The Body Image of Women with Intellectual Disability

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Abstract

Women and their body image have been a focus for research throughout the latter part of the twentieth century; however, rarely does that research extend to women who may experience different lives through their identification as intellectually disabled. This doctoral thesis addresses a gap in understanding the way that New Zealand women with intellectual disability perceive their bodies and the historical, cultural and social influences affecting their perception.

Twenty-five women ranging in age from 21 to 65 years provided the data for this study. All women identified as having an intellectual disability and received some support to live with various levels of independence. Each woman participated in three interviews. Body image questions were included in semi-structured interview guidelines that explored aspects of the woman’s past and current life.

An interpretive constructivist approach was taken to understanding the women’s perception of their bodies. The information that the women shared has been viewed through a critical lens informed by both feminist and disability scholars. Thus the construction of the women’s bodies is interpreted rather than their own. In order to develop the construction, the interview transcripts of each woman were analysed from two perspectives. Firstly, the woman’s data were rewritten into her “story”, providing a preliminary understanding of how she constructed her body image. Secondly, all interviews were coded and themed utilising Braun and Clarke’s (Braun & Clarke, 2006) framework. This process provided a way to engage with the data and draw out the significant points that informed the women’s construction of their body.

The identification of three themes, “beauty and the body”, “a fit and functional body” and “a gendered body” that provide discrete perceptions of the women’s body, supports the contemporary view of multiple body images. Further analysis of the women’s body image suggested interplay between internal and
external factors. Most women compared their body size to social standards of weight. Less typical of other women was their emphasis on their clean and tidy body as representing their competence and the comparatively infrequent and limited use of beauty practices. For many of the women, sexuality was ignored or controlled.

Lacan’s (2002) mirror stage, as an explanation of the psychological development of body image, is utilised to integrate an embodied conception of the women’s body image. Finally, and importantly for disability research, the idea of “becoming” is utilised to explore how the women are limited or perceive few possibilities for self-expression through their body. Through examining both possibilities and limitations the research gives direction to future policy and practice that impact on the lives of women with intellectual disability.
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To the women who contributed their stories to this research my sincerest thanks. I respect their willingness to trust me with their personal information that has had an impact on their body image. I am grateful for their patience, both in answering questions when being interviewed and waiting to hear about findings.

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Chapter One: Introduction

This doctoral thesis is about women with intellectual disability and their bodies. Both how the women perceive their body and their practices in relation to their body will be explored in order to understand how they construct their body image. There is a wealth of information about women without disability, their body and body image, a smaller but growing literature about women with physical disability, but very little that addresses the body image of women with intellectual disability. The obvious question might be why women with intellectual disability would be any different from other women, however that misses the embodied nature of self and the historical, cultural and social influences that have positioned women with intellectual disability as different from other women. Chapter One provides an introduction to the research, positions myself as the researcher and outlines the structure of the thesis.

My interest in this topic began quite serendipitously when I was preparing for a wider study on the mental health of women with intellectual disability. The initial interest in mental health followed on from both conversations with women with intellectual disability, who highlighted concerns about access and care in mainstream mental health services, and observations from previous research that suggested quite different mental health outcomes for individuals with intellectual disability who had seemingly similar life experiences (Conder, Milner, & Mirfin-Veitch, 2011; Conder, Mirfin-Veitch, & Bray, 2007; Conder, Mirfin-Veitch, Sanders, & Munford, 2008; Mirfin-Veitch, 2001, 2010). The intention was to explore both resilience factors and, where applicable, the women’s experiences of mental health care. Thus both women with and without mental illness were interviewed.

Although there had been an initial exploration of the literature in the preparation of the research proposal, it was during a further reading of mental health conditions commonly experienced by women with intellectual disability that a very low incidence of eating disorders related to body image was noted.
Having had a long-term interest in health and the actions people choose that may impact on their health and wellbeing, I wondered what role body image might have in the health behaviours of women with intellectual disability. Furthermore, recognising that body image is a broad concept that might have significance for many aspects of the women's lives, including their mental health, I was interested in the opportunities that the women had to participate in practices that are associated with making the body attractive. There was an obvious synergy between my broad interest in body image and the mental health study. A life story, narrative, approach (Booth, 1996; Chase, 2005; Hall, 2004; Kincheloe, 1997; Walmsley & Johnson, 2003) had already been chosen for the mental health study and that was also well suited to the focus for my doctoral research.

Typically, life story research involves interviewing people with experience of the topic of interest. As a qualitative researcher interviewing women I am exposed to their reality, their ability and their tendency to surprise in ways that might both question and reflect assumptions. Whilst life story informed data collection, analysis relied on my interpretation of what the woman saw as ‘ordinary’. Feminist research methods have informed both my approach to and analysis of the information that participants share. To make sense of the inconsistencies between signifiers and our experience we might draw on various models. Goodley (2011) illustrates this when he claims “Disability politics is necessarily hybridised” (p.171). Whilst the topic of inquiry for the current study was initiated from within the medical model, that is the diagnosis of anorexia, the exploration of body image was intended as an open question, more akin to phenomenological inquiry, but with consideration of the tracings overlayed by theories of normalisation and social role valorisation and the structures that supported the women in their everyday lives. Signifiers for the women in this study included those associated with having a female body, an intellectual disability and, in some cases, a physical disability.

In addition to the women’s voices, which are intended to be at the forefront of the written report, there are numerous influences on the final decisions
regarding this research. In writing about women’s embodied lives, researcher reflexivity is crucial (Rice, 2009) and extends to representation of self in the written report. As Heyes (2007) suggests, it is particularly important when writing about other women’s bodies and commenting on their body image that the researcher should be conscious of her ‘self’. Furthermore, Walmsley and Johnson (2003) warn of the dangers of a lack of clarity as to whose voice is being represented within research with women with intellectual disability that has used a life story approach. These and other theorists (for example, Gilgun, 2005; Tierney, 1997; Tracy, 2010) have guided my choice to write this thesis in the first person. By writing in the first person my intention is to make clear my role in the construction of the women’s body image that is presented.

An idea that has gained some ground through the 1990s is that of ‘becoming’ (Grosz, 1994; Hickey-Moody, 2009), which Hickey-Moody suggests provides a “concept of the body as a responsive, generative form” (p.6). Extending the meaning, I suggest that my journey that has led to this research illustrates how I continue to evolve as a nurse and as a researcher. In other words how I am ‘becoming’. We are, to some extent, products of our culture with the associated signifiers, which might include attitudes toward people with intellectual disability, health beliefs and views of the ideal body (Guba & Lincoln, 2005). Working through the stages of the research it was somewhat inevitable that I would be conscious of my embodied self, including my position as an academic, middle class woman.

One example of this consciousness was evidenced at the time of my mother’s death (in 2012) when an older cousin telephoned from another city and in the course of the conversation she relayed a story about the positive influence that my mother had had on her developing self-concept and independence with beauty practices as an adolescent. As her mother’s younger sister, my mother bridged the generations in a similar way to how another cousin did for myself some years later. Reflecting on this process I saw the reproduction of family values as presented in our embodied self. Alongside this reproduction was the subtle shift from each generation as the woman in the middle translated various fashions of the time.
Coincidentally, data analysis was well developed at this time and I found myself thinking about the place of family in the women's body image and body practices that I was seeing in the data. Relevant questions related to their sense of continuity but also whether they challenged the values of their family or, extending out, those of their service.

A further example can be seen from the early days of planning the research topic and, to some extent to this day, as I struggle with the goals of health promotion in relation to healthy body weight, dieting and exercise. Whilst recent approaches to promoting health attempt to move the message from control to caring for the body (Moulding, 2009), the underlying point is still that the overweight body is unacceptable. As Moulding points out, what is strange about this is that underlying health promotion principles is the concept of empowerment of the individual, yet the health promotion message reifies a ‘norm’ that is acceptable to society rather than being located within the individual’s perception of what self-care might mean for their body. That norm is wrapped within a concept of health and prevention of illness that my own ‘health promoting behaviour’ demonstrates I accept at least at some level. With an early review of literature identifying a high prevalence of obesity amongst people with intellectual disability, these health beliefs could be seen through influencing the questions that were designed to ascertain the woman’s control of her diet and engagement in exercise. Yet, despite choosing these questions, I remained troubled that I was making assumptions about the body and health that might have little relationship with the woman’s embodied self.

Such confusion might not be surprising given my long career in nursing, a profession that has commonly objectified the body (Lawler, 1991). Furthermore, to understand my attitude towards people with intellectual disability it is important to acknowledge that I entered the profession as a psychopaedic nurse at a time when many people were institutionalised and the medical model was dominant. My introduction to other frameworks for understanding disability, such as normalisation and the social model of disability, came through my career as a nurse educator some years later. There have been numerous influences over the
years but I would now situate my approach, whether as a nurse or a researcher, within relational practice that values persons. It is from that perspective that I approached this doctoral study.

**Structure of the thesis**

This doctoral thesis is divided into eight chapters. Beginning with Chapter Two each chapter is outlined below.

**Chapter Two**

Bodies and body image have been written about for centuries. Chapter Two provides an overview of the ways that certain bodies have come to be seen as ‘other’. Tracking a common understanding that saw the body separated from the mind at least as early as Plato, through to the influence of Descartes. Aligning beauty with firstly the mind and then later the body, bodywork has grown out of cultural and social expectations of the ideal body. “Bodywork” in this thesis refers to the way that women work on their own bodies (Twigg, 2000). The medical model, with its emphasis on the objective (body) as that which can be known, is considered both for the impact on women and on disabled people. In critique of the medical model, the social model of disability and social constructionist approaches to the body are explored. The human rights movements and the rise of social models brought about important changes in the lives of people with intellectual disability, particularly in the area of community participation. Neither the medical model nor social models provide an understanding of embodiment, and, in the subsequent section of this chapter, I examine the more integrated idea of development of body image through the mirror stage associated with psychoanalysis. Throughout, the implications of each main theoretical perspective are considered for disabled people and for women.
After just a brief reading of the literature on body image the lack of clarity about the term ‘body image’ was apparent to me. Indeed, there is some question as to whether the term remains useful given more recent understandings of bodily perception (Featherstone, 2006). However, given that this doctoral study was generated from a question about body image, my choice is to use the term. Following an overview of the theoretical perspectives, common conceptions of body image are identified in order to define the term body image as it is used for this doctoral study. With little research specific to body image and women with intellectual disability, the literature review section has been focused to reflect relevance to the study. Beginning with an overview of what is known about people with intellectual disability and their body weight, the review progresses through literature that measures or assesses satisfaction with body size, the relationship between body image and self-esteem, physicality and appearance. In addition to understanding conceptions of the body and the research that informs current knowledge of body image and embodiment, being ‘othered’ has had significance for people with intellectual disability in terms of their separation from, or integration into, society. Towards the end of Chapter Two a brief history of New Zealand’s approach to institutionalisation and then community integration provides a background for the lives of the women in the study. New Zealand is one of a small number of countries that have closed all the major, large institutions for people with intellectual disability. The outcome of these closures means that people are now supported to live in the community. An understanding of that support contextualises the research and analysis that is presented in later chapters. At the conclusion of this chapter my justification for the research is presented.

Chapter Three

The approach taken for this research is constructivist, interpretivist, with a feminist and a critical lens that inform my worldview. Beginning with the genesis of the study, Chapter Three then presents my ontological and epistemological views. Constructivism is explained, including strategies for ensuring quality within the research process. Whilst constructivism provides the overarching framework,
the influence of both feminist and disability standpoints is considered. Researchers engaging with women with intellectual disability must be particularly attentive to the use of voice and relationships. My perspective on both is addressed with further deliberation as to how reflexivity can assist where there are power differences between the researched and the researcher. Having provided methodological considerations the rest of this chapter sets out the process that was pursued from proposal stage through to dissemination. Ethical approval for the study was gained from the New Zealand Multi-regional Health Research Ethics Committee, with 25 women subsequently recruited through People First. The women are introduced by their pseudonym along with some basic information to assist the reader to follow their individual stories within the subsequent chapters that present the results of the thematic analysis. In recognition of some of the challenges posed by interviewing people with intellectual disability, the process followed for the series of three interviews for each participant is explained. In addition to data collection through interviews, a figure rating scale was used to assess the woman’s body satisfaction. The steps of data analysis, utilising Braun and Clarke’s (2006) suggestions for thematic analysis bring the chapter to a close.

Chapter Four

The results are presented as three themes, with the first theme subdivided into two chapters. Chapter Four introduces the theme of ‘Beauty and the Body’ and the subtheme of ‘trim and whole’. As the title suggests the women identify with the size and shape of their body in terms of understanding the social imperative to be thin, not fat and with a tendency to consider the whole rather than parts. Included are the actions that the women took to achieve the body shape and size that they desired. Throughout this chapter, and the three subsequent chapters, the women’s voice is utilised to illustrate their thoughts and feelings. In Chapter Four their comments are integrated with literature to build a construction of their body as represented by size, shape and physical features.
Chapter Five

The second subtheme of ‘Beauty and the Body’ is named ‘tidy, clean and conservative’ as that was the predominant message drawn from the women’s engagement with hygiene and body practices. Body practices aimed at beautifying were of interest because these are strongly linked to women’s body image. Monitoring appearance is a component of beautifying practices, with the women’s use of mirrors setting the scene for their engagement with ways to adorn their bodies. This theme illustrates that, unlike many women, as a group, the women in this doctoral research were conservative in their choice of clothes and use of make-up, with a few finding self-expression by colouring their hair. Reliance on others to assist with shopping, limited budgets and a seeming lack of influence of peers may have contributed to the apparent conservatism.

Chapter Six

Whilst the being trim, clean and tidy were important to the women, the second theme demonstrates that their physical and mental health also influenced their construction of their bodies. Thus, this theme is titled ‘A Fit and Functional Body’. A fit and functional body is important both for physical ability and as representing the women’s competence. The chapter has two subthemes: ‘being active’ and ‘being competent’. The data represented by ‘being active’ aligned most closely with perceptions of the body found in concepts of physical fitness. Physical fitness was related to the trim body, suggesting internalisation of the social ideal, but also to necessity, as walking was a primary mode of transport for the women who lived independently. In contrast ‘being competent’ drew on the women’s challenges when physically or mentally unwell, bringing to the fore their sense of embodiment as well as how they felt about being supported to maintain their personal hygiene. A few women valued independence with personal hygiene as evidence of their cognitive competence.
Chapter Seven

The final results chapter raises the important issue of gender in relation to body image. Titled 'A Gendered Body', this theme, however, suggests that sexuality has generally been underemphasised in the lives of the women, with the result that they do not hold many of the expectations usually associated with female gender. There are three sections to this chapter: their reproductive body, which includes consideration of issues such as menstruation, contraception and parenting; boyfriends and marriage; and experience of sexual violence, defined broadly to include harassment through to unwanted sexual intercourse. Whereas for the previous themes literature specific to women with intellectual disability is sparse, with this theme there is a small body of research. Drawing on that research it is evident to me that the women in the doctoral study have similar experiences to other women with intellectual disability, including a lack of education and of control over their reproductive body. Providing some hope, younger women's knowledge of their sexuality and responses to more recent experience of sexual violence suggest that attitudes might be changing.

Chapter Eight

The final chapter of this thesis begins with an overview of what the women said about their body, their satisfaction with their body and their body practices. The women’s construction of their body is situated within a Lacanian perspective to understand their embodied self and drive for an Ideal-I (Goodley, 2011). Recognition of their body as ‘othered’ and ‘risky’ is elaborated to gain a deeper understanding of their construction before turning to examine the political and social influences on their body image. Such influences are important to identify if the research is to be meaningful and offer suggestions for improvement in the lives of women with intellectual disability. Taking the view that body image is relational and fluid, the next section of this chapter draws on the concepts of rhizomes and body without organs (Braidotti, 2003; Coleman, 2009; Goodley, 2007a, 2007b; Grosz, 1993, 1994, 2011) (Hickey-Moody, 2009) to envision change, including
repositioning of the bodies of women with intellectual disability, changing their opportunities and limitations.

The final sections of Chapter Eight return to researcher reflexivity as I consider the benefit of taking a constructivist approach to the research and the usefulness of the chosen methods. Attending to the ethical issues that arose during the research provides the opportunity for me to consider how these might be addressed in future research. Drawing on the points made in the earlier sections of the chapter, I have made suggestions for future policy and practice in education and service provision to drive the change envisioned. The chapter concludes with limitations of the research and suggestions for future research.
Chapter Two: Othered bodies

Introduction

Both feminist and disability studies literature portray the bodies of their interest as ‘othered’, often making that a central concern for how women and disabled people have come to be valued within society. A full discussion of such positioning is beyond the scope of this thesis, however I will provide an overview of some dominant perspectives within this chapter. An understanding of these perspectives is relevant and useful for interpretation of the research data and the subsequent discussion. Traced from Socrates and Plato is the view that the body is separate from the mind or soul, a premise that has been influential in objectifying the body and subsequent scientific study, particularly post Descartes classic dualistic position (Bordo, 2003). Challenging the sciences that emphasised the natural body, social constructionism proposed that ‘othering’ was founded within social life (Wolf, 1990). I will suggest within this chapter that both may have some relevance for the body image of women with intellectual disability, however the concept of embodiment will be more useful (Goodley, 2011). In choosing the psychoanalytic approach of Lacan’s mirror stage to provide an explanation for the development of ‘self’ and body image, I am acknowledging interaction of mind and body.

Adopting an embodied perspective, both psychological and sociological traditions inform the definition of body image used for this doctoral research. Prior to discussion of relevant research on the topic, I will provide the definition of body image that I have chosen. Both feminist and disability researchers have drawn on perspectives of body image in various ways to explain and challenge the position of women or, separately, people with disability within society. For research with women with intellectual disability, bringing these two research interests together provides initial perspectives to inform data collection and interpretation. Furthermore, a constructivist approach, as chosen for this study, requires some understanding of the socio-political context within which the
women are situated. Concluding the chapter I discuss the influence of human rights, normalisation and social role valorisation on the provision of support for people with intellectual disability in New Zealand.

**Influential conceptions of the 'body' over time**

To understand how bodies have come to be 'othered' within our society it is important to consider how Western views of the body have changed over the centuries. A major point of discussion has been whether or not the body and the mind were viewed as two separate entities or should be seen as a whole (Synnott, 2008). Through written accounts, understanding of the body can be traced to the ancient Greeks, including Socrates, Plato and Aristotle. Plato (1941) separated the body from the mind, with the appetitive body never capable of reaching the pleasures that can be achieved through the mind. As Grosz (1994) identifies, for Plato the mind is supreme and knowledge achieved through intelligence will be infinitely more rewarding than that accepted without thought. The body was, thus, the vessel by which the mind was imprisoned, a concept further developed through other dualistic approaches (Bordo, 2003). In more recent times and taking dualistic approaches to a new level, Descartes excluded the mind from scientific consideration by separating the body, as a functioning organism and thus open to objective study, from the mind or consciousness (Grosz, 1994). The mind for Descartes was, of course, self-evident and existed outside of nature, but whilst one's thoughts provided proof of one's own mind, there was no objective way to be certain of the minds of others. Thus the mind was positioned as subjective and able to reflect on the body as object.

The implications of such conceptions of the body are somewhat complex but necessary to understand. In defining the mind as the source of greatest pleasure, Plato aligns true beauty as metaphysical and linked to goodness, a relationship that has continued, even though the alignment of beauty with the mind may have shifted (Bordo, 2000; Brand, 2000). By the time of Kant, in the eighteenth century, Western standards of beauty could be seen to align with particular physical features of persons that made them desirable, which Kant identified as the blonde,
blue-eyed women typical of his country (Brand, 2000), a perception that remains dominant in many societies. Alongside such physical features of beauty, however, there remained a connection with the mind through the association of beauty with goodness (Carroll, 2000), which was fostered through Christian teachings of immortality for the soul as the path to enlightenment, whilst the mortal body was linked to appetitive desires to be controlled (Bordo, 2003; Grosz, 1994). This relationship can still be seen in many studies that link appearance, for example, being tall and attractive, with personal characteristics, such as being successful and capable (for example, Bennett, 2012; Black, 2004; Gimlin, 2002). Whilst something of a halo effect remains in terms of beauty being associated with goodness, the beauty standards that women in Western societies aspire to today have more to do with physical characteristics than with the morality, or perhaps more accurately, the etiquette of the day (Sentilles & Callahan, 2012), with Bordo (2000) suggesting that it was the Cartesian separation of mind and body that influenced this shift.

**Development of the medical model**

From the perspective of scientific development, the influence of the separation of body as objective and mind as subjective was to afford greater certainty to that which could be objectively studied, giving rise to what has become known as the medical model. Significantly it also meant that body and body image research, either ignored any connection between body and mind, or, recognising the implausibility of that state, accepted an interaction between the two as cause and effect (Grosz, 1994). It can be seen that it was through this separation that the term “body image” arose, with its obvious connotations for an object that could be visually assessed. Women, positioned as object, were referenced against the standard of the male body. Within medical and psychological research about women’s body image the predominant focus was on women with eating disorders, conditions that could be named and for which treatment might be sought (Orbach, 1978). Although more recently social and cultural influences on the woman’s perception of her body dominate, these continue to neglect any interpretation that
might suggest a dynamic, active, and relational embodied person (Butler, 1990; Coleman, 2009; Grosz, 1994).

Just as the medical model positioned women as object referenced to men, people with intellectual disability were positioned as object referenced to people without disability and thus they were seen as ‘abnormal’. Research focused on the causes, treatments and management of their abnormal conditions (Oliver, 1998; Parmenter, 2004; Simpson, 1999). As with bodily conditions, the focus for medical science became prevention and cure, in the process recognising and naming conditions. In approaching the study of intellectual disability from an objectivist perspective, both medicine and psychology introduced differentiation and labelling, including intelligent quotient (IQ) testing (Simpson, 1999), with classifications of mild, moderate, severe or profound intellectual disability attributed to people. There was little or no consideration given to the subjectivity of IQ testing, meaning that once a person was classified further education opportunities were determined accordingly (Simpson, 1999). Furthermore, labelling has served the purpose of supporting efficient and fiscally conservative state-led approaches to managing people (Goodley, 2011).

The attitude of those working within a medical model is illustrated in the textbook I had as a student of psychopaedic nursing in the 1970s as the following excerpts from the Foreword by Sir Samuel Curran (Hallas, 1974) demonstrate:

A much deeper understanding of the causes of mental handicap is being achieved and the new researchers under way give us every reason to believe that great strides will be made in prevention. (p. x)

As regards care, a better understanding of the motivation for learning is emerging, and with proper nursing and educational provision we have good reason to think that great strides can be made in improving the capability of a large fraction, if not all, of those suffering from mental handicap. (p. xi)

Psychopaedic nursing registration was a comparable qualification to specialist intellectual disability registrations in other countries, however the name is unique to New Zealand and was developed in the early 1960s to differentiate
between psychiatric hospitals and those hospitals established specifically for people with intellectual disability (Watson, Singh, & Woods, 1985). For us, as students, there was little or no consideration given to the subjectivity of IQ testing, noted above, let alone the human rights issues that were about to become influential in future provision of support for people with intellectual disability. Although the direct link to a physical deficit wasn’t always clear for people with intellectual disability, we were encouraged to see ‘them’ as ‘other’ and in need of cure and training. With few exceptions, the aggregating of separate bodies into an amorphous mass all dressed the same was the common approach. With seasonal variation, the most ubiquitous uniform for women was the corduroy pinafore and skivvy.

