dalzeil, 2001). But even the Minister of Disability Issues admits, “We live in a disabling society” (Dalzeil, 2001:12).

The pervasive impact of cultural conceptions of disability leads Lippman to consider the alleged autonomy around a woman’s right to accept or reject testing and her right to terminate or keep the pregnancy when the fetus is found to have a genetic condition.

But is there really a choice? Is a full range of options truly available? Continuing a pregnancy when the fetus has been found to have Down syndrome cannot be

considered a real option when society does not truly accept children with disabilities or provide assistance for their nurturance. (Lippman, 1998:19)

Lippman advocates for a system of support for women “that does not view the birth of a child with a disability as a technological failure” (1998:30). It is not only technology that is viewed as a failure, but also parents themselves can be perceived as having failed at their parental obligations by giving birth to a child with disabilities. Brookes (2001) interviewed several women in Australia with personal experience with prenatal diagnosis to ascertain the moral reasoning that guides women through decision-making. One of the participants expressed that the community around her asked why she didn’t receive testing for her child with a genetic condition, as if it would have been the right choice to not bring the child into the world at all. It seemed as if she neglected her parental responsibilities (Brookes, 2001). Remennick also observed in Israel that there is an “emerging social pressure for comprehensive prenatal screening as an indispensable part of *good motherhood*” (2006:21).

The idea of prenatal testing as a part of good parenting arises through varied concerns that parents must consider. The decision to undergo PGD or to have prenatal testing is a choice fraught with trouble. For Mormons potentially facing these choices, policies from the Church may dictate acceptable action. But how people interpret these mandates for their own situation is another matter. People may find that operating within a framework of religion can become a further complication. Marcia Inhorn’s (2002-2011) collection of work, for example, shows how complicated decision-making can be within a religious framework. LDS participants in this research project used their religious backgrounds to inform their opinions, however many stressed the importance of individual autonomy according to circumstance. Some of the responses from the participants were similar to what Hewison, Atkin, and Green (2008) discovered when they examined religious beliefs about prenatal screening among Indian Sikh, Indian Hindu, Pakistani Muslim, and African-Caribbean Christian groups. Hewison et al. found that religious beliefs were not an “absolute moral code but more of a framework in which to make decisions in a way that allows for individual interpretation: religious beliefs occur within a broader moral framework” (2008:84).

LDS people undergoing prenatal testing may also consider what the social environment within the Church would be like for raising a child with disabilities. Broader society may be disabling as Dalzeil (2001) suggested, but what about religious society? How does a religious institution’s attitude towards people with disabilities influence parents’ decision to undergo genetic testing? In order to answer that question, we can turn to previous works on this topic of religion and genetic testing.

Several considerations factor into genetic decision-making. In *An Anthropology of Biomedicine*, Lock and Nguyen state, “Religious beliefs also play a part in decision-making, as do family economics, the reproductive experiences of extended family members, and attitudes to disability in general” (2010:312). Lock and Nguyen summarised the ethnographic work done by Duana Fullwiley, who interviewed 42 Senegalese women about prenatal diagnosis, and noted, “She reminds us that research has shown that in the West very many people exhibit ‘amalgams’ of belief involving fate, faith, and science” (*ibid.*:325). Understandings of prenatal genetic technologies are often linked with spiritual beliefs. Rapp stated:

Religious orientation is a complex matter when viewed from a pregnant woman’s point of view: she is both the reproducer of a child and guardian of its future and moral education, and a bearer of a religious tradition which wields cosmological power over her own actions and intentions. (1998:156)

The discourse surrounding proponents of prenatal diagnosis emphasises autonomy and choice for pregnant women and their partners. This autonomy may complicate the pregnancy experience by adding further dilemmas of choices, such as whether or not to have the testing, and whether or not to terminate the pregnancy or keep the baby when test results are positive (Rothman, 1993; Reiter, 1999; Rothenberg and Thompson, 1994).

According to Teman et al. (2011) because of the “pro-life” stance of many religions, scholars view religion as being in philosophical opposition to prenatal diagnosis. However, when Rapp interviewed women about prenatal testing and other reproductive technologies, she stated: “we often ended up spending much of our time discussing religion” (1998:145). Religious beliefs, then in the context of reproductive genetic technologies may be at the forefront of people’s minds. Indeed, a major theme discussed in relevant research is that medical practitioners and genetic counsellors need to address the spiritual concerns of the patient (Cole-Turner, 1999; Harris et. al, 2004; White, 2009; Reis et. al, 2007; Parker et. al, 2011). Reis, Baumiller, and Scrivener (2007) examined the use of spiritual assessments in genetic counselling by surveying members of the National Society of Genetic Counsellors in the United States. The outcome of the survey sites the importance of religion and spirituality in healthcare and the role it plays in decision-making processes of the patient. By better understanding moral decision-making processes, medical practitioners and care workers will be more suited to help those found at these crossroads of choice.

Philosophical debate into the meaning of genetic testing for members of the population have often been undertaken from the position of fixed religious doctrines (Anderson, 2009). Cole-Turner (1999) observes, “Something about genetics strikes many people as profoundly religious.” Religious and spiritual beliefs bring meaning to uncertainty

and factor into the heuristics of genetic decision-making (White, 2009). For example, Ultra-Orthodox Jewish women use the status of their faith as grounds to reject prenatal testing, believing that God will not give them challenges above what they can handle. Although rejecting testing did not alleviate the uncertainty, their faith provided structure to make their situation meaningful (Teman et. al, 2001). Barbara Katz Rothman (1993) interviewed women about the experience of prenatal diagnosis and similarly observed her informants sometimes rejected amniocentesis and the potential of abortion because of their religiosity and spirituality, noting, “This alternative belief system says that things happen ‘for a reason,’ and the value lies in rising to meet the challenge, accepting what the world offers” (1993:69-70).

According to Rapp (1998), reproductive genetic testing transforms pregnant women into “moral pioneers,” forging their way through new and complex issues. Some of these women use religion as the means to elucidate solutions to difficult decisions that genetic testing presents. Anderson (2009) sent a survey to collect doctrinal stances on prenatal genetic counselling to thirty-one different United States denominations and noted, “patients professing a belief in the divine are likely to seek comfort, guidance and equilibrium from their faith” (2009:52). For example, Rapp cited a case in which a single woman who was raised Mormon but had since not been an active member, received prenatal testing. When her unborn son was diagnosed with Down syndrome, she went back to her Mormon roots for support when she decided not to terminate the pregnancy.

As well as providing support in managing the uncertainty of testing, religion can also help to explain the suffering associated with certain outcomes of genetic tests. For example, Kalfoglou et al. (2005) conducted a study in which twenty-one focus groups throughout several areas in the United States were asked about various aspects of genetic technologies. One concern was that genetic technologies aim to eliminate suffering. Many of Kalfoglou et al.’s participants maintained that suffering, disability, and difference were integral aspects of the human condition. Evans (2006) conducted 182 qualitative interviews among various denominations as well as people who were non-religious in the United States. Evans asserts that religious persons view suffering differently than non-religious persons. Some religious persons believe that suffering is essential to human growth in order to become more godlike while another frequently cited belief about suffering is that it develops empathy. Frank (1995) notes that people with chronic illnesses or disabilities seek to find purpose in their suffering, “...the storyteller seeks to reclaim her own experience of suffering. As she seeks to turn that suffering into testimony, the storyteller engages in moral action” (Frank, 1995:18). Religious views of suffering play a substantial role in genetic testing deliberation.

Religious authorities furthermore have expressed strong views on the morality of prenatal genetic testing for women (Cole-Turner, 1994; Evans, 2006). However current research on this topic has shown that when genetics brings up uncertainty in moral issues, the path to the correct moral action when using associated reproductive technologies can be interpreted in surprisingly unpredictable ways through recourse to religious frameworks (Rapp, 1998).

Now that we have a firmer grasp on conceptions of disability and the various ways people utilise religion in the context of genetic testing for disability, the next section of this thesis will explore participants' conceptions of disability and what life is like to be a Mormon and have a disability in the New Zealand context. People making decisions to undergo prenatal testing are often concerned about what their child's life would be like if they were to have a disability. The best way to explore this is to ask people with disabilities themselves and their parents or caretakers.

### **III. Interlude: The Spirit Journey and the Quest Narrative**

In order to understand the ways in which the Mormons in this study were viewing disability and genetic testing, it is imperative to comprehend Mormon cosmology. The spirit journey, as professed by Mormon theology, begins with the pre-existence where spirits dwell before coming to Earth—the mortal realm, where spirits gain a body. After death, the spirit is separated from the body until the resurrection where the spirit and body are reunited once again in perfect form. The phases described make up part of what Mormons call the plan of salvation (LDS.org, 2012: Plan of Salvation). These three phases of the spirit journey correspond well with Franks' (1995) illness and disability narratives. The pre-existence is synonymous with the quest narrative, the chaos narrative could be considered life on earth, and the resurrection correlates well with the restitution narrative.

Anthropologist Fenella Cannell summed up the spirit journey and the motive of physical embodiment as understood by Latter-day Saints:

For Mormons, the body is not the enemy of the salvation of what Christians usually call the soul; in order to be saved, one must have a body on earth and in the Celestial Kingdom...The earthly body is the instrument through which we meet trials and acquire knowledge, which is our task on earth as agreed to pre-mortally by all living beings. This teaching forms part of the Mormon doctrines on the Plan of Salvation...The only way to get from spirit body to spiritual body is via life on earth. (Cannell 2005:343, 353)

Gaining a body is one of the most crucial steps to take in order to progress along the spirit path. A current LDS apostle, Elder Russell M. Nelson, affirms the significance to Mormons of physical embodiment in no matter what form:

For reasons usually unknown, some people are born with physical limitations. Specific parts of the body may be abnormal. Regulatory systems may be out of balance. And all of our bodies are subject to disease and death. Nevertheless, the gift of a physical body is priceless...A perfect body is not required to achieve a divine destiny. (LDS.org, 1998: Nelson)

#### **The Pre-existence Quest**

Quest stories tell of searching for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges. The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking. (Frank 1995:117)

Frank references Campbell's Hero's Journey Narrative structure when describing quest narratives. The first stage of the hero's journey is the *departure*—"beginning with a call" (1995:117). Mormon theology teaches that spirits waiting to come to earth possess individual identities. Some people interpret this to mean that spirits were called to certain bodies in the pre-existence and the spirits had the ability to accept or reject that call.

Frank mentions the spiritual body-self in *The Wounded Storyteller* but the particular belief system of Mormons incorporates another dimension of viewing the spiritual body-self in terms of disability. The spirit, even before it has a body, possesses autonomy. This autonomy is expressed in the LDS doctrine of agency: "Agency is the ability and privilege God gives us to choose and to act for ourselves. Agency is essential in the plan of salvation. Without agency, we would not be able to learn or progress or follow the Savior" (LDS.org, 2012: Agency).

Before spirits became spirits, individuals existed as what Mormons call "intelligences." Kent Condie, an LDS scholar, observes, "It is a common belief among Mormons that God placed each intelligence in a spirit intended for a specific temporal organism..." (2006:38). Condie notes, "Joseph Smith and other Church presidents made statements suggesting that some human spirits 'excelled' in the pre-existence and that their placement in a specific terrestrial body reflects, at least in part, their progress in the preexistence" (*ibid.*:40). Being placed in a body that has a disability, then, could demonstrate the spiritual valour of an individual in the pre-existence.

As mentioned earlier, some Mormons believe that being born with a disability means to be foreordained to fulfill that role in this life. Condie elucidates:

Foreordination, which is a rather unusual LDS teaching, is the concept that certain spirits were called or assigned in the preexistence to carry out certain functions in this lifetime. Doctrine and Covenants 138:55-56 states that many of the 'noble and great ones . . . were chosen even before they were born.' (Condie 2006:41)

Many participants often shared how they believed that before the spirits of people with disabilities came to earth, they were called and willingly volunteered to live out life with a disability or impairment. For example, it was revealed in a priesthood blessing to Carol's son Isaac that his spirit chose to have a disability:

He's been given blessings and he's been told that he agreed to take on this body with its handicap...Isaac was given a blessing when we found out that Isaac had cerebral palsy. The first thing we did was call our home teachers and my husband and home teachers gave him a blessing. The home teacher actually was the voice, and he spoke and he said in the blessing, 'Isaac, you chose—in the pre-existence you chose to have this disability, you chose this body with this,' I can't remember the exact words but, 'you chose, and agreed to take this body as it was.' He could've blessed him to take

the disability away, but he didn't because Heavenly Father wants—it's part of his plan. He wanted and Isaac agreed to the plan. So Isaac agreed to have this disability—both Isaac and I *agreed*. (Carol)

Dave believes that his son, Edward, who has Down syndrome, not only agreed in the pre-existence, but volunteered to come to earth with a disability for a “harder task.” I asked Dave if he thought that the spirits of people with disabilities were any different in the pre-mortal existence. He replied:

Yes, I do. They'll probably have to be a special kind to say, 'right, I'll go. I'll take that problem. I'll go and do that.' But I also believe that they're sort of like volunteers, like they could've had the chance you and I had. But when offered a chance to come [to earth] normal or to have some sort of disability they said, 'ok, we'll take it.' Because as I said, when we all go back to Heaven in judgement day, we'll all be perfect. So they've done their thing, they've done their trial so—he'll [Edward] be perfect. He'll be well and truly blessed. It just makes us strive harder to be there with him, like he's setting the pace. Heavenly Father has given us a special spirit to look after and nurture him and get him through life. But any children to me are special—he's just a little bit extra special. They're very really special, eh. Because, before they come, they are sort of given a task—or asked—or volunteered to come this way for a harder task. (Dave)

Just as Dave believed that his son Edward volunteered for his task, Robert knew from an early age that he was meant to be deaf. When I asked him if he believed that spirits volunteer to come to earth with certain challenges, he mentioned his Patriarchal blessing<sup>3</sup>—a personal and sacred blessing given to members of the church by a patriarch: “Without going into too much detail if you know what I mean, yes I do believe as confirmed by my own Patriarchal blessing” (Robert). John related the story of how he and his wife, Beverly, consistently prayed for Robert to receive the ability to hear—until one day he asked them to stop:

Well, Robert himself has kind of alluded to me once or twice growing up—and it was—the first time was probably around about when he was twelve—we prayed EVERY DAY that Heavenly Father would bless Robert to hear, EVERY DAY we prayed that. And it was almost like vain repetition—but we did! We even met at the temple—there was the bishop at the time, who travelled with [an apostle] in New Zealand, going around doing great miracles. He was the temple president. I was talking to him one day when I was told who he was, and he said, 'if that's what you want, never stop praying!' And Robert had blessings and we fasted and we prayed for YEARS! And then when Robert was twelve he said, 'I want you to stop praying for me to hear.' He more or less said, 'I'm supposed to be like this.' (John)

In this “alternative way of being ill,” as Frank (1995) phrases it, many participants believed that their spirits, or their children's spirits agreed to come to earth disabled in the

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<sup>3</sup> The Patriarchal blessing mentioned here is different from the priesthood blessing mentioned by Carol above. Patriarchal Blessings are only given once in a lifetime by a specific person called to the priesthood office of Patriarch (LDS.org, 2012: Patriarchal Blessing)

pre-existence. As life progresses, the purpose of the disability becomes apparent and the Quest unfolds.

## IV. Being Disabled and Mormon in New Zealand

Participants conceptualised disability within and around the framework that their religiosity provided. However, membership within this particular religion caused some further complications that will be discussed in detail in this chapter. Members with disabilities who participated in this study expressed the challenges of not only having a disabled identity but also having a Mormon one. To give an overview of the difficulties this identity carries I will first briefly discuss the current climate of stigma that comes with a Mormon identity.

In the beginnings of the LDS Church in the United States, members were persecuted for their beliefs and driven from state to state until finally settling in Utah. In New Zealand, members have a very different but an equally rich Mormon heritage. One Sunday, during what is called a fast and testimony meeting where members who choose to stand up at the pulpit and share their beliefs, a young man who had just moved from Auckland spoke about his great great grandmother who was one of the Māori leaders who prophesized of the Mormon missionaries coming from the East bringing the gospel to their people. Despite the different beginnings from the United States Mormons, New Zealand Mormons also sometimes face a social stigma.

Mormons are a controversial topic. I had similar problems throughout my research journey as Cannell ran into on her research for the “Anthropology of Christianity.” She outlined the abhorrent responses to her research in a section titled “The Mormon ‘repugnant other’.” Her colleagues expressed concern for her safety, and shared with her recent scandals of Mormons in the media, or other generally negative reactions (2005:338). In the United States, members certainly feel what Mormon sociologist Armand Mauss noted, “A thriving anti-Mormon enterprise continues to exist in the United States” (1984:447). Even today, *Washington Post* reporters observed that being prejudiced against Mormons is “one of the last acceptable prejudices” (Bell & Bell, 2012).