Whilst the dominance of this model may have waned, it clearly remains influential as, for example, the state relies on labels to monitor entry to services, a strategy that perpetuates the idea of ‘othering’. For women with intellectual disability, the combination of their objectified female body and their labelled impairments suggest a potential for dualism to have multiple influences on their body image.

**Shifting from a medical model to social models**

A major concern with the medical model was that the seemingly objective became accepted as natural, inherent characteristics, leaving little room to question their validity. Responding to this immutable position was the rise in the social constructionist and critical paradigms through the latter half of the twentieth century. A number of feminist arguments throughout this time referenced the objectified body back to the dichotomy between male and female bodies (Butler, 1990; Grosz, 1994), thus maintaining a link with dualism. However, the focus shifted to the subjective with socialisation of women, influenced by the beliefs of the time, thought to have a major role in the attention that they afforded their bodies. It can be noted that through these developments the language was more commonly about “bodies” rather than “body image”, although the intention of explicating a relatively stable perception of the body remained.
Internalisation of social expectations is largely seen as developmental. As young women are socialised to understand the inferences portrayed by their appearance, including sexual desirability, they become conscious of the gaze of others (Bordo, 2000; Fredrickson & Roberts, 1997). Accompanying this consciousness girls begin to objectify their body, using third person “her body rather than my body” language to speak about their body (Calogero & Thompson, 2010, p. 154). At their mother’s side, young girls are taught the routines associated with beauty and desirability (Calogero & Thompson, 2010; Hurd Clarke & Griffin, 2007a), such as learning to apply make-up (Brand, 2000) or the controls necessary to shape their body, such as constrictive undergarments (Sentilles & Callahan, 2012). The practices of their mother may continue to influence women throughout their lives, either by the women replicating their mother’s bodywork, or by their rejection of it (Hurd Clarke & Griffin, 2007a). Furthermore, the attention to body details, both through comments the mother may make about her own body and those from either parent about their daughter, teaches the young girl to scrutinise and objectify her body (Calogero & Thompson, 2010; Hurd Clarke & Griffin, 2007a). Throughout their adolescence young women try out various ‘looks’ by applying make-up, wearing different clothing styles and experimenting with their hair (Black, 2004). Peer influence is added to parental influence, with the suggestion that those young women who engage in more conversation with peers about socially ideal standards have a higher chance of internalising appearance ideals (Calogero & Thompson, 2010). In addition to consideration of how to present as appropriately feminine, it is at this stage that young women also face cultural constraints on their developing reproductive body, including attitudes that position it as abject (Ussher, 2006), adding another layer of gaze to their behaviour. Bordo argues that it is this socialisation that encourages girls to display their femininity and act to please, beginning their lifetime of bodywork. The degree to which women have agency over the practices that they engage to “improve” their body is contested within the literature (Grogan, 2008; Gimlin, 2002; Stuart, 2012; Calogero & Thompson, 2010; Davis, 2008), with Calogero and Thompson identifying the sense that one is in control as having its basis in cultivation theory. Exposure, generally through television, to the socially idealised standard of
thinness and beauty, as well as the associated rewards or punishments for meeting these ideals begin at an early age and within western society has become difficult to avoid (Calogero & Thompson, 2010). For women to resist or challenge social expectations takes courage as they can be seen to be questioning not only the beauty practices but also the moral inferences associated (Brand, 2000; Danto, 2000; Gimlin, 2002). Instead, various authors have suggested that most young women will accept that a main recourse to power within their society is through participation in those beauty practices that represent the current standard of the ideal body (Bartky, 2008; Fredrickson & Roberts, 1997; Sentilles & Callahan, 2012; Ussher, 1989).

Supporting their contention of the social construction of the ideal female body, feminist writers point to the influences that have fashioned what is identified as ideal. Up until the twentieth century, bodywork relevant to the fashions of the time was generally undertaken by a select group of women in society, that is, those of the upper classes (Sentilles & Callahan, 2012). The purpose of much of their bodywork was primarily to demonstrate social position (Shilling, 2008). For women of lower classes their body image related more closely to the body's functionality (Grogan, 2008) and, whilst there remains some suggestion that function is important, particularly for those women who grow up in poverty (Hurd Clarke & Griffin, 2007a), class boundaries are not as clear. Influencing this change has been a number of technological changes that have made women both more aware of their own image (for example, through mirrors and photography (Black, 2004; Danto, 2000)) as well as facilitating a rapid growth in mass media. The ability to reach many people through media has fostered marketing of products whilst developments in surgery and understanding of physiological processes have meant greater access to procedures that can alter appearance (for example, cosmetic surgery (Black, 2004; Davis, 2008; Grogan, 2008; Heyes, 2007)) and to exercise or health programmes (Shilling, 2008). Increasingly beauty has become associated with flawlessness and glamour, driving women to become less accepting of their face and body (Higgins, 2000) while they try to emulate the pictures of the 'touched up' models in the magazines.
There are, however, groups of women who cannot hope to meet Western ideals of beauty, which are often attributed as being slim (Balceitis, Cole, Chelberg, & Alicke, 2012), fair skinned, blue eyed and having blonde hair (Brand, 2000). Such groups include those of ethnic minorities, women of colour, and those with physical impairments (Carroll, 2000; Fredrickson & Roberts, 1997). Coleman (2009) explains the difficulties such women face as being stuck with the assumptions and often limitations attributed to their race, age, class and so on, trapping their body image and closing off options that might be available to women who can more easily meet the Western ideal. For many women with intellectual disability, associated physical impairments or features determined by genetics (for example, facial and stature characteristics as seen with Down Syndrome) may place them among such a grouping of women.

Parallel to feminist debates (led by women), disability rights activists (led by disabled academics) were challenging medical model conceptions of disability (Barnes, 2010). With Marxist origins, the social model grew out of ideas published by the United Kingdom’s Union of the Physically Impaired Against Segregation in 1976, which were further developed by Oliver in his professional and academic career (Oliver, 2009). Oliver (2004) considers the social model to be a tool for change at political and social levels and should be used to push for full citizenship of disabled people. Aligned with other citizenship movements, such as the more general human rights movements of the 1960s (Smith, 2009), North American activists were expressing similar sentiments to their United Kingdom colleagues, albeit from the alternative standpoint of minority politics (Goodley, 2011). Fundamental to the social model is the understanding that the social exclusion of people with impairments is due to the way that society interacts with them and it is this exclusion that they experience as disability (Rioux, 1997). Thus, interventions and research relevant to disability should be aimed at changing social and political systems (addressing social pathology) rather than individual pathology, as is the focus of the medical model (Rioux, 1997). With a focus on individual pathology, the medical model perpetuated social constructions of disabled people as different and ‘other’ in a similar way that women were
positioned in comparison to the male ‘norm’. Such attitudes were used to justify segregation and deny human rights for disabled people (Oliver, 2009).

For a number of authors, the research foci from the medical model suggested an assumption that intellectual impairment was an unfortunate state for the individual and was due to an innate deficit (Moore, Beazley, & Maelzer, 1998; Oliver, 2009), rather than being socially constructed as they proposed (Smith, 2009). The relative fluidity of tests, such as IQ, demonstrates social construction and is particularly evident for people with intellectual disability who have no obvious physical disability. People with mild intellectual disability are, nonetheless, more readily accepted as being socially constituted than people considered as having more severe intellectual disability (Goodley, 2001; Thomas, 2004), therefore the relativity of intellect remains contentious. From the understanding that disabled bodies were socially constructed, in much the same way as female bodies, the disability rights activists wanted social change to bring about inclusion and remove ‘othering’. As I will explain later in this chapter, the social model of disability has been influential in terms of changing some structures in society, such as giving disabled people a voice at policy level, creating more accessible space and shifting some attitudes. However, it may be critiqued that it has done so at the cost of recognising the importance of embodied difference. In other words the focus on the political has been at the cost of consideration of the impact of the impairment on the person.

**Critiques of social models**

The pre-eminent social model, social constructionism has been challenged from both feminist and disability perspectives. Grosz (1994) and Butler (1990) position social constructionist approaches as problematic in that they neutralize the sexual specificity of bodies and focus on gender as a social construct and thus open to change, whilst the body is to be understood as given, natural and unchanging. A further problem with association of body with one dimension, such as gender in the case of a feminist social constructionism, is that it ignores other features of the body that may have relevance for body image (Butler, 1990).
Furthermore, the relative disregard that the social model (and one could argue normalisation, which will be discussed shortly) has for the embodied experience of impairment misses the relational nature of self-identity (Goodley, 2011; Simpson, 1999; Watson, 2004), affecting self-esteem. For women with intellectual disability this may include both physical and cognitive impairment (Harter, 2012). Jenny Morris (1991) poignantly writes about how the courage to go out as a physically impaired person is not just about being able to move around but, importantly, it is also about coping with people staring and acting with condescendence towards you. Reminiscent of what Pink (2011) more recently describes as the move from embodiment to emplacement, that is the recognition that there is interaction of environment with the embodied self. Whilst social models do not necessarily adhere to an understanding of separateness of body and mind, as Descartes proposed, reflection on and studies about body image have tended to take a position that would see the woman’s body as object. In doing so, social and cultural influences on the woman’s perception of her body dominate, neglecting any interpretation that might suggest a dynamic, active, and relational embodied person (Goodley, 2011; Hughes & Paterson, 1997; Morris, 1991; Shakespeare, 2011; Shildrick, 2009; Thomas, 2004).

From the 1990s there has been a move towards a more integrative concept of body and mind, one which does not leave biology behind but, also, does not accept uncritically a binary of male and female (Butler, 1990; Ussher, 2006). Such a view takes the body as constructed but not in the sense of a passive, prior sexed, object but rather assigns active construction (constructivist) such that meaning comes from the multiple social, political and cultural influences being interwoven with the natural body (Grosz, 1994). Further, Butler (1990) identifies that any interpretation of gender that comes from such interaction would suggest “... a complexity whose totality is permanently deferred, never fully what it is at any given juncture in time.” (p.16), a concept that might be inferred from the suggestion of unfixed and multiple body images (Calogero & Thompson, 2010; Pruzinsky & Cash, 2002). In seeking an alternative to social constructionism, Grosz (1994) suggests that development of gender works from the outside in. By outside in, she means the way in which bodies are socially inscribed to become the
subjects that are required by society and understood in terms of dominant cultural discourses, including the feminine roles associated with being female. Recognition of the multiplicity of inscribers working on the body including, what is taken into the body (for example, nutrition), the ways in which the body is adorned (clothing, jewellery), physical bearing (such as height, posture) along with personal history and many other possibilities have to be taken into account. It is important to note that Grosz is not meaning for the body to be seen as a blank page, biologically there are some limits, but it is the interaction between inscribers and the material of the body that form her focus. Her interest is in questioning how sexual difference interacts with sexual identity without recourse to predetermined conceptions of gender roles, a point picked up by Coleman (2009) in her critique of social constructionist and constructivist approaches to the study of bodies. For Coleman the influence of these two approaches means, “sex, gender and heterosexuality are assumed as explicatory models in advance” (p. 207), providing a structure within which bodies are reproduced. Grosz’s (1994) conceptualisation of the body has been influential in more recent research with young women (Budgeon, 2003; Coleman, 2009).

In Coleman’s (2009) analysis bodies are understood as “assemblages” (p.13), “how I look” relates to “who I am” and, of course, vice versa, with the pivotal role of relations further experienced through bodies interacting with other bodies. These interactions provide the affective component (feeling) with regard to the possibilities of becoming leading her to summarise “Bodies become through relations which are neither random nor inevitable but which assemble through the intensity of experience” (p.214). Furthermore, Budgeon (2003) illustrates how 16 to 20 year olds in her study understood their essential embodiment, resisting representational interpretations, leading her to suggest that bodies “can be thought not as objects, upon which culture writes meanings, but as events that are continually in the process of becoming – as multiplicities that are never just found but are made and remade. “ (p.50, italics her emphasis).

The influence of the more recent feminist thought can also be seen in the critique of social model approaches to disability studies. As indicated above, social
constructionism has also done little to address difference, including ‘othering’ for people with impairments, leaving some to seek a more radical change that shifts the focus from the individual and their deficits, to valuing the person for who they are and a society that is truly inclusive and not premised on a dichotomous object/subject understanding (Clapton, 2009). Attention to embodiment would incorporate impairments, including how these influence their body image but, as Clapton and others (Clegg & Lansdall-Welfare, 2010; Corker & Shakespeare, 2002; Goodley, 2007b, 2011; Hughes & Paterson, 1997; Morris, 1991; Shakespeare, 2011; Shildrick, 2009; Thomas, 2004) suggest, also promoting a shift in social perceptions that place value on others according to current standards. For people with intellectual disability, then, the hope is that these theories will provide an avenue to a society that does not judge them on their dis-ability but rather values the individual’s ability and celebrates difference. Recognition that it is a layering of the social on the natural, ignored in early conceptualisations of the social model in its distancing from the medical model, is fundamental, with Van der Tuin (2011) drawing on the works of Bergson and then Barad to suggest that what is needed is an onto-epistemology, a way of seeing things and how they are represented as “entangled, durational, and agential” (p.39). For the women with intellectual disability who are the focus of the current study, such a point would appear to be crucial, particularly when the only other similar qualitative study of women with intellectual disability has noted “it is not really possible to talk about women’s bodies in straightforward and positive terms without tapping into more complicated issues.” (McCarthy, 1999, p.184). McCarthy chooses to confine her exploration of sexuality to what she identifies as a social constructionist approach rejecting Freudian psychoanalysis. However, other authors have suggested that psychoanalytic feminists fit within social constructionism (Grosz, 1994). For the current research the limitations of social models to explain how the body and mind interact to construct self-identity means that psychoanalysis is worthy of further consideration.
Psychoanalytic influences on understanding ‘otherness’

Whilst the medical model focuses on functional aspects of the body, with seeming disregard of interaction between body and mind, the social models pay little attention to the mechanism that sees the infant develop a concept of self, including body image. A turn to psychoanalysis offers a theory for the mechanism that explains how the infant develops a self out of the multiple sensations experienced, ultimately developing consciousness of, and interacting with, the social world in which they live (Grosz, 1994). Freud is best known for the development of psychoanalysis, with his focus on development of the ego and sexual drives informing his treatment methods for women patients, which are frequently critiqued in feminist terms (Bordo, 2003; Butler, 1990; Grosz, 1994). For my purpose, however, it is Lacan’s perspective on the developmental stage, termed the “mirror stage” that is the focus of this section. Writing in French, Lacan outlines the mirror stage in a short chapter based on lecture notes and published in Écrits (Lacan, 2002). The following account is based on both the 2002 translation and other scholars’ analyses of Lacan’s mirror stage. As with Freud, Lacan’s interest in psychoanalysis was linked to his profession of psychiatry and treatment of adult patients (Sadler, 2006; Webster, 1994), however that is not the focus for this thesis. Also put aside are the dominant gender constructs that they drew on for their description of female and male identity.

Within psychoanalytic approaches the family is seen as the microcosm of society and culture and hence the site of the origins of the human ‘being’ (Goodley, 2011). Lacan’s mirror stage, from approximately six months to eighteen months of age, brings awareness of a ‘whole’ body to the infant “a Gestalt phenomenon” (Sadler, 2006, p.13). As Lacan describes it, this first recognition of an “ideal-I” (Lacan, 2002, p.4) is fundamental to later identification with others. Up until that time the body is known through its parts, which are either able to be seen or felt. In addition, the infant relies on their primary caregiver for the purpose of gratification of desires and pleasurable interactions, having no concept of personal boundaries not seeing them as separate and “trapped in his motor impotence and nursling dependence” (Lacan, 2002, p.4). Harter (2012) suggests the influence of James’ earlier work on the ‘I’ self and ‘me’ self on the psychoanalytic interpretation
and sees this aspect as crucial to the infant having the cognitive capacity to be influenced by their social world, a point that may be relevant where the child has a cognitive impairment (Sadler, 2006). Recognition of the self brings with it recognition of the other as separate, however the reality of a body in which parts continue to have needs that are met by the other creates confusion, the image of existential wholeness does not match the reality of their dependence (Lacan, 2002). According to Lacan, the child resolves their confusion through identification both with their whole image and that of the other, to set up the Ideal-I (Goodley, 2011). Such is the basis of human relationships and the unconscious drive to achieve the ideal self, inferring continuous development (Lacan, 2002). Crucial to their understanding is the symbolic world into which the child is born as it “integrates and regulates not only the imaginary … but also the very interplay between the imaginary and the real” (Sadler, 2006, p.16). The primary function of the mirror stage is thus, “to establish a relationship between an organism and its reality” (Lacan, 2002, p.6).

However, a key point of Lacan’s theory is that it is based on desire of what is lacking (Goodley, 2011; Grosz, 1993), with the consequence for a lifetime of seeking satisfaction and perfection in self and relationships. It is through an image of their self that the person is able to respond to social influences, including recognition that others have a perspective of them (Harter, 2012) and through playing various active and passive roles find their identity, including their sexual identity as female or male. Both feminist and disability studies have utilised Lacan’s work to provide a more interactive mind-body understanding of the development of body image, one that has potential for understanding the body as ‘becoming’, as well as to identify the origins of deeply held perceptions of ‘other’ bodies. Grosz (1994) positions Lacan’s theory as inside out, meaning person to social, although in reality perceptions of both internal and external stimuli provide the basis for integration and ego development (Goodley, 2011).

Crucial to understanding the attitude of others to people with disability is recognition of their own embodied self and Lacan’s Ideal-I, culminating from the mirror phase, has been offered as the origin of anxiety for people when
encountering bodies that are dis-abled (Goodley, 2011; Shildrick, 2009). Whilst in the initial mirror stage the child is not verbal, once language develops signifiers from their culture embed meaning for their anxiety. For Shildrick (2009) such an understanding of identity formation is fundamental to realising that, even with greater emphasis on equality and diversity as a result of social and cultural changes, the disabled body is positioned as other because of its threat to individual identity. For Goodley (2011), however, the Lacanian analysis may also provide a way to challenge the culturally determined signifiers of ability and disability, such as Hickey-Moody (2009), indeed, demonstrates through her dance group. If, as Lacan suggests, all individuals are left struggling with a concept of a less than perfect body, which is further understood once they apply cultural signifiers, then there is no natural/able body and therefore no natural/disabled body. Further evidence of the culturally determined nature of signifiers is seen in the variation of how people with disability are valued. In contrast to the Western countries that draw on autonomy and individualism, there are other cultures that have an interdependent and collectivist focus. In some communities (but not all) where the outcome for how people are viewed can be quite different, with a priority on relationships and community, social inclusion may be a more likely consequence (Goodley, 2011).

Lacan has been criticised for his underdeveloped analysis of the mirror stage that essentially integrates the ideas of others, often without acknowledgement (Webster, 1994). Furthermore, proof of psychoanalytic theory in regard to the process of self-identity is elusive, with such internalised conflict not directly observable, rather being interpreted from behaviour that emerges at a later age. The dependence on physiological drives over social relations as the foundation of conflict has had implications for Freud’s and Lacan’s assumptions regarding the basis of subsequent interpretations of the mental health of women (Bordo, 2003; Chodorow, 1978). Some feminists, however, do not necessarily see that as reason to totally reject psychoanalysis, preferring to consider both its strengths and weaknesses in interpreting the development of self-identity (Bordo, 2003; Butler, 1990; Chodorow, 1978; Grosz, 1994). Thus, whilst it is recognised that there is a risk with adopting Lacan’s mirror stage, as these authors suggest, it does provide
an explanation for the development of body image that is integrative of psyche and body as well as recognising that it is never complete. Furthermore it suggests a process that is supported by the development of language and concepts, which may be particularly relevant for the participants in this study.

**Definitions of body image**

With the above points in mind my attention turns to establishing a definition of the term ‘body image’. Actual definitions are often missing in literature, despite the focus of the research being on one or other aspect of body image. This could suggest that there is a common understanding of the term and as such it needs no definition. However, even a brief reading of feminist scholars, for example, Bordo (2003), Ussher (1989); and psychological approaches, for example, Pruzinsky & Cash (2002), Calogero & Thompson (2010) would indicate that it is a mistake to assume that there is a shared understanding of what is meant by body image. As Bordo (2003) suggests body image is inevitably tied with conceptions of the body, such as whether to be seen as separate from mind or soul; a site of social construction; or gendered. While Ussher (1989, 2006) links women’s body image to the struggle to meet idealised perfect bodies with the contrasting messages of their imperfect natural body controlled by hormones. Although I am choosing to keep the term “body image” for this study, it is with recognition that it can be associated with a static image, for example a perception of “What I look like” rather than the more complex meaning I intend. One strategy that has been offered as a way around the more static perception is to refer to the body without image (Featherstone, 2006, 2010). As identified in the previous pages, an understanding of bodily perception is much more than the visual image, and Featherstone suggests using this alternative concept to recognise the potential for bodies to affect other bodies through proprioception and feelings of intensity.

Underlying different understandings of body image would appear to be whether the purpose of the analysis is to explain or to identify women’s perceptions. Very often it has been identification of self-perceptions and self-attitudes that have been the focus of individual research on body image, however,
whilst the interest of psychologists has been limited in this way, as opposed to much of the feminist research that focused on explanation, more recently the psychological research would appear to recognise an interaction between internal physiological structures that develop cognitive potential and external socialisation influences, such as is consistent with social construction theory (Harter, 2012). Furthermore, although psychological research has often been focused on females and their appearance (Cash, 2004), it seems reasonable to conclude that an individual's body image is not fixed (Calogero & Thompson, 2010) nor one-dimensional, hence Pruzinsky and Cash (2002) have suggested that the plural be applied, so that rather than speak of a person's body image the term would be body images. In the editorial to the new journal, Cash (2004) identified that ...

Body image refers to the multifaceted psychological experience of embodiment, especially but not exclusively one's physical appearance. It encompasses one's body-related self-perceptions and self-attitudes, including thoughts, beliefs, feelings and behaviours. (p.1).