However, Mormons have become a prominent media topic recently. As I am writing this, Mitt Romney—a Mormon, is the Republican candidate running in the mid-term elections against President Barack Obama; “The Book of Mormon,” a Broadway musical poking fun at Mormons, swept the Tonys last year and tickets are sold out several months in advance; *Newsweek* coined this time as “The Mormon Moment” and featured it as the cover story in June of 2011. New Zealand has picked up on this excitement with a little curiosity of its own. Radio New Zealand National featured a programme on 29 January 2012 that explored Mormonism and interviewed LDS missionaries to learn what life is like as a missionary. And

on 21 January 2012 they hosted an interview with featured guest Joanna Brooks—a prominent liberal Mormon.

Other than this recent exploration into the Mormon faith, most people in New Zealand I come into contact with were generally unfamiliar with the Latter-day Saint Faith, or if they are they hold few previous assumptions. To be Mormon in New Zealand is almost an entirely different experience than in the United States. The stigma a Mormon identity carries is not as pronounced. However, in some instances the lifestyle of a Mormon is markedly distinctive and can reveal Mormon identity and thus difference. Practicing Mormons abstain from several things including alcoholic beverages, coffee, tea, and tobacco. Many observances contribute to the lifestyle of being Mormon that in a certain context can make one stand out. Although most of the participants I spoke with found solace in their religious beliefs, being disabled and being Mormon was to be allocated with two stigmatized identities.

For example, growing up deaf in Dunedin was a difficult and lonely experience for Robert. His parents, John and Beverly, wanted him to get out and meet other kids who were deaf his age. But he said he found out that because of his Latter-day Saint morals, he did not even belong among other deaf children.

John: There was a time he acquiesced to go on a camp. He didn't really want to but we convinced him that it'd be good for him to go so that others could see—

Beverly: Well, just so he could meet other deaf people his age.

J: And he absolutely dreaded it! He told us when he came back that he cried himself to sleep.

B: He hated it! They were horrible to him. And they were all interested in drinking and that sort of stuff as well. So, of course he's not—so he didn't fit in anywhere did he?

J: No. And he went to this camp and he was horrified at their behaviour! Because you know, Robert as Beverly said, is very righteous.

B: In a nice way.

J: Yeah. I don't think he was judgemental of other people. He had expectations. He wouldn't join in anything that was dodgy in any way. And they were all away from home and they just wanted to have fun and flare up. And Robert wasn't comfortable with that. No. (John and Beverly)

John and Beverly related that because Robert was Mormon, he was bullied at the camp. Even among other deaf children he was an outcast. This narrative of stigma can be further examined under the context of Goffman (1963), who is well known for analysing the management of social stigmas that result from alliance to a particular creed and the management of corporal stigmas such as disabilities. “Physical deformities” and “tribal stigma” are two types of the stigmatized identities that Goffman explores. While Robert was among people of his own physical “deformity,” his “tribal stigma” of belonging to the Mormon religion set him apart. Needless to say, not all disabilities are physically visible, such

as deafness, learning, or behavioural disabilities. These “internalized stigmas” can easily remain undisclosed. However, active Mormon participants uphold strict observances, which can easily distinguish them. The Mormon participants with disabilities or their caretakers seemed to possess a unique dramaturgical self-awareness—they did not try to conceal either of their identities, rather they seemed to be intent on sharing their beliefs and helping others to learn more about disabilities. But as John and Beverly demonstrated above, even when Robert was in a context of others with a shared stigma, he still had to manage the other stigma he possessed.

## **Mormon Rites of Passage**

As Robert’s experience illustrated, it can be difficult to find acceptance even among people like himself with a Mormon identity. And then again even among Mormons it was difficult to feel like he belonged. New Zealand Mormon participants with disabilities faced specific challenges to their faith. As with many religious institutions and cultures, rituals and rites of passages are key to establishing identity within that faith.

Active members of the LDS Church have specific rites of passages and coming of age ceremonies that are essential for establishing an identity as a virtuous Mormon, and in some instances even hold the weight of salvation. However, as Beatson observes, “An impairment ‘makes it difficult, dangerous or impossible to perform tasks, to participate in community life and play social roles in the ways taken for granted by non-impaired people’” (2000:30).

In the Mormon culture, there is a hegemonically enforced checklist of standard rites of passages through which every active member must pass. The constituents of the quintessential lifestyle of a typical faithful Mormon include events such as baptism at age eight, receiving the priesthood at age twelve for men, serving a mission at age nineteen (or twenty-one for females optionally), and then for both men and women: marriage in the temple and producing offspring. Conversely, a Mormon with disabilities faces the challenges of potentially not achieving these rigid cultural milestones. Some exceptions are made, some face difficulties in the process, but some overcome and achieve and the following section provides some detailed responses to these obstacles as negotiated by the participants.

## **Baptism and the Priesthood**

Latter-day Saints are baptised starting at age eight—an age where LDS doctrine deems that a person has developed enough accountability to be able to make an informed decision as to whether or not they wish to be baptised and officially join the Church. When it comes to people with severe intellectual disabilities, however, the question of whether or not they are accountable for their actions and therefore whether or not they need to be baptised is a decision that parents of these children must consider. The Church disabilities website discusses this concern and advises, “This is a matter between parents, the child, and local priesthood leaders. If the child has a basic understanding of gospel principles and wishes to be baptised, then baptism may be possible” (LDS Disabilities Resources, 2012).

After baptism, worthy male LDS members may receive the Aaronic Priesthood at age twelve. The offices of the Aaronic Priesthood are deacon, teacher, priest, and bishop. With the priesthood males can perform certain ordinances such as blessing and passing the sacrament, and performing baptisms (LDS.org, 2012: Aaronic Priesthood). The Aaronic Priesthood is subsidiary to the Melchizedek Priesthood, which is required in order to enter the temple and receive endowments, administer blessings, along with other ordinances (LDS.org, 2012: Melchizedek Priesthood). Whether or not male<sup>4</sup> members with disabilities can receive these priesthoods is of course decided usually on a case-by-case basis between themselves, their parents, and church leaders.

## **Missions**

At age nineteen worthy LDS males are strongly encouraged to serve a mission. Females may consider going on a mission at age twenty-one if they are unmarried—but the social pressure for females to get married is greater than the encouragement to serve a mission. Mature couples may also opt to serve a mission or may be called to be presidents over a mission area. A mission is a two-year commitment where missionaries are called to serve in any of the 340 mission locations worldwide (LDS Church, 2011). The main objective

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<sup>4</sup> Mormonism is a patriarchal institution with clearly gendered-role divisions. Some participants emphasized the Priesthood as a normalising and power-giving institution, one that assigns a hierarchical advantage in spite of disability; however the Priesthood is only available to males. This option, that was found to be so healing, is not available to women. The focus on males throughout this section is partly because the majority of participants or children of participants with disabilities just happened to be male, and because the specific social pressures mentioned here are geared toward men. I discuss the unique burdens LDS females endure when it comes to reproductive decisions and raising children with disabilities in one of the subsequent chapters.

for missionaries is proselytizing, but they also engage in philanthropic service, and looking after recently converted members.

### **Marriage and family**

Marriage is an essential doctrine in Mormon theology. Mormons have a unique belief that in order to achieve the highest degree of heaven, they must be married in the temple. This belief often seems to put an unwarranted strain on single members of the Church (Canell, 2005). Having a disability invariably adds to the anxiety single members feel.

Having children is another essential doctrine of Mormon theology. Cannell found that when viewed from an anthropological perspective, Mormons are a different branch of Christianity in that they do not ascribe wholly to ascetic principles. She elaborates, “Instead, it requires all Church members to marry, preferably in an LDS temple and to other Church members, and to have as many children as they can reasonably support” (2005:343).

Sociologist, Armand Mauss elaborates:

It is well known that Mormon families tend to be large—even since the abandonment of polygamy—though church policy is not so much anticontraceptive as pronatalist. A unique theology of the family lies behind both the fertility of Mormon couples and the church’s strong commitment to family life. (1984:445)

Members of the LDS Church believe in eternal families, having children is seen as the responsibility of parents to bring spirits from the pre-mortal existence into this world. Canell expounds, “Indeed, it is through the continued bearing of children that Mormons will achieve the highest blessing of heaven and become, in their turn, like the being we know as God” (2005:343). The emphasis to have and continue bearing children engenders an interesting problem if disability is genetic, or for parents who are aging and therefore more likely to produce fetuses with anomalies. This issue will be further discussed in Chapter Five.

In the next section examples from fieldnotes and interviews will be discussed regarding some of the struggles parents of and people with disabilities faced while striving to undertake standard Mormon rites of passage:

Robert desired to serve a mission but had difficulties convincing the Church leadership that he was able enough to do so. When a member decides to go on a mission he sends in application papers and if he is accepted, he will receive a letter back informing him where he will be serving. However, if his application is rejected, his papers are sent back. When I asked Robert about his papers getting rejected at first in our email interview, he added how he feels the Church in New Zealand can underestimate Deaf members:

Many Deaf members in the US are called to a mission without hesitation by church leaders. On the contrast, I was the first and only Deaf missionary from New Zealand

to serve a mission and to my knowledge no one else yet since 2003. Briefly, I was almost denied a mission due to my deafness! This is a good example of how church leaders can underestimate Deaf members. The Lord confirmed that I [would] serve a mission and I held onto His words till I was called. (Robert)

For Robert, serving a mission was a transforming experience for him. He met other LDS members who are deaf and was able to serve among them. He finally found a place where he belonged. John and Beverly recounted how their son desired to go on a mission but was rejected twice because he was deaf. But despite the challenges, Robert's mission led him to the woman who became his wife and the mother of his two daughters.

B: Well, all his life Robert wanted to go and serve a mission. That was his goal! And then the Church said, you know people with a disability—it's no reflection on them if they don't serve a mission. It's as if they had done it, honourably. And Robert was devastated! ...Robert's papers were sent in—how many times did they come back?

J: Twice.

B: Twice they came back.

J: But we were spared that, the District President didn't tell us that.

B: That's my brother! And he kept sending them in, saying that here was this young man—and eventually they came back...And then Robert's mission call came back and he was called to Phoenix! In American Sign Language, which he didn't know anything about—but anyway, when he went to the mission home that's where he met Debra! She was part way through her training. And she was going to New York and she was in the ASL class as well and he met her there. And I think he wrote to her once or twice during the mission. When she got off her mission she visited a friend in Mesa and he happened to be there with his companion 'cause they kind of covered both areas and they met again. And the rest is history! (John and Beverly)

Parents of children with disabilities worry about whether their children will ever be able to get married. Retrospectively, Beverly expressed the sorrow she felt for Robert and her concerns that he would not get married. However, she believes now that everything worked out for him as if God had planned everything all along:

And as you look back you can see how the Lord's really—he's got a plan for Robert. Just the way things have worked. At the time you think Oh! This little kid has got such a hard life! And it's so lonely! You just think, Oh! He'll never find anyone to marry! I needn't [have] worried, because it just worked out. You can just see it in hindsight that the Lord was working there all the time. Even if you didn't see it then, when you look back you can. It's quite amazing. Absolutely amazing. (Beverly)

In another story, Nicola's twenty-one-year-old son, Jonathan, was born blind and autistic. She and her husband decided to postpone his baptism until he was twelve years old and then subsequently waited to give him the Aaronic Priesthood until he was sixteen. In spite of his disability, Jonathan has opportunities to serve within the church.

He reads the scriptures with us every weekday morning. Which helps with his reading and his understanding...we're not quite sure what his understanding is. He got baptised when he was twelve, which is when we felt he had about an eight-year-old's

understanding. And he received the Aaronic Priesthood when he was sixteen and was ordained a Priest and he blesses the Sacrament, which people just love because he does such a nice job of it. And he plays the organ every second Sunday. So it gives him wonderful opportunities to do things that he wouldn't have otherwise. (Nicola)

As previously mentioned, going on a mission is a significant rite of passage for males. The stigma of not having served a mission or not being able to serve one is the source of many rumours in the community and a life-long “discrediting stigma,” as Goffman (1963) would categorize it. The stress placed on serving a mission is another source of anxiety for members with disabilities if they are not able to serve when they want to. Nicola and her husband were grateful for the fact that the Church makes exceptions for people in special circumstances and that they can be “honourably excused” from the pressure to serve a mission.

I think it's helped that the emphasis on serving a mission has changed. At one point we thought ‘should we try and get him on a mission?’ and then we just realised that that wasn't going to be a go. And now they say that people can be honourably excused. We just figured that he'd be honourably excused. (Nicola)

Whereas some people are relieved to be honourably excused, some people do not wish to be excused and would rather serve. Because Ben has Asperger's and ADD, he also had problems getting his papers accepted. He recognised that there were other opportunities to serve, but he had his hopes set on a full-time mission. I asked him how it made him feel when his “papers got sent back” to him (which indicated that he had not been accepted). He responded:

Kind of annoyed. Kind of wished that my doctor hadn't written it down. Yeah. I was kind of annoyed, I was like, ‘ah, what if I can't serve a mission?’ and then I was just like really gutted and then I just thought about the other opportunities to serve, like I had an opportunity that I could've served a temple mission, and I could've done like a service mission where I didn't really have to interact with many members of the public. But yeah, I was kind of annoyed when they were sent back. (Ben)

Fortunately for Ben, the Church provides counselling through its social services program, LDS Family Services. The only LDS Family Services in New Zealand is located in Auckland and Ben had to be interviewed by a counsellor before he was permitted to serve a mission. When he finally was approved to serve, he was called to the Auckland mission. He was therefore able to draw support from his counsellor throughout his mission if he needed it. When I asked Ben what was the most difficult part of his mission experience, he swiftly responded, “Companions! That was probably a real issue.” (Ben). Ben's mother, Fay, describes the struggles of his mission experience and how pleasantly surprised she was that he was able to successfully complete a mission:

People with Asperger's generally can't serve a mission. They'll either drive their companions totally nuts, or they just can't cope with being changed. Because, like autistic people, they like their routine—routine works really well. But then on a mission it is relatively routine as well. Like you get up you have that study time, and then you go out. So he had to actually be seen—we filled out all his papers, and stuff like that. And he saw an LDS counsellor—he came down from Auckland. And he had little appointments with him for a little while—taught him some coping mechanisms. He was based in Auckland and Ben was sent to the Auckland mission. We always said to him if anything got too much and he was told that he just lets the mission president know that he needs to see this guy. And I think he saw him or he saw another counsellor once or twice...But generally, LDS Services and stuff were quite good with the support with him. And when he made it to twenty-four months, we were just so excited 'cause we thought well, yeah, we'll let him do this. We know what his track record is like. If he comes home at any stage, that's fine too! But he lasted! Very exciting. (Fay)

Ben, who has recently returned from his mission, expressed his desires to eventually start a family. He believes that as long as he can help his future family understand his needs, they will be able to better support him.

I think I'd take every opportunity I could to help people understand more about my disability. Kind of like what I was saying before about education. Like people's education and understanding of disabilities, the more they're able to help I guess manage them. And so in future relationships like starting a family and getting married—not in that order. But just helping those individuals understand where I'm at, where those disabilities put me. And so when they can see those disabilities having an effect on me then they can kind of help provide that support. (Ben)

Like Ben, Jennifer also expressed that she would like to start a family. For Jennifer, the fact that she has an intellectual disability does not deter her from the hopes of one day having children. When I asked her if she has thought about her future and whether or not she wanted to have children, she responded, "I'm not gonna stop it because of the fact that I've got an intellectual disability—SLIGHT! So. So I can handle it" (Jennifer).

While some of the parents upheld expectations and hopes for their children to pass the typical milestones, for Steve and Vivian, having a son with Down syndrome was a paradigm-changing experience that revealed that they could not have the expectations for their son that they had for their other children:

For a normal child you pretty much know what they're gonna do. They're gonna do this, and then they're gonna go to high school, and then they're gonna go to college and then they're probably gonna go on a mission and get married and have kids. But for Jacob, it's been an open field ever since he was born! We just take every stage as it comes! (Steve)

Even though they knew they could not hold the same expectations for Jacob, Steve and Vivian's aspiration for him were to be treated the same as everyone else. They decided Jacob should get baptised so he would have what all of his other siblings had, even though

they believed that he did not require it. Steve and Vivian were able to find another way to let Jacob serve as a missionary when Steve was called to be a mission president—they brought Jacob with them. Despite having Down syndrome, Jacob was able to become a missionary: “And when we went on the mission, we had Jacob made an Elder so he could be called Elder all that time!” (Vivian).

In spite of the importance of marriage for Mormons, Steve and Vivian felt that getting married was not the best option for Jacob, even though he has an LDS girlfriend who also has Down syndrome.

Vivian: His girlfriend knows she has Down syndrome. She’s very aware of it, sometimes when she bears her testimony she says, “I always wanted to have children but I have Down syndrome, so in this life I won’t be able to.” She’s even higher functioning than Jacob is. In some ways.

Steve: She’s a smart cookie! She’s not very pretty but she’s smart!

V: [Laughs.] Oh! [Laughs.]

S: But Jacob likes her!

V: They do, they love each other! And for a long time they talked about getting married. And whenever—we’ve gone through all of our kids getting married—Jacob would talk about him getting married and we always said, ‘well, Jacob, you have to wait till you’re twenty-five. You don’t even talk about getting married until you’re twenty-five!’ That was safe for a long time! [Laughs.]

S: Finally he turned twenty-five!

V: And then he turned twenty-five! And he started talking about getting married to Trisha and I just didn’t know what to do, but then finally it dawned on me! And so one day I said to Jacob, ‘you know when you’re married, you just can’t come home and watch a movie on your television or get on the computer or something. You have to cook dinner and you have to do all the dishes and you have to plan what you’re gonna cook. You have to buy the groceries, and you have to clean your house, and you have to talk to your wife.’ And [laughs] it was a miracle! That was the end of it! He never talked about it again! (Steve and Vivian)

While Steven and Vivian did not know quite what they could expect from Jacob, Dave and his wife from Fiji, Nirmala, hold high expectations for their three-year-old son, Edward, who has Down syndrome, to be able to have a baptism like his siblings. They also hope that he might be able to serve a mission as well:

As I was saying, we’ve got a lot of support from church. Someone said that he doesn’t have to be baptised. But I’ll give him certainly the same thing that everyone else has got. Maybe he’ll go on a mission too. (Dave)

Even though, as Dave related, some people believe that people with certain disabilities do not need to be baptised, Carol was grateful that her son Isaac was baptised even though he did not need to be. When I asked Carol if she believed Isaac, who has cerebral palsy and concurrent epilepsy, is not accountable and therefore exempt from judgment, she brought up that he has been baptised and that he holds the Priesthood: “He has been baptised. I’m very

grateful that he has been baptised. Because he's been baptised and he was told in a blessing that he would hold the Priesthood of God and he does have the Aaronic Priesthood" (Carol).

However, the practicalities of being able to practice the ordinances he is allowed to perform such as serving the sacrament was hindered by Isaac's disability. Carol recounts how he was able to serve the sacrament, but because of a seizure that affected his ability to walk, he can no longer pass the sacrament. Even though this unfortunate event constrains Isaac from serving the Sacrament, the fact that Isaac has been baptised and holds the Priesthood is a source of comfort for Carol. Despite the fact that this life is full of barriers for him because of his disability, Carol believes Isaac will not be inhibited in his progression in the next life because of the Priesthood.

The Church is accommodating and makes exceptions to the rules in certain circumstances. But the disappointment of not being able to serve a mission was devastating to Carol's son Isaac. He was honourably excused from serving a mission as well, but Isaac still desperately wanted to go. Carol describes the ordeal:

And he was also—he was honourably released from serving a mission because of his disability because he wanted to serve a mission but unfortunately as part of his illness, he was becoming so *obsessed* with it. Yes. He was becoming SO OBSESSED. "I'M GOING ON A MISSION! I'M GOING!" He was determined that he was going to go. But because of his disability, he couldn't particularly because of his epilepsy. And because of his OCD—was not able to be controlled with medication. He became so obsessed and he started having very very bad seizures. Like really really bad where he'd stop breathing and—oh it was horrible ones that they had to stop him going to church because he became so obsessive and so violent to the staff afterwards. (Carol)

This section has previewed what life is like for participants who try to live up to the standard Mormon lifestyle in spite of disability. The next section will survey some previous literature of the significance of religion in the lives of those with disabilities and then will explore what church is like according to participants. Informants discussed the shortcomings of the Church when it comes to providing for people with disabilities. People undergoing prenatal testing may consider what kind of environment would a child with a disability live in and may make judgements on whether or not the environment is supportive enough. The next section will examine the narratives of participants, explaining what kind of upbringing the LDS Church provides for people with disabilities.

## **Disability and the LDS Church**

Religion and spirituality can often provide meaning and hope to the lives of the disabled and of those who care for them. Bennett et al. (1995) as cited by Selway and Ashman

(1998) observed that religious beliefs, prayers, and church attendance were sources of strength and support for parents of children with disabilities. To illustrate, Boswell, Glacoff, and Hamer (2007) conducted in-depth interviews with thirteen adults with disabilities and different religious affiliations in the United States to examine the significance of spirituality in their lives. Informants related that spirituality helped them to cope with their situation and gave meaning to their lives, which led to greater acceptance of themselves. Boswell et. al observed, "Participants indicated that they described disability and spirituality as essential, interactive dimensions of their lives" (2007:35).

In order to examine the impact of religion in the lives of fathers raising children with special needs, Marks and Dollahite (2001) presented a qualitative study of nineteen LDS fathers of children with disabilities in a predominantly LDS community using questionnaires that asked both how religion positively influenced their lives and if there were any negative aspects of religion in their lives. The fathers interviewed expressed positive ways in which religion was beneficial to their fathering of children with special needs. The fathers expressed how congregational members provided assistance and support at times when they most needed it. Several of the participants in this study recounted stories of the support they received from church members. Dave was one of the participants who also appreciated members for their help, "That's what I like about the church is they're non-judgemental. We don't judge. We accept people for what they are. And there's a lot of help there, a lot of understanding" (Dave).

Marks and Dollahite (2001) also conveyed that religion provided a framework for the importance of being a father in the "eternal perspective." This framework placed significance and gave meaning to the role of being a father. At times, religious practices within the home such as prayer or priesthood blessings established a special bonding experience between fathers and their children (Marks and Dollahite, 2001).

Dyches, Marshall, and Olsen (2003) examined further evidence of the positive influence of religion in the lives of family members of people with disabilities. Using an ethnographic approach, Dyches et al. explored the unique LDS experience of living with a child with disabilities for thirty-two LDS parents living in Utah. When dealing with the hardships of chronic illness and disabilities, they found that families draw support and hope from spiritual beliefs. They examined the dynamics of disability and participants' LDS faith in the family. Dyches et al. claimed there was a higher level of functioning among families grounded in a religious philosophical framework (Dyches et al., 2003). They concluded that the LDS faith had unique views regarding kinship and family life that might promote different perspectives of disabilities. Many of the families interviewed by Dyches et al. expressed a

common theme of transcendence from the struggles to a transformation of their experience into a spiritual blessing. Religion played a major role for them in this process of coping. LDS beliefs helped the families understand the purpose of having someone with disabilities in their lives. Another one of the major themes in the interviews that Dyches et al. conducted, is the belief that children with disabilities will be exempt from judgment in the afterlife, perfected, and exalted. As discussed in the previous section about baptisms, many of my participants also believed that people with certain disabilities would be exempt from judgment.

The participants in this study expressed a similar hope found through religion that Glover and Blankenship (2007) discovered in their research. Glover and Blankenship located Mexican Americans and Mexicans around the Texas/Mexico border to take a survey about their beliefs about God when it comes to disability. They found: "Overall, it appears that God is viewed as a beneficent, rewarding, and just entity, who does not use disability as a means of punishment" (2007:47). Furthermore, they concluded that, "This study also revealed that God offers a sense of hope to consumers and to their families in terms of dealing with disability" (2007:48). Glover and Blankenship further suggested that in medical settings, religious and spiritual beliefs regarding disability should be taken into consideration for a more comprehensive treatment (2007:41).

Even though the participants in this study more often found solace in the LDS religion, they sometimes expressed frustration with the Church. Organised religion, moreover, can be seen as patronizing, or as a hindrance adding to the difficulty of being disabled. Selway and Ashman pose the question: "Do religious organizations foster positive or patronizing attitudes toward persons with a disability?" (1998:436). Boswell et al. (2007) found that organised religion tended to be problematic for many participants. Whether it was the physical ability to attend meetings that posed a problem or not feeling accepted, participants expressed that organised religion was a source of "frustration" (2007:38). Parker, Mandleco, and Olsen (2011) also found that it might be hard for LDS families with children with disabilities to attend church meetings due to several factors, some of which include architectural inaccessibility, difficulties in bringing the children to meetings, or reactions from members of the congregations to children with disabilities.

Nicola was one of the participants who was more sympathetic rather than frustrated when it came to support from the Church. She knew that the people in the Church were limited in their ability to help Jonathan. When I asked her if Jonathan had received any special help from the Church she responded:

No, not at all, he never had any help. No, it was hopeless basically. There was one time in primary where we had a teacher and she was a personal friend of mine and I

was the Primary President and I got her to do braille stuff for Jonathan. I mean the Young Men's program is so useless in New Zealand anyway. My older son hated it and we made him go. But we never made Jonathan go, because we knew he would just absolutely hate it. None of the men were coping with their own callings well enough to have any spare time to help Jonathan. So no, we've never had any help basically from the Church or church members. People are not in a strong enough position to have anything spare, I think. Well, I don't resent it, I just think there's this fantasized view of this great scout leader who gets your son out doing things and stuff like that, but it just doesn't happen. Well it would've been nice, but I was just realistic and realised that most people in the Church in New Zealand are only just coping and this was just pushing them beyond what they could possibly do. I mean, it might've been nice...I stopped doing seminary for one year to see if somebody else could get something more out of him, but they didn't. He was a very good teacher and he tried. But because of the autism, he's actually very hard to get through to until you know him...I guess you read these Ensign articles about these fabulous scout leaders and programs and stuff like that, and so you get this romantic view of leaders doing great things for kids. And just mostly, it's not been my experience—in the Young Men's program particularly. (Nicola)

Furthermore, Steve and Vivian pointed out that the attitude the Church maintains toward people with disabilities is a good one, but the materials and support are lacking, even where they live in Utah—the headquarters of the Church.

I think their attitude is great—the Church attitude is great, they know what special children they are. People in the Church understand that, generally speaking. I think the Church itself is not really functioning well providing for handicapped children. No. We never could find a scout program for him. And so he only went to scouting a little bit and that scoutmaster just quit and they never got another one going and besides that it wasn't through the Church it was through the RA—the Retarded Child Organization. And so I think as far as that goes, Jacob has never had any special classes or anything. He really has not been taught the gospel by the Church. He's picked up things from going—he's gone to all the classes and he's listened and I think it's because he's sharp enough, he's picked up a lot. But there hasn't been *special* training for him. (Vivian)

Not only is support lacking but sometimes just going to church became a problem for Shauna with her sons with behavioural problems. I inquired if going to church was helpful or if it was more a problem with her sons. She responded:

Yeah more of a problem in a lot of ways, like not sitting still or being quiet in meetings and stuff like that. Particularly for the youngest one because he was hyper—he was sorta very hyper, yeah, he was just very difficult to sort of work with. He used to sit in sacrament all the time and at the top of his voice go, 'I'M HUNGRY, WHEN IS IT TIME TO EAT?' He just used to be loud all the time and wriggle, jiggle, wriggle, jiggle, all over the place and that and you always try and shut him up. It's usually just the older ones who are more intolerant and that's just yeah—it's like me, I just sit there now as an older person and you see kids running around or jumping up and down and that, and you sorta look at it and I think—well, I could be like some older people and go like [in a mock harsh tone], 'Oh I wish they'd SHUT that kid UP!' or 'THAT KID!' You know, 'CAN'T THEY CONTROL THAT KID!?' You

know, I don't look at that and I just smile and think, 'Yeaah, I've been through it. Good luck!' (Shauna)

Where the previous participants received little if any support from the Church, Fay related how she received support from the Church for her problems with chronic fatigue. However, she observed that the help was not always consistent.

Church was actually quite supportive! Sometimes. Sometimes. They would do meals and bring meals over and things like that. Sometimes you'd go down to the door and there'd be groceries! And you'd think obviously church has dropped them off! ...So that was really good. That support system is good—*when it works*. When we lived in Waimataitai, we were half an hour from Timaru where most of the members are. I guess sometimes I was a bit resentful, I shouldn't have been, but we're only human! It's that my husband would be off doing his home teaching, helping other families, and no one would come and visit us. And you'd think, 'I could really do with a hand.' So basically, it didn't work there in that situation. (Fay)

Initially, church members showed support by going along to take sign classes with John and Beverly so that they could communicate with Robert when he was young. However, as he grew older, not all of the church members were always helpful or friendly with Robert. He observed that when his family couldn't interpret for him, few people would try to communicate with him. He also notes that members of the church can often underestimate people with disabilities.

My parents and my brother interpreted for me at church. I am grateful for their services to keep me included in the branch otherwise I would be very lonely and on my own. When my parents or brother are not around at church, no one really attempts to communicate with me. Unfortunately, I will have to say based on my own experience in both New Zealand and USA, most LDS members do not have a clue what other people with disabilities are going through in their lives and they tend to unintentionally hurt their feelings. I noticed that they felt uncomfortable being around people with disabilities and underestimate their potential abilities they have to offer in the community and church. (Robert)

Whereas Robert felt underestimated, Jennifer often felt overwhelmed at church. Church for Mormons is three hours long, consisting of Sacrament meeting, Sunday school, and then Priesthood or Relief Society. Because there is no paid clergy, lay members are called to teach the classes and conduct the meetings. Jennifer expressed her struggles to understand everything at church with her intellectual disability. I asked Jennifer if she thought there was a certain way that LDS members thought about disabilities. She answered:

There probably is. But you know. I think people should just be more open. They should think that somebody else might have a learning disability or something so that they need to try and lower it. So that it's more understandable. If I'm with the kids then that's better 'cause it means I can *understand*! Even better. What do I not like? Sitting in a class that I can't understand. That just annoys the hoot out of me! (Jennifer)

I then asked Jennifer why she continues to go to church if it annoys her, she countered, “Cause it’s the only thing that’s going to save me from my life” (Jennifer).

Ben and Carol were the only participants who mentioned that they utilised the Church’s counselling services. Ben noted that the service was beneficial to him but he thinks that people are not aware of the support that the Church provides. “It was beneficial. I don’t think it’s widely—I don’t think members on a wide scale understand the support that the Church does provide. And so I think that there are a lot of members that would need that sort of help but don’t really know that it’s there” (Ben). The Church has recently enhanced its online disabilities resources website and it continues to expand the LDS Family Services programs—but from what my participants have suggested, the Church could work on making these services more publicized and more widely available.

To summarise these stories, if “community attitudes” can be disabling, as Beatson (2004) suggested, is the LDS community attitude denigrating, or accepting? The participants suggest maybe that the community attitude in the church, despite all best intentions, sometimes can be demeaning and help is not always available when needed. The Church is working, however, to improve their approach and increase support for members with disabilities. But as suggested above, there is room for improvement in increasing awareness of these support networks and materials.

The upcoming chapter will further explore the difficulties faced by participants by comparing their narratives of suffering to Frank’s (1995) chaos narrative. This interlude represents the earth-life phase of the spirit journey.

## V. Interlude: Life on Earth and the Chaos Narrative

The second illness narrative Frank portrays is the Chaos narrative: “Chaos stories are sucked into the undertow of illness and the disasters that attend it” (Frank 1995:115). Life can sometimes be utter relentless chaos. Nobody knows that better than caretakers and parents of and people with physical, mental, or emotional impairments. I am grateful my participants were willing to be so open with me and share their stories, even the difficult ones to tell. Chaos narratives are unsettling: “Chaos stories are also hard to hear because they are too threatening. The anxiety these stories provoke inhibits hearing” (*ibid.*:98). Of the three schemas of illness and disability narratives Frank outlines, chaos is an “anti-narrative.” In a few of the interviews, I recognised some of the elements that make up the chaos narrative. This section is where I will highlight some of the chaos stories told to me.

Frank analyses the story of Nancy, a woman with chronic illnesses who also takes care of her mother with Alzheimer’s. He evaluates her story and outlines the components of the chaos narrative, “The second feature of chaos narrative in Nancy’s story is the syntactic structure of ‘and then and then and then.’ This staccato pacing of words pecks away at the reader just as Nancy’s life pecks away at her” (*ibid.*:99). The disjointed but continuous pacing that Frank describes is noticeable in Carol’s narrative of her son Isaac. The quote is quite lengthy, but I feel including the entire piece uninterrupted is necessary in order to grasp the whole effect of the chaos narrative.