Crucial to developing an understanding of body image is the meaning given to the term ‘embodiment’, as discussed in the preceding pages. Whilst the above definition identifies the importance of embodiment in relation to body image, it is not clear what is meant by the term. The simplest understanding might be the influence of interaction between body and mind on one's body image. In other words most writers appear to use the term to move beyond a Cartesian understanding of body as separate to mind, as seen above in Lacan’s mirror stage. What is more strongly debated is their relative success in moving from a dualistic approach, which sees body as object and mind as subject to a more unified, necessarily interactive corporeal understanding of the body (Grosz, 1994). There is no intention to engage in an in-depth discussion of the relative merits or otherwise of the different understandings of embodiment beyond those suggested above. At the most fundamental level, the definition of body image that best fits with my understanding is one that encompasses a recognition that the lived experience is through the body and it is that experience, inclusive of physical, social and psychological, which comes to determine the individual's ‘knowing’ of their body. Such ‘knowing’ is fluid and relational, a recognition that, while it may
not have been put into words at the time, was made evident to me from the early
days of my nursing practice. A simple example of sharing with a middle-aged man
his excitement at moving his middle finger of his paralysed hand just three days
out from a life-changing stroke, a movement that would have been ‘automatic’ and
‘subconscious’ to him just four days before but at which now he had worked with
all his mind and body to achieve, no doubt with an understanding of the social
implications of recovery. As the professional sharing this event, there was the
choice of responding with hope and encouragement or taking a neutral or negative
approach. In sharing his excitement, I gave him acknowledgement of the work he
was doing to process the impact of his stroke on his body image.

Whilst I acknowledge that body image is a complex concept, researchers
generally approach body image study from a particular perspective, often breaking
down aspects into component parts. The next section provides an overview of
research methods and selected findings of relevance to the current study.

Body image research

Body image has been the subject of research in a range of disciplines. A
number of authors have combined research projects, such as Ussher (2006), who,
in her study of women’s reproductive body drew on interviews, both her own and
others, to examine various life-stages. Other researchers have given consideration
to a range of findings from both quantitative and qualitative research, as is seen in
some of the more high profile books on women’s body image, such as Wolf’s “The
Beauty Myth” (1990) and Bordo’s “Unbearable Weight” (2003). Most recently Cash
(2012) has edited a full encyclopaedia on body image. Following his multifaceted
definition of body image (Cash, 2004), chapters cover specific aspects of body
image and are written by many of the experts in their respective fields. Drawing on
a range of research methods and results some chapters could be viewed as a meta-
synthesis of results taken from previous studies, not a surprising development
given the quantity of research that exists for some aspects of body image. Chapters
of the encyclopaedia that are relevant to the current study are further discussed
below and in the later themes and discussion.
At the planning stage for this research an initial search focused on finding specific literature related to women with intellectual disability using terms 'body image' along with 'intellectual disability' and other comparative terms, such as 'learning disability'. With either none or few articles identified, depending on the database searched, a broader search using the term 'body' instead of 'body image' identified prospective alternatives, leading to searches based on 'sexuality' both as a general term and broken down to aspects such as 'menstruation' and 'menopause'. In addition 'body size', including 'weight', 'overweight' and 'obesity' showed promise as having the potential to provide some insight into the body image of women with intellectual disability. As body image, which is a self-perception, is the focus of this study, studies that solely drew on the opinions of others, such as parents, support staff or health professionals were excluded, which resulted in consideration of relatively few articles. A limitation of this search is that it may not have reached articles published in languages other than English.

With the outcome of little specific published research on body image and women with intellectual disability, a choice was made to explore within the fields of psychology and sociology, which were seen as offering the best fit with the wider study on women’s mental health. Perhaps not surprisingly, body size is a major focus for many studies with attempts to quantify dissatisfaction with size common. The first section below outlines current knowledge about body weight and people with intellectual disability. This section is followed by a limited review of the body satisfaction literature, particularly that which has used various rating scales or questionnaires. There is copious literature on body satisfaction, possibly because it is amenable to brief quantitative tools that can be used with students who form something of a captive participant group in tertiary education settings. However, as that group is not that relevant to the women in this doctoral research I have made the choice to limit its use. Self-esteem and body image are thought to be closely related (Harter, 2012), therefore an introduction to more recent findings regarding this relationship is included. Whilst much of the satisfaction literature comes from psychology, literature that attends to the body and physical function is more commonly situated within disciplines such as sport and recreation. Although recognised for more than a century (Lindwall, Aşçi, Palmeira, Fox, & Hagger, 2011),
the importance of physical competence has received less attention than body satisfaction until recently. In addition to concerns with weight and physicality, body image is also manipulated by clothing, cosmetics, beauty practices and hairstyles, with relevant literature more likely to be found within sociology. Key points from relevant research related to each of these are provided here as an introduction to the perspective taken in the current study.

**Body weight and people with intellectual disability**

As noted previously, the early research on body image and women was focused on eating disorders, most frequently seeking to describe, classify and pathologise (Bordo, 2003). Eating disorders related to body image generally include anorexia nervosa and bulimia nervosa however it is rare for women with intellectual disability to receive such diagnoses. In contrast, they are more likely to receive a diagnosis of binge eating disorder, although the underlying reason for such behaviour is poorly understood (Jones & Samuel, 2010). Clearly one group for whom the latter is an issue are people with Prader-Willi Syndrome, with it being a feature of their genetic difference (Napolitano, Zarcone, Nielsen, Wang, & Caliendo, 2012). However, in their review of the literature, Jones and Samuel (2010) also note that binge eating may be associated with depression and a variety of situational conditions associated with institutional living. Reflecting feminist critics of medical models, who more commonly align eating disorders with social constructionism (Bordo, 2003).

Whilst eating disorders have, for some time, been identified with pathology, more recently being overweight or obese (as defined by Body Mass Index below) has been linked to poorer health (Burrows & McCormick, 2013). With the ramification that body weight in itself is defined as a health concern and has become a marker for population health (Ministry of Health, 2012a). Although challenged for accuracy of scientific evidence that relates fatness to poor health outcomes (Monaghan, 2005: Patterson & Johnston, 2012), never-the-less, measurements of weight have become an accepted strategy for determining the
health of people with intellectual disability in much the same way as it is accepted for the population in general.

People with intellectual disability are documented to weigh, on average, more than the general population, with one review of data from the United States, England, Ireland, Australia and Germany finding that all countries had a higher prevalence of obesity in intellectual disability populations compared to the wider population (Rimmer & Yamaki, 2006). Whilst the margin differed across countries, being female and/or having Down syndrome increased the chance of being overweight or obese. Furthermore, these authors suggested that environment may play a part, as they demonstrated patterns that showed those people who lived with their family or were independently flatting were more likely to be obese than those living in supervised residential settings. Similar findings in terms of overweight and obesity as well as living patterns have been documented from a large prevalence study in one region of the United Kingdom (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008). Interestingly, that study also demonstrated that women with intellectual disability were twice as likely to be underweight compared to the general population. Living alone or with family again featured but along with help needed with eating and drinking, difficulty walking, younger age, and poor understanding, perhaps reflecting a more complex disability for many of these underweight women. Finally, an analysis of data from the Special Olympics International Health Promotion database, including 11,643 athletes of which 4493 were female, confirms the general trend both in terms of overweight and obesity and that women were more likely to be so (Temple, Foley, & Lloyd, 2013).

There is no research in New Zealand that has sufficient numbers to establish the prevalence of overweight or obesity for women with intellectual disability, however a small study identified that the women (n=32) using one service were more likely to be obese than women in the general population (65.63% versus 30.2%) with a significant proportion of these women being in obesity categories two and three (Stedman, 2011). Findings from analysis of data held by the Ministry of Health would support the much higher rate of morbid obesity within the intellectual disability population in that for the 2007-2008 year they were four
times more likely to receive treatment for that condition than those in the general population (Ministry of Health, 2011). Treatments included surgical interventions such as gastric banding. These data can be positioned against a backdrop of the New Zealand population having the third highest rate of obesity in the Organisation for Economic Co-operation and Development countries (OECD) with an increase in average Body Mass Index (BMI) recorded as 26.1 in 1997 to 27.7 in the most recent 2011/12 Health Survey (Ministry of Health, 2012a). As noted in this survey, BMI is “calculated by dividing the person’s weight in kilograms by the square of their height in metres” (p.34). Obesity is indicated by a BMI of 30 or more, whereas a BMI of 25 to 30 is identified as overweight, despite research that has clearly indicated the limitations of these measurements in terms of diagnosing obesity (Romero-Corral et al., 2008).

Whilst it has been suggested that perception of body size may have an impact on weight control within the general population (Lynch et al., 2009), studies that have considered such a relationship among women with intellectual disability are rare (for example, Napolitano, et al., 2012). Instead the focus of research has been on strategies used to encourage people with intellectual disability to lose weight (Jinks, Cotton, & Rylance, 2011), with a feature missing from most of these studies being the perception of the person with intellectual disability, both in terms of their satisfaction with their current body size and with the weight loss programme. Thus, there is evidence that overweight and obesity measures are more common for women with intellectual disability and associated with specific conditions; that if the women are binge eating there is greater likelihood that they are depressed; and that their weight management may be related to their social and living arrangements. Whilst most of the above literature has been published since I began my doctoral studies, it reinforces my initial thinking that there was little known about women with intellectual disability and their body image. From that position I found myself in the vast and varied research on body image that had been done with non-disabled women. The difference in quantity was manifest.
Satisfaction with body size

Within our society body weight has become a major focus for many women with both the influence of standards of beauty portrayed in the media (Grogan, 2008; Sentilles & Callahan, 2012) and concerns about the effects of obesity implicated (Burrows & McCormack, 2013; SPARC, 2005; Yeats, 2010). Dissatisfaction with body size is a common finding across age groups and regardless of whether it arises when people are asked to rate their current and preferred size on a rating scale, through questions in a survey, or whether it is discussed in a qualitative interview. However, as illustrated below, despite general agreement, there are interesting differences in terms of what dissatisfaction might mean for individual women based on variables such as age, culture, poverty, education and so on. Many of these variables also influence the actual body size of the woman, highlighting complexity and inter-relatedness.

One common approach within the psychological literature has been to explore body size satisfaction through the use of figure rating scales that assess body size perception, ideals and thus satisfaction (Gardner & Brown, 2010). Stunkard (2000) and others developed one of the earliest and most frequently used scales in the early 1980s. The underlying assumption of such scales is that the participant’s perception is going to provide a realistic approximation of their beliefs about body size, it therefore being important that the person can meaningfully relate to the scale. The Figural Rating Scale (FRS) published by Stunkard and others presents nine figure drawings from very thin to very obese (Gardner & Brown, 2010; Lynch, et al., 2009) and has been used in a number of studies. The figures on the FRS are positioned at a slight angle and without facial features, leading Thompson and Gray (1995) to suggest that they might be difficult for some people to relate to as well as being disproportionate in the limbs, therefore not a good representation of the human body. In response to their criticism of various figure scales and the lack of reliability and validity testing by many authors (although not the FRS), Thompson and Gray (1995) developed the Contour Drawing Rating Scale (CDRS). As with the FRS, the CDRS used nine drawings ranging from very thin to obese. They were front-view and included
facial features, with attention to detail for each figure so that the perceiver would be better able to pick size differences. The difference between each figure was consistent (see Appendix 1 for the female version of the CDRS). As with the FRS, the CDRS has been widely used since being developed. Both of these rating scales present figures numbered from left to right and with numbers 1 and 2 representing very thin and 8 and 9 obese. There is one recent study that used the FRS to explore body image perception with people with Prader-Willi syndrome, many of whom had intellectual disability (Napolitano, et al., 2012). Through this study they were able to demonstrate that the 43 male and female participants with Prader-Willi syndrome (aged 10 to 47 years) were able to complete the FRS, with similar findings to their parents’ ratings suggesting reliability. As this study included BMI results for the participants, they were able to identify that adult women were seen as more accurate with their assessments of their current size than males who tended to underestimate, although it is important to acknowledge the few participants. Of the 21 participants in the study that were over 20 years of age, five were overweight and 14 obese and all indicated a preference for a slimmer figure on the rating scale.

Within the general literature rating scales identify that women overestimate their weight (Calogero & Thompson, 2010) but with variations related to their actual size. For example, normal weight women might be less reliable than under or over weight (Sanchez-Villegas et al., 2001); obese women have been found to both underestimate (Parker & Keim, 2004) and be more accurate (Bulik et al., 2001) in their assessments. There does seem to be a suggestion that women who are overweight or obese may prefer to be that way with a number of studies demonstrating that such women are more likely to view overweight figures as desirable (Anderson, Janes, Ziemer, & Phillips, 1997; Harris, Bradlyn, Coffman, Gunel, & Cottrell, 2008; Parker & Keim, 2004; Swami et al., 2010b; Thomas, Moseley, Stallings, Nichols-English, & Wagner, 2008). Although, as shown in Parker’s small study, whilst the women might see overweight figures in this way, they often did want to be smaller than their current size (in this study 76% had a BMI over 30), with 52% of her overall group wanting to be a lot thinner (which was rated as ≥2 sizes). It should be noted that both Thomas et al. (2008) and
Anderson et al. (1997) were studying African Americans and there is the suggestion of cultural difference in terms of attitude to body size that has to be considered. Evidently it is not a clear picture, however, whilst preferred sizes might vary, the overall impression is that women are dissatisfied with their body size (Bulik, et al., 2001; Liburd, Anderson, Edgar, & Jack Jr, 1999; Swami, et al., 2010b). There is, however, some evidence that cultural influences on ideal body size are shifting, with Liburd et al. (1999) finding the 33 African American women in their study preferred the slimmer silhouettes on the scale specially developed for this community by Anderson et al. (1997) for the earlier study. Furthermore, there is qualitative interview research with 30 Fijian girls after the introduction of television to their country, which showed a shift to a thinner ideal (Becker, 2004).

An important consideration that is relevant to body satisfaction across both culture and current body size is the degree to which the woman has internalised social standards of the ideal body (Calogero & Thompson, 2010), with some studies (for example, Cattarin, Thompson, Thomas, & Williams, 2000; Coleman, 2009) indicating that internalisation differs among women. A further individual difference affecting body satisfaction is the experience that the woman has had of bullying as a child and negative stereotypical responses to her size as an adult (Davison, 2012; Harter, 2012).

Socio-economic status has also been demonstrated to impact body satisfaction with Parker et al.’s (2004) study of 25 women in the United States, and Swami et al.’s (2010b) much larger international study of 4,019 women across 25 countries coming to similar conclusions that people of lower socio-economic status accept a larger figure as ideal. From their results Swami et al. went further to suggest that socio-economic status may be at least as important a variable as the exposure to Western media in terms of what women will choose as an ideal body size. In addition, some studies suggest that as women move further away from the thin ideal, they adapt their expectations regarding what is an ideal body size (Grogan, 2008; Tiggemann, 2004). As Chrisler (2007) argues, adipose tissue increases and body fat distribution changes as women age. However, the comparison of difference in relation to their new ideal remains similar, meaning that they may be no more or less satisfied. Comparisons between women across
age ranges may be influenced by the different exposure to ideal figures, particularly those of their youth, which may remain more constant despite the ideal in society having changed (Grogan, 2012).

Chrisler (2007) warns that care should be taken with these quantitative approaches to assessment of women’s satisfaction with their bodies, urging for consideration of qualitative studies that provide the opportunity for women to express their own thoughts about their body. In her review of the literature she noted that both taking care of their body and becoming more “authentic” (p. 19) by engaging less with beauty rituals and celebrating their changing features provided positive examples of how women coped with their aging body. Furthermore, in her review of mostly quantitative literature, Tiggemann (2004) suggested that an important finding that had been virtually ignored was the shift in the value women attached to the difference between their body and the ideal, suggesting that while body dissatisfaction levels may remain relatively constant, women see it as less important because their goals, such as finding a mate for the purpose of reproduction are not prioritized over other social activities that may provide self-fulfilment. In Hurd Clarke and Griffin’s (2007a) qualitative study satisfaction with appearance was linked to a focus on health and pragmatism about aging. Similar points are made by Grogan (2012) in summarising work on aging and body image in which she also notes that there may be different social consequences for older women with less expectation that they will be slim, however she suggests that this aspect has not been adequately studied. Davison (2012) also suggests that older women may have less anxiety about meeting social standards. 

Aside from the one study of people with Prader-Willi syndrome (Napolitano, et al., 2012) little attention has been paid to body weight satisfaction amongst people with intellectual disability. In their integrative review of obesity interventions for people with intellectual disability Jinks et al. (2011) noted that the viewpoint of this group of participants regarding their body size is rarely sought. The only qualitative research that indicates women with intellectual disability’s satisfaction with body size is McCarthy’s (1999) study, where three of the 17 women stated dissatisfaction with their weight. However, ten commented
on wanting to lose weight. At the time of commencing my doctoral study McCarthy's was the only research specific to women with intellectual disability that I was able to locate. I am aware that restriction to English language literature might mean that work published in another language was missed.

**Body image and self-esteem**

Generally seen as a component of self-concept, there is a close interaction between body image and self-esteem for many women. Self-esteem was always going to be a consideration in the wider study of the women's mental health, however, it clearly also has relevance for body image. Self-esteem can be considered a combination of self-worth and competence (Pelican et al., 2005). From her considerable volume of research on self-esteem, Harter (2012) identifies perceived physical appearance as the one domain of self-concept that consistently affects global self-esteem. While the direction of the link between body image and self-esteem is not clear (Harter, 2012; Lindwall, et al., 2011), women with higher self-esteem, in general, are more satisfied with their bodies (Grogan, 2008). For those placing a high social value on the ideal body, challenges regarding success or failure to meet ideal standards, possibly internalised from comments or actions of others, can have a significant effect on the individual's self-esteem (Harter, 2012; Pelican, et al., 2005). From their study of women aged between 20 and 65 years Webster and Tiggemann (2003) suggested that the strength of the relationship between self-esteem, self-concept and body dissatisfaction reduced as women aged, which they attributed to increasing perceptions of cognitive control. As noted by Davison (2012), however, body image is a subjective construct and the social implications for women, who judge themselves less attractive than others would judge them, has not been studied, although studies have shown that those women with more negative body images are more likely to avoid social situations. While there remain unanswered questions within the general literature, there is clearly an even larger gap in terms of what is known about women with intellectual disability and their body image. Yet, if the comparative social importance of bodily presentation is as important as presumed by many authors, challenges for women
with intellectual disability as they pursue a valued place in an integrated society might include their perception of their body.

**Perceptions of body physicality**

In addition to appearance, physical competence has been related to self-esteem and body image from at least the end of the nineteenth century (Lindwall, et al., 2011). A common approach to differentiating how body image (physical self-worth) might be linked with self-esteem has been to separate body image into components, such as sport competence, physical condition, attractive body and strength, whilst also considering self-efficacy (Marsh & Sonstroem, 1995; Sonstroem, 1996; Sonstroem, Harlow, & Josephs, 1994). Utilising Sonstroem et al.’s modelling, a number of the studies have explored the relationship between exercise, body image and self-esteem, often through some type of intervention or self-reported questionnaire. Findings from such studies that have focused on adult women suggest that exercise has a positive effect on perception of physical competence and acceptance (Elavsky, 2010; Elavsky & McAuley, 2007; Levy & Ebbeck, 2005).

Elavsky and McAuley's (2007b) initial study followed three randomised groups of menopausal women (n=164; mean age 49.9 years) who took part in either three by sixty minute weekly walking sessions, two by ninety minute weekly yoga sessions or were the control group not participating in exercise. Whilst their study did not demonstrate enhancement of global or physical self-esteem for any group, the walking group had enhanced self-perception of their physical condition and strength and both walking and yoga groups demonstrated benefits to perception of body attractiveness. In terms of mental health and menopausal symptoms, the women, who had all been sedentary at enrolment into the study, had enhanced their positive affect if they belonged to either the walking or yoga group and reduced their negative affect for the walking group alone at the end of the four months (Elavsky & McAuley, 2007b). In contrast, from the Elavsky and McAuley study, a subsequent follow-up two-years later with the same women found the gains they originally noted tended to lessen although not completely
disappear (Elavsky, 2010). However, through the analysis of this latter data, Elavsky noted that a higher self-perception of physical condition and body attractiveness was associated with higher physical self-worth.

Utilising cross-sectional survey method, rather than experimental, Levy and Ebbeck (2005) explored the role of physical acceptance with a group of 122 women aged 22-79 years. For their study they replaced sport competence with physical competence, as they considered it a more relevant focus for the women. While the women as a group engaged in only light to moderate exercise, those who reported a higher level of exercise were more likely to report higher levels of physical competence and physical acceptance. Analysis of their data provided evidence for links between exercise self-efficacy, perception of physical competence, physical acceptance and global self-esteem. An advantage of this approach was that it demonstrated women’s perceptions about their body without intervention.

Using mixed methods, results from the qualitative component of their study led Dionigi and Cannon (2009) to suggest reciprocity between the factors, such that whilst self-esteem might be improved by exercise, a higher self-esteem might also mean that the person is more likely to continue to exercise. Both a cultural and gender element has also been considered to influence the relationship (Latner, Knight, & Illingworth, 2011). As one of the few studies that provide a comparison between the three major ethnicity groups in New Zealand, Latner et al.’s study might be of particular interest. Comparing Australian and Hawaiian groups they found that the young people from Hawaii (made up of a larger cohort of Pacific Islanders) related fitness to self-esteem more so than those from Australia (where the proportion of Pacific Islanders was less). At the same time, the Pacific Island participants were generally more positive about their bodies than the comparison groups of Asians and Whites. In addition, for the undergraduate women in their study, fitness predicted self-esteem whereas it did not do so for the men. Interestingly, there is a group of researchers adapting the tools developed to test models of interaction between the various physical self-concepts and self-esteem for use with French-speaking people with intellectual disability (Maïano, Bégarie,
Morin, & Ninot, 2009; Maïano, Morin, Bégarie, & Ninot, 2011). Their work to date has been with adolescents but in their findings it would appear that girls relate their physical attractiveness as, or more important, than other elements.

With the increasing focus on the science of sport and medicine, including surgery, people have become more anxious about their body failing if they don’t maintain their health and fitness regimes (Shilling, 2008). Unpicking the reason why women engage in exercise and how that might relate to physical acceptance have been a group of researchers drawing on self-objectification theory (Prichard & Tiggemann, 2008, 2012a, 2012b; Strelan, Mehaffey, & Tiggemann, 2003). Whilst there is good evidence that those who are physically active are generally more positive about their bodies, it does depend on the reason they engage in the physical activity (Choate, 2005; Lox, Martin Ginis, & Petruzzello, 2010; McGannon & Spence, 2010; Snapp, Hensley-Choate, & Ryu, 2012) and the type of activity (Paulson, 2005). For example fitness-type classes, strength-based training and circuit training have all been identified as shifting women’s focus to the functional aspects of their body and improving their body image (Daniels & van Niekerk, 2011; Henry, Anshel, & Michael, 2006; Martin Ginis, McEwan, Josse, & Phillips, 2012; Paulson, 2005; Prichard & Tiggemann, 2012a). Whilst Lox et al. (2010) come from the perspective of motivation theory and suggest that there are both intrinsic and extrinsic motivators. The person who exercises predominantly because that is who they see themselves to be, ‘an exerciser’, is demonstrating integrated regulation, whereas when personal goals, such as achieving a certain level of fitness or weight loss, is the motivator, the person demonstrates identified regulation. As is evident in the self-objectification research, there are a number of women who are not dissatisfied with their bodies and for whom body function, rather than looks, is the motivation for exercise (Avalos, Tylka, & Wood-Barcalow, 2005). Most of the research that seeks to illustrate a relationship between physical activity and body image is experimental, often incorporating a control group and intervention group/s and utilising various instruments to collect data (Daniels & van Niekerk, 2011; Henry, et al., 2006; Martin Ginis, et al., 2012). Whilst clearly popular research tools, the various survey instruments were not assessed for the current research. Although the work published by Maïano et al. (2009; 2011) is
promising in that it is demonstrating that such tools can be adapted for people with intellectual disability, such a specific approach on one aspect of body image was not the intention for the current study.