In the meantime, Isaac was ten—he was having so many difficulties, so many troubles, he was so difficult, because of his OCD and the fact that he had brain damage means that every time that he became obsessed with something he would go absolutely berserk, and also because his epilepsy was so bad it was all leading up to a fit, then he’d have a fit and spend the next couple of days with absolute exhaustion, or the next few hours. As it got really bad, he’d fit and have a SERIOUS *grand mal*—it didn’t take 48 hours, it happened sooner, or it could. And the whole cycle would start again. He’d just start getting obsessed about little things and then the symptoms of before you have a fit you get all hyper and you do all sorts of—and it would just go and it would cause him—his anxiety would cause him to have a seizure and then he’d have a seizure and it would be so bad that we had to get medical intervention, usually had to go in an ambulance and then he’d sleep for hours and hours afterwards. And because his body was so battered from the convulsing which was so bad that—well this was happening and our lives were absolutely terrible! My children, my older children, because he was number four, my older children were young teenagers or twelve going on thirteen, fourteen, sixteen—now the way they felt about it, he was destroying their lives! If they had friends over, the friends had to be part of this screaming and throwing things. When we went out, he’d run around smashing up

places. It was destroying them. So we decided and it was through prayer and through promptings from the Holy Spirit, we realised that we needed to take Isaac to Dunedin where there were better facilities available, because there were less people wanting them. Because there was just—we just couldn't get him into anything in Auckland. So we brought him down here, and that affected the children **BIG TIME** because they didn't want to leave their friends and home. So we put our house—it was rented out for a year and we came down here. Now the children's lives became so badly affected and my husband's and myself, that when we were down here he was wanting to kill us! This is how violent he was becoming. But it wasn't his fault! He was very very ill. And he couldn't take the drugs that are required for very obsessive, violent people. He couldn't take them. It didn't work. They were of no use to him. Even Valium wouldn't work on him! Just because the Tegretol that he was on just was so efficient in its job that it just flushed—yeah. Anyway, the family was so affected that he was coming at my children with knives wanting to kill them. He had me—and I fell pregnant again with William who comes to Church with me and Isaac—I was expecting William so I was *very* vulnerable. And it was *really* frightening because Isaac would have me holed up in a neighbour's garage while he was—this was like when my husband had to go and do some shopping or something—because you couldn't take Isaac shopping! It's terrible and he was brought home from school because they couldn't, just couldn't manage him. So I was holed up in the neighbour's garage while he was running around—I could hear him, running around in the house going 'Where's mum? I'm gonna kill you, mum! I'm gonna kill you!' Or words to that effect and it was terrible. What happened in the end was because his seizures were so bad and because his violence was so bad and they went hand in hand. He became **SO** violent that in the end he had a seizure. Now, none of the people who gave you respite care, the lady in charge, she had told me [in a mock voice], 'I will not put any of my workers at risk to look after your son!' So there was only one lady, who was a member of the Church. And she, because she had the same understanding that we did, and because she was my friend, she was prepared to do it. And unfortunately, and I'll never forget the day it happened, at her house—it was a cold day and she had a fire, and she had a fire guard, and he was doing one of his usual tantrums, he was going absolutely nuts and throwing things around her sitting room and he threw the fire guard away and then he had a major *grand mal* seizure into the fire! So she pulled him out—her neighbour, who could hear it all, came running down—he grabbed, while she rang the ambulance, he took Isaac in the shower with him and just the water was just showering on him. The ambulance arrived and I think he had to stop him fitting as well as treating for his burns. And she had to ring me up and I was at the Globe Theatre rehearsing a play, and she had to tell me that my son had been in a fire and was now in hospital. So we had to go, my husband and I, we had to go rushing up to the Dunedin hospital. It was absolutely horrific. And I remember saying to my husband, 'I'm his mother!' What a stupid thing to say. But this was how I was reacting. I was pregnant with another and this child was, we didn't know what we were going to be confronted with. Was he going to be dead? Or was he going to die? Or what? What was going to happen? Well we got there to our *relief*, his burns were minimal and his burns—because she caught him **SO QUICK**, it was only in his hand, on his good hand, the side of him...The only part of him that was burnt, and they were bad burns, but it was only in minimal areas. It was only in two areas. And he still to this day, has the scarring and the scarring on his hand. He will always have that, that's how bad it was. So they had to treat him and also for his violence as well, they realised at that stage that Isaac—he could not be cared for at home. He was a danger to himself and a danger to others. And he needed professional care. And very sadly, my husband and I had to sign papers for him to go into care for a month of special—this was after he was released from the hospital this

was afterwards. They realised this when they sent him home to us because the burns had healed sufficiently—but he was having such violent—we found it difficult to even look after his burns, because he was so violent and we couldn't keep him safe. So my husband and I—it happened at the hospital when he went for a check-up. They had to call in these people and we had to sign forms for him to go into care for twenty-eight days. So we had to leave that hospital. We *knew* that it was going to be a lot more than twenty-eight days. We knew that it was a severe case and we were not capable of giving him 24/7 care because we just didn't have the resources or the knowledge or the skills to be able to all the time, because we had to sleep. So anyway. We had to walk out of the hospital, we had to leave Isaac there and the caregivers who were trained were going to take him for twenty-eight days to their home, which was on a farm. And the whole situation would be assessed. And well we just sat in the car and we cried and cried and cried. It was a *horrible* moment because we realised that we couldn't give him the care that he needed and we felt like failures as parents. We knew we weren't failures, but that's how it *felt*. It felt like I was a failure. (Carol)

Carol recounted these and many more stories to me in our interview. But I am sure as Frank indicated, “In the chaos narrative, troubles go all the way down to bottomless depth. What can be told only begins to suggest all that is wrong” (1995:99). But for Carol, the chaos is mitigated by her spiritual beliefs and understanding of the plan of salvation.

In LDS author Kathryn Soper's memoir, *The Year My Son and I were Born* (2009), the majority of the book is a chaos story. She tells of the shock of finding out her son has Down syndrome as he was already born prematurely. She expresses the grief she struggled with and describes the severe depression she had, as her life seemed to be crumbling around her. The earth-life part of the spirit journey is the most challenging. When everything is in complete disarray, it is hard to imagine life ever improving: “Chaos is the opposite of restitution: its plot imagines life never getting better” (*ibid.*:97).

Parenting a child with a disability can be challenging. Moreover, caretaking and teaching people with disabilities can be arduous as well. For instance, Shauna recounted her time as a primary special care aide of a little girl who had severe disabilities:

She had been basically malnourished, mistreated—so she was developmentally delayed as a baby. She had been starved, she had been kept in a cot, she had never learned to walk or crawl properly. So basically she was hugely developmentally delayed. She was in foster care and the school had suggested that they leave her when she turned five in kindergarten a little bit longer so that she could develop more... Yeah so she was developmentally delayed, she couldn't read, she couldn't write, she couldn't speak. There was very little language. She had dreadful tantrums—that was just frustration of not being able to express herself, and the living conditions that she was in—she was not in a good situation where she would have the kind of care that would help her progress, which she should have progressed a lot more than what she was. She spat, and she scratched, and she walked past the kids and if she didn't like something she would suddenly just yank out and snatch their hair. If she didn't want to do something, you've got all those behaviours. And stuff like that. She was very very draining to have to work with. Lovely little thing—I mean, all her

growth was stunted. She used to regurgitate her food and chew it all in her mouth so her teeth rotting. Yeah it was really—she was a tough wee cookie to have to work with and you had to be really really firm. She wasn't toilet trained...She was very challenging. Very tired after three years. I was going into my fourth year with her and so that's one of the reasons why I won't go back to primary special care. (Shauna)

Shauna not only had difficulties working with children with special needs, but she also had children with ADHD and another child with depression.

Well I just had very hyperactive—actually it was my fifth child that was very very hyperactive. He just drove us nuts. Absolutely nuts. I was a screaming mess most of the time because you know if you said, 'no, leave it alone' or 'stay away' or whatever—the other kids knew. Most kids will push a couple of times but they knew you meant business and you stopped but he just never stopped with anything and having five children it was like I knew this was more than just me being a tired mother and just can't be bothered anymore, there was definitely something there. My middle son also—once I started looking at behavioural issues and the way I was dealing with them and the way to change them and things like that I realised actually—my middle son actually was the same and that's why he drove me to absolute—yeah. Yeah—I mean, I basically had a breakdown at one stage because I just couldn't deal with it. And really I probably shouldn't have been doing home-based care. But you know you do when you've got five kids and you need to feed them and you need to pay the bills. (Shauna)

Not all of the participants were explicit about their ordeals—some only alluded to the pain that hid beneath the surface. Robert describes his lonely existence as a deaf person in a hearing community. Notice the subtle hint to the distress that he endured growing up:

The disadvantage of being the only deaf person in a hearing world is that you will have to learn how to survive a lonesome life! I was not exposed to the Deaf community much till I was older, even in my twenties. No one will want to attempt to experience what I endured back then. (Robert)

However, the stories told by my participants cannot quite be considered the chaos narratives that Frank describes. Spiritual meaning lifts their stories. As will be discussed in subsequent chapters, the narratives participants tell are of dreadful, unremitting pain but they are alleviated by the numinous element of their experiences.

## VI. What is disability?

The following chapter sheds light on how participants view the role of disability in this life by asking “what is disability?” and “what does disability mean?” It will compare the participants’ perceptions of disability to Beatson’s (2004) different conceptualisations of disability.

In order to gain an understanding of how the Mormons in this particular study view disability, one of the questions I asked the participants was along the lines of, “Why do you think that God gave us disabilities in this life?” Their answers were varied but I noticed a common theme—the discussion of disability as the result of the physical nature of this life—a theme that parallels Beatson’s observation:

Disability begins in nature. Its unavoidable first premise is the existence of a flaw in the human organism. Whatever social factors are involved in constructing the total experience of being disabled, it cannot be denied that at its foundations lie abnormalities or losses of anatomical, physiological or psychological structure or functioning. Disability resides in the body. (Beatson 2000:97)

The perspective many of my participants held is divergent from the social constructionist view of disability according to Vehmas and Mäkelä who assert, “The ‘Western’ conception of disability as an individual’s biological condition is incorrect and harmful” (2008:42). The social model of disability contends that disability is a by-product of social oppression. However, (as indicated before) for participants, disability is often not seen as a plight of subjugation, rather a corporal circumstance personally undertaken and given from God as a channel for ultimate transcendence.

While my participants understood the physiological origin of impairments, they ascribed somatic impairments as a natural consequence of the physical nature of this world. Informants acknowledged that this world is not perfect. This belief stems from Mormon cosmology and beliefs about the fall of Adam and Eve. The Church’s online gospel topics reference states that because Adam and Eve transgressed “they experienced spiritual death. They also became mortal—subject to physical death” and, I might add, subject to physical impairments. The online reference continues, “As descendants of Adam and Eve, we inherit a fallen condition during mortality. We are separated from the presence of the Lord and subject to physical death. We are also placed in a state of opposition, in which we are tested by the difficulties of life...” (LDS.org, 2012: Fall of Adam). Needless to say, the difficulties in life may include having or caring for someone who has physical, intellectual, or emotional

impairments. Nicola put it concisely when I asked her why she believed her son was born blind and autistic. She stated:

The way we see it is that we live in a fallen world where bad stuff happens and where there are genetic disorders and so on. And it just happened that Jonathan was born with a genetic disorder because Mark and I just happen to be carriers. And we just have to make the most of it. (Nicola)

Harris, Parrott, and Dorgan (2004), who researched opinions on human genetics and religion with seventeen focus groups in the United States, found that some of their participants were prone to think that disability is a form of punishment from God. While the Fall brought upon the imperfections of the world, for Vivian, having a son with Down syndrome was not viewed as a punishment:

Well, I don't think Jacob was born as a punishment for us—I think Jacob was born because the sperm and the egg didn't get together right. And it was one of the physical manifestations of what goes on in this world. And I think a lot of the tests that we go through are exactly that, just that's the way life is set up! But I think that Jacob's spirit was sent to us, especially to us—I feel that way. And I just think that that's what it is! They come to test people. But I think they're born because of natural physical situations. (Vivian)

Shauna was introduced to a variety of disabilities while she worked with children with special needs in daycare and high school. She discussed how most of the children she worked with were disabled or had behavioral issues that occurred because of abuse and neglect from their parents. But some of the children she worked with were disabled simply because of genetics. When I asked her why she thinks we have disabilities in this life she stated:

Oh, I think there is a reason because a lot of the children that I work with—it hasn't been a genetic reason—it's been a reason, it's been alcohol fetal syndrome, it's been like this little girl, I mean she would've been probably just an ordinary little girl without all these disabilities if she hadn't been abused as a baby. So, you've got the different types of disability; you've got the parent-made disabilities, and then you've got the genetic disabilities, and I just think that's life—that genetics sometimes don't work together and you know. (Shauna)

Ace's mother, (as previously mentioned in the introduction) was a matron in a mental health hospital in the Pacific Islands. Ace was born on the mental hospital grounds and spent most of her childhood there. I inquired about her experience with what other people thought about her unique upbringing. She described:

Sometimes kids can be very great and they can be very judgmental at times. And I think—I was maybe eight, and I told someone and they were like, 'so you live with all the crazy people?' And I'm just like, 'they're not crazy, they're just different' and trying to explain, because my mother was very firm about 'these people aren't crazy they're just suffering from an illness' just like someone suffers from diabetes in a way. I was trying to explain that to them, but in the Pacific Islands mental health is very stigmatized, it's still very—it's a huge thing. If you're afflicted by a mental illness it's

like ‘your family must’ve done something’ or ‘you’re not a good person and so this is why it’s happening to you.’ I was baffled why people would put this upon the person. (Ace)

Even though mental illness was significantly stigmatized in the Pacific Islands, at a young age Ace learned that some people have mental illnesses not because of any sin or curse, but that disability was a biological condition that affected some people. She acquired a passion for helping to illuminate the medical reasons for mental illness. I asked her to explain why she felt that mental disabilities were more stigmatized in the Pacific Islands as compared to New Zealand and she responded:

I think it’s a combination of—in the Pacific Islands it’s very heavily religious—and there’s a lack of grey area sometimes, so it’s like really good or really bad. And so people with mental illnesses, they don’t understand it, they’re not educated on that it can be a result of an imbalance of chemicals in your brain or anything like that. So they just attribute it to the only thing they know which is this religious, ‘oh they must be bad.’ (Ace)

In contrast to the Pacific Islanders that Ace described, participants generally recognised and understood the biophysical origin of impairments, but at the same time, they stressed the spiritual significance of the occurrence. Interviewees seem to recognise what Ingstad and Whyte observe, “But the core meaning of disability for most of us is a biopsychological one” (1995:3). However, for many of the participants, there was a deeper meaning behind the biopsychological one—the numinous. Carol illustrated:

We have disabilities medically because they are a result of damage either before birth or after birth. So we have disabilities because of physical causes. But my view on that goes further than just a physical cause. To me, it’s not a coincidence. Heavenly Father can do ALL things. And I know that if Heavenly Father wanted to, he could have cured Isaac’s disability. He could’ve taken it from him, because there are times when—and I have heard of miracles happening in the church where blind people have seen and disabilities have been taken away from them. But I believe that Heavenly Father—if we are disabled and he doesn’t take it from us, it is for our growth and for our protection—because we are greatly strengthened by disability. (Carol)

Just as Carol believed that disability is strengthening, John viewed disability as a challenge or a task that enables one to grow. He recognised that some people may not have the means necessary to do things the way society thinks they should be done, but John maintained that for his son, being deaf was an opportunity to prove that he was capable of accomplishing great things.

To me it’s simply that an individual doesn’t have the—what’s the word—the advantage of all of their faculties and that it is harder for them in life to function fully as other people do and therefore they’re always going to have to work harder for one reason or another, depending on what the disability is. But unless of course it’s a mental deficiency where their brain isn’t capable of functioning in certain ways—

Robert's experience has proven that there are ways around achieving your potential. And I think that's how I feel about it. It's harder work. But it can be done. (John)

These informants comprehended that impairments were caused by physical imperfections; however, they might agree with Beatson, "To say some people are biologically inferior is not to pass a value judgment on the intrinsic worth of their lives" (2000:99).

Disability may reside in the body as Beatson stated, but for participants, disability does not reside in the spirit. Disability is a critical aspect of identity here in this life. Of the four dimensions of disabilities that Beatson conceptualises, *identity* is an essential model to understanding participants' beliefs about disabilities. Although they recognise that they have a physical impairment, "it is not a deficit at all, and therefore no fixing is required" (2000:43). But also at the same time impairment is not a permanent condition of their spiritual selves. For informants, this spiritual model of disability is an essential component of an eternal identity—people with disabilities agreed or volunteered to have an impairment in this life as part of the necessary steps to take in order for their spirits to progress.

## What does disability mean?

After briefly describing what disability *is* according to participants, it is fitting to cover what disability *means* to them. Beatson outlines three different stereotypes of disability, in the section of his book titled, "Able-Bodied Representations of Disability." I found my participants most often referenced two, *The Victim* where "disability [is] the object of pity, charity and love" and *The Hero* where "disability [is] the object of veneration, admiration and praise" (2000:389).

Participants Steve and Vivian described their opinions on the meaning of disability obtained from the experience of raising a son with Down syndrome. What they depict seems to be a combination of attributes from Beaton's *victim* and *hero* stereotypes. They felt that Jacob does not need to prove himself in this life—he is here to help others learn charity, but at the same time, they recognised what an exceptional person Jacob is.

V: Personally, I think about it and I don't think we really know how things will work. But I do feel like he will be one of the noble spirits and obviously as only a spirit before earth life, he hasn't had to prove himself because that's how he was allowed to come down in the situation that he's in.

S: When I blessed him as a baby, I remember near the end of the blessing saying something—I said, 'Jacob, most people come into this life to be tested, but you've come into this life to test others—to test their charity and acceptance and love.'

V: And I had a couple of experiences that gave me a very real feeling about what a great person Jacob is. It was really wonderful. So we've always known that. And that's always made us treat Jacob nicely because he's a wonderful person. [Chuckles]. He really is. (Steve and Vivian)

## The Victim

Of the stereotypes of disability that Beatson constructs, *the victim* seemed synonymous with how several of the able-bodied participants perceived people with disabilities. As *the victim*, when viewed from an LDS perspective, people with disabilities are not so much victims of pity as they are the conduit for providing charity and learning opportunities for the people around them—congruent with what Beatson described, “They [the disabled] still stand apart from normal society, but provide members of that society with the occasion to discover their own potential for philanthropy” (Beatson 2000:393). When I asked my participants what they thought the meaning of disability was, many of them responded that people with disabilities are here for us to learn from, provide service for, to test, and to try us. I asked Michael if his religious beliefs influenced his experience while he worked caring for men with special needs. He reflected:

At the time I wasn't attending church and I wasn't religious at the time. But in retrospect, I can kinda see how much someone with an intellectual disability brings to everyone else around them. I don't feel like—when someone has an intellectual disability people think ‘aw, poor them.’ But really I've come to consider that perhaps they're here to help everyone else, not for us to help them. ‘Cause you always tend to think, ‘ah, they've got a disability, they're there to be supported.’ But I really think God puts them here to test us, to try us, and to help us. Because, they're not afraid to show emotion and that includes happiness and they can make a lot of people happy. (Michael)

Beatson describes how religious institutions have certain prescribed roles for those with disabilities. He elaborates, “Christianity, in particular, has a major doctrinal role for the afflicted, cast as they are amongst the humble and meek to be elevated on the Day of Judgement, when the proud and mighty are laid low” (Beatson 2000:394). From the early days of the LDS Church, caring for the afflicted and the impaired was a fundamental element of Mormonism—especially considering the importance given to communitarian and humanitarian values. The second prophet of the LDS Church, Brigham Young, is quoted as having stated, “Let us have compassion upon each other, and let the strong tenderly nurse the weak into strength, and let those who can see guide the blind until they can see the way for themselves.” (LDS Church, 1997: Teachings of the Presidents of the Church:219) Michael continues:

Like I said, it's more for the benefit of the people around them—rather than them. I don't think that them having the disabilities, especially to that point where it affects their agency, has anything to do with *them*. But I think that they're more to help the people around them. (Michael)

Ace's response validated Michael's opinions that the purpose of people with disabilities is to help others learn: "I think they're here to test the people around them—if anything. I guess we could learn so much from them" (Ace).

Sam's experience of care work gave him an appreciation for people with differences. Like *the victim* model Beatson described, Sam noted that people may have a tendency to feel sorry for people with disabilities. However, he considered that people with disabilities can help others learn what the true meaning of life is.

I guess from my religious beliefs, life isn't meant to be perfect. It's never going to be in this life. And, some people are going to be less fortunate than ourselves. But in saying that, I think a lot of the time we actually look at these people and think that their quality of life must be really miserable because we compare it to our own state. But I also think part of it is also an attitude. Like, if you find someone [who is] in a wheelchair, you know they might have a better outlook on life than a businessman who's making a lot of money. So, I think that there are some subtle purposes of people being in the situation, whether it's to teach others to love or to help someone focus on the true meaning of life. I think there's a lot of purposes for disability or people with disabilities. (Sam)

As Sam, Ace, and Michael demonstrated, Diane noted how careworkers frequently attain an appreciation for people with disabilities because of their work:

I suppose when you look at the eternal perspective, that this life is just part of the whole big picture. And I think for people who work with people with disabilities, often they learn a lot and gain a lot from the service they give. (Diane)

## **The Hero**

*The hero* is another role ascribed to the disabled. Beatson expounds, "These are specific instances of a widespread cultural phenomenon—the attributing of superhuman powers to the disabled. They are sometimes considered mouthpieces of the gods, or alternatively as the vessels of a special spiritual grace." (2000:396). What Beatson describes was often the paradigm for my informants. This point is exemplified by a comment Nirmala made during our interview about her son, Edward, who has Down syndrome, "When I see him I feel near to God" (Nirmala).

Beatson elaborates, "Some acquire charisma by triumphing in spite of their disability, whilst others become super-heroes simply by being extraordinarily courageous in coping with their impairment" (Beatson 2000:397). I found that some of the participants felt that way

about people with disabilities. Sam reflected on his experience of caretaking and remarked how there must be a purpose certain people have disabilities because if he were in a similar situation, he indicated, he would not know if he would have the same amount of patience. Fay similarly commented on how people with disabilities can be inspiring:

I think if you look at it with a positive mental attitude, rather than a hindrance you can inspire others and you can actually do lots of things yourself, if you're the one with the special needs or the handicap. You see stories all the time and in books about people that have overcome and that's very inspirational to other people too. Though, I guess it's one of those things—like also the chronic fatigue I found it'll either hit you and you spend the rest of your time lying in bed, or you battle it. (Fay)

Beatson describes *the victim* and *the hero* stereotypes as “able-bodied representations of disability,” but what do people with disabilities think of themselves? Frank observed that the wounded storyteller desires to be viewed as the hero of his or her own story (1995:134). He considers, “what sort of ‘heroes’ do ill people take themselves to be?” (*ibid.*:119). Ben and Robert answered this question when I asked them why God gave people disabilities in this life:

Because we can handle it. Because He knew we could handle it...I think Heavenly Father's provided a way that humbles us and helps us understand the great need that we have—or how much we depend on Him. Just kind of helps create a way in which we can more fully understand mortality and our purpose and how we can overcome those things with our relationship with Father in Heaven. (Ben)

I can assure—this question could be very difficult for a person with disability who doesn't have religious beliefs. Fortunately, I was born in the Church and the gospel of Jesus Christ taught me the purpose of this life, which is to meet God in the next life. There are many different purposes. For example, it allows me to develop Christlike attributes such as patience and empathy. Other people had informed me that they appreciated me for setting an example for them by keeping on moving forward without giving up! For me, being deaf allowed me to mature rapidly and develop good characteristics. My parents can confirm that I was never a ‘teenager’ but transferred from a child to an adult due to my deafness experiences. (Robert)

## Special Spirits

He's special to me. David said he's like angel sent from heaven. Angel sent to earth. (Nirmala)

People reflect some of the platitudes imbued in the popular-culture vernacular surrounding disability, such as the clichés, “supercrip,” or “pillow angel.” There is rhetoric among Mormons that people with disabilities are not only gifts and blessings, but they also are “special,” “valiant,” or “noble” spirits. Frank clarifies that “People tell their own unique

stories but they compose these stories by adapting and combining narrative types that cultures make available” (1995:75). The vocabulary used in participants’ stories were informed by the popular-culture narratives of disability and often modelled by it or at least closely mirrored it—“Robert is a very special person! There’s no doubt!” (Beverly). Other researchers also came across the notion of disability as a blessing—Press, Browner, and Tran (1998) examined the views of pregnant women towards disability in the context of prenatal testing and found that:

For a few informants, such children were even superior to normal children. Thus, as Lynne Koenig indicated, ‘a handicapped child is even a little better off [than others] because...they are already perfected spirits and don’t have to prove themselves down here.’ (1998:53)

Participants’ jargon may have been similar but their enactment is made unique by the element of their religious beliefs. A former LDS apostle wrote, “Those who are close to the handicapped can frequently feel the nobility of the spirits who are confined in differently shaped bodies or who have crippled minds” (Faust, 1984). Many of the participants who had children with disabilities believed what Faust taught.

And he has one of the *strongest* spirits that I know. He is such a *strong* person. And you can see the spirit in him—it’s *so strong*. And he is spiritual and he *is* an example to others...He must’ve been a very very very valiant spirit... But Isaac, I can see that Isaac is a very valiant spirit, a very strong spirit... you can *see* that he’s a special spirit. You can see it in his countenance. He is a special spirit and other people at church—I believe they must be able to see it too, because everyone is so lovely to Isaac. (Carol)

### **...Or not**

Conversely, many participants did not expressly view people with disabilities as somehow extraordinarily special. They would concur with what Frank contested, “The danger of imagining ill people as heroes is putting this same weight on them; the phoenix as an expectation becomes a burden, not a liberation” (Frank 1995:135). The pressure to be a hero can be an unwarranted stress and further distance people with disabilities away from everyone else. The Church’s Priesthood Handbook of Instructions encourages leaders to not teach that disability is a blessing:

Leaders and members should not attempt to explain why the challenge of a disability has come to a family. They should never suggest that a disability is a punishment from God. Nor should they suggest that it is a blessing to have a child who has a disability. (LDS Church, 2006: LDS Priesthood Instruction Manual)

Some seemingly positive views of disability often expressed in religious rhetoric, such as the notion that disability is a blessing, could be received as denigrating to the disabled or

their family members. Selway and Ashman (1998) cited an incident of a case study of Margaret Orlinski: “While Margaret was deemed special by her community because of her disability, she was also segregated.” The authors note, “Thus, the blessing of Margaret’s disability also alienated her from the community that exalted her” (Selway and Ashman, 1998:435). Furthermore, Soper discussed in her memoir and on a podcast interview (2010) her experience of having a child with Down syndrome. She observed attitudes from other Mormons that viewed her son as a “superhuman” or “angel baby.” She was concerned that by placing her son on a pedestal, they were actually distancing him from everyone else (2009:273). Many informants felt likewise—they only desired to be seen or have their children be seen as normal. Diane related a story about how her friend dealt with people telling her that her son is special because he is blind:

But [chuckles] some people say things like ‘oh this person—’ like my friend’s son was born blind...and people used to say to her, ‘Oh there must be a special reason he was born blind.’ And she said, ‘Yes, his eyes don’t work’... You know, because sometimes we can get this romantic view of [how] this person must be really special to have come to earth like this. But I don’t know. I just think life happens and we have genetic makeup or we have accidents or whatever and that’s just what we’re dealt. (Diane)

I asked participants what they thought about the rhetoric of people with disabilities as having “special spirits.” Some of them countered:

People can misinterpret things. People can accept their disabilities in two different ways—accept it and live it along or feel remorse and resent it for life. I cannot speak generally since every individual beings are different. I do not like to ‘measure’ who is most important! I know that everyone is a child of God and we all have the same goal, which is to enter into highest degree of the Celestial Kingdom. (Robert)

While as I have previously noted, official LDS doctrine does not endorse the view of disability as a blessing, some Mormons believe that raising a child with disabilities is seen as a blessing. Some of them had similar responses that were reminiscent of one of Teman et al.’s (2011) Ultra-Orthodox Jewish informants who related a narrative about raising children with disabilities:

My friend told me that these children are considered gifted, they are highly evolved souls. It is considered by people that you are on a spiritual basis high enough to accept it. It’s considered really a divine privilege. You have to be on a very high level to embrace it that way. (2011:73)

Inversely, Nicola did not particularly appreciate being told that she was special for having a child who was blind and autistic. I asked her if people at church tell her that Jonathan is special. She replied:

Well, not anymore, they don’t dare! [Laughs]. But more when he was a baby. I think people try to say it in terms of comfort. They think that somehow it will help to think

that there is some meaning in it. And people do try to find meaning in lots of things. But not these days, nobody says that anymore. Rather than thinking—and I don't—it's interesting in an LDS perspective a lot of people put a lot more meaning into it than what we do. Like, people will say, 'Oh, you must be very special parents for Heavenly Father to send you this special child.' And we just say, 'No thanks, I don't really want to be that special' [Laughs]. And so I don't take that meaning from it. I don't see any great reason why he came to us. And I've never received any revelation that this was the case. And, I don't like people telling me stuff about myself, if you know what I mean. (Nicola)

Perhaps participants with disabilities or the parents of children with disabilities maintained a set of beliefs that have a dialectical relationship as to whether or not people with disabilities are indeed special spirits—this notion is demonstrated in Soper's memoir: “A *special spirit*—I still hated the phrase, but maybe it was true after all. His presence was ethereal, as if only the most delicate bonds tethered him to earth. He was not of this world—that I knew.” (Soper 2009:183)

## **Is having a child with a disability a blessing?**

Beatson perceived that the first thing that people want to know when they are having a baby is if it's a healthy baby (2000:100), then, when a child is born with a disability it is a cause for grief over once held expectations. Dave and Nirmala experienced this when Edward was born. But now they see the whole experience and Edward himself as a blessing. “But we're quite happy. We've been blessed. He's blessed us in our own way” (Dave).

Carol also viewed having and raising Isaac as blessing and a learning experience. She observes how her faith has been strengthened throughout the years because of this experience:

And as a mother I did grieve for him because he was struggling with things that he shouldn't have to struggle with. But then because of my faith, I accepted each time that there's a reason for this and that it will all work out in the end. And that he's going to be okay...And it is a huge blessing that he is my son—that Heavenly Father gave me this very special spirit and also, I felt honoured to have him as my son because I learned so much from him. It's a very humbling experience and it's a very teaching experience. And it's a very faith promoting experience to have a disabled child—your own spirituality grows because you realise how special that child is and how much love that he has...But having Isaac in the family with a disability, although at one time it threatened to destroy us, has actually made us stronger. So having a person with a disability in your family, it is actually a blessing. It's a blessing in disguise. And you often don't see it as a blessing, but it is. It is a blessing. (Carol)

Even if they were unsure when Jacob was first born, Vivian perceived that having Jacob turned out, unequivocally, to be a blessing in their life. She expressed her devastation at finding out he had Down syndrome and her anxiety about what his life would be like. Steve and Vivian prayed for comfort and they became adjusted to the idea that Jacob was who he was and they were grateful for that: “They sometimes say, ‘you have trials in life’ and he’s turned out to be just a blessing in our life. He really has!” (Vivian).

Unlike the participants above, some participants were hesitant to say that having a disability or having a child with a disability was a blessing. After having worked several years with people with disabilities, I asked Sam if he thought it would be a blessing to have a child with a disability. He responded: “I’m trying to think how to word it. It is a blessing to have people with disability in your life, but it’s not something you wish to come upon someone” (Sam). Other participants were equally conflicted. That is possibly one of the reasons for the previously mentioned attitude from the Church that it does not endorse the view that a child with a disability is a blessing officially (LDS Church, 2006). Soper describes a discussion of this matter with her husband, Reed, in her memoir: “I couldn’t call it a blessing anymore than I could call it a tragedy. As Reed said, Down syndrome wasn’t inherently good or bad, right or wrong—it just *was*. What it meant was up to us” (2009:297). She came to the conclusion, however, that her son Thomas brought out a stronger love from within her family:

By sharing his abundance, Thomas helped us rediscover our own. His innate goodness sparked ours. His raw humanity released ours. His unrestrained love awakened ours, calling it forth from deep, heavy sleep. Maybe the heaven we found in Thomas was a long-lost heaven inside ourselves, a sublime Pole within our very skins. (2009:322)

## VII. Opinions on Genetic Testing

Having discussed the different aspects of what it is like to be Mormon and disabled and what disability means to the participants, this chapter explores how participants conceive of genetic testing. I found that informants maintained an array of opinions on a spectrum starting from being extremely opposed to all genetic testing to a slightly more liberal position, believing in individual choice and being non-judgemental. I will first discuss whether participants viewed genetic technology as an intrusion onto God's territory or if it was a gift from God. Then, I will present participants' general views and personal experiences with prenatal genetic testing. Finally, I will recount the various ways some of the informants navigated their reproductive choices of potential pregnancies after having a child with a disability.

### Genetic Testing: Playing God or Gift from God?

This section examines whether or not participants believed that genetic testing was within the "appropriate realm for humans to play a role." This section also considers, is genetic testing trespassing on God's territory? Or is genetic technology, like other technologies, a gift from God? Concerning genetic testing and prenatal diagnosis, Harris et al. (2004) contested that "strategic efforts should be made to acknowledge and respect the beliefs of individuals who believe that genetic technology is beyond the appropriate realm for humans to play a role" (2004:115).

In "Christian lay understandings of preimplantation genetic diagnosis," Doolin and Motion organised focus groups in New Zealand consisting of various Christian groups. One of those groups was made up of Latter-day Saints. Several issues were discussed in these focus groups, one issue brought up was whether or not these technologies were unnatural or "playing God." From the LDS group one man stated:

I can see now, with my...understanding of the plan of our Heavenly Father, how [PGD] to me seems like an intrusion into Nature. It seems an intrusion into something that is natural—whether a child comes out with a flaw or not. (2010:677)

Before I conducted fieldwork, I speculated that in general, Mormon participants would probably not use the phrase, "playing God." But maybe I was projecting too much of my own

opinions and assumptions on what the participants would say because several of them did, in fact, use the phrase “playing God” in our discussions about the various forms of genetic testing. Michael talked about “playing God” when it came to designer-babies. But he believed that no one would be born that shouldn’t be born. Carol also expressed how “life is beautiful and whatever way we’re given it, it’s still a gift from God.” She cautioned that no one has the right to “play God...and deny somebody the chance of life!” (Carol). Sam expressed similar concerns as Carol and Michael:

Obviously, I believe in God and that he does have a plan and a purpose to all things. And, even though we’re in this life, there’s a lot of what we call corruption. You know like, whether it’s on a genetic level or on a social level, nothing is perfect. And so when we have these situations where we can start to see whether people are going to have disabilities when they’re born or not, it puts some very big choices in our court of what we can do, of what we can control. And, I think that sometimes man thinks that they’re the biggest most important thing and that they know best and so they try and play God sometimes. But I believe that all life that is created should have the opportunity to come out and live out its life. And, that if you destroy that life, it misses that opportunity and you become accountable for being the one that hit that ball out of the park. (Sam)

Although, not everyone used the exact phrase of “playing God,” many of my interviewees expressed unease with genetic testing in a similar manner to Doolin and Motion’s LDS participant.