**Working on appearance**

The relationship between self-esteem and body image can also be seen in the many practices with which women engage to enhance their appearance. Frequently the approach to studies about appearance (or bodywork) utilise qualitative approaches, generally incorporating either individual interviews or focus groups. Most of the studies draw on constructionist or constructivist approaches, relating appearance practices to social influences, often also being associated with determining the social position of people (Lennon, 2012). As with the physical body, self-objectification theory has been used to explain women's approach to their appearance, notably in choosing clothing (Tiggemann & Andrew, 2012b; Tiggemann & Lacey, 2009). A limitation of many of the studies is that they have recruited from groups of women who might be expected to have an interest in bodywork, thus are not meant to be generalizable. It is much more difficult to get a reading on the use and range of bodywork across all women.

For many women in the studies, appearance work includes visits to salons for facials, nails, hair removal and other treatments (Black, 2004), however McCarthy's (1998) regret that the women's embarrassment limited her exploration of hair removal might suggest that such visits are rare for women with intellectual disability. McCarthy offers no comment on the women's use of cosmetics or hairstyling, which are commonly used by many women as a way to enhance their image and meet the standards that they believe are expected, for example, in their workplace (Coleman, 2009; Dellinger & Williams, 1997; Gimlin, 1996; Hurd Clarke & Griffin, 2008; Muise & Desmarais, 2010; Stuart & Donaghue, 2011). For older women cosmetics, hairstyling and colouring and clothing can be used to counteract feelings of invisibility that begin in middle age (Gimlin, 1996; Holmlund, Hagman, & Polsa, 2011; Hurd Clarke & Griffin, 2007b; Hurd Clarke & Griffin, 2008; Hurd Clarke & Korotchenko, 2010; Muise & Desmarais, 2010;
Tiggemann, 2004; Weitz, 2008). Whether these activities are undertaken at home or in a salon, the literature leaves little doubt that they are considered an important component of bodywork for some, if not most, women.

Whilst the main focus of McCarthy’s (1999) research was sexuality, she asked the women what they liked and disliked about their body and included questions that might draw out other ways that the women thought about their bodies. The women mostly thought cleanliness and personal hygiene were important, although she noted that their standards of hygiene did differ. Lennon (2012) has commented that cleanliness, particularly in relation to clothing, can convey social class and cognitive ability. Interestingly, other research might consider aspects such as use of deodorants when discussing cosmetics, yet none appeared to seek information about how the women perceived being clean. However, McCarthy’s focus on clothes as an expression of self is shared by some other literature (for example, Grogan, 2008; Holmlund, et al., 2011; Stuart & Donaghue, 2011; Tiggemann & Andrew, 2012a, 2012b; Tiggemann & Lacey, 2009). In addition to clothing being important for the reasons outlined in the previous paragraph, clothes also tell the woman when her weight or body shape is changing (Grogan, 2008; Holmlund, et al., 2011). For the women in McCarthy’s study clothes were a source of pleasure when they were dressed up, however, unlike other women, choosing what they wore each day was limited to the clothes that they may not have had any say in purchasing. A major difference to the wider research is the lack of personal control many women in McCarthy’s study appeared to have in relation to their choice of clothing as well as their sexuality. Many of the women in McCarthy’s study were residing in institutions. From that perspective, and given my memory of institutional clothing, I was interested to explore the reality for women in New Zealand, none of whom would be residing in large institutions.

In conclusion, the limited research that has explored aspects of body image with people with intellectual disability would suggest some similarity with body image research in general, for example, dissatisfaction with body size. However, the voice of women with intellectual disability has not often been sought in the research with women in the general population, with explicit exclusion criteria
often including intellectual disability. What is clear is that the broad dimension of body image for women with intellectual disability has not been researched, and while it might be assumed to be little different to that of other women, the few studies on specific aspects that are outlined above would question that assumption.

**Situating the research within the New Zealand context**

Within New Zealand parents began questioning the support offered to their children with intellectual disability as early as 1949, when the Intellectually Handicapped Children’s Parents’ Association was formed, followed in 1955 with the Association beginning to provide short stay homes in the community (IHC New Zealand, 2013). Despite their initiative, as with other countries in the Western world, in New Zealand the numbers of people living in the large institutions continued to grow through into the 1970s (IHC New Zealand, 2013; Tøssebro et al., 2012). Although it should be noted that Prentice (1985) reported that about 60% of people with intellectual disability were believed to be living in the community in 1985 when deinstitutionalisation was barely started, suggesting many did remain with their family or live independently. From the 1970s disabled people’s rights were taking hold in both the United Kingdom and the United States (Oliver, 2009) and were adding their voice to the inappropriateness of institutions. Fundamental to the United Kingdom-based social model of disability is the understanding that such social exclusion of people with impairments is due to the way that society interacts with them and it was this exclusion that they experienced as disability. The social model sought full citizenship for disabled people (Smith, 2009), a sentiment echoed by North American activists at the time, albeit from the alternative standpoint of minority politics (Goodley, 2011). Notably the social model of disability was developed and led by disabled people, usually male and with a physical impairment. In contrast, professionals and parents led parallel shifts in the conception of rights for people with intellectual disability (Walmsley, 2001).
By the time that institutions reached their peak numbers, the human rights movement, influential parents and professionals were swaying political opinion away from further growth. Whilst there were no doubt financial aspects to the change in direction, the principle of normalisation and subsequent social role valorisation has also been identified as a major player (Burrell & Trip, 2011; Caruso & Osburn, 2011; Tøssebro, et al., 2012; Walmsley, 2001). The conception and to some extent, therefore, the positioning of people with intellectual disability within the principle of normalisation has differed. The initial Scandinavian approach was rooted within human rights and called for changes that would see people with intellectual disability provided with opportunities typical of their society (Tøssebro, et al., 2012). Within the United States, Wolfensberger (2011b) took the principle in another direction, changing it to Social Role Valorisation in the 1980s, identifying that the best way to shift the perception of people with intellectual disability was to address social roles and encourage the person to adopt appropriate role behaviour. Whilst either conception was aimed at providing opportunities for people with intellectual disability within their community, they were clearly premised on the understanding that the individual should adapt to meet an acceptable standard of social behaviour, not on recognition of variability and complexity within the population (Oliver, 1998; Walmsley, 2001). In other words they remained objectified and ‘othered’, although with a sense that such a position should not prevent them from receiving similar rights to other members of their community. The contrast with the social model of disability is clear in that the focus remains on the individual adapting, rather than society. Whereas empowerment and social change led by disabled people was the goal of the social model, Wolfensberger (2011a) questioned the usefulness, indeed social morality, of pushing a model that people with intellectual disability would struggle with due to their particular cognitive limitations.

Political will for change in the way that people with intellectual disability should be supported was evident from a moratorium on building large institutions in 1974 at which time it was estimated that 45.5% of residents with intellectual disability could be living in the community (Watson, et al., 1985), however it took another two decades before the institutions started to close and three until the
process was completed. It is now some years since the final closures, meaning that most people with intellectual disability now live either in their family home, independently, or in a form of residential support. Movement into community support stimulated growth in the number of Non-Government Organisations (NGOs), which have become the major providers of services. These services differ in the number of people they support and geographical spread. With a range of NGOs offering supported living services, the actual model and number of people living together differ. Entry to any support package within New Zealand begins with a needs assessment that is completed by a regional Needs Assessment and Service Coordination (NASC) service contracted by the Ministry of Health. Once the person’s needs are identified they can choose their provider/s (although that choice might be limited in rural areas). There are both residential and non-residential contracts, which service providers may enter and people that they support will then come under the contract assessed as appropriate to their needs. More recently the Ministry of Health (2012b) has introduced an individual funding model that is intended to give disabled people more control of their support package. In addition to coming under one or other of these contracts, which support their residential requirements, people may attend a day service that will also have a contract with the Ministry of Health or Ministry of Social Development. The day service may or may not be provided by the same NGO as their residential or supported living service. To further complicate matters, the person will be eligible for benefits that are provided through Work and Income and which may be used to part fund their support package, depending on the model being used by their chosen service. Whichever model of service delivery and package of income support accessed, most people with intellectual disability have minimal disposable income.

Policy is led by the New Zealand Disability Strategy (Ministry of Health, 2001), which was published to provide guidance for the implementation of the New Zealand Health and Disability Act 1999. The vision of the Strategy was for a non-disabling society, with the social model of disability a clear influence throughout. Prior to the development of the Strategy, the National Health Committee had begun to consider the position of people with intellectual
disability, however they waited two years before completing and releasing ‘To have an ‘ordinary’ life’ in 2003 (National Health Committee, 2003). They explain what they mean by ‘ordinary’ as that people should have...

... their lives taken seriously, being able to give and receive love, have enduring personal relationship, having their cultural values respected, being given opportunities to grow, learn and develop throughout life, and being valued by others for what they have to offer (p. 5)

... suggesting that social role valorisation influenced the thinking of the time. Overall the document was critical of the lack of progress on citizenship and other rights for adults with intellectual disability over the preceding years and called for a move towards an era of community membership. Not surprisingly, perhaps, the goals of this document remain a long way from being realised. Interestingly the ‘body’ is only indirectly considered within the document in relation to reporting poor health which, as indicated above, seems not to have improved in subsequent years (Ministry of Health, 2011). In addition there would appear to be no consideration of development of self-identity, of which body image may be relevant, for the newly labelled ‘citizens’.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2008) was adopted in 2006, some years after the above New Zealand documents were released. New Zealand ratified the Convention in September 2008. New Zealand has not signed (nor ratified) the optional protocol. The Office for Disability Issues has responsibility for coordinating and reporting on New Zealand’s progress towards meeting its responsibilities under the Convention (Office for Disability Issues, 2013). Following ratification of the Convention, attention has been drawn to the inadequacy of funding models and support packages in terms of promoting an ‘ordinary’ life and fostering community integration, with the Ministry of Health subsequently developing a new model, currently being trialled in a region of the North Island (Disability Support Services, 2013). There is a clear agenda for this model to shift both perceptions and expectations, so that people with disability have greater control of their support, and connection with their community is
emphasised. Whilst the aims, if achieved, may support an overall change to the perception of people with intellectual disability within New Zealand society, the new model does not impact the current lives of the women interviewed for this study. It does, however, provide a driver for policy change that might be relevant to the findings of this doctoral study.

**Summary**

The focus for this doctoral research is the body image of New Zealand women with intellectual disability, aged between 18 and 65 years. The approach taken to understand the women's perceptions is constructivist. As will be discussed in Chapter Three, constructivism has the capacity to provide a conception of the women's body image that acknowledges multiple body images and multiple influences. With consideration of the various perspectives outlined earlier in this chapter, I align myself with others who have drawn on various positions in their understanding of ‘othering’ (for example, Shildrick, 2009; Van Der Tuin, 2011).

Whilst the medical model and social constructionist approaches to the study of body image have been critiqued in recent years (Butler, 1990; Coleman, 2009; Grosz, 1994) they remain useful as they inform current inscribers on women's bodies and, as such, will be relevant to discuss in relation to the research findings. Having some understanding of the dominant influences through their lifetime provides a context for their construction of their body image. For many of the women it could be expected that the medical model informed their experiences throughout their life, beginning with labels for their ‘conditions’ and measurements of their intellectual functioning influencing their education and living situation. Older women would have lived experience of the shifting influences of the medical model and normalisation principles, whereas younger women might be expected to have predominantly experienced community-based services that espouse integrative philosophies, such as normalisation and social role valorisation.

In contrast to the more extensive research with women without intellectual disability, there is little evidence for the impact of socio-cultural influences on the
body image of women with intellectual disability, as would be inferred by social
model approaches. The research, therefore, needed to consider how these might be
explored. Although not wishing to make it a focus of interpretation, however, I
anticipated that a social model approach would not be sufficient due to the lack of
recognition of the implication of the lived experience of impairment on the body
image of the women. It was therefore important to consider a theoretical position
that allowed for an interpretation inclusive of an embodied perspective, as can be
seen in Lacan’s psychoanalytic theory. Whilst I do not want to align myself with the
inevitability of gender constructs as suggested by psychoanalysis, Lacan’s mirror
stage provides an explanation for the drive towards achieving the socially
desirable body. Exploring body image with women with intellectual disability
might help me to understand their drive for an Ideal I. Thus, my positioning of the
women leading into this research is based on an understanding that they will
actively construct their perceptions of their body. That construction will be
influenced by their social world and the extent to which they understand the
meaning of interactions within that world.

While there is copious research that explores various aspects of body image,
particularly with younger women, there has been very little research with women
with intellectual disability. Perceptions of body weight and satisfaction with size,
self-esteem, physicality and the impact of having a physical impairment on the
ability to function would all appear to be important aspects to consider in the
women’s construction of their body. Furthermore, being able to adorn the body or
otherwise change appearance through make-up, cosmetics, hairstyling and
clothing should be explored for how these might inform the women’s body image.
Particularly relevant is the shift from institutionalisation and the impact that might
have had on women’s bodywork. Having provided a setting for the research, the
next chapter picks up my intentions for the research and describes the
methodology and method chosen to explore the women’s construction of their
body.
Chapter Three: Method

Introduction

The opportunity to study body image arose within the context of a planned project to explore mental health and wellbeing with women with intellectual disability. As demonstrated in the previous chapter, mental health has been associated with self-esteem and body image. In addition, although others express concern about the prevalence of obesity amongst women with intellectual disability, little is known about the women’s perception of their body or satisfaction with that perception. As one of three named researchers on a proposal for a mental health study that had been accepted for funding, I saw that there was a chance to address this gap in knowledge. As the body image component was added into an already developed proposal the method for the study of body image, as described within this chapter, is cocooned within the process for the wider study. However, prior to description of the research process it is important to consider my view of reality and how knowledge is constructed, thus the chapter begins with my ontological and epistemological position, which led me to taking a constructivist, interpretivist approach. As will be seen, whilst constructivism dominates, interbreeding (Guba & Lincoln, 2005) occurs as feminist and disability standpoints as well as critical theory are clear influences on both method and interpretation. Voice, relationships and reflexivity are all deemed important concepts for this research with women with intellectual disability and are considered individually within the chapter prior to being drawn on as I explain each step of the research process.

Genesis of the research

The mental health of women with intellectual disability had been a concern for my colleagues and me for some time, based on both previous research that we had conducted at the Donald Beasley Institute (Mirfin-Veitch, 2010) and
conversations with women that led us to believe that mental health and the treatment of mental illness were of concern to them. The Donald Beasley Institute is an independent research organisation that specialises in research with people with intellectual disability and it is based in Dunedin, New Zealand. Following the successful application to Lotteries Health New Zealand for funding a project on mental health and wellbeing, my further reading on prevalence of particular mental health disorders raised my interest in women’s body image as I considered a range of reasons why anorexia nervosa was reportedly rare compared to its incidence among women in the general population (Lunsky & Havercamp, 2002). As described in the previous chapters, my initial interest quickly diversified as I considered other information. The more important point for understanding this chapter is that the study of body image might be seen as coming from a particular “data set” within a wider “data corpus” (Braun & Clarke, 2006, p.79). Braun and Clarke define these terms as data corpus incorporating “all data collected for a particular project”, while data set refers to “all the data from the corpus that are being used for a particular analysis” (p.70).

As I had been involved in the larger study from its inception, discussion with the Principal Investigator raised the potential for me to include additional questions to our semi-structured interviews and then conduct analysis of the relevant data set for doctoral purposes. My interest in body image made it the perfect topic for my Doctor of Philosophy and it fitted within the broader considerations of the women’s mental health and wellbeing. Subsequently the research was extended and the necessary steps were taken to include specific questions in the interview schedule.

**Positioning self as researcher**

For any researcher about to undertake a study within the field of intellectual disability it is important to first think about the perspective that will best answer their question and with which they and the people studied will be comfortable. This latter aspect will be influenced by the researcher’s worldview. Whilst I appreciate a role for studies that are based on the premise of individual pathology,
my research interests generally lie with social approaches. It has been suggested that the two rarely meet (Walmsley, 2001). Furthermore the alignment of the positivist and postpositivist paradigms with an objective, dualistic perspective challenges my sense of the world and, indeed, people, a crucial consideration for all research on body image.

Deciding on my position for this research has not been a straightforward path; there seemed to be so many considerations. Inevitably I have ended up with some major and some more minor influences, which Guba and Lincoln (2005) suggest is “interbreeding” (p.192), as paradigms that have the capacity to interact with each other are carefully considered and drawn upon as they fit. From a personal perspective, exposure to multiple paradigms, particularly critical theory and constructivism, have informed my basic assumptions and worldview. Early university education across a range of disciplines introduced Marxist, then feminist, and finally cultural perspectives. Alongside that university education I was developing my role as a nurse educator, where feminist and cultural worldviews were becoming increasingly significant. Whilst these worldviews remain influential in this research, ultimately my decision was to take a constructivist approach as the overarching framework. Having had some training in grounded theory, however, I also see something of an iterative process happening in terms of my own thinking as I read from literature to data to analysis to literature and so on (the constructivist self). Thus, from a fairly straightforward interpretation of body image, my thinking on the topic and how the data might be represented shifted throughout the process. Ultimately, my decision has been to present the themes as separate and then integrate these to re-present the whole body within a critical constructivist framework in the discussion chapter.

**The constructivist paradigm**

Within constructivism meaning comes through interpreting the world and objects that are within the world, as they exist (Crotty, 1998). In this respect meaning is relative, relying on social realities or values, and the language available to participants within the social setting (Glesne, 1999; Guba & Lincoln, 2005;
Howell, 2013). Language is considered the key to constructivist theory; pivotal both in terms of how the individual comes to understand his or her self (Howell, 2013) and how the person communicates their understandings to others (Hardy, Gregory, & Ramjeet, 2009). Unlike the positivist who might ‘posit’ knowledge to be confirmed through observation, the constructivist considers knowledge the result of collective understanding, subjective, provisional and reproduced through cultural forces (Crotty, 1998; Guba & Lincoln, 2005). As such constructivist research is not aimed at providing predictions or truth but rather understanding (Howell, 2013), making it ideal for addressing the broad research aim of how women with intellectual disability perceive their body.

Social constructionism is generally differentiated from constructivism as they come from different angles; however, the two intersect and meet in construction of reality (Howell, 2013). For the constructionist the focus is on the development of shared social knowledge, influenced by hegemony. Whereas constructivism is an individual process whereby people make meaning for themselves. For the purpose of this research it is useful to consider the intersections. In researching the topic I am interested in how the women make meaning of their body but also the influences that there may be within their social world that shape their body image. However, I am also mindful of the limited vocabulary or communication skills that might make it difficult for the women to express their ideas about their body in interviews. Thus the construction of their body that is presented here is, in reality, my construction. I did not work through a consensus process such as might be expected if it were their construction being reported (Howell, 2013) and it was necessary to draw on additional information to gain a sense of how the women constructed their body.

**Relativism, problem or strength?**

Knowledge, in the constructivist sense, is tied to both the social context and individual variables and is therefore relative; thus, consideration should be given to what that means for the research. Among the concerns about relativism is the problem that truth only holds in the given situation; therefore, it is possible that
something can be true for some whilst false for others, making generalisations impossible (Howell, 2013). Although often identified as a major weakness of constructivist assumptions, Guba and Lincoln (2005) suggest that physical sciences are becoming more accepting of the fluidity of knowledge, with Kuhn's (1970) concept of paradigmatic shift evident in this thinking.

Furthermore, Harding (2007) points out that while epistemological relativism might seem recent, ethical relativism has long been identified. Although not universally accepted, it is not uncommon to recognise some moral practice as based within a culture. Indeed, my preference for relational models of ethical analysis suggests an acceptance that there is not necessarily one right way. It is, however, useful to add that such a position need not end with a position devoid of any bottom lines but rather can be likened to ethical pluralism (Volbrecht, 2002), whereby the particular moral stance must be supported by sound argument. Borrowing ideas for questions from Harding (2007, p. 57), whilst accepting that the research is relativist, the important considerations might be:

Can this research raise new questions about women with intellectual disability and their body image?
Will the interviews and interpretations provide some insight into the women's reality and their understanding of their body?

Because of the transitory position of constructivism, the findings of this doctoral research might open up possibilities, leading to change in how people construct or ‘other’ women with intellectual disability and how the women themselves construct their body image, including that their construction is itself fluid, as suggested on page 38.

**Constructivism and critical theory**

As indicated above, early influences on my tertiary education and role as a nurse educator included those from a critical paradigm. That there are links between constructivism and critical theory is recognised (Guba & Lincoln, 2005;
Howell, 2013; Kincheloe, 1997), with constructivism providing the opportunity for addressing social structures that oppress individuals as opposed to simply identifying the oppressors. This facility might be particularly important when considering the position of the women in this study, as Howell notes “oppression is more endemic when subordinates accept the hegemonic inevitability of their position in society” (p.80). Therefore, in considering how they construct their body image it is useful to reflect on how women with intellectual disability have been socially constructed within society and to raise questions and challenge those constructions that are oppressive.

Patton (2002) provides some useful questions for the constructivist to address:

How have the people in this setting constructed reality? What are their reported perceptions, “truths”, explanations, beliefs and worldview? What are the consequences of their constructions for their behaviours and for those with whom they interact? (p.132)

Furthermore, given the interbreeding of approaches as noted above, it is useful to consider the question he asks of those taking a narrative approach, as I have through the wider exploration of the women’s lives. For narrative researchers he suggests that they consider: “What does this narrative or story reveal about the person and world from which it came? How can this narrative be interpreted to understand and illuminate the life and culture that created it?” (Patton, 2002, p.133). Finally, from a standpoint perspective, which in the case of this research includes both feminist and disability: “How is [feminist/disability] perspective manifest in this phenomenon?” (p.133)

**The influence of disability studies on this research**

Both feminist and disability research can be considered standpoint approaches (Harding, 2007). Constructivism, from either a feminist or disability standpoint, considers that social change is an expectation of the research. Within
disability studies, emancipatory research is presented as an ideal that provides opportunity for disabled people to control every aspect of the research, from conception to dissemination (Oliver, 2009), however it is very difficult for people with intellectual impairment to achieve due to the very nature of their impairment (Bigby & Frawley, 2010; Conder, et al., 2011; Ramcharan, Grant, & Flynn, 2004; Walmsley, 2001; Walmsley & Johnson, 2003). Participatory research might be seen to be a step down from emancipatory, in that it has less stringent requirements of the level of involvement of disabled people (Ramcharan, et al., 2004), however, as Ramcharan et al. suggest, there are many challenges in terms of determining what is actually meant by participation of people with intellectual disability and these have an impact on the way that the research represents their voice.

Rather than take either an emancipatory or participatory approach, the current research follows the growing body of research, led by interpretivist approaches, that has provided opportunity for people with intellectual disability to tell their story (Felske, 1994; Goodley, 2001; Walmsley & Johnson, 2003). Both the normalisation movement (Walmsley, 2001) and more general social science research (Ramcharan, et al., 2004) influenced the early development of involving people with intellectual disability in this way. There was an expectation that interpretivism within disability studies would both tell different stories by including people who had not previously been heard in research and, by seeking ways other than the spoken voice, tell stories differently (Ferguson, Ferguson, & Taylor, 1992). A feature of much of this research is the desire on the part of the researcher to act as an advocate for the oppressed by questioning patterns of living and challenging disabling barriers (Moore, et al., 1998; Walmsley, 2001). Furthermore, by concentrating on the details of the daily lives of people with intellectual disability along with their social context, research may increase the understanding of others (Björnsdóttir & Traustadóttir, 2010), potentially bringing about social change. These ideas influenced recruitment and the interview structure, in that the research provided opportunity for women whose story had not been told and those stories gave insight into their daily lives and thus aspects of their body image, even when that was not the specific focus of the questions.
Whilst it might be more immediately effective for research to be initiated and led by people with intellectual impairment, the reality is that researcher-led studies can also be valuable in addressing oppression (Guba & Lincoln, 2005) (Watson, 2004). (For example, most of the background research utilised in the “To have an ‘ordinary’ life” document (National Health Committee, 2003) was researcher-led). Behind my decision to study body image with the women with intellectual disability was recognition of the social implications of how women present and, whilst one small study was never going to result in major changes, there was the hope that the findings might be used to affect the multiple influences that there are on both how the women present and how they feel about their body.

**Considerations for a quality constructivist approach**

Quality research is an important goal for all researchers, however measures of quality differ depending on the approach taken. It is widely accepted that both validity and reliability, emphasised in quantitative studies, have a different meaning in qualitative research (Guba & Lincoln, 2005). Indeed, these terms are rarely used as relevant to judging the quality of constructivist or other qualitative approaches to research. Even a brief reading of the literature indicates that alternative conceptions and detail for assessing qualitative research has formed an ongoing discussion for the past three decades (for example, Guba & Lincoln, 2005; Howell, 2013; Patton, 2002; Sandelowski, 1986; Sandelowski & Leeman, 2012; Tracy, 2010). Whilst the reader might be left with some confusion, it soon becomes evident that there are general principles that are shared by the various authors and it is these that inform my considerations of quality assessment.

Rigour or trustworthiness of the research process is fundamental to the research being seen as of value by others (Braun & Clarke, 2006; Guba & Lincoln, 2005; Patton, 2002; Thomas, 2006; Tracy, 2010). This means that the researcher must take care to describe each step from initial development of the idea through data analysis and reporting of results, not in terms of following a prescribed method but rather that they are open and honest about how they came to their findings (Guba & Lincoln, 2005). Various strategies within the method may
enhance the sense of trustworthiness, for example, careful consideration of negative cases, that is those which provide an exception to a developing theme (Patton, 2002), evidence of inclusion of various representative views in the quotes used (Guba & Lincoln, 2005), or having another researcher or stakeholder check the codes and developing themes (Thomas, 2006). The reflexivity of the researcher and clarity about the participant-researcher relationship are also important to assessing rigour and will be considered separately below.

Whilst not utilised in all qualitative research, triangulation is also considered a useful strategy to enhance rigour (Howell, 2013; Patton, 2002). It is relevant to the current study in that alongside the multiple interviews with the women, they were asked to complete the CDRS and my colleagues and I kept field notes that documented our own perceptions at the time. As Patton (2002) notes, these multiple slices of data can be useful for understanding differences as much as similarities.

The credibility of the research is ultimately judged by those that read it (Patton, 2002). It is they who then determine its usefulness or transferability (Howell, 2013; Sandelowski & Leeman, 2012). As Sandelowski and Leeman note, there is a joint responsibility in regard to transferability, in that the researcher must make their findings accessible, by choosing a writing style that is clear, but the reader also requires the knowledge necessary to see how the findings might transfer to a different situation. Their emphasis on ensuring that themes are well described so that the reader understands what they encapsulate is particularly pertinent to this study of body image, whereby alternative groupings of the data could have been configured (Sandelowski & Leeman, 2012).

Various authors suggest that there is an ethical dimension underpinning the considerations of rigour in knowledge production through qualitative research (Guba & Lincoln, 2005; Lather, 1997; Patton, 2002; Tracy, 2010). Whilst there is interplay between the above criteria and the ethical dimensions, I am choosing to discuss the latter under the following headings of voice, relationships and
reflexivity. Each of these seemed particularly relevant to how the research would unfold.

Voice

As noted above, language is critical to constructivism, however, in considering my approach to this research ‘voice’ became an important and multifaceted concept. My choice of using first person in writing this doctoral thesis is guided by the advice of others who see it as fundamental to presenting a constructivist account (Gilgun, 2005; Tierney, 1997; Tracy, 2010) and also essential when the topic relates to the body (Heyes, 2007). By writing in first person I am clearly placed within this research, a point that will be further elaborated upon in the section that follows on reflexivity. For the reader it brings clarity to my role and, where appropriate, the role of the other interviewers in the research. In addition, voice includes a desire to listen to women with intellectual disability, to provide opportunity for them to express their ‘voice’, while considering I would interpret their voice and give expression to it in writing (Guba & Lincoln, 2005). Given the centrality of language to expression of ‘voice’, a complexity for this research was always likely to be the limited expressive language that some of the women might have. Thus, there was the initial challenge of finding ways for the women to share their ideas, as will be discussed in more detail later in the chapter when explaining the approach taken to interviewing the women.

As illustrated in the previous chapters, disabled people and women share common experiences of being objectified and studied (Harter, 2012; Olesen, 2005; Oliver, 1998; Parmenter, 2004; Reinhartz & Chase, 2003; Simpson, 1999), with early qualitative researchers trained in objectivity both in the field and in their writing (Guba & Lincoln, 2005). Such approaches have left research participants feeling exploited and done nothing to end their oppression (Olesen, 2005; Oliver, 2009). From that perspective, voice is a significant element of the social model of disability, particularly with its emphasis on emancipatory research as the predominant way to bring about change in the lives of disabled people (Barnes,
2010; Oliver, 2009; Parmenter, 2004; Smith, 2009). Furthermore, from the perspective of the body, providing a voice for women is essential for understanding their different experience to that of men (Bartky, 2008). For over three decades, feminist methodologies have assumed women's knowledge and experience as valid, promoting methods of conducting research that are open, honest and respectful of the participants (Klein, 1983; Olesen, 2005; Reinharz, 1992). Whilst there are differences between disability studies and feminism, disabled women have identified that the two interact in their lives (Morris, 1991; Thomas, 2004).

Although in deciding the topic and method I compromised the level of participation by women with intellectual disability, it remained important to me that the women would have their voice represented as strongly as possibly in the analysis of their data. However, I was also aware that I held the power in this study, as ultimately their voice would be analysed through my eyes and ears and not theirs (Lincoln, 1997; Olesen, 2005). Whilst I could make every effort to keep myself out of their story, it would be dishonest to suggest that was achievable (Walmsley & Johnson, 2003). When the person shares their life experience for the purpose of analysis it is clear that the researcher will determine how that information is conveyed, including selection of quotes for inclusion in the report (Fontana & Frey, 2005; Olesen, 2005; Ramcharan, et al., 2004). As the women could be expected to vary in their eloquence, it was important to ensure that the women with fewer words were also heard. Booth (1996) suggests care in changing language and editing so as not to lose the personality of the participant and for the most part this advice is followed in the results section, as has there been careful selection of quotes to be as representative as possible of the diversity of the women.

Ultimately, however, my voice in this research might be likened to what Chase (2005) terms the “authoritative voice” (p.664) in that, whilst remaining respectful of the women’s contribution, analysis went beyond the women’s words to find deeper meaning and expose the background stories that might lead to social change. Based on Guba and Lincoln’s (2005) understanding of paradigms it could
be argued that in using an authoritative voice in this way I was moving between constructivist and critical paradigms, or ‘interbreeding’ as explained above. From the perspective of my own voice it is important to acknowledge my own history (Guba & Lincoln, 2005; Heyes, 2007), as previously outlined. Just as Guba and Lincoln predict, adding to my many selves, the voices of the women also presented contradictions that, along with my reading of texts and my many attempts at writing ideas through the process, have not resulted in a formulated summary of body image. The concept of reflexivity, addressed below, best explains the process necessary to account for the many voices interacting in a constructivist approach.

**Relationships**

Encouragement to express voice comes through the relationship that the researcher and participant develop. Although the traditional sense of ensuring informed consent, confidentiality and honesty are important for any research, ethical issues for research using interviews with constructivist interpretations must also consider the relationship established with the participants (Olesen, 2005; Tracy, 2010). As its foundation, constructivism relies on relationship between self as researcher and others as researched (Howell, 2013). Oakley (1981) identified many years ago there is little utility and it is morally problematic when the researcher attempts to remain detached when the goal of the research is to understand the position of the participant, a situation that requires exploration of potentially intimate and deeply personal information best explored through a close and honest relationship. Subsequent feminist researchers have variously considered and problematized the relationship between the researcher and participant (DeVault & Gross, 2007; Olesen, 2005; Reinharz & Chase, 2003).

Being ethical is at the heart of research relationships. This means much more than following ethical review process to also include a sensitivity to situations as they arise in the field and a knowing of the self in terms of how you relate and respond to others (Guba & Lincoln, 2005; Tracy, 2010). Although Oakley (1981) promoted a close relationship between researcher and researched, other feminists have suggested that this is unrealistic in all situations (Reinharz & Chase, 2003),
with a more appropriate focus being on establishing rapport. In line with the recommendations of the above authors, the research relationship was carefully considered from the start, although our previous experience meant we were also aware that the actualising of the relationship is not always predictable. Friendship may develop as a natural consequence if there is mutual liking, however entry to the relationship should include clarification of expectations and boundaries (Reinharz & Chase, 2003). We were mindful that particular care should be taken to explain our role, so that it was not confusing for the women, who may have seen it as an opportunity for social contact (Olesen, 2005). Equally problematic might be if they had seen us as a professional coming into their life in a surveillance role (Gilbert, 2004). For this reason he suggests establishing the view that the person has of you when entering the research relationship.

Further considerations include how much self-disclosure is appropriate and the extent to which the researcher should provide answers to participant’s questions or offer advice (Fontana, 2003; Reinharz, 1992; Reinharz & Chase, 2003). Self-disclosure is often used to equalise the relationship, however should be used carefully so as not to take over or influence what the women might feel comfortable sharing. Self-disclosure is part of the reciprocity of relationships, in that ideas are then compared and there is a valuing of what each other brings, however such reciprocity does not always come easily in interviews with people with intellectual disability (Booth & Booth, 1996). For example, there were significant differences between the lives of the women who were interviewed and my own life, therefore it was important that I entered the relationship with the intention of listening in order to gain insight into their lives (Hesse-Biber & Piatelli, 2007) (Reinharz & Chase, 2003). In her earlier work Reinharz (1992) suggests waiting for cues as to whether the woman expects self-disclosure. Interestingly, few of the women demonstrated interest in my own or the other interviewers’ lives outside the research relationship, however some did seek advice. In line with other researchers (Hesse-Biber & Piatelli, 2007; Oakley, 1981; Scott-Hill, 2004) responding to such requests was seen to be appropriate to this research.
Reflexivity

Reflexivity is commonly identified as important to managing the power and contextual differences between the researched and researcher (Hesse-Biber & Piatelli, 2007; Olesen, 2005; Reinharz & Chase, 2003). Thus, there is a connection between ethical considerations of relationship, as outlined above, and concepts of reflexivity. Furthermore, being reflexive included maintaining awareness of the influence that I, as the researcher, had on both the raw data of interviews and then on how that data are represented. From a constructivist perspective, reflexivity also encompasses being cognisant of the context and hegemony within which women share their experience, including consideration of where their ideas come from (Gubrium & Holstein, 2003). As a means of building knowledge, as a constructivist researcher, I needed to recognise multiple realities and through reflexive practice probe deeper to examine social, historical and hegemonic influences to raise questions about current thinking (Guba & Lincoln, 2005) (Hesse-Biber & Piatelli, 2007; Kincheloe, 1997). Howell (2013) refers to such praxis as “the process by which the relationship between reflection and practice or theory and practice can transform society and individuals within it” (p.25).

Although participatory research might mean reflexivity for both the researcher and participants as they co-construct knowledge, in this case, praxis was conducted by myself, supported by my supervisors. Significant for the topic of body image is the difficulty that people with intellectual disability have theorising abstract concepts (Walmsley & Johnson, 2003), which would have made a co-construction more challenging. However, just as I might consider where the women have sourced their ideas, it is equally important to think about the influences on my own thinking (Hardy, et al., 2009; Kincheloe, 1997), particularly those that might not be shared by the women (Olesen, 2005), including an awareness of absence in their life or my own (Scott-Hill, 2004). As the previous chapter showed, there is a range of opinions about body image and women’s attitude to their bodies. Thus self-reflexivity for this research also meant an examination of my own body image, associated practices and the control that I have on such things as my weight, appearance, choices in clothes, make-up and
hair style. The significance of being a nurse, who has been in the privileged position of seeing other bodies at an intimate level, as well as having women friends with whom I share information about body practices, should also not be ignored.

Reflexivity continues through to writing and presenting the results from the research to various audiences (Lincoln, 1997). If the research is to have an impact on the daily lives of women with intellectual disability, it is important to share the results in a number of formats and with those who may stand to benefit, such as the women themselves and the people who support them. Interestingly, following Lincoln (1997), this latter group may also be among those who are challenged by the findings. Whilst the research is presented within the current context for academic purposes, strategies that are more inclusive of a wider audience, or, indeed tailored to a specific audience, have been and continue to be considered for dissemination. For example, each woman received a copy of her “story” at the end of the research and there have been four conference presentations (abstracts in Appendix 2).

From research findings to making meaning

Whilst constructivism forms the dominant approach to this research, there are various influences including critical and standpoint feminist and disability theories. Ultimately the research is aimed at making meaning of the data collected in terms of what they tell me about the women’s body image. As stated above, there are similarities in the end point of constructionism and constructivism (Howell, 2013), however, constructivism allows for a broader understanding, including the idea that bodies might be always changing, moving and capable of transformation in response to both internal and external influences. In her use of Deleuze’s ideas, Coleman (2009) makes the point about the young women and their use of images in her study that it is not about exposing a truth but rather immanence. If bodies are always becoming, then what is exposed is “incomplete and constituted through its relations” (Coleman, 2009, p.71); from which I interpret that the information about their body that the women in the current
research share is relational and tied to the moment in time. Internal and external influences that are likely to have a role in the women’s construction of their body were described in the previous chapter, including the proposal that Lacan’s mirror stage might provide a way to understand their internalisation of an Ideal I. In coming to my construction of their body these perspectives will be intertwined with the data from the interview transcripts and field notes. The next section of the chapter provides a detailed description of the method used to collect and analyse those data.

**Planning the research**

Accepting a constructivist approach and the importance of relationships and power within constructivism (Patton, 2002), as well as in research with people with intellectual disability (Boxall & Ralph, 2009; Munford, Sanders, Mirfin Veitch, & Conder, 2008; Walmsley & Johnson, 2003) led our approach to various stages of the research process. Furthermore, with awareness of the literature regarding emancipatory and participatory research, an important deliberation at the very start of planning was the degree of participation with women with intellectual disability that we would aim to achieve. Weighing up various factors we settled on what might be seen as the minimum if the research was to be meaningful for the women we hoped would benefit (Grant & Ramcharan, 2009; Ramcharan, et al., 2004; Zarb, 1992); that is, having in place an advisory group inclusive of women with intellectual disability.

The research advisory group was ultimately made up of two women with an intellectual disability and a clinical psychologist. Both of the women with intellectual disability had previously advised on research projects and one had a particular interest in mental health services. The psychologist was employed in a dual disability service (intellectual disability and mental health). This group worked with us on the research questions, recruitment strategy and interview guidelines; then, before extending the project to include body image, they were further consulted. At a later date the advisory group met to discuss research findings and dissemination.
In addition to the formation of an advisory group initial planning included consultation with other stakeholders. Such stakeholders included local and national branches of People First New Zealand, a self-advocacy organisation with links to the People First international organisations, Ngāi Tahu, the local iwi or tribal group, intellectual disability and mental health service providers. All stakeholders supported the research. In addition, the national People First group agreed to assist with recruitment as will be discussed below.

Initial planning culminated in the proposal that went to Lotteries Health with the stated aim:

This research has been designed to understand the experiences and events in the lives of women with intellectual disability and will explore the issues or factors that women perceive as promoting or impeding positive mental health and wellbeing. Linked to this aim, the research team will seek women’s views on the factors that contribute to resilience and recovery. From a theoretical perspective a phenomenological approach will be taken in order to understand the lived experiences of women with an intellectual disability. Such an approach enables the complexity of each woman’s life to emerge. Particular emphasis will be placed on an exploration of each woman’s interpretation of the impact of her individual life experiences. (Lotteries Grant application 265091)

From this broad aim I narrowed the focus for my doctoral study by posing the following research question:

How do women with intellectual disability perceive their body?

More specific objectives for the study were to identify:

1. How did the women think and feel about their body.
2. How the women perceived their body size and shape;
3. What the women did to maintain or change their weight;
4. Whether the women were satisfied with their presentation (for example, hair, clothes);
5. What control the women had over their presentation.

As can be seen from the aim, a comprehensive exploration of each participant's life was already planned and it was likely that some of this data would also be relevant to her body image. To strengthen the focus on body image, specific questions were added to the semi-structured interview schedule (Appendix 3 for full interview schedule).

**Ethical approval**

Ethical approval for the mental health study was sought and gained from the New Zealand Multi-regional Health Research Ethics Committee soon after Lottery Health agreed to fund the study (reference: MEC/09/05/054). At the time of the study research with people with disability in New Zealand required ethics review by a Health Research Council approved committee that had jurisdiction in the regional district of the participants. Due to the intention to recruit across a number of districts, the multi-regional committee was appropriate. Once my doctoral study had been approved by the university and accepted by the reference group, I prepared an additional application to seek the ethics committee’s approval for both extra data collection and my use of that information for my study. The expedited process available from the committee was used for the purpose and subsequently approval was granted (Appendix 4). At this point in time recruitment to the study had not started, therefore the information, participant interest and consent forms were able to be adapted and had been included in the expedited request (see Appendices 5, 6 and 7).

As part of the ethical process for the mental health study, protocols had been prepared to address either situations where women disclosed abuse or concerns that the interviewer had regarding the women’s mental health (see Appendices 8 and 9). While a number of the women did share their experience of sexual violence, in all cases it was historical and was known about. None of the women
wanted assistance for coping at the time of the interviews. The protocol for concern regarding mental health was utilised for one woman who was unwell when first interviewed.

**Inviting women to contribute to the study**

With the support of the national People First organisation, local branches and contacts within the South Island of New Zealand were asked to assist with recruitment of women for the study. The decision to access women through the advocacy network was purposeful and reflected our growing interest in ensuring that we promoted citizenship and personal decision-making among people with intellectual disability (Mirfin-Veitch, 2010). A limitation to using People First might be that it relies on the person identifying as having an intellectual disability and thus women who may live with the label of intellectual disability ascribed by others but who do not identify as having such themselves will not choose to participate. However, by going directly to People First meetings the women members received ‘first-hand’ information about the proposed research, rather than relying on the dissemination practices of various support services. This approach was intended to be responsive to the issue of women and people with intellectual disability having historically been denied the opportunity for participation in research (Beazley, Moore, & Benzie, 1997; Booth & Booth, 1996; McDonald & Keys, 2008; Olesen, 2005; Walmsley & Johnson, 2003). In addition, the members of People First use a diverse range of disability services, therefore it was also anticipated that this strategy would help us to reach a wider cross section of women, including those using residential, vocational and independent living services.

Following a request to local coordinators of People First, the research team was invited to attend a meeting at which a slide show was used to provide information in both words and pictures to facilitate the women’s understanding of the research. Two researchers attended the meetings at main centres and either a colleague or myself went to the smaller centres. Written information sheets, also inclusive of both words and pictures, were available for the women to take away
and assist them with further consideration of whether or not they wanted to take part. If the women chose they could complete a participant interest form at the meeting, alternatively they were provided with envelopes if they wanted to do so at a later date. Once completed interest forms were received we contacted the woman to arrange an appointment for the first meeting.

Choosing to recruit through People First did have the outcome of participants who received a range of service support and women who hadn’t previously participated in research. We found that it was necessary to be particularly careful at the arranged meetings to ensure that the women who put themselves forward understood the research process and purpose. Whilst the documented tendency of women with intellectual disability to acquiesce or please (Booth & Booth, 1996; Goodley & Rapley, 2002) might be part of the reason such women volunteered, for some it also seemed plausible that they saw the research as an opportunity for social connection (Olesen, 2005), particularly locally where some of the women had previously met the research team. At such times we carefully negotiated with the person to avoid later disappointment. In effect this strategy meant that we were confident that those participant interest forms that did come forward were from women who seemed likely be able to engage in an interview at the least. As was found later in the research process, although some women demonstrated satisfactory understanding of the research process, they actually had difficulty with comprehensive verbal responses when it came to the interviews. This issue has also been found and documented by others (Booth & Booth, 1996; Goodley, 1996).

The women’s agreement to take part

Following previous experience with consent procedures (Munford, Sanders, Mirfin-Veitch, et al., 2008; Munford, Sanders, Mirfin-Veitch, & Conder, 2008) we planned each of the steps in the consent process carefully. As noted above, information sheets and consent forms were reviewed and approved firstly by the advisory group and secondly by the ethics committee ensuring that the potential participants would understand them. The information meetings had further
supported understanding and provided an opportunity for women to ask questions and hear the questions of others without any pressure to sign up to the next step of the process. The women could choose to go away from the meetings and talk with others whilst they thought about whether or not they wanted to participate and send in their interest form. Finally, consent was approached as an ongoing process, so that at each step of the research the woman was asked again if she was happy to take part and the third interview provided an opportunity to change and remove or agree to her data being included in analysis.