I do not believe that anyone should intervene [in] God’s creations in the process...No. I believe that we should accept each person as unique beings. I repeat, I do not believe in intervening the development of a child within a mother. I accept both hearing and deaf children. I have a daughter who is hearing. I am happy that she does not have to experience what I did as [a] deaf individual. I believe that we should leave God’s creation alone and accept each individual who are either hearing or deaf during this mortal life on the earth. The Lord knows what He is doing and we have to trust Him in all things. (Robert)

In contrast, where biomedical technologies are sometimes seen as an intrusion on nature, some participants expressed their beliefs that technology is a gift from God. As Michael stated, “I don’t think [genetic testing] is bad. God’s only ever given us technology to help.” An LDS scholar believed that genetic technology not only helps people but is also a part of God’s plan. He published his opinions in a Mormon Scholarly Journal, *Dialogue: A Journal of Mormon Thought*. He speculated:

We can consider God as the creator of spirits while scientists, by using genetics, could play an important role in controlling and designing the mortal bodies into which some of these spirits are placed. I do not have a problem with this idea. In fact, God may be waiting for us to develop bodies by genetic engineering or cloning to house more advanced or complex spirits that he will create...In the future, geneticists may play an

ever-increasing role in controlling and designing some human bodies, but only God can create the spirits that go into these bodies. (Condie 2006:46)

Harris et al.'s (2004) research question asked about God's role in terms of genes. Some of their participants believed that God works through genes, or that he can intervene. For Ben, his feelings about genetic technology were an ambiguous mixture of wondering whether it was inspired from God, or if it was interfering with God's plan:

It's an interesting topic because God gives—like I believe that God inspires all people for all forms of good. And so the interesting topic of discussion is did God give people intelligence and understanding for the purpose of curing those disabilities or ailments? Or did God create people in a particular way because that's how he wanted it? But I guess, I really don't know. (Ben)

## **Prenatal Testing**

Whether or not genetic testing is an intrusion onto God's territory or a gift from God, the chance of miscarriage is often what deters women from opting to have amniocentesis or other prenatal testing services for genetic conditions like Down syndrome<sup>5</sup>. However, with advances in prenatal tests and with the development of technology that does not involve invasive procedures to the womb, the risk of miscarriage will be eliminated and therefore will no longer be a deterrent. Doolin and Motion (2010) contend that as the use of these genetic technologies becomes more common, it is important to understand the social implications that may result. Considering these technological advances, one Time Magazine reporter considered:

But with women learning more about the genetic contents of their womb than ever before, a growing number of expectant parents will be faced with wrenching ethical dilemmas when the news is not what they expected. What is the value of a life? What can a person with a disability contribute to humanity? Which disabilities are tolerable and which are not? (Healthland.time.com, 2011)

Generally the Mormon participants viewed prenatal genetic testing negatively, especially because of the risk of miscarriage and the correlation with termination. But their opinions sometimes varied depending on the condition. When it comes to genetic testing, Shakespeare posits, "Equally, parents or relatives of people with one condition may minimise the problems of that condition, in contrast to another condition, and vice versa" (Shakespeare 1998:678). Some of my participants did just that. Beverly expressed hesitancy when it came to autism. Beverly worked with children with special needs in addition to raising Robert. That

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<sup>5</sup> Fetal cells from amniocentesis or chorionic villi will identify other chromosome disorders as well as Down syndrome. Many of these are incompatible with life.

experience made her grateful that Robert was only deaf and wasn't born with autism.

In another story, at the time Vivian was giving birth to Jacob, genetic testing wasn't available. She expressed the sorrow she feels for mothers now who have to go through "tentative pregnancies" (Rothman, 1993). She had no idea her son would be born with Down syndrome. But because of their experiential knowledge of raising a child with Down syndrome, Steve and Vivian opposed genetic testing when it comes to Down syndrome. However, they equally expressed uncertainty if it happened to be for another condition like autism.

V: It's a little bit of a problem because Jacob went to school with handicapped children. And there would be one or two kids in his class—and there was a Downs kid who was really hard to deal with. He got angry. And he wasn't sweet, whereas most of them are. And people if they found out at three months that they're carrying a Down syndrome child, they're gonna stew and fret for six months—and worry and wonder, and not know what's gonna happen. We just went sailing along, you know, nine months like we always did for all our kids. Jacob was born and I didn't have six months of stewing and fretting—we stewed and fretted after he was born! And then but he is—until you adjust to what you've got! So I just can't really feel good about genetic testing. I don't know there's some children—you know, an autistic child, I don't know you'd have to talk to parents of autistic children about what they thought about that. They have a hard road to hoe—not like ours. Autism is *tough*! They're unresponsive, they're cold.

S: And there are worse syndromes than that too!

V: Oh, there are!

S: So I don't know. Again, I don't think either one of us would've thought of having a genetic test even if it were possible. (Steve and Vivian)

Because of Dave and Nirmala's ages, they were offered prenatal testing for their son Edward. Nirmala shares her experience of being offered amniocentesis and why she chose to reject it:

When I was pregnant, I went for the scan where they see if your children have Down syndrome. But I didn't, because I missed by one week. But then we thought, 'it doesn't matter what happens, we're gonna keep the baby.' Because it's a life. We can't take him out just because he's different. So we just kept him. We didn't want to—they wanted us to do the blood—you put [a] needle in there [gestures to stomach] then take the blood out... Yeah, because there was a chance to lose it too. So we don't want it, I said we'd just keep him... I didn't want to lose him. It would not be good, because he's quite good! I would've lost him for nothing. And if we had done the test too, because he had the full kind of Down syndrome—trisomy 21—he said he got full—not just a little bit. They would've like—they could've taken him out if I had a scan. So, lucky I didn't! I love him! He brings more love in the house, you know. He's so cute. He just wants a happy home. (Nirmala)

Nirmala's husband, Dave, shared his thoughts when the doctor offered them prenatal genetic testing:

The doctor gave us a choice when his scans showed up—there's a lot of women that

get that injecti—the thing where you take the fluid out. But then it could kill the baby. I said we didn't want it all. We'll just take what we get. We're pretty lucky we got a real real real real real mild case. So if it went the other way, well he probably wouldn't be here today...But no, it really hits you when he's first born but what got me was the choice—we could do the test but there will be a certain percentage that he won't make it. Or we could get rid of it totally. I just said, 'No!' Nirmala and I said, 'Well do you want the test?' and we said, 'No you don't.' The doctor said, 'You can do it, but we can get rid of it totally.' I said 'No!' It was hard for us to have our first child. Then all the other children afterwards—they're two years apart. So it's hard to handle if you know what I mean. (Dave)

As Dave and Nirmala expressed, finding out whether or not their son had Down syndrome in the fetal stages was not worth the risk of miscarriage that comes with amniocentesis. Because of their beliefs, Dave and Nirmala felt strongly about continuing the pregnancy either way. As it turned out, Edward did in fact have Down syndrome.

With current technological advances in prenatal testing underway, how will other expectant parents proceed when the risk is eliminated? Jo An Simons of the Ruderman Family Foundation—a foundation that supports children with special needs in the Jewish community—expressed her concerns about prenatal testing, “Expectant mothers have already been given this simple blood test and the test has been administered without one essential aspect: accurate information about the joys and challenges of having a child with Down syndrome” (Simons, 2012). This reaction reminded me of what Steve stated during our interview:

People oughta have the right to have genetic testing. But I wish there were an education program that went along with it to teach people that if genetic testing detects Down syndrome, just count that as one of the great blessings—it'll bless your family—I mean, it certainly has ours... I just don't think anybody that could see a video replay of all of Jacob's waking moments in life—anybody who could see that wouldn't want to have him aborted. (Steve)

## **When Genetic Testing Leads to Termination**

I was in a way a bit annoyed that they gave that choice. Like he's a good doctor and he helped us, with the previous cases. He was a really good doctor, but when he gave us that choice I felt like really mouthing off at him. But you can't. You're supposed to protect life—preserve life not say, 'Oh here's a chance but it might end up killing the baby or you can get rid of it now if you'd like. We can give you tablets or an injection and you can get rid of it.' (Dave)

The medicalised view of genetic difference seems to consider that when a fetus presents a genetic anomaly, the most common logic is to terminate the pregnancy. Ingstad and Whyte suggest, “In many Northern countries, the abortion of a defective fetus is considered

more acceptable than that of a ‘normal’ one, suggesting that the ‘human’ status of an impaired individual is more negotiable” (1995:10). When the diagnosis comes back positive for a genetic abnormality, prenatal diagnosis may ultimately lead to termination of the pregnancy. Fitzgerald et al. (2012) observed:

Finally, the medicalised view of difference is apparent in clinical consultations (studied in the South Island of New Zealand in 2004) in which termination is framed as the reasonable response to fetal difference and agreement to undergo amniocentesis is understood as logically agreeing to termination should genetic difference be discovered as a result. (Fitzgerald et al., 2012)

Dave and Nirmala both were firm in the decision not to undergo the genetic testing. Nirmala was sympathetic (if somewhat cynical) to why doctors would offer her the test. While Dave was bemoaning the medical perspective, she expressed how doctors think they’re doing a good thing because people with disabilities can be a financial drain on the economy and are dependent on others for help.

D: Oh, it’s just the *choices* they say, ‘Get rid of him, or do you want to get rid of him?’ I can understand some people would.

N: Doctors, they might think that it’s not worth bringing them—they can’t do things by themselves. That’s the medical way, you know. But if it is your own blood, you can’t just kill them. (Dave and Nirmala)

Fortunately, once Dave and Nirmala made the decision to reject the amniocentesis, the doctor respected their decision. “The best thing that I liked about it, we had a good doctor, he gave us that choice. We took the other one and he stood beside us” (Dave).

Fitzgerald et al. continue, “A further push towards a medicalised view of genetic difference is through the inclusion of fetal abnormality as one of the four legally permissible exceptions for abortion which is legislated through the criminal code” (Fitzgerald et al., 2012). The four exceptions for abortions in New Zealand are similar to the LDS Church’s exceptions listed below. The mental health of the mother and fetal anomaly are permitted exemptions in New Zealand law, whereas those exceptions are not explicitly mentioned in the LDS Church. Nevertheless, the LDS Church is sometimes viewed as slightly more flexible when it comes to the abortion issue than some other conservative religious traditions. There are several exceptions where abortion may be considered. This is what the Priesthood Handbook of Instructions states regarding abortion:

The Church opposes elective abortion for personal or social convenience. Members must not submit to, perform, arrange for, pay for, consent to, or encourage an abortion. The only possible exceptions are when:

1. Pregnancy resulted from forcible rape or incest.
2. A competent physician determines that the life or health of the mother is in serious jeopardy.

3. A competent physician determines that the fetus has severe defects that will not allow the baby to survive beyond birth. (LDS Church, 2006: LDS Priesthood Instruction Manual)

Shauna brought up the LDS guidelines regarding abortion and mentioned the exception when the health of the mother is at risk termination is acceptable. She went so far as to interpret it to mean that even in the case where the ‘mental health’ of the mother is at risk then it is permissible. From the beginning of the battle of women’s rights regarding abortion, whether or not mental health was implicitly encompassed in the general health and mortality of the mother has been a debate. In 1973, the LDS First Presidency issued a statement proclaiming: “The Church opposes abortion and counsels its members not to submit to or perform an abortion except in the rare cases where, in the opinion of competent medical counsel, the life or good health of the mother is seriously endangered...” (Lee, Tanner, and Romney, 1973). In this instance, with the use of the general phrase “good health,” it could be argued that mental health is included. Shauna argued:

Well, I think if you’re a Christian person, and even within our own church, and you—we know that we don’t agree with abortion—I think that it would be an extremely difficult thing for somebody to have to live with if they made that choice. But then, you’ve got to look with—like I said, the Church also recognises the *mental health* of the mother. And choices like that. So in the end, it’s between you and God. I just wouldn’t like to be in that situation. I wouldn’t. And I think that the majority of people who perhaps understand what we believe in the plan of salvation and that we’re all spirit children and that we come into this earth life to receive a body and that there is more after—I think that perhaps most would accept that as their challenge in life. Yeah I don’t know. And so it just has to be a private and personal thing that the couple make—and that you be non-judgemental! (Shauna)

Another issue I discussed with my participants was at what point did they believe the spirit enters the body. Views of when ensoulment occurs are often dictated by religions (Anderson, 2009), however the LDS Church has no official stance on this matter. The status of an embryo as a potential human being influences opinions on PGD and termination (Cole-Turner, 1999). I received extremely diverse opinions from my participants. One couple I interviewed even entered into a debate with completely contrasting opinions when I brought up the question. Some participants believed the spirit enters the body at the moment of conception, while others believed it was at birth. Some believed that it occurred at an early stage of embryonic development. Many mirrored the Church’s stance by declining to express an opinion. Although the Church is not against IVF or PGD, the people who believed that ensoulment happens at conception were opposed to the discarding of embryos that takes place during the IVF/PGD process. Most participants, however, were against termination of pregnancy regardless of when the spirit enters the body.

When discussing how positive results for a genetic anomaly from prenatal diagnosis often leads to termination of pregnancies, participants expressed how they felt about abortion and when it is acceptable, if at all. Several participants again took a similar stance as the LDS Church regarding abortion. Moreover many articulated that for exceptions, communication with God is a key factor in deciding how to move forward: “But it’s probably something you’d have to counsel with Heavenly Father about whether or not it’s ok. I think it’s a decision you’d have to make on a per child basis, rather than a general rule of thumb” (Michael).

Many participants did not have anything against prenatal genetic testing itself, but like Sam, they expressed hesitancy about what people do with the results, “When people do genetic testing it’s not so much them getting in there and checking it out, it’s the decisions that come afterwards” (Sam). Like Sam, Steve only had reservations against genetic testing when it led to termination of the pregnancy, especially in the cases of Down syndrome. Steve related his concerns:

Well more than anything I think we usually feel sorrow for people who through genetic testing determine they’re going to have a Downs kid and then have it aborted, because they’re missing one of the great blessings in life. (Steve)

Regardless of when and whether abortion is acceptable or not, Nicola brought up an interesting point—what is the message we send to people with disabilities when we choose to abort, or encourage others to abort, a fetus that is just like them? She considered this question as she faced the possibility of being pregnant again after having Jonathan:

Basically the gene wasn’t mapped at the time, so they couldn’t have done that. I’m pretty sure it is mapped now, so we could. But it’s an interesting question; I mean what is it saying to Jonathan? No matter what happens, what does it say to him if we choose not to have a child that’s like him? Yeah, I really don’t know. At one point I thought I was pregnant a third time and I’d had a whole lot of quite invasive tests to try and find out what was wrong with Jonathan and so on. And I think if I had been pregnant, I possibly would’ve had an abortion because I just would not have coped with having another child at that time. I mean, that sounds appalling. Though, I’m glad I never actually had to make that decision, but I certainly felt like it, if I had been pregnant then, I don’t know if I would have coped. I just wasn’t ready to have another child, especially as we could well have had another one that was disabled and whether I would’ve coped or not. It was an interesting time. I wasn’t particularly coping well with life for about the first five years of Jonathan’s life. Just sort of muddle along and just cope, really, that’s about it. I wouldn’t have done well. But coming back to that I really can’t say. I think there are just so many ethical issues with it. And especially about the message that you send to the child who has a disability. I mean if he had found out that we were pregnant with a child who was going to be like him and we abort it, or something like that—I guess it’s different with preimplantation, it’s a different message. But it’s still an interesting one. Does it say that he’s not of worth because we would choose not to have another one like him? And of course knowing what I know now that he’s grown up and he’s just delightful, my feelings now would

be different from what they were then when he was just really really challenging. So you can't see the end from the beginning. I guess what you'd have to do is be inspired and pray about it. Because that's what we did when Mark had a vasectomy... And that was the strongest answer that we've had ever for anything was that he should have a vasectomy. That was interesting. I guess we would've pondered and prayed about it and done whatever we felt was the inspired thing to do. (Nicola)

## Choosing not to have more children

Like Nicola's story at the end of the last section, many of the participants who had children with disabilities, instead of opting to have genetic testing for any further pregnancies (if it was even available at the time), some of the women dealt with the uncertainty of having another child with a disability by deliberately choosing not to have more children.

The grief that Beatson (2000) describes of how it is often unbearable to imagine when going through the experience a second time. As Nicola described, she couldn't cope with the thought of having another child right after Jonathan and would have even considered abortion, but instead she and her husband decided not to have any more children. However, Mormon custom encourages members to encourage each other to have large families—mothers who purposefully decide not to have more children often yearn for the family that they wish they had. Nicola wanted more children after Jonathan—she decided to adopt, she describes how her plans were halted when she found out that Jonathan was not only blind, but had autism as well.