Written consent was obtained prior to the first interview. The first appointment with the woman began with introductions and description of the research, questions were encouraged and the woman was asked to tell us what she understood about the research. Being able to relay back the main purpose of the research was deemed a reasonable indication that we could go ahead with the woman signing the consent form. A copy of the form was provided for the woman and was referred back to along with the information sheet at subsequent interviews as part of the process of ensuring ongoing consent.

The women participants

Twenty-seven women expressed interest in the project and twenty-five were subsequently interviewed. Of the two women who did not proceed to interview, a parent expressed doubt about her daughter taking part at that time and a decision was made within the context of the time frame for data collection not to pursue her involvement later. The second woman provided no explanation but was not available for interview once the research began. One of the twenty-five women chose not to be interviewed on the third occasion, instead reading through her story with her support person allowing for inclusion of her data in the analysis.

Intellectual disability was self-identified and, as their stories unfolded, confirmed by either the woman’s attendance in special education when they were younger or more recent testing for IQ and functional assessment. As noted all were capable of conversation and some level of independence. Table One presents the
women by pseudonym, age, ethnicity and living situation at the start of the research. Ethnicity is identified using the standard statistical approach in New Zealand, which includes the opportunity to identify more than one. Pākehā is an indigenous term that loosely translates to mean New Zealand European (NZE). Māori are indigenous New Zealanders and people from any of the smaller islands of the Pacific are generically referred to as Pacific Islander as small numbers could make the person identifiable if their specific island group was identified. Six women identified a history of mental illness or autism spectrum disorder. The implications of these conditions for their body image will become evident in the following chapters, however I have chosen not to identify those with mental illness in Table One due to the risk to their anonymity.

Table 1

Participants by age, ethnicity and living situation

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Living situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amelia</td>
<td>29</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Barbara</td>
<td>47</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Carla</td>
<td>40</td>
<td>NZE/Pacific Island</td>
<td>Independent</td>
</tr>
<tr>
<td>Diana</td>
<td>47</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Eva</td>
<td>34</td>
<td>NZE</td>
<td>Residential</td>
</tr>
<tr>
<td>Francisca</td>
<td>43</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Georgia</td>
<td>21</td>
<td>Maori/NZE</td>
<td>With family</td>
</tr>
<tr>
<td>Hesta</td>
<td>46</td>
<td>NZE</td>
<td>With family</td>
</tr>
<tr>
<td>Ilona</td>
<td>56</td>
<td>NZE</td>
<td>Independent</td>
</tr>
<tr>
<td>Julia</td>
<td>32</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Kura</td>
<td>51</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Lynda</td>
<td>25</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Marika</td>
<td>54</td>
<td>NZE</td>
<td>Independent</td>
</tr>
<tr>
<td>Nadia</td>
<td>41</td>
<td>NZE</td>
<td>Independent</td>
</tr>
<tr>
<td>Ophelia</td>
<td>37</td>
<td>Maori</td>
<td>Independent</td>
</tr>
<tr>
<td>Patricia</td>
<td>49</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Quiana</td>
<td>33</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Rosa</td>
<td>51</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Sylvia</td>
<td>65</td>
<td>NZE</td>
<td>Independent</td>
</tr>
<tr>
<td>Tanya</td>
<td>29</td>
<td>NZE</td>
<td>Independent</td>
</tr>
<tr>
<td>Ursula</td>
<td>60</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Vera</td>
<td>46</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Wilma</td>
<td>22</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
<tr>
<td>Xena</td>
<td>44</td>
<td>NZE</td>
<td>Independent</td>
</tr>
<tr>
<td>Yolanda</td>
<td>34</td>
<td>NZE</td>
<td>Supervised flat</td>
</tr>
</tbody>
</table>

Notes (continue on next page). Ethnicity NZE – New Zealand European or Pākehā; Māori – Indigenous people of New Zealand; Pacific Island – coming from one of the islands of the Pacific.
All women received some level of support. Within living situation categories a supervised flat indicates that there is a support person either sleeping at the property, or present for most of the waking hours that the women would be at home; residential indicates a larger facility with a number of people with or without an intellectual disability that require medical care; independent means that the person is flatting either by themselves or with one or two other people and has a few hours of support weekly; two women lived with their parent/s.

Talking with the women

The majority of data for this research was collected through interviews with the 25 women participants. The women were interviewed in their own home or at a day service, depending on their choice or arrangements that could be made with their service. In terms of its impact on the women’s choice of site for interviews, it was concerning that services often made last minute changes to where we were able to interview the women. Most women had chosen to be interviewed at their home, however, there seemed to be reluctance for services to facilitate them to be at home during the day.

As discussed in previous chapters, my approach to interviewing has been strongly influenced by feminist perspectives (DeVault & Gross, 2007; Oakley, 1981; Olesen, 2005; Reinharz & Chase, 2003) in which the fundamental importance of relationship between the interviewer and interviewee remains a key consideration. In developing a relationship with the participants there were a number of issues that needed to be thought through. Firstly I had to think about how I positioned myself with the women, for whilst Oakley (Oakley, 1981) and others (Reinharz & Chase, 2003) suggest that friendships may develop from research relationships, this is not necessarily the case. Following the advice of both Olesen (2005) and Gilbert (2004) I was careful to explain the research process, including the number of visits the women could expect, while also listening for their expectations from the relationship. In the event, although it seemed that some enjoyed the contact for the social reasons, all the women that I interviewed recognised the limited nature of the relationship. Some of the local women were already known to one or other member of the research team and do have occasional contact. The process of the three interviews with the final point of
returning their ‘story’ to the women was intended as a thank-you but also provided an indication of closure of the research relationship.

Self-disclosure on the part of the researcher was a second point to consider (Fontana, 2003; Reinharz, 1992; Reinharz & Chase, 2003), whilst often seen as a way to build relationship, in talking about body image there was always going to be the risk that I offered my own ideas rather than waiting to hear from the women. Writing about psychotherapy, Larner (1999) discusses the need for the therapist to be aware of, and open to, difference. Similarly, with this research it was important to be mindful that the women’s lives were very different to those of the researchers’. Although many of the women struggled to provide answers, I kept an enquiring approach in favour of making assumptions, attempting to remain open to hearing their experience and perceptions of their body image. Where self-disclosure was useful it was in the more general sense of telling the women a little about myself (which the other interviewers also did) to encourage initial rapport. We were more selective with self-disclosure in relation to body image, in part because of the risk of acquiescence; however, it was occasionally useful.

A further consideration of self-disclosure relates to the women interviewed as, within a comfortable relationship, there is the concern that the woman may share information that could expose her identity (Fontana, 2003). Most of the women were novice research participants and, although interviews are commonly understood in our society (Gubrium & Holstein, 2003), this meant that it was difficult to anticipate how the women would see their relationship with us and thus what they would consider appropriate to share. Confidentiality was crucial both at the time of the interviews and later in writing up. Hence pseudonyms have been chosen for each woman and the town in which they live is not identified in the results. Where there seemed any risk to the woman being identified minor details may have been changed, and/or the pseudonym is not provided because it is the linking back through a number of interview excerpts and other data that would make the woman identifiable.
The interviews with the women were guided by the semi-structured schedule that used an ontological narrative approach (Somers, 1994; Thomas, 2006). An ontological narrative approach draws out the personal story as it fits within the social context. Somers (1994, p. 618) argues that this is the way “we define who we are” and that it is the process by which we change our identity over time. To understand the women’s body image therefore requires an understanding of how she situates herself within the social context. Initial questions assisted us to build a picture of the woman’s life to date, with subsequent questions narrowing to the fields of interest, that is, their mental health and body image. With the woman’s permission the interviews were recorded and subsequently transcribed by a professional transcriber. One woman (Sylvia) preferred the researcher to take comprehensive written notes and her interviews were not recorded.

The first interview, which immediately followed the written consent process, was aimed at finding out about the woman’s history, current living arrangements and interests. Such questions might be considered low threat and thus contribute to development of the research relationship (Reinharz, 1992); as well, our intention was that it would help the woman to become familiar with being recorded. Whilst successful with the former, some of the women remained very conscious of the recorder; at times this was affecting what they told us “on record” as opposed to either before or after the interview. Field notes assisted us to capture some of these points. The second interview, which was usually the next day, focused on more difficult questions, including those related to their body image. The rationale for the interviews being on consecutive days was both process and procedural. Firstly and most importantly, it was believed that would assist the relationship and provide an opportunity for the woman to think about the topics and be ready with more detail at the second interview. Secondly and from a practical perspective, we were usually travelling to do the interviews and it was cost effective in terms of time and money. Such considerations are important in a country with a small population base from which to draw participants and where travel is therefore a necessity. In this study it was also purposeful in consideration of rural and urban differences in service provision.
Whilst one hour was allocated for each interview, the actual time differed depending on the needs of the woman and the amount of information she chose to share, could articulate, or was able to remember. Variations in time is not unusual with qualitative interviews (Reinharz, 1992), in part this can be due to individual women choosing what and how much they want to share (Briggs, 2003) but more significantly for this research it was often about the woman's language and memory. Cognitive theory suggest that for people who have difficulty with language it is likely they might also have difficulty with autobiographical memory (Harter, 2012). White (1995) discusses the importance of “landscapes of action” (p. 31) to enable storytelling. By this he means that the person needs to be able to recount events, order and timing to tell their story and these were elements that some women struggled to relate. Similar findings are not uncommon in intellectual disability research, with Booth and Booth (1996) identifying concerns some years ago. Based on both other literature and our own experience (Conder, et al., 2007) these difficulties were not surprising.

Strategies that we tried to enhance the women’s memory included suggesting that they brought photographs to the interview. This strategy had limited success, as many of the women were not able to produce photographs, providing a reminder of our different worlds. Another way to encourage responses was to offer a range of options or use the other information that we had available to ask a more direct question. Such information was often based on our observations of the women’s environment, particularly photographs or objects that might have a special meaning for them. We could also draw on the information that they had provided on their interest forms or our knowledge of the service that supported them. Whilst these strategies are often considered leading (Booth & Booth, 1996) and in some cases did generate an agreeable response that would support that opinion, in other cases it provided the women with clear options and they did not agree with the suggestion offered, supporting Goodley and Rapley’s (2002) thesis that acquiescence is not inevitable when interviewing people with intellectual disability. In writing the results of the study care has been taken to identify when data came from such interactions (Howell, 2013). Finally, at times we sought the women's permission to get clarification from another person, usually their
nominated support person. This choice was limited to details such as dates and medications.

Prior to the third interview the transcripts from the first two interviews were used to write a narrative account of the information that the woman had shared. It was anticipated that formulating the information in such a way would assist the women’s understanding of what they were consenting to have included in the analysis phase. The third interview was used to review their “story”, checking details and gaining their consent with regard to those data, some of the identified strengths of multiple interview techniques (Reinharz, 1992). The third interviews were not recorded unless the woman had made a major change in her life, such as moving home. Once corrections were made after the interview the woman could choose to have a copy of her ‘story’.

**Use of the Contour Drawing Rating Scale**

As outlined in Chapter Two, a number of scales have been developed to test women’s perceptions of their size and satisfaction with their weight over the past decades. With due consideration the relatively straightforward and clearly drawn Contour Drawing Rating Scale (CDRS) (Thompson & Gray, 1995) was selected for use with the women. The CDRS has a reported test-retest reliability of .78 and concurrent validity variously reported as .59-.71 and .72-.76 (Gardner & Brown, 2010), making it adequate for the current purpose. My intention with this scale was to gain an impression of how the woman perceived her size, her satisfaction with her size and, from a practical perspective, to provide a tangible way of shifting the conversation to the topic of body image.

Perception of size is generally assessed against BMI, providing a test of concurrent validity, however this was not attempted in the current research. We discussed with the advisory group whether or not to weigh and measure height of the women with the decision being not to do so. It was considered that the women might find the measuring uncomfortable or invasive, affecting the relationship and interview. It was likely, and, indeed, turned out to be the case, that not all women
would be able to stand on scales, either owing to their physical disability or their balance. The option to get BMI by asking the women for their height and weight (Forbes et al., 2005) was suggested, however the advisory group thought it unlikely that many of the women would be able to provide this information and where the research relationship suggested it might be appropriate to ask the woman this advice was found to be correct. On the balance of these factors, plus we would need to purchase a stadiometer and scales and attend to their calibration if we were to take accurate measures, and the purpose of the CDRS was to provide a talking point rather than a source of generalizable data, we ultimately chose to simply comment on the scale sheet whether or not we perceived the woman to be estimating her size reasonably accurately. I acknowledge that there is a danger in that this might be seen to privilege our perceptions over those of the women (Stanley & Wise, 1983).

The CDRS was usually shown to the women during the second interview before asking questions about body image; however, discretion was used depending on the way interviews progressed. The procedure for using the CDRS was to ask the woman firstly which figure on the scale she thought would represent her body size and, once she had selected, which she would like to be. Language was adapted according to the woman’s understanding and, particularly when the women chose figures that didn’t appear to make sense, she was asked why she chose that figure and/or her understanding of the scale and what the various sizes represented. The women’s selections were recorded on a single page. Results of the CDRS are presented and discussed within the subtheme “trim and whole” (see Chapter Four, including Table 3 on p. x).

**Field Notes**

Field notes are useful to aid memory and as another means of understanding the interview transcripts when read and analysed at a later date (Schwalbe & Wolkomir, 2003). They contribute to a research diary, which Altrichter and Holly (2005) suggest might also include other items that relate to the research, such as photos and thoughts about method both reflecting on the past and considering the
future steps. Following the advice of Altrichter and Holly, a research diary incorporating field notes was kept and proved valuable in analysis. Immediately after the interview our observations were documented, including the way that the woman greeted us, her comfort with the interview and any particular detail that might be relevant to later analysis. For example, on one occasion the air temperature was rising to a degree that the woman was finding it increasingly uncomfortable and it was important to note that appeared to influence her ability to focus. Indeed, the interview was stopped for that reason. Another observation we shared was the variance in whether or not the woman adopted the social practice of offering refreshments, which Schwalbe and Wolkomir (2003) suggest might be signifying, and in the case of our interviews, perhaps indicating the adoption of the social role of host.

Data analysis

To understand how the women constructed their body image an inductive approach was taken to analysing the interview and other data. The benefit of this approach was that it provided a way to identify the women’s perceptions of their body and the influences that were affecting their body image and body practices as discrete elements that could then be further analysed for a deeper understanding of their overall construction. Accepting of broadly qualitative approaches, constructivism does not dictate specific methods for analysis, thus, consistent with the wider research the inductive approach variously described by Thomas (2006) and Braun and Clarke (2006) was utilised. Thomas provides some detail for drawing out themes and writing the results, suggesting that inductive analysis allows the researcher to isolate the main themes from the data and provide a meaningful summary responding to, but not limited by, the objectives of the study. It is important to remember that Thomas’s purpose in describing inductive analysis is to provide an acceptable strategy for evaluation research. Braun and Clarke’s (2006) description of thematic analysis follows inductive reasoning, similarly to Thomas (2006). However, they have suggested a framework for thematic analysis that provides more structure and is particularly suited to demonstrating the rigour of that analysis. As a broad approach thematic analysis...
does not suggest any particular lens for viewing data, although it is accepted that the researcher is active in the analysis (Braun & Clarke, 2006). With the topic being women’s body image, including that these women are identified as having an intellectual disability, it was almost inevitable that the data would be seen from a critical perspective drawing both on feminist and disability theory. There were a number of steps in the analysis of both the mental health (data corpus) and body image data (data set), and where the former is relevant to the analysis of the latter it is included in this section. The CDRS results are reported as raw data with descriptive statistics.

Following the first two interviews with each woman we wrote the ‘stories’ that would be taken to the third interview with the woman. Writing the women’s stories provided a discreet method as I read and reread the transcribed interviews to identify main points and generate a cohesive account of their mental health and wellbeing, including body image, against the background of other experiences within their life (Goodley, 2001). Although the stories remained recognisable to the women, in the process of writing it is acknowledged that we inevitably influenced them by choosing key points, relevant headings and related content (Harrison, Johnson, Hiller, & Strong, 2001). The main purpose of this exercise was to make the transcript information palatable to the women, as opposed to sending them raw transcripts that can be difficult to follow. For thematic analysis the stories were not used apart from after the third interview where they informed any changes made to the original transcript. Working with the data at this point did, however, give us a good sense of it and can be likened to early steps of the inductive process of familiarising oneself with transcripts (Braun & Clarke, 2006).

The research team followed Thomas’s (2006) guidelines to code the transcripts in relation to the aims of the mental health component of the study, that is, without apriori expectations an initial level of coding was applied to the transcripts of each participant by the person that had conducted the interview, with a selection of transcripts also coded by all three members of the team. From this initial step codes were agreed at a meeting and then I coded all transcripts with a second member of the team checking a selection for accuracy. This aspect of
analysis is mentioned because it provided me with a good overview of all interviews and ultimately influenced the analysis and development of themes related to body image.

Concurrent with the coding and analysis of the mental health data I began analysis of the body image data. Initially guided by the sections that contained their answers to the body image questions I summarised each woman’s transcript providing insight into the depth of their response. At that time the information that had been captured on the audiotapes where the women were choosing from the body scale drawings was also marked and recorded in writing. The scale drawings were then examined for the women’s choice of ideal shapes and comparisons between current and ideal shapes made. To aid interpretation of the responses to the scale all available data were utilised, this included interview recordings and transcriptions and field notes of the interviewer. Analysis at this point was a combination of simple recording of results alongside inductive analysis from the data. The results from the scale drawings provided a beginning understanding of the women’s perceptions of their body, including the role of body image within issues such as weight control and hence informed the next step of analysis.

Working with all the data specific to body image led to my first attempt to define categories/themes which, at that stage, became identified as “body image and weight” and “body image, hygiene and ornamentation”, both of which can be seen to be influenced by the nature of the questions that were asked, in line with what Thomas (2006) refers to as “upper-level or more general categories” (p.241). However, as I was also working with the full transcripts, it soon became apparent that analysis of these in totality would have much more to offer in terms of coming to understand the women’s perception of their body. To that end I developed a set of questions with which to examine each transcript. These questions were:

Does the woman provide a coherent picture of her body image?
If yes, what can be concluded about how the woman sees her body (broadened to include self-concept because of the relationship between the two)?
What life events appear to have had an impact on the woman’s body image (this may include women for whom there isn’t a coherent picture)?

Does the woman indicate any control over issues that might affect her body and hence how she sees herself (this may include women for whom there isn’t a coherent picture)?

Is there anything relevant to body image that I am missing?

Reading through the transcripts with these questions in mind meant that I could identify more detailed interviews for initial analysis and coding. By this stage I was aware that some of the women had not provided a coherent picture of their body image and realised that those transcripts would provide an additional challenge. However, all women had provided some information that was related to their body image. For some women, such as Barbara, body image and the broader self-concept were clearly tied together. At the end of this exercise I had summarised all data in relation to the above questions.

Beginning with the more detailed transcripts I began coding throughout each interview for content that related to body image interpreted as widely as possible. Coding was done by hand directly onto the word documents by highlighting and then naming the section. Although familiar with electronic coding tools, which Thomas (2006) suggests might be helpful if there is a large quantity of text, I felt that the limited depth in the interview data did not necessitate use of one of these and that the basic computer software would meet my needs. I don’t regret this decision. A distinct advantage of using this approach is that the coded data are still embedded within the interview to easily track back to context but it can also be cut and pasted into a separate document so that you can pull the extracts related to one code together, much as an electronic tool would do. Using Braun and Clarke’s (2006) framework this step is identified as “Phase 2: generating initial codes” (p.89). The process is illustrated on the next page in Table Two. At the end of this
phase there were 36 identified codes. This step would be most closely aligned with Thomas (2006) identifying lower-level codes.

Table 2
Illustration of Phase 2: generating initial codes

<table>
<thead>
<tr>
<th>Data Extract</th>
<th>Coded for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yeah, I wear makeup. Especially when I’m going to work I put some makeup on. Cos my mother always says: oh you look pale. ... cos we never wear lipstick we always wear that lip balm/lip gloss. My sister's the same. She said: you people look pale without lipstick. But we like the lip gloss. WM10 int 2 5/11</td>
<td>Use of make-up</td>
</tr>
<tr>
<td>INTERVIEWER: .. Do you look at yourself in the mirror? RESPONDENT: Yeah, I do at times, like especially if I’m going out anywhere and I’m dressing up for anything in particular. I mean, yeah, I don't always do it but only when I’m sort of going out and I’m trying to make myself look nice and tidy to go out to people’s places and that, so I know I look presentable to go out to each other's place and that. WM 17 Int 2 13/22</td>
<td>Mirror use</td>
</tr>
<tr>
<td></td>
<td>Meeting social expectations</td>
</tr>
<tr>
<td></td>
<td>Self-expectations</td>
</tr>
</tbody>
</table>

In phase three, Braun and Clarke (2006) suggest that the goal is to pull together the codes into themes. It is usual at this stage to have more themes than are ultimately presented in phase five as the final themes, and that was indeed the case with this research (see appendix 10, which also illustrates overlapping codes as Thomas (2006) notes is acceptable to qualitative coding). At the end of phase three the working themes were: functional body; body related to cognitive ability; body related to mental health; body beautiful; body as a representation of family and belonging; the sexual or gendered body. Further analysis (phase four) both by revisiting the original data as coded, and as a whole, meant that some of these themes were collapsed together and some of the data were recoded into another theme. An example of the latter was the body as representation of family and belonging, which could be seen in data that collated into the two subthemes within “Beauty and the body” as well as the theme “Physically functioning body” as it was the family influence that affected how they saw or acted on their body within these themes. Both cognitive ability and mental health coding were mostly subsumed into the “Physically functioning body”, although mental health in particular was also implicated in beauty practices. Throughout the process constant referral back to the original interviews looking for both fit and difference was important, as it is
for any qualitative analysis (Silverman, 2011), but also because I was particularly aware of the limited and, at times, disjointed answers from the participants.

The final phases of “defining and naming themes” (p.92) and “writing the report” (p.93) that Braun and Clarke (2006) identify are evident in the results section of this document. Within each of the next four chapters the theme or subtheme will be described and presented along with excerpts from the transcripts that support the theme. Chapters Four and Five relate to the first theme of “Beauty and the Body” with this theme divided into two subthemes “Trim and whole” (Chapter Four), which also incorporates the descriptive statistical data from the CDRS, and “Tidy, clean and conservative” (Chapter Five). Chapter Six introduces the theme “A fit and functional body” and Chapter Seven “A gendered body”. Each of the themes can be viewed as partial constructions of the women’s body image and it is in Chapter Eight that these partial constructions are drawn together and interpreted through a critical lens to arrive at an understanding of their integrated construction.

An additional element of reporting was the sharing of findings with the women involved in the study in a format that had the best prospect of being accessible to them (Walmsley, 2001). To that end a summary of findings of the full research at the level of thematic analysis and in plain language was sent to each woman. The more theoretical analysis related to body image has not been shared with the women. As noted by Aspis (1999) sharing theory imbued with jargon with women with intellectual disability is not easily managed and the current study had the additional challenge of the women being spread throughout the South Island of New Zealand meaning that the repeated visits which would be necessary for such work made it impractical. Dissemination of the research findings has included presentations at conferences. Publications are planned and will include academic journals, professional magazines and newsletters with the intention being that it is as wide as possible to reach the many different people who may influence the body image of women with intellectual disability.
Summary

This doctoral study is positioned to understand how women with intellectual disability perceive their body, thus a constructivist approach is appropriate. In choosing that approach, I bring a critical lens informed by both feminist and disability standpoints. Both of these standpoints emphasise the importance of voice, relationship and reflexivity and these have influenced various steps in the method used for the research. Although there are additional challenges when participants have an intellectual impairment, there are ways to address these challenges and provide an opportunity for research participation that ensures their perspective is heard. The current research recognised these challenges through a carefully planned recruitment strategy and an ongoing consent process. Additionally, providing the women with their story in a format that made their data meaningful to them assisted their understanding. As the following chapters will indicate, rich data were not available from all interviews; however each woman’s contribution was valued for what it offered to the themes. Invaluable to reaching the end point of thematic analysis was the repeated reading of transcripts, including for body image specific content and for the wider study on mental health as both ultimately had relevance for how the women saw their body.

Within the next four chapters the women’s construction of their body is viewed from different perspectives, namely “Beauty and the body”, “A fit and functional body” and “A gendered body”. Of course bodies are not “bits” and it is important to remember when reading these chapters that they each only provide a perspective on the whole that is the women’s body image. That whole will be drawn together in the discussion (Chapter Eight), which follows.
Chapter Four: Beauty and the body: “trim and whole”

Introduction

Body size, shape and the relative importance of various features of women’s bodies have fascinated both Western media and research for over a century (Grogan, 2008; Sentilles & Callahan, 2012). As suggested in Chapter Two, prior to the twentieth century, women were more likely to hold an internalised view of self, associating beauty with disposition rather than, what was then considered the more vain, external representation of their body (Sentilles & Callahan, 2012). Throughout the twentieth century, however, there is evidence that women increasingly moved their identity to align with their external body, strongly influenced by media and the consumer culture (Black, 2004; Grogan, 2008; Sentilles & Callahan, 2012) (Harter, 2012). Such moves have implicated both attempts to meet or maintain the ideal body shape and an increased focus on the products available to enhance the body, including cosmetics and clothing. With these points in mind the interview schedule included questions aimed to draw out the women’s perceptions of their physical bodies and the beauty practices they performed (see appendix 3 for interview schedule). The theme “Beauty and the body” emerged through the responses that the women provided to these questions, and has been divided into two subthemes for the purpose of reporting. This chapter focuses on the subtheme of “Trim and whole”, illustrating that the women’s construction of their body image was influenced by their perception of their body size and conception of their body as a ‘whole’.

As my initial interest in the topic of body image began with consideration of anorexia nervosa and overweight in women with intellectual disability, exploration of what the women thought about their body size and shape, and whether there were particular aspects that they liked or disliked, provided a logical entry to the interview questions about body image. Aside from beauty ideals, body size has also been a major focus of health research as the effects of
both anorexia nervosa and obesity became implicated in physical and mental health outcomes. In presenting contemporary perspectives on body image in a special issue of the *Journal of Health Psychology*, Grogan (2006) notes that body image can have a direct effect on health behaviours, including under and over eating, smoking and whether or not we engage in exercise. Within New Zealand health messages suggesting the danger of obesity to future health outcomes are reinforced in various documents, even when the focus is on the benefits of exercise (SPARC, 2005), with monitoring of the prevalence of overweight and obesity a feature of the regular Health Surveys (Ministry of Health, 2012a). Chrisler (2012) suggests that the focus on physical health and obesity that has become dominant in communities where food is plentiful plays into the commonly perceived social role for women as nurturer and may influence dissatisfaction when overweight, as that suggests lack of concern for both own health and that of dependents. With these points in mind the CDRS tool was presented to the women to ascertain their perception of, and satisfaction with, their body size. Use of the tool was followed by questions about their overall satisfaction with their body, including body features they particularly liked or disliked. Whilst there are multiple influences on standards for an ideal physical body, eating patterns are commonly implicated in health messages associated with overweight or obesity (Chrisler, 2012) and led to the inclusion of questions about the women’s food shopping and eating patterns. In a study of Special Olympians (all of whom had intellectual disability) Malinauskas et al. (2007) found that food intake assessed through a questionnaire did not have an impact on body weight and indicated the need to consider energy balance in addition to the control that people have over their food choices. Thematic analysis resulted in drawing together data elicited through these questions to understand how the women constructed their physical presentation. In presenting the results of this subtheme body size, as represented by a ‘trim’ body, has been separated from features. As will become evident later in the chapter, the women tended to view their body as a whole, rather than a collection of features that they either liked or disliked. The numbers that follow the quotes used within this and the subsequent chapters relate to the interview number and page number of the transcribed interview.
A ‘trim’ body

The majority of the women interviewed shared a desire to meet the social standards for a trim body, with most of those who considered themselves overweight expressing dissatisfaction with body size commonly found in other research with women. As discussed in Chapter Two, two previous studies with people with intellectual disability have confirmed such dissatisfaction (McCarthy, 1999; Napolitano, et al., 2012) amongst their participants. In addition, age appears to be no barrier to the desire to meet social standards, as Chrisler (2007) argues in her review of literature related to weight and body dissatisfaction amongst middle age and older women, a point reiterated more recently by Grogan (2012). The compelling influence of media on changing social standards, illustrated in Becker’s (2004) study of young women in Fiji, serves to remind us of the influence social standards can have on body size dissatisfaction. For the women in the doctoral study the desire to have a body that met social standards was initially expressed through their choices on the CDRS, but elaborated upon as the interview progressed. Twenty-four women responded to the CDRS, with one woman declining to make a choice on the scale, however she was happy to discuss her body image, including her weight, with her interviewer. Women were asked to choose from among the nine drawings on the CDRS both their current shape and their desired shape (see Appendix 1). The woman’s choice on the scale provided one interpretation of their satisfaction with their body size. To gain a deeper understanding, the interview audio and/or transcript of the participant making their choice and, any comments that the researcher made on the scale at the time of the interview, were considered. For ease of reporting the nine figures on the scale are numbered 1-9 starting from the left hand side. Table Three provides detail of the women’s responses.
Table 3

Current and preferred size on Contour Drawing Rating Scale

<table>
<thead>
<tr>
<th>Participant</th>
<th>Current size</th>
<th>Preferred size</th>
<th>Difference between current and preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amelia</td>
<td>8</td>
<td>4</td>
<td>-4</td>
</tr>
<tr>
<td>Barbara</td>
<td>1</td>
<td>2</td>
<td>+1</td>
</tr>
<tr>
<td>Carla</td>
<td>9</td>
<td>5</td>
<td>-3</td>
</tr>
<tr>
<td>Diana</td>
<td>6</td>
<td>4</td>
<td>-2</td>
</tr>
<tr>
<td>Eva</td>
<td>7</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Francisca</td>
<td>1</td>
<td>5</td>
<td>+4</td>
</tr>
<tr>
<td>Georgia</td>
<td>7</td>
<td>4</td>
<td>-3</td>
</tr>
<tr>
<td>Hesta</td>
<td>7</td>
<td>4</td>
<td>-3</td>
</tr>
<tr>
<td>Ilona</td>
<td>7</td>
<td>5</td>
<td>-2</td>
</tr>
<tr>
<td>Julia</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Kura</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Lynda</td>
<td>5</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Marika</td>
<td>5</td>
<td>3</td>
<td>-2</td>
</tr>
<tr>
<td>Nadia</td>
<td>7</td>
<td>6</td>
<td>-1</td>
</tr>
<tr>
<td>Ophelia</td>
<td>3</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Patricia</td>
<td>5</td>
<td>4</td>
<td>-1</td>
</tr>
<tr>
<td>Quiana</td>
<td>2</td>
<td>1</td>
<td>-1</td>
</tr>
<tr>
<td>Rosa</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Sylvia</td>
<td>7</td>
<td>4</td>
<td>-3</td>
</tr>
<tr>
<td>Tanya</td>
<td>5</td>
<td>1</td>
<td>-4</td>
</tr>
<tr>
<td>Ursula</td>
<td>8</td>
<td>6</td>
<td>-2</td>
</tr>
<tr>
<td>Vera</td>
<td>8</td>
<td>3</td>
<td>-5</td>
</tr>
<tr>
<td>Wilma</td>
<td>4</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Xena</td>
<td>7</td>
<td>1</td>
<td>-6</td>
</tr>
<tr>
<td>Yolanda</td>
<td>declined</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Mean current size 5.16. Mean preferred size 3.5

In interpreting the table and the women’s response, it is important to remember findings outlined in Chapter Two that suggested that women in the general population have a tendency to either under- or, more commonly, overestimate their current size (Bulik, et al., 2001; Calogero & Thompson, 2010; Parker & Keim, 2004; Sanchez-Villegas, et al., 2001). Of the 24 respondents it was clear that some did not understand either the discrete differences of the drawings on the scale or the task as presented to them. Where there was any doubt about understanding, the researcher spent time explaining the figures and what they represented in terms of body size to the woman. However, Barbara, Francisca, Julia
and Rosa chose figure 1 to represent their current shape, with Quiana choosing figure 2. For none of these women did the researcher, or transcripts, suggest that their choice was accurate and, although objective measures were not taken, it is clear that these women were not extremely thin as would be suggested by the figure that they chose. As Chrisler (2007) has noted, quantitative approaches have limitations. The women’s qualitative interviews provided the opportunity to gain a more accurate impression of their satisfaction with their body size and factors that may be influencing their thinking. These results are presented within this chapter, whilst the limitations of the CDRS will be discussed in Chapter Eight.

I don’t want to look fat

Although the common media image of the ideal body tends to extreme thinness, as identified in Chapter Two, there is research that suggests that women will be satisfied with various sizes, with cultural differences, age, socio-economic status and current body size all considered to be influencing the women’s viewpoint (Anderson, et al., 1997; Becker, 2004; Harris, et al., 2008; Parker & Keim, 2004; Swami, et al., 2010; Thomas, et al., 2008). Furthermore, the degree to which they have internalised the ideal body size has been considered to be an important consideration in at least two studies (Cattarin, et al., 2000; Coleman, 2009). In addition, the ideal may be more closely aligned with an image to which they attach meaning, for example a family member or peer, while many women simply identify that they want to look like themselves (Grogan, 2008). Values that they have internalised from their social context will be relevant; however, both Butler (1990) and Grosz (1994) argue that it is much more complex than constructionist standpoints suggest. In calling for a move from the dichotomous position that constructs woman as ‘other’ through gender relations, in their separate ways they call for recognition of the dynamic embodied person who might have multiple influences including other bodily experiences influencing their body image. Evidence of such variation can be seen through interviews regardless of whether the woman was satisfied or not. For example, Barbara was slim, and whilst she chose the extremely thin figure, she provided the following reason:
Barbara: Yeah. I don’t want to look like those.
Interviewer A: Why not?
Barbara: Cos I don’t want to look like that.
Interviewer A: What is it about those ones that you don’t like?
Barbara: I don’t want to look fat.
Interviewer A: Do you think they look fat?
Barbara: Yes.
Interviewer A: And what do you think these ones look like down here where you’ve chosen them?
Barbara: Thin.
Interviewer A: Thin, and you’re quite thin.
Barbara: Yeah, and I want to stay like that.
Interviewer A: Right, okay. You don’t think they’re too thin?
Barbara: No.
Interviewer A: Well you said you’d like to be that wee bit bigger didn’t you?
Barbara: Yeah, a wee bit bigger.

Despite not being able to accurately identify her current size, Barbara clearly related her reasoning to the social attitudes towards fatness expressed by Orbach (1978) and more recently Bordo (2003). Kura, also drew on a perception of fatness as undesirable, telling the interviewer:

Interviewer A: So what do you like about it the most? If you’re looking in the mirror what do you like most about your body?
Kura: A trim body.
Interviewer A: You’ve got a trim body.
Kura: Not fat.
Interviewer A: Yep. Okay, what do you not like about your body? Is there anything about your body you don’t like?
Kura: No.
Fatness was something to be avoided for those who were trim, while those who were overweight identified it as a cause of their dissatisfaction. Yolanda, when asked if she was happy with her weight, described herself as “... real fat ...” and “… an ugly girl ...”. (2/7) Georgia commenting on what she liked about her body “… Not much” with “My weight” what she disliked and “... I am too fat ...” the response to why she felt miserable if she looked in a mirror. Hesta “I just like being thin. I don’t like being too fat.” (2/1).

Whilst a number of the women used the word “fat” to describe an undesirable state, in most interviews the origin of attitudes to fatness was not immediately obvious. However, Tanya explained her choice ...

Interviewer C: Most like her. So why would you like that one?
Tanya: Cos she’s skinny.
Interviewer C: Okay and what do you think is good about skinny?
Tanya: [audio unclear] down here all a lot skinnier. [points to the figure on the scale]
Interviewer C: Right. Like this one...so you think skinny looks better because you don't have the weight down your side and your back - is that what you're thinking?
Tanya: Yeah.
2/17

By using the figures, Tanya was able to illustrate what she saw as desirable about the thinnest figure. Interestingly, she would seem to be identifying the features seen in many of the models used to promote fashion in magazines. Whilst this would be a typical response among young women, as various studies have shown (Becker, 2004; Cattarin, et al., 2000; Coleman, 2009; Prichard & Tiggemann, 2012a; Snapp, et al., 2012; Strahan, Wilson, Cressman, & Buote, 2006), Tanya was the only woman in the current study to make such an overt comparison. In doing so she illustrated the variance in influences on body image that are seen as women age, with younger women more likely to use media as reference, while middle age
and older women (as were a number of those in this research) may be more likely to use other references (Grogan, 2012).

**Seeing beyond fatness**

There is a building literature that explores the issue of “fatness” with women who have come to appreciate their body size (Gimlin, 2002; Saguy & Ward, 2011). Organisations such as the National Association to Advance Fat Acceptance in the United States of America challenge the stigma attached to fatness by encouraging women members to be proud of their size. However there would appear to be no similar groups in New Zealand. For most of the women in the study who described themselves as fat, seeing beyond fat was a challenge. In as much as satisfaction with body size is socially constructed, it is likely that the closer the woman is to the ideal the more likely she will be satisfied with her size. And that would appear to be the case with most of the women in the study. Wilma declared with a chuckle, that she liked “anything and everything” about her body and, when questioned further, agreed that she was happy with her weight; it seemingly being something she really didn’t think too much about. In contrast, being underweight could be a concern for Ophelia ...

For years it took me a long time to ever put anything on because ... I used to be just washed out by the time my seizures came one after another... I probably could say that I have been able to keep sort of a good weight and ... know that I’ll never sort of put too much on and like when I have put anything on ... I can lose it so quickly.

2/11

It is interesting to see how Ophelia recognises that her epilepsy, which has never been particularly well controlled, can have both a positive and negative effect on how she views her body. As will become more evident through later chapters, her epilepsy had further influences on Ophelia’s body image.
Whilst Wilma and Ophelia were among those women not overweight, for the women who were overweight, it is important to note that there was still not universal dissatisfaction with their bodies in relation to their weight. Eva, when asked what she liked about her body commented, “My whole body. … Yeah, cos I like it.” She followed these statements up with “I love it” whilst also acknowledging about her weight “I think it goes up and down” (2/1), a factor quite likely with the progression of her heart disease, both in terms of fluid retention and the difficulty that she had with mobility. For Eva, her weight may appear much less important than her general health and the wider impact that was having on her body and daily living, inviting a pragmatic approach (Grogan, 2012; Hurd Clarke & Griffin, 2007). While Eva was singularly positive, among the overweight women body satisfaction was more likely to vacillate as they recognised that they were not meeting the social ideal but wanted to feel good about themselves. There is a suggestion that women who are overweight will shift their expectations regarding their ideal weight (Grogan, 2008; Tiggemann, 2004).

Nadia provided a good example of vacillation as she went from declaring that she did not like to look in the mirror because she saw herself as “ugly”, to suggesting her body was “pretty okay” (2/30). She commented on seasonal variations, being happier with her weight in the summer but when asked if she weighed herself, her response to using scales initially was “I'm too scared. I'm too scared I'm going to break it.” Then commented ...

... But sometimes I'm actually really quite surprised. I actually had to weigh myself – oh I must have just weighed myself just recently and I thought: hell. I said: okay, that can't be right. I said: yeah, okay. Well it's just the way it goes. ... Some days you have bad days and some days you have good days. But I'm eating good stuff ... basically .... Cos you've got to have a piece of chocolate now and again.

2/32

Throughout her interview Nadia interspersed references that suggested she was less than satisfied with her body and her appearance along with humour to
deflect any suggestion that she might be unhappy. Nadia’s preference on the CDRS had been for one size smaller than her estimate of her current, meaning that she would have still been in the overweight category, illustrating a shift in ideal. Meanwhile her use of humour, strong family and community support and an ability to keep herself busy point to a level of resilience, that was also seen with Eva (Choate, 2005; Snapp, et al., 2012). By shifting their ideal body and drawing on these other factors in their life, Nadia and Eva were able to maintain a positive self-esteem, possibly reflecting Harter’s (2012) findings that connect body image with self-esteem, as discussed in Chapter Two.

In addition to Harter’s (2012) work, other research posits a relationship between body self-image and emotional wellbeing, usually with a focus on the role of exercise as a variable. For example, Daniels and van Niekerk’s (2011) small study of 49 women with a mean age of 54.2 years, found that exercise not only improved body image for the experimental group, it also improved their affect, while Harvey et al.’s (2010) large population-based study of 40,401 Norwegians, indicated that leisure time activity was a factor in lowering the risk of depression. In developing a model for a resilient (positive) body image, Choate (2005) draws on both having a positive physical self-concept and coping strategies as well as socio-cultural factors as critical elements. Whilst the role of exercise in maintaining a desired physical appearance is discussed in Chapter Six (A fit and functional body), emotional wellbeing did surface in the current research when some of the women who had experience of mental illness spoke of their body size. For Carla, who was mentally fragile at her first interview, responding to the question about what she most disliked ...

Carla: How I’m overweight.
Interviewer B: Okay, I know how that feels. Have you done anything about trying to lose weight?
Carla: Yeah, and it’s really hard.
Interviewer B: It is hard. Yeah. Have you always been overweight or has this just happened lately?
Carla: I used to be skinny at one stage when I was in the [mental
Carla’s affect and general mental health at this time were a concern for the research team, initiating our protocol for her safety. Illustrating the shifting construction of body image and the interaction between self and environment, when visited for her final interview there was a marked change in Carla’s affect and confidence as she had moved into a supportive community and, having lost some weight, was feeling proud of her body, something that she wanted to be noted.

As can be seen in a number of the quotes above, the women’s identity influenced their body image in relation to size, thus while this aspect of their body image could shift, there might also be a continuance linking present with past in some way. Earlier bullying and negative responses to weight during adulthood can impact on how women see themselves (Davison, 2012; Harter, 2012). There was evidence from Vera, who was also challenged with recurring mental illness, linking her body image back to childhood when she was subjected to bullying associated with her size ... “I used to get called ‘fatso’ and not very nice names.” (1/9) Interestingly bullying was less evident among some of the other women who discussed being overweight from childhood, such as Ursula who reasoned, “I was the biggest one in the family” (2/2). For Ursula, this, and other links to family, which will be discussed in future chapters, provided an important component of her identity, supporting other research that suggests as women age their ideal body may be more closely related to past values or that shared by their family (Grogan, 2012). However, judging by the women who identified as needing to lose weight, some women were subjected to the opinion of others, usually positioned within health rather than appearance as the rationale.

**Taking action to reduce body size**

From the constructivist approach that I have chosen for this research, it might be expected that women would self-initiate measures to change their body
size, having first internalised that their body is different to the social ideal. There was certainly evidence of that being the case for a few women; for example, Ophelia recognised her risk for underweight as a health concern whilst celebrating the benefit as it facilitated her achievement of an ideal body size. From the perspective of someone who saw herself as overweight, Hesta, provided another example ...

I just like being thin. I don’t like being too fat. .... Sometimes I might put a bit on in the winter, if I eat too much chocolate and don’t exercise, but I’m trying to cut down and not to eat too much chocolate. .... And I don’t like putting the weight on. .... Oh look at me I look a bit fat today so I better cut down on this chocolate. (2/1)

However it could be inferred that more commonly other people led the women’s attempts at weight reduction, particularly when they were significantly overweight or had identified health risks. Reflecting awareness of concerns about health outcomes for people with intellectual disability, mentioned in Chapter Two (Ministry of Health, 2011), a number of the women had health checks initiated by their service. Not surprisingly, given that a number were overweight and/or found to have risk factors such as high blood pressure, either reduction or maintenance diets were commonly advised. Such responses fit with the medical model that has seen BMI-based weight recordings associated with a number of chronic illnesses, to the extent that obesity (and to some extent overweight) measures have become identified as disorders in themselves (Patterson & Johnston, 2012). While the evidence linking fat with poor health is controversial, most support that extremes of weight, some types of fat and places where it is stored can contribute to diseases, such as cardiac and diabetes (Monaghan, 2005). However, many of the women in the study that were concerned about their weight would have been assessed as overweight or mildly obese. After identifying her dissatisfaction with her body size, Ursula shared the following ...
Ursula: I’m on a diet actually.
Interviewer C: Yeah. So why are you on a diet Ursula? Is that for your weight or your health or because...?
Ursula: They said I was born fat and I was trying to lose.
Interviewer C: Yeah.
Ursula: And see but these were a bit tighter these trousers, they’re not now.
Interviewer C: No, that’s great.
Ursula: I’m trying and trying and trying to take it off. I might look fat but oh...
Interviewer C: What part of your body do you like best? What do you like most about your body?
Ursula: My stomach actually.
Interviewer C: You like your stomach?
Ursula: Yes, I do.
Interviewer C: And why do you like your stomach?
Ursula: Exercise.
Interviewer C: Yeah.
Ursula: And drinking and...
Interviewer C: Yeah.
Ursula: ...small meals.
Interviewer C: Yeah, so you like it because you think it’s got smaller?
Ursula: Yeah.
Interviewer C: Because you’ve been exercising...
Ursula: Cos I was a big one.