So we actually had genetic counselling, but I mean I already understood about autosomal recessive genes and things like that. And, we decided that we weren't prepared to risk having another child that would have a disability. And we actually at one point looked into adopting and we were in the pool for about three or four months. We had made it through the process and we were waiting for a baby. And then we found out that Jonathan was autistic as well as blind. So then we thought uh, that's going to be a bit tricky now. So we decided not to adopt after all. But actually that was really helpful to us because it helped to make it our decision, rather than something that was imposed on us. Otherwise, I wanted lots of children, but because of this decision obviously, we weren't going to have lots of children and I felt cheated. But once I decided not to adopt, our two boys were a perfectly adequate family, then that was actually quite reassuring. I stopped pining for the family that I didn't have and decided that it would be my choice after all. I think for me that's one of the key things is choice—to basically take the power back to myself. (Nicola)

As I discussed in a previous section, members of the Church are encouraged to bring as many spirits into the world as they can, which causes some consternation for aging parents or when disability is inheritable. Most Mormons believe in eternal families. Having children is sometimes seen as the responsibility of parents to bring spirits from the pre-mortal existence into this world. Even with a commitment to family life, continually bearing children

can become a burden. Shauna discusses the breakdown that brought her to the decision to stop having children and also made her more sympathetic to other women choosing whether or not to terminate a pregnancy:

My opinion is that it is a very personal thing between the parents. And that nobody should interfere with that, even as a member of the Church, I mean we don't agree with abortion or things like that, but we do—we do recognise that if it affects the health of the mother—like if it's going to cause sickness to the mother or that—that choice has to be their choice. And so, my opinion is the mental stability of whether that person can deal with it—it's like with my last child and the—the *stress, the immense stress*—and it does—and I take my hat off to some of the parents that I work with, you know with their children, and you take your hat off to the ones that work so hard to—and do such a good job—for me, that's about basically—I had a breakdown. And the thought of me having any more children and having to deal with what I was dealing with, I could not cope anymore. So that was *my choice—that was MY CHOICE not to have any more children*. And it would be like I guess, for the person in that situation—it's a very deep and a personal choice. I think—in the Church we would look at it and say, 'This is a special child—this may be a very special child. And this may be your trial' And—you know that the Lord takes care and that. But I just think that it's a very very personal choice. And you make that choice. And you live with it. (Shauna)

For Steve and Vivian, having more children wasn't even a consideration when their last child was born with Down syndrome. They knew that having a child with Down syndrome was going to require a significant amount of attention and that Jacob would become a lifetime companion.

V: No, it was hard to have Jacob, I was thirty-eight and I was tired—so tired through that pregnancy. And we had no intention of having more kids. I never did think of having more, did you?

S: I think we viewed Jacob as a lifetime project at that point. (Steve and Vivian)

Two of the participants were pregnant when they discovered their sons had disabilities. As previously mentioned, for most Mormons, abortion is not considered an option. Beverly found out her son Robert was deaf while she was pregnant with her second child. When the geneticist told her the news, he also mentioned that her son she was carrying might also be deaf. This revelation distressed her so much that she decided not to have any more children. However, as she says below, she came to later regret the decision to stop having children:

B: Well I remember what Doctor Stuart said. He said, 'he's deaf' and I said, 'well what can I do to help him?' and he sort of looked at me a funny way and he said, 'oh! That's not the usual response!' But actually it was very depressing to me because I was pregnant and they told me 'your new baby has a one in four chance being deaf.' To tell that to somebody who is six months pregnant isn't the greatest news!

J: And we hadn't even considered that!

B: I felt that was really *badly* handled. Very badly! I didn't need to know that. They could've told me after! But then Chris seemed to hear so—but when he was five we found he was deaf in one ear.

J: But I think we—I don't know if we really discussed *reasons* for it. We decided that we'd settle on the two children. And it's probably because we thought, well you know, a number of reasons but we didn't know enough about deafness for a start—what kind of challenges Robert was going to face because I didn't know that much about deafness. We thought it's going to take a lot of work and effort—didn't want to compromise it too much by having—

B: Well I actually didn't want to go through another pregnancy thinking 'is my child going to be deaf or not' because at that stage, it was like John said, it was all so uncertain. We didn't know how we would cope with everything. So we stopped at two.

J: [Reading from the information and consent form] But it's an interesting question 'could you describe something about choice, issues of reproductive choice around genetics and disability' when you look at children who have been born and ask yourself, should something have been done differently to begin with? And you look at the child and you say, it's kind of like saying well that child is just a mistake. And no child is ever a mistake! They're a blessing. But that's derived through hindsight and maturity!

B: [Laughs] Yes! In hindsight I would've had more because then maybe Robert would've had a deaf brother or sister! It might've made things easier for him. I wish no one had said to me about the genetic issue, really. (John and Beverly)

Carol was also pregnant when she found out her son had cerebral palsy. She was worried at first that the child she was carrying might have a disability as well, but she was determined that no matter the outcome, she would carry through with her pregnancy and love the child just as much as any of her other children.

And I was seven months pregnant and I thought, oh! What if another child— And I remember talking about it with the doctor and I think, I can't remember exactly, but I can remember the doctor at one stage saying to me, 'well, Carol, if you found out that this child was also disabled, would it affect your decision?' I mean—I couldn't! I was seven months pregnant! And my reaction was 'No!' If this child was handicapped, then so be it! If I found out before, I wouldn't DO anything, if I'd have found out at three months or when I was a lot less along—it wouldn't have made any difference so we decided that a test would be of *absolutely no point whatsoever*! Because it wouldn't make any difference. And if Isaac—if I had've been told—because I did have a scan, that was when scans were in their infancy, 'cause Isaac's twenty-nine—they gave me a scan and if they had've told me, if they had've picked up anything, I would've said, 'I will have this baby.' It would've made no difference *whatsoever*. I would've kept on going. All right, I might've been pre-warned that I was going to have a disabled child. But that only would've strengthened me to prepare myself and study up as much as I can. So, yes I did worry for my child that I was carrying but it wouldn't have made any difference whether she was disabled or not. I would've felt the same way about her as I felt about Isaac! I must admit I was very relieved when she wasn't disabled, when she was perfectly normal. I was very happy. But I didn't love her any more than Isaac who was not perfect. I loved them *the same*! (Carol)

## Genetic testing and the spirit journey

Many of the participants reject genetic testing on the grounds that it hinders the spirit journey and goes against the doctrine of free agency. As I have already made clear, most Mormon participants believe in autonomy in the pre-existence—spirits choose to have the bodies they're born with. By having genetic testing or PGD, people are not letting the spirit choose the body it wants to go to and consequently, inhibiting the spirit journey. Some of my participants expressed their opinions that we should not have the right to exercise that power over other spirits:

Well, I feel about that very strongly. Who are we to make a call like that?! Who are we to say who lives and who dies? If you are carrying a baby inside you, that is the body that is being prepared for one of Heavenly Father's spiritual children! Who are we to say that that spirit can't have that body, because we've decided that we don't think it should happen! ...Who are we to say that because it's defective that it's not worthy of life!?! (Carol)

Carol believed that PGD and termination are both unacceptable and beyond humans' rights to exercise that power over someone else. Fay similarly expressed hesitancy about prenatal genetic testing and PGD, "I think everyone—well, being a member of the Church you know the plan that Heavenly Father has and do you deny someone because they might have a gene that MAY go bad?" (Fay). But some participants displayed their disinclination towards prenatal genetic testing because as mentioned previously, it impedes an individual spirit's autonomy and therefore the potential spirit journey. John debated the complications surrounding prenatal testing:

But, if you're looking at it from a gospel point of view and the Lord has a plan for somebody and that person is exercising their agency like Robert perhaps choosing to come to earth deaf for whatever reasons he knew at the time of accepting that calling or assignment. I come along and say 'no I don't want that for you I'm going to change that!' On the other hand if you've got the opportunity to prevent somebody from having some horrific disability then should you? I don't know! (John)

Like John, Sam was apprehensive about prenatal genetic testing. For Sam, every life has a purpose. He cautioned that people in these situations should consider the consequences for the fetus' spirit.

But I think if you're going to create life you kinda have to stick with it because—I guess, every person has their own conscience. And, to kinda just kick someone out of

this life without their say in it, even if they are a couple of cells glued together, it's a big call that can have some serious consequences. Especially coming from a religious point of view, believing that there's a bigger picture to life. For myself, this life has a lot of purposes to it and if you create life and then stop it from coming into this life, you're hindering someone else's journey. (Sam)

When it comes to these participants' opinions about genetic testing, several factors came into play. Mainly, the risk of miscarriage acts as the biggest deterrent. Beliefs about termination also play a role. Experience and exposure to certain types of disabilities may influence opinions as well. Furthermore, genetic testing may act against God's will and constrain another spirit's agency and inhibit its journey. The next chapter is the final interlude, which will explore the spirit's journey through the resurrection.

## VII. Interlude: Restitution Narratives in the Resurrection

We are all in some way impaired. Shakespeare and Watson observe, “No one’s body works perfectly, or consistently, or eternally. Illness...is the human condition. Mortality...is the inescapable essence of being alive” (2001:24). However, Mormon doctrine teaches that after death, through the resurrection our bodies will, in fact, work perfectly for eternity—but during this mortal life, we all face illness and impairments. But those sufferings can become a journey.

Campbell calls initiation ‘the road of trials,’ easily identified in any illness story as the various sufferings that illness involves...This road leads through other stages, such as temptation and atonement, until the ending or ‘apotheosis.’ The quest narrative tells self-consciously of being transformed; undergoing transformation is a significant dimension of the storyteller’s responsibility. (Frank 1995:118)

The “apotheosis” that Campbell and Frank mention is quite literal for Mormons. Mormon theology teaches that all humans are essentially “gods in embryo.” The ultimate goal of the spirit journey is to become like God. This process however, requires a transformation. An essential component of this transformation is the resurrection— “Resurrection is the reuniting of the spirit with the body in an immortal state, no longer subject to disease or death” (LDS.org, 2012: Resurrection) All of the participants believe that after death, during the resurrection, their bodies will be made whole. Some even joked about how maybe they’ll be taller or prettier. But all believe that disabilities will be taken away. Frank would call this principle, a prospective restitution plot—disability in this life is a permanent condition but all look forward with hope to the future of complete restitution in eternal life.

The Church’s disability resources website advises parents of children with disabilities, “Remember that you are preparing for eternity. Your child’s disability is temporary. The spirit is not disabled” (LDS Disabilities Resources, 2012). Carol shared her beliefs about her son Isaac’s disabilities: “And because of our faith we see that Isaac will not—we KNOW that Isaac will not be disabled in the spirit world—Yes, I know that...Isaac’s spirit doesn’t have cerebral palsy or OCD or epilepsy” (Carol).

Similar to Carol’s beliefs, John and Beverly shared their beliefs that their son will not be deaf after the resurrection. When I asked Robert if he believes that he will not be deaf after the resurrection, he responded positively, “Yes, I do indeed! It will help me to remember what it is like to hear again as I did back in pre-mortal existence and appreciate music again” (Robert).

Nicola likewise believed that her son Jonathan's disabilities will be taken away in the resurrection:

Well I believe that Jonathan's disability is for this life only and that when he is resurrected—after we die, then eventually we'll be resurrected which means that we get our physical bodies back but they'll be in a perfect form, so that he'll be able to see and his brain will work more like us. I presume. But maybe we'll be more like him, I don't know. But that any deficiencies in this life will be remedied in the resurrection, so he'll be able to see, which would be very cool. (Nicola)

I asked Nicola whether she knew if Jonathan had any concept of what the resurrection will be like for him. She replied:

Well you see, in his world, he's not disabled. He's never seen. He's totally blind. He has an enormous musical talent and other intellectual capabilities that we don't have. I don't think that he sees any deficiency in himself at all. Which is rather sweet, really. I think he believes in the resurrection but it would be at a child's level. But I don't know. He has no concept of what sight is. He knows it's really annoying because I can see when he's up to things and he doesn't realise I can. (Nicola)

In another interview, Diane shared a narrative from her experience of working with a boy with a severe disability and how through that experience she was able to see a glimpse of eternity:

And, I suppose when you look at the eternal perspective, that this life is just part of the whole big picture...But also—I had an experience with a student I worked with in a year ten camp and abseiling was one of the activities. And we tried to get him to—he was in a bad mood that day, and he's never in a bad mood, but he doesn't cope with camp situations with a lot of noise for very long. And it was day four, and he'd been doing really well. He didn't want to get dressed or come with us, but I made him. But, I said you don't have to do anything. But the next thing he's out of the van with a harness and a helmet. We took him to the top of the cliff and we strapped him all up. He got to the edge of the cliff attached to the instructor, and he wouldn't go over the edge. And so we brought him back up again. I got another teacher to show him how it works on a wee grass slope. And then I said to him, 'do you want to try the cliff?' and he said, 'yep' and he's nonverbal—he doesn't speak much at all. So he goes, 'yep' and he pushed past everybody else and went to the edge of the cliff. It still took him a few minutes to get over the edge, but he went down and he was so proud of himself. And for that moment, I didn't see him as the guy with autism and Down syndrome, I saw the teenager who wanted to do the adventurous thing that everybody else was doing. And you know, and I saw the full person without a disability...So yeah, that was really really good...As I said, sometimes I think life just happens and we deal with what we get the best we can. And then, the next life is when things are made right. Just that at resurrection our bodies are made whole and our infirmities are taken away. And so, any impairments in this life will be healed. So the people that have struggled in this life and have serious disabilities will be whole...We all have challenges in this life and some people obviously have huge challenges, but in the resurrection those will be lifted, and we'll see the whole person. As I said with the abseiling—like I got a wee glimpse, I got a glimpse into eternity when he was whole again. (Diane)

The prospective restitution plot looks forward with certainty that eventually current illnesses will be healed. Belief in the resurrection provides this hope for the LDS participants. But the quest to be healed requires perseverance through earth-life. As Frank stated, “Cure is life, and life is the fundamental quest” (1995:182).

## IX. Testimony

Becoming a witness assumes a responsibility for telling what happened. The witness offers testimony to a truth that is generally unrecognized or suppressed. People who tell stories of illness are witnesses, turning illness into a moral responsibility. (Frank 1995:137)

This chapter reflects Frank's account of when illness becomes testimony by exploring how the participants in this study turned their stories into testimonies. All illness and disability narratives can become testimonies. These participants (because of their Mormon faith) have a self-ascribed duty to bear testimony to their beliefs and experiences. Many participants believed that having a disability, or having a child with a disability is a faith-promoting experience. All disability narratives they told, in no matter what form—chaos, restitution, or quest—become an opportunity to bear testimony to their faith.

Participants shared how they gained strength to meet challenges from their faith in the gospel. The trials and tribulations that participants endured are often viewed as opportunities for growth, “The hero's moral status derives from being initiated through agony to atonement: the realization of oneness of himself with the world, and oneness of the world with its principle of creation” (*ibid.*:119). Congruently to what Boswell et. al (2007) and Marks and Dollahite (2001) observed in their studies, my participants also expressed how they obtained strength and support from their faith. Carol recalled how her faith provided her the strength she needed as Isaac's disabilities became more pronounced: “I felt incredible sadness that it's so sad to see someone I love having so many difficulties in life. But it's the gospel that has helped me through every time...That is where my strength comes from” (Carol).

Many of the participants shared similar experiences of gaining comfort from their faith. For example, Nirmala shared how her faith provided understanding. She recounted how she prayed when she found out Edward had Down syndrome, and she continues praying as a source for strength. Nicola would also pray for strength regarding her son Jonathan. She responded affirmatively when I asked her if having the LDS religion in her life makes a difference in how she dealt with trials:

Oh, enormously. I mean basically, I don't think I would've coped without an understanding of the resurrection, of the purpose of life, being able to pray and get help. A number of times we've hit brick walls with Jonathan, thinking, 'How are we going to deal with this.' And I think, 'Well, if he's Heavenly Father's son first, he'd better help me.' So I'd pray and we'd get ideas of what we could do to try and help him to develop. Basically, we are who we are because of our beliefs. And, without that, I don't think Jonathan would've accomplished anything near as much as what he has...Certainly our faith has made raising Jonathan much easier. No doubt about that. (Nicola)

Even though Robert faced many difficulties throughout his life, he also drew strength from his faith and understanding of the plan of salvation. “The plan of salvation helps me to understand the purpose of this life, which is to prepare to meet the Lord. It helps me to keep moving forward with this knowledge” (Robert). Ben also stated that his understanding of the purpose of life that the gospel provides helped support him through his struggles.

I guess having an understanding of the purpose of life, having an understanding of why I’m here has helped me understand the challenges that we each face... I think in a very loving way the gospel is—it’s there for those that have challenges. We all have our challenges. We come to this earth and some may have a mental disability, they might have a physical disability, some people may have a disability and they don’t even know it...I think the gospel is really there to help us and to provide that support and bring that understanding. (Ben)

Even participants who were involved in special needs education and care grew from their experience and also turned to the gospel for strength. Frank perceived, “The pedagogy of suffering means that one who suffers has something to teach...and thus has something to give... Relationships of caring are no longer asymmetrical, even though the real instrumental work of doing care is asymmetrical” (1995:150). When Shauna struggled teaching and caring for difficult children, she reminded herself of the plan of salvation and that everyone is a child of God:

I had to constantly remind me that she’s a child of God—when I felt like throttling her [laughs] to be honest there were times where you just felt like—[laughs] yeah. And so a lot of the children, the students that we work with, they’re very difficult sometimes and you very very, sometimes you really would like to—yeah. You do get very uptight sometimes and very wound up with some of their behaviour because it’s continuous and they push and they push and they push and they try and they try and they try, and so I just remind myself that she’s one of Heavenly Father’s children—or he or she is a child of God...We believe that we come to this earth life to receive a body and it’s the body that we need to be able to house the spiritual-ness in us. And—that this is just part of this journey in our life and that those of us that may have physical disabilities, mental disabilities, genetic disabilities that it’s just—just for this earth life time and that our bodies will be perfected in the next life and so—yeah that’s probably what keeps me sane when I’m working with some of these children is that I believe in a life after death and I believe that there is a purpose and I believe that trials that we have in this life will be for our—you know for our learning and our growing and our development. (Shauna)

Participants were living witnesses and expressed a moral responsibility to bear testimony to the faith acquired from the gospel that helped them meet the joys and challenges of life with disabilities.

## X. Conclusion

The objective of this final chapter is to summarise the general findings of this research to more clearly relate the results of the project, concerning the experience of living with disabilities and caring for people with disabilities, back to the issue of prenatal testing and the questions it invokes about disability. This conclusion also discusses the practical implications of this research as demonstrated by the participants' narratives and perceptions of disability as well as how their religious beliefs provide a framework to conceptualise these matters.

This project provides accounts from some New Zealand Mormons with extensive experience with disabilities in conjunction with both anthropological perspectives of disability and ethnographic accounts of prenatal testing. This thesis provides a distinctive perspective from a community imbued in the current context of much debate around prenatal testing, which is due in part to continuous advances in genetic technology in addition to the political activism of Mike Sullivan and the Saving Downs group in taking the New Zealand Ministry of Health to the International Criminal Court for crimes against people with Down syndrome.

When referring to the discourse on prenatal diagnosis, Rapp found that the views from women of different class, ethnic, and religious backgrounds were absent from the literature (1999:4). Since then, there has been an increase of interest on this topic and a growing body of work has emerged exploring specifically Muslim, Jewish, Catholic, and Christian views of spirituality and genomics. This research contributes to this emerging literature by adding some New Zealand Mormons' perceptions of genetic testing and disabilities in order to contribute to the continued diversification of the discourses on the ethics of prenatal diagnosis.

Being a "halfie anthropologist" (Abu-Lughod, 1991) did present some personal tensions for me in my role of researcher, but it proved valuable in establishing a connection where participants could trust and reveal opinions to me that sometimes went against doctrine. My own understanding of these issues has been greatly enhanced by listening to and interacting with the participants of this study. Knowing firsthand that Mormons are often perceived to be a homogenous group of people, I went into the project expecting standardised opinions on this topic but was surprised to find that the participants maintained a range of ideals. I hope that the findings will be relevant to medical communities, religious communities, and the lay communities faced with some of these difficult questions.

By conducting this type of ethnographic research, these insights provided by the

participants could also prove valuable to genetic counsellors, ethicists, and people needing to make these decisions for themselves. As Davis (2000) promoted, doing ethnography of peoples' life experiences with disabilities can contribute to the improvement of their lives. Hopefully in some way, this project improves the lives of the disabled by sharing some of their stories and providing awareness into the way this small community of New Zealand Mormons views these issues. The narratives in this thesis demonstrate the complicated nature of disability and genetic testing especially when it is intertwined with spirituality.

Parents faced with prenatal testing and vital decisions of who is born and who is not may consider several cultural, medical, and environmental concerns influencing the life of people with genetic difference. While society may infer that undergoing prenatal testing is an essential part of good parenting (Remennick, 2006), some participants felt that there was not enough information given to parents about the positive and negative aspects of raising a child with a disability. As France et al. (2011) suggested, people confronted with genetic-decisions often turn to others' personal accounts of life experiences. To understand the implications of prenatal screening options, the experience of people affected by genetic conditions need to be consulted (Shakespeare, 1998). This thesis provides narratives from people who raised children with disabilities, worked with people with disabilities, and lived life with disabilities in a New Zealand context. But the people interviewed also had the distinctive experience of being Mormon incorporated into their stories.

## **Participant Models of Disability**

The participants shared their experiences of dealing with the double-stigma of being Mormon and having a disability. From the beginnings of the LDS Church, members were oppressed because of their beliefs. Even to this day, Mormons have a strong sense of connection to their heritage of persecution. This element of knowing what it is like to be victims of prejudice makes Mormons what Goffman deems, "the wise" to being rejected and stigmatized (Goffman, 1963). Their history provides a situational context for understanding disability. Even within people of similar disabilities, some participants faced ostracism because of their Mormon identity. Furthermore, they could not quite fit in within their own religious community either because of their disabilities. Some of the participants or their children narrated the struggles of having to navigate through Mormon rites of passage like getting baptised, getting the Priesthood, going on a mission, or starting a family. Some

expressed frustrations with not being able to do these things, while others were grateful that the Church provided exceptions and other opportunities for service.

Being a fully integrated member of the LDS Church can sculpt the experiences of people with impairments or their caretakers. Significance and experience of impairment is constructed by the culture in which it exists (Ingstad & Whyte 1995). Because culture influences the way people experience disability, in relation to prenatal genetic choices, LDS parents may potentially consider the “community attitudes” (Beatson, 2004:35) within the members of the Church. The participants candidly expressed their frustration with the lack of support from the Church that simultaneously gave them so much comfort and strength. Even though the Church is striving to provide more services and more materials for people with special needs, not all of the needs can be met especially in this distant corner of the world where the LDS community is relatively small. Some research participants felt that the Church could work on improving awareness of the services it provides as well as encouraging and promoting disability awareness in its communities.

Even with online Church disability resources delivering information about the Church’s stance on disabilities, the participants demonstrated the complexities of perceiving the various reasons people have disabilities in this life. Some believed that people with disabilities are here to help us learn and to help others around them. Some believed that people with certain severe disabilities are only here on earth to gain a body and to have this life experience but are exempt from judgement. The participants mediated whether or not people with disabilities were victims, heroes, special spirits, or blessings. They openly shared the extremely difficult challenges and sometimes even the chaos that comes with life with disabilities. Understanding the complex challenges that living with disability presents to people facing the potential of termination of or giving birth to an individual with impairments can prove crucial to making these decisions.

While participants were wise to the fact that living with disabilities is challenging, many also maintained that there was a spiritual significance to disability. Participants were acutely aware of the disabling nature of life on earth. They knew of the biophysical origin of impairments but most believed there was a deeper meaning to disability. On the other hand, a few participants believed that there was not much significance to be ascribed to disabilities—it was just the way it was. Moreover, the informants emphasised that “life is tough.” But they also spoke of the fortification that they gained from their faith in the gospel. The participants expressed their testimonies that these beliefs often provided a framework to answer life’s questions such as the purpose of disability.

Several paradoxes were revealed pertaining to the participants’ perception of

disability. A number of components factored into participants' conceptualisation of disability—relating back to Beatson's (2004) models of disability. In some aspects, the informants were aligned to the social model of disability that believes that society is disabling. This was demonstrated through their displays of a great capacity and need to love and care for people with disabilities. However, the belief that disability will be healed in the resurrection brought participants into the realm of the medical model of disability, which seeks restitution. Participants' way of conceiving disability reflected the dynamic and fluctuating quality of disability that Beatson illustrates. The narratives related by the participants show how complicated models of disability can be.

In relation to doctrine, disabilities are biophysical impairments that resulted from living in a fallen world, and while most people understood disability to be an essential component of eternal identity—most believed that people with disabilities agreed or volunteered to have an impairment in this life as part of the necessary steps to take in order for their spirits to progress into the eternities. Disability was thus a spiritual choice, but most importantly, it was only transitory. This outlook towards disability cannot quite be relegated to the victim or hero stereotypes that Beatson describes (2004). The eternal nature of the spirit's sojourn within Mormon doctrine teaches that the impaired are only temporarily disabled. This belief demonstrates the dynamic quality of the participants' understanding of disability. The consequent spiritual model of disability which results from such a framing involves both an oppositional relationship to medical models of disability as deficit and thus the ethical rejection of genetic testing, while also holding on to the hope of complete restitution in eternal life.

## **Participant Perceptions of Prenatal Genetic Testing**

Additionally, LDS participants' understandings of prenatal genetic technologies in relation to disability are derived from and informed by their spiritual beliefs. Religiosity and personal experiences are the frameworks used to interpret the moral dilemmas surrounding reproductive decision-making. As Evans (2006) suggested, with the continuing development of new biomedical technologies, it is important to grasp a variety of opinions on their evolving significance. After completing the interviews with participants and hearing a range of opinions on prenatal genetic testing, it is clear that many participants rejected prenatal genetic testing because of their spiritual understanding of disability and a strong commitment

to a spirit's right to choose and a spirit's right to life. The rhetoric of choice and rights that is so often expressed in the abortion argument was applied to the unborn spirit and framed within the doctrine of the free agency that spirits possess when choosing to come to earth with impairments. However, because the Church still maintains several exceptions to the rules, some participants also applied choice arguments to the parents' right to choose while many emphasised the importance of communication with God for direction and non-judgement for whatever parents decide.

The absence of rigorous doctrine on issues of PGD and prenatal genetic testing, allows for some flexibility when it comes to making personal decisions. Even though the Church is strict in some areas, members can become "moral pioneers" (Rapp, 1998) in their own lives. Thus, participants were not homogenous in their opinions because of the leeway that the Church provides. Some participants were uncomfortable with genetic testing—suggesting that it encroached on God's territory and people should not try to play God. On the other hand, some participants viewed technology as a gift from God and that if used correctly, PGD or other genetic technology could be furthering God's will and plan for humans. These contrasting opinions display Lock and Nguyen's (2010) argument that people's perception of genetic testing is an "amalgam" of religious beliefs and understandings of these technologies.

Although participants' views on prenatal genetic testing varied, most seemed to express apprehension or concern when genetic diagnosis leads to termination. These Mormon lay-experts in this study can contribute to the diversification of the discussion around the ethics of prenatal diagnosis and provide a different perspective from which to view the argument. Latter-day Saint participants had a unique perception of the purpose of life and a unique outlook on what it means to be disabled. The informants incorporated their faith into the actionable to draw strength from and give meaning to their experience. Some participants were more open to the idea of termination of pregnancy because of the hardships they had to endure. Some were sympathetic to women who chose this option but would not choose it for themselves. A few of the participants outright rejected termination and genetic diagnosis even in the embryonic stages. Some of the women, when faced with the possibility of having another child with inherited disabilities, dealt with their circumstance by choosing not to have more children. All of them agreed, however, that life is precious.

While some argue that choice to terminate a pregnancy when genetic testing reveals a genetic anomaly is preventing suffering, many informants indicated that disability does not determine quality of life. This sentiment is similar to the one that Scully observes: "At one extreme of the disability critique of genetic diagnosis lies the argument that these techniques infringe the future person's right to life" (Scully 2008:798). Several of them conveyed their

firm belief that everyone deserves a chance to live, no matter the disability. Beverly stated for example, “Everybody has a reason for being here” (Beverly). This belief demonstrates their eternal understanding of disability and their beliefs that spirits need to gain a body in no matter what form, no matter how briefly in order to progress in the spirit journey. Ace contributed, “Everyone is equal and everyone should have the opportunity to live” (Ace). Continuing the rhetoric of rights of the unborn spirit, Nirmala asserted, “Everybody has a right to live” (Nirmala). And Dave added, “Everyone deserves a chance” (Dave). The various perspectives signify how intricate the cognitive processes to form opinions about disability and prenatal testing truly are. Additionally, the narratives provided will hopefully deliver insight for people caught at the intersections of disability and genetic choice.

Limitations of this research include the presence of only a very small number of participants with disabilities themselves; future research could be conducted speaking to several more people with disabilities. Any further research could also explore Mormons who have used PGD or prenatal testing and how they come to terms with their decisions.

## **The Spirit Journey**

Frank declares, “Serious illness is a loss of the ‘destination and map’ that had previously guided the ill person’s life...” (1995:1). However, for the participants in this study, the map is already laid out and the destination is eternal life. The participants related that the doctrine of the plan of salvation provides inspiration in times of darkness and chaos. Frank aptly pointed out that “The road of trials can become a journey” (1995:171); for the participants, this journey is a spiritual one. The participants I interviewed have a nuanced understanding of disabilities. They have an even-handed awareness that it is not easy, but there is a purpose.

The narratives related by the participants reflected Frank’s illness and disability narratives of restitution, chaos, and quest. I compared these narrative plots to the LDS doctrine on the plan of salvation in the interludes woven throughout the thesis. The quest storyline reflected what happens in the pre-mortal realm where spirits are called on a journey. The chaos plot was compared to how participants viewed the difficulties that come with mortality. The restitution stories represented participants’ beliefs that in the resurrection our bodies will be restored to their perfect frames. All of these narratives are quintessential aspects to the spirit’s passage throughout eternity.

However, the main and most important story participants told was of the spiritual journey as a quest. Participants understood disability as one part of the quest to eternal glory. As mentioned previously, the participants believed that the spirits of the disabled were called and chosen to live this life—and they willingly accepted this call. This view suggests that disability is not a technological or medical failure—it is a choice. This earth-life is but one part of the journey, “Postmodern times may be pandemonium, but they are not void. Illness stories provide glimpses of the perfection” (Frank 1995:185). No matter how chaotic this life is, the disability narratives as told by Mormon participants provide glimpses of the eternities.

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## Glossary

**Amniocentesis** is a procedure used for prenatal diagnosis for inherited or chromosomal abnormalities. A sample of amniotic fluid surrounding the fetus in the uterus, which contains fetal cells, is taken via the maternal abdominal wall into the uterus with ultrasound-guidance. The fetal cells are separated from the fluid and tested. This procedure takes place between the 15th and 19th week of pregnancy. Amniocentesis is offered to women with pregnancies at high risk of being affected. The rate of miscarriage is 0.5-1.7% (Sangalli et. al, 2004).

**Chorionic villus sampling (CVS)** is another form of prenatal diagnostics in which a sample of the chorionic villus or the placental tissue is taken and tested to determine chromosomal or inherited conditions in the fetus. The sample is taken via the abdomen under ultrasound-guidance. CVS is conducted earlier than amniocentesis, within 11-14 weeks of pregnancy. CVS has a rate of miscarriage at 0.5-1% (Health Centre for Genetics Education, 2007).

**Cordocentesis** or percutaneous umbilical cord blood sampling (PUBS) is another prenatal diagnostic test. A sample of blood from the fetal umbilical cord is taken and tested for inherited or chromosomal abnormalities. This procedure is performed during weeks 20-24 of gestation (Insight Radiology, 2009). PUBS can obtain information that amniocentesis or CVS cannot, but carries significant risk at 2% rate of miscarriage (Health Centre for Genetics Education, 2007).

**Preimplantation Genetic Diagnosis (PGD)** is another form of prenatal testing that occurs at the preimplantation embryo stage. Embryos are obtained via in vitro fertilization (IVF) in which the female undergoes hormone treatments to hyperstimulate the ovaries to produce several eggs that are then fertilized—sometimes requiring intracytoplasmic sperm injection (ICSI). After a three-day incubation period when the embryo is at the eight-cell stage, one or two cells are removed and DNA is extracted and examined for inherited, sex-linked, or chromosomal abnormalities. The technique used to examine the cells for chromosomal abnormalities is called fluorescent in situ hybridization (FISH). Polymerase chain reaction (PCR) is used to analyse cells for single-gene disorders. The embryos without anomalies may then be implanted in the uterus (Basille et. al, 2009).

Procedure	Screens for (Abnormalities)	Description	Rate of Miscarriage	When Screened (weeks after conception)
Amniocentesis	Inherited, chromosomal	Amniotic fluid containing fetal tissue taken through abdomen wall	0.5 - 1.7%	15-19 weeks
Chorionic Villi Sampling (CVS)	Inherited, chromosomal	Chorionic villus/placental tissue taken through abdomen wall	0.5 - 1.0%	11-14 weeks
Percutaneous Umbilical Cord Blood Sampling (PUBS)	Inherited, chromosomal	Blood sample taken from fetal umbilical cord	2%	20-24 weeks
Preimplantation Genetic Diagnosis (PGD)	Inherited, sex-linked, chromosomal	Embryos obtained via in vitro fertilization (IVF). Cells removed from embryo and DNA extracted/examined	n/a	prior to implantation
SafeT21/ MaterniT21 PLUS	Chromosomal	Blood taken from mother and DNA screened for trisomies 13, 18, and 21	n/a	10 weeks

**Figure One: Prenatal Diagnostic Testing**