Whilst Ursula could relate her recent weight loss to a body feature of which she was proud, her preferred choice on the CDRS was a figure that would be deemed overweight and when her comments about body size in relation to family, and, “I might look fat but oh...”, are considered it would seem that she might not have originated the idea that she needed to lose weight. Four other women identified that their general practitioner had recommended reduction diets, with
two of these women having been referred to a dietician. A factor in the degree of influence such professionals had was the woman's independence. Sylvia recognised that she was overweight and chose figure 4 as her ideal on the CDRS, but she commented that her dietician had "given up on her" because she did not lose weight. Sylvia illustrated the internal conflict seen in other women who are identified as overweight or obese, who choose smaller figures for their ideal but also see overweight figures as socially desirable, with women of lower socio-economic status being more likely to fit with this pattern (Anderson, et al., 1997; Harris, et al., 2008; Parker & Keim, 2004; Swami, et al., 2010; Thomas, et al., 2008). As previously noted, Sylvia chose not to have her interview audiotaped; however, field notes recorded the content of the two meals a day she prepared for herself, suggesting she was not eating excessive amounts, she also held a health belief that "some fat in reserve" is ideal. Thus it might be concluded that, whilst Sylvia knew what a socially ideal body size should be, when her beliefs and patterns of living were taken into account, it did not fit with her construction of her body and the influence of others with different beliefs was marginal.

Vera, also unhappy with her weight, saw a way out herself but, where Sylvia could take the initiative (evidenced in other parts of her interview), Vera seemed unable to take her ideas forward. As will become evident in later chapters, Vera's mental health impacted on her body image in various ways, including necessitating medication that has side effects associated with metabolic disorder. In addition to her negative thoughts about her body expressed as "I don't like my body very much", she suggested an alternative to dieting as she explained ...

Vera: Yeah. I want to have one of those operations.
Interviewer A: Do you?
Vera: Yeah.
Interviewer A: What one's that?
Vera: That operation on my stomach.
Interviewer A: Okay.
Vera: Yeah.
Interviewer A: Do you think that would ever happen?
Vera: No.
Interviewer A: No? Why not?
Vera: I don’t know. I’m a bit of a chicken when it comes to having operations.
Interviewer A: Hm. Have you talked to your doctor about that?
Vera: No.
Interviewer A: Does your doctor talk to you about your weight?
Vera: Yeah. Yeah, sometimes.
Interviewer A: What do they say?
Vera: They say lose a bit of weight and stuff. But I have been trying to lose weight and stuff.

Apart from Vera’s fear of surgery, it is noteworthy that records of the Ministry of Health in New Zealand identify that surgical intervention, such as gastric banding, is not unusual for people with intellectual disability (Ministry of Health, 2011). While Vera might not choose to go through with such surgery, her point illustrates reliance on opportunities presented by others in the lives of many of the women. Publically funded surgery is clearly an option for other people with intellectual disability who meet the criteria with general practitioners the gatekeepers to such interventions but, as Vera suggests, the people who might benefit are not necessarily going to raise the possibility themselves. Interestingly, Vera is another woman who reduced her weight between the first and third interviews. Living with virtually twenty-four hours a day support, a move of residence to a different part of town meant she was able to walk regularly to her day activities. This increase in activity could then be combined with dietary support. Although the comparative influence of others was most overt when women spoke about weight reduction diets, among the women who were satisfied and proud of their weight were a number that had little control of their eating patterns and diet. Therefore, a focus on only those who were overweight and dissatisfied might miss the overall role of services in shaping the women’s body image.
Making food choices

Whilst I believe that a physically active body is more likely to influence body size, I also accept that a balanced diet will enhance the effects of activity. Physical activity is discussed separately in Chapter Six, my focus for this chapter is on the relative influence of the women and/or others on the food that they had available to them. Included in the semi-structured interview were questions about their diet that encouraged the women to discuss what they knew about food and meal preparation, budget implications for what they could buy and who influenced their decisions. From the above data it is clear that most of the women understood that there was a socially mandated ‘trim’ ideal, although they differed, as do other women (Cattarin, et al., 2000; Coleman, 2009), in the degree to which they had internalised that for themselves. Exploration of their nutrition knowledge and opportunities to self-select their food provides some evidence for the ‘work’ they would do to achieve their ideal body and the messages they might receive from those people closest to them on a daily basis.

For the women who were living independently, with minimal hours of assistance each week, it soon became clear that funders chose shopping for food as a primary purpose for their support. Some of the women indicated that they required minimal, if any, support with shopping but they appreciated the regular contact of a person who could support them in less tangible ways. Nadia explained how she and her support person manipulated her time by shopping fortnightly and then enjoying “a coffee” out the next week. Ophelia’s support person was responsive to her needs in various ways, including enabling her to shop for budget priced meat that she could not have accessed without private transport. Indeed, Ophelia remarked on the difference when she moved towns between interviews with her one regret that she no longer had access to a freezer and the transport provided by her previous support person to enable her to keep the freezer filled with budget priced meat, noting ...

... so it's sort of quite hard to find different things sometimes what I can and can't eat cos like even my fridge has like got a very small
freezer ... So, yeah, you're sort of very limited to how much you can sort of put in some parts.

Guidance as to food choices for the women living independently seemed to be mixed, suggesting that some support people saw their role as accompanying and assisting with transport or cooking (in some cases) but not influencing or educating. For Ilona there seemed to be a disjunction between what assistance her support person might offer and the information that she was receiving from a dietician. I acknowledge that given the support person was not interviewed and Ilona did not elaborate on the support provided with grocery shopping, it may be that she was more active than implied by the following information. While Ilona was keen to tell her interviewer about how she was adhering to the dietician's advice about portions and taking note of food labels to assist with selection, her interpretation of this advice suggested that there were gaps in her new found knowledge. Having a liking for unhealthy snacks, Ilona had accepted that she should choose alternatives but rather than choices such as fruit and nuts, she had filled her pantry with 'light' ice cream and biscuits made for diabetics on the understanding that these would be suitable on a daily basis. As with Sylvia, Ilona's main motivation for weight loss was driven by health concerns identified at her health check and, whilst she indicated a desire to be slimmer, her ideal weight measured on the CDRS would still have her in the overweight category. However Nadia explained in some detail the support she received with cooking meals (from a different provider from the one that assisted with shopping) and it was very evident that support person interpreted her role as following Nadia's direction regarding what to cook and not otherwise involving Nadia in the process at all. For people supporting these women in their independence it is likely that they are interpreting the women's rights as espoused through such documents as The New Zealand Disability Strategy (Ministry of Health, 2001).

Although Ophelia provided an exception, independent living women had a tendency to be represented among those who were overweight to a greater degree than those who lived in supervised homes. In this way they probably reflect much
of society in that they have an understanding of the thin ideal but the competing influences, for taking actions that might assist them along with their drive to achieve that ideal, differ with each individual. Comments such as Carla's in noting that fruit was "too expensive" and Ophelia's above points about budgeting, along with their non-existent education qualifications, suggest that, as a group, the women fit within the population of people who are considered both most accepting of, and vulnerable to, being overweight, that is those of lower socio-economic status (Parker & Keim, 2004; Swami, et al., 2010). As Bordo (2003) reminds us, however, the social stratification that once meant women of lower socio-economic groups were less inclined to work at body weight has changed as overweight and obesity have become implicated in perceptions of excess and lack of control. Thus the women in the study who were overweight and living independently may be representative of a transition that is in part related to their age. Health messages appeared to be impacting most on their desire to lose weight but these were moderated by their beliefs and habits. Although some indicated a preference for the slim ideal, seven still chose figures that would be deemed overweight and few seemed ready to make the lifestyle changes currently pushed by the health sector. Apart from Sylvia, there was no obvious resistance by the women to the public health messages, such as is seen amongst the groups of women who challenge the stigmatisation associated with being fat (Gimlin, 2002; Saguy & Ward, 2011)

While the women who were living independently were buying their groceries according to preferences and budget, the women who were supervised within their home were more likely to have food choices made for them. Management of pooled money for shopping may also have meant that they had a greater range of food able to be afforded. As with the other group of women, it was clear that the social ideal of being trim was recognised by these women, with a number expressing satisfaction in their body size because it met acceptable standards. Whether this was because they had internalised a desire for slimness or due to it representing ‘goodness’ (Bordo, 2003), not only of the wider society but also the values of their NGO, is unclear. Evidence for this latter aspect could be seen in the difference between services with regard to shopping practices, participation in
preparing meals and the menus on offer. Some services appeared to make choices about the weekly menu that were closely aligned with nutritional guidelines for the women, whilst others used flat meetings for the people to choose what they wanted on the weekly shopping list, based on personal preferences, and the whole flat participated in the shopping. Although there is a confounding variable, in that the latter group also had a history of mental illness or physical disability, they were the most likely to be overweight and dissatisfied with their bodies within the cohort of women that lived in supervised settings. In contrast those who had choices made for them were both the slimmest and most satisfied with their body weight. From this evidence it would seem that their NGO, through support people, had a pivotal role in influencing the body weight of the women. Furthermore, I suggest that the pride the women expressed in their trim bodies had become linked to their identity and self-esteem through the values of their support service, as will become more evident in later themes.

**The body as a whole**

While the women had an opinion about their global or whole body, with some being proud of their ‘trim’ appearance, once asked about features of their body that they liked the women often struggled to identify any one aspect. In itself, this might not be a surprise as women commonly find it difficult to nominate physical features that they like, whereas those that they dislike come readily to mind (Grogan, 2008; Tiggemann, 2004). However, the women also found it difficult to nominate specific features that they disliked. There is a suggestion that nominating specific parts of the body requires that the person can fragment their body and it has been noted to have both a gender and developmental component (Calogero & Thompson, 2010; Harter, 2012), suggesting cognitive and social influences. Mirror use will be discussed in the next chapter but it was notable that the women reported minimal use of mirrors, suggesting that they may not have a ‘picture’ in their mind of what other see of the detail of their body. In addition, it is not known how many women were like Amelia ...
Interviewer B: Okay. Right. Now do you look at yourself in the mirror?
Amelia: I can’t see.
Interviewer B: You can’t see.
Amelia: Yeah.
Interviewer B: If you looked in the mirror over there you wouldn’t be able to see your face?
Amelia: That’s right.
Interviewer B: So why do you wear glasses?
Amelia: To see.
Interviewer B: To see. So if you stood in front of the mirror would you see your body?
Amelia: No.
Interviewer B: No. So you don’t know what you look like?
Amelia: Yeah.

This section of transcript from Amelia illustrates how easy it is to make assumptions. Vision is a little acknowledged concern in the day-to-day lives of people with intellectual disability despite evidence from Special Olympics research that indicates many athletes require corrective lenses, as well as it being a known difficulty to treat eye conditions associated with some syndromes (Jensen, Taylor, & Davis, 2013; Special Olympics New Zealand, 2012).

With the women not particularly forthcoming in regard to questions about features they liked or disliked, there are limited data to share. Of note, McCarthy (1998, 1999) also reported few responses to questions about what the women liked or disliked about their body in her study. Unlike other women who will usually nominate legs, buttocks and stomachs as features that they dislike (Grogan, 2008) the only woman in the current research that mentioned these was Ursula, who, as noted above, was currently happy with her stomach because she had lost weight. Ilona gave some serious consideration to the question but in the end responded, “Oh that’s hard ... No, I’m all right.” (2/22) Tanya was able to isolate the
scar on her neck from the surgical removal of a tumour as something she wasn’t happy with. However, her reasons for disliking it were twofold “... it sometimes gets real itchy and sometimes really sore”. (1/16) Her interviewer noted that she wore her hair so that it covered the scar and asked whether she also worried about its appearance, which drew out an agreement. Similarly, it was following the interviewer offering an example of a feature that she didn’t like about herself that had Amelia respond “Oh me too”. (2/4)

Finding a feature that they liked was almost as difficult, with Ilona, despite struggling to name a feature that she did not like, most forthcoming about her best features, responding “my face” and then adding “... and hair done”. (2/22) Five women choose their hair as their best feature. It is possible that hair was seen as a safe feature to identify; for example, Francisca initially commented, “I’m embarrassed”, (2/38) when asked what was her best feature, perhaps recognising the social inappropriateness of vanity. With further encouragement she stated “I don’t know” and then said “my hair”. (2/39) As will be discussed in more detail in the next chapter, hair styling and colouring was a main focus for the women’s beauty practices with evidence that others supported these practices. Such support possibly implies to the women a social acceptance of having pride in hair. Furthermore, when the woman has a physical disability, hair can provide a focus away from their disability, with Georgia responding to what she liked about her body ... “Not much. The only thing is possibly my hair colour.” (1/19) Georgia’s hair colour was natural and noted to be particularly attractive by her interviewer, with Georgia confirming that she receives compliments from others. Similarly, Hesta’s close relationship with her family provided a focus for her to report her best feature “And people say: oh you’ve got lovely eyes. Where did you get your lovely eyes from? I say: it’s probably from my mother cos she’s got the real hazel eyes as well so.” (2/3) Interestingly in this latter case, Hesta was careful to report what other people saw as her best feature and by locating the feature as familial avoided taking any personal credit, limiting the risk of being seen as vain.

As suggested above, it is possible that there is both a cognitive and social element to the women’s limited responses of features that they like/dislike. Apart
from choosing to be humble as might be suggested in the responses above, it is, however, interesting that so few women could identify features that they were not happy with because a number of them had a ‘visible difference’, in facial features or other bodily appearance. In other research that has explored the impact of ‘visible differences’ it is not clear whether people with intellectual disability are included, however some general findings include a significant proportion of participants indicating psychological distress (Claessens et al., 2005; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004) and appearance-related anxiety (Harcourt, Rumsey, & Paraskeva, 2011). The current research included a number of the women with various ‘visible differences’ but, given their overall confidence, it is possible that these features were simply part of their identity and therefore not remarkable. Rysst and Klepp (2012) concluded from their limited study with 20 men and women, that it was those with ‘deviant’ bodies (including cleft lip, amputations, burns injury) that were more likely to accept their bodily limitations, value their self and work on body image components that they could. Having a ‘visible difference’ very clearly positions the person as ‘other’; however, there may be a time factor in terms of the impact. In the current study Ursula illustrated that a more recent ‘difference’ could have a significant impact on appearance-related anxiety as she frequently returned to her dislike that she had “to wear this darn hat”, which she had been expected to wear since a seizure had resulted in a head injury. In this case the hat was representative of a number of changes in Ursula’s life, including greater dependence and lost freedoms as well as the obvious meaning that can be taken as making her stand out as other. Harcourt et al. (2011) and Rumsey et al. (2004) both note that it is not necessarily the severity or type of the disfigurement that influences the level of distress, although site can make a difference, as can the person’s perception of difference from others. In Ursula’s case the hat was a very obvious difference from both perspectives.

In addition to Ursula, three other women commented on a dislike of ‘othering’ in relation to specific features. For Ophelia it was the potential to have some body part named ...
Ophelia: And like yeah I mean no there's not really a lot I don't sort of really dislike about my body. But I mean the only time that I sort of maybe ever feel like that is when someone might pinpoint anything at you or try and be critical or anything like that.

Whereas both Tanya and Yolanda were more specific, providing examples from their school days ...

Tanya: This girl called me 'handicap' and...
Interviewer C: Yeah, and you didn't like that.
Tanya: Yeah. Cos I had an operation on my eye...
Interviewer C: Yep.
Tanya: ...I've got a lazy eye, had an operation on my eye and – yeah.

For Tanya it was a peer's response that upset her, while Yolanda’s experience was initiated by a teacher ... “I got shown in front of students what my disability was at [school’s name].” (1/5) Yolanda did not provide a context or purpose for the actions of the school but the memory remained with her as painful. For these three women, then, having a feature of their body become the focus of other’s attention was unpleasant; however, although a number of other women might be considered to have a ‘visible difference’, for example Barbara’s scoliosis or Vera’s poorly healed and contracted forearm, they did not reflect a particular dislike for that aspect of their body. As will be seen in subsequent chapters, these women often followed a similar pattern seen in the Rysst and Klepp (2012) study by choosing to focus on body practices that they could influence.

It would seem that some of the women could focus on specific features of their body that they liked or disliked but in most cases their attitudes were based on either positive or negative comments from others, similar to that noted regarding weight above (Davison, 2012; Harter, 2012). It could be considered quite heartening that so few women with a “visible difference” expressed concern
about these features but, without a deeper analysis of their construction of their body, including both internal and external influences, I withhold that conclusion. Subsequent chapters will contribute to a wider understanding of how the women’s attitudes might be interpreted. Overall it does seem that the women are more likely to consider their body as a whole, providing a basis for their body image.

**Summary**

In summary, the results from the CDRS and the transcripts reflect that for this group of women their body size could be a source of pride or of shame and sometimes vacillated between the two extremes. Typical of women from comparable societies, satisfaction with their body size generally decreased as the women’s weight increased. The majority of the women provided competent assessments of their size when identifying their current figure on the scale and, although without BMI measurements it is not possible to comment on degree of accuracy, comments from the interviewers would suggest that their estimates were within one size plus or minus. In other words some of the women may have slightly underestimated their weight, while some may have slightly overestimated. There was none of the women that could be said to be significantly underweight, despite some choosing such figures on the scale drawings. Difficulty conceptualising their body shape in relation to the scale appeared to underlie the choices of these women. Whilst it was more evident how the women felt about their body size, few identified features that they either particularly liked or disliked. Whilst body size, shape and features might be seen to provide the structure for beauty, the literature tells us that how women further beautify their body is equally important. The next chapter explores the beauty practices of the women in the research.
Chapter Five: Beauty and the body: “tidy, clean and conservative”

Introduction

The previous chapter introduced the women’s perceptions of their body, identifying their global perspective particularly in relation to size and shape. In addition to the influence of marketing and perceptions of beauty, body size has come to be associated with health messages and it was these that appeared to be most influential in this aspect of the women’s body image. In contrast, although there are some exceptions, health messages are less pervasive in beauty practices that might enhance the look of the body. Instead, social messages are more commonly aligned with presenting a body that infers status, including socio-economic and cognitive competence, with occupation frequently implicated. For example, most of the 20 American women in Dellinger and Williams’ (1997) research wore make-up to work, with most citing confidence and credibility as benefits. While the 15 women in Stuart and Donaghue’s (2011) discourse analysis emphasised that it was their women peers to whom they wanted to compare favourably in their choice of clothing. From a social constructivist point of view, exploration of the women’s beauty practices had the potential to draw out the role of the various influences discussed in Chapter Two (Black, 2004; Brand, 2000; Grogan, 2008; Harter, 2012; Sentilles & Callahan, 2012). Whilst changes to body size, shape and features can be challenging, it is potentially easier for women to change their appearance through the clothing they choose to wear, application of make-up, hairstyles and jewellery. However, although beauty practices have become common among women, there remain constraints associated with cost, ability to make choices and to carry out the practices such as applying make-up (Black, 2004; Grogan, 2008), each of which may be a consideration for the women interviewed.

Research that considered beauty practices to be a significant aspect of a woman’s body image, as well as a suggestion women with intellectual disability
might be denied choice in such practices (McCarthy, 1998), led to the inclusion of questions about beauty practices in the interview schedule. The depth of responses from the women differed; however, the subtheme of ornamentation provides some insight into the women's attitudes and behaviour in regard to their clothing and beauty practices, such as hair care and use of cosmetics. Whilst there are little ‘rich’ or descriptive data, it is possible to sketch a picture of the women's interest and participation in the use of bodily ornamentation whether for their own pleasure or intended to influence the perception of others.

This chapter is divided into sections related to the women's various body practices of clothing, cosmetics and hair styling but begins with a glimpse into the women's use of their reflection through mirrors and how that might influence their body image.

**Reflection in the mirror**

Mirrors provide a view of how we might be seen by others, with Coleman (2009) suggesting that the young women in her study used them to consider what they looked like at the time but also to imagine other images. Indeed, she found that her participants were seldom without a mirror, using them to regularly check their make-up. While this might be considered a developmental stage, Black's (2004) study suggested that mirror time remains important as the adult women she interviewed continued to use them for self-evaluation. Given this reported behaviour it might be expected that the women interviewed for the current research would also refer to mirrors to evaluate their appearance and perhaps imagine what they might change. There was, however, limited evidence of such use.

When the women did use mirrors it was mostly to ensure a tidy appearance, with hair frequently the focus, with Dianna telling her interviewer “Well I look in mirror, I do hair...” (2/16). Carla commented that she used the mirror when “Brushing my hair ... I don't really concentrate on it [her reflection] I
just concentrate on brushing my hair.” (2/9), a sentiment shared by Georgia who, when asked whether she looked in the mirror, replied …

Georgia: Sometimes. When I brush my hair.
Interviewer B: And how do you feel about yourself when you look in the mirror?
Georgia: I feel miserable.
Interviewer B: Oh do you?
Georgia: Yes, cos I’m too fat.

For those women who were overweight a mirror provided a reminder of their body size and consequently they preferred to avoid frequent use but they might use it for specific purposes, such as Nadia …

Nadia: I don’t like looking at myself in the mirror.
Interviewer A: What about when you’re all dressed up to go out somewhere?
Nadia: Oh when I’m all dressed up I’ve got to see if I’m looking all charm, yeah. Like say if I go away and get my hair all done up, yeah, they actually give me the mirror to see what I look like, yeah, I say: oh that’s pretty.

Despite her discomfort, Nadia did suggest that she was more accepting of her image than she had been in the past …

Nadia: Well you can’t really be different you’re just one person. Yeah. If you’ve got one person in you you’ve got to get up, get off and get up with your life and stuff like that. You know I’m not as bad as what I was.

2/34
Perhaps not surprisingly the women who were more satisfied with their bodies were more positive about their reflected image, with Marika telling her interviewer that she feels ... “Good, especially when you get your hair done and sorts of things, you know.” (2/22), although still relating her image back to her hair and suggesting self-evaluation was for a specific purpose. Whilst staying with a specific purpose, Ophelia was able to see beyond her hair to include her appearance in general when she looked in the mirror...

Ophelia: Yeah, I do at times, like especially if I’m going out anywhere and I’m dressing up for anything in particular. I mean, yeah, I don’t always do it but only when I’m sort of going out and I’m trying to make myself look nice and tidy to go out to people’s places and that, so I know I look presentable to go out to each other’s place and that. 2/13

There was no evidence of the women using mirrors to try out different looks in the way that Coleman (2009) suggests, nor did they appear to use mirrors throughout their day. Only Wilma, who, as noted in the previous chapter, was happy with her body, suggested that she might look in a mirror without a specific purpose jokingly responding to how she felt about her reflection ... “Good, but I don’t like myself in the mornings, because I’m still half asleep when I’m looking in the mirror” (2/1). For most of the women, mirrors provided a tool to ensure that they were presentable when going out. When used for admiration it was in relation to having had their hair done and probably initiated by their hairdresser, as Nadia suggested. Limited use of mirrors might have implications for the women’s beauty practices as few appear to place much emphasis on what their reflection can tell them about how they might be seen by others. As will be seen through these next sections of the chapter, this does not mean they are not conscious of presenting an image but rather the feedback on that image may come from other sources in many instances. Interestingly, none of the women specifically mentioned looking in mirrors when clothes shopping, however it might be implied from some of their responses that they would do so.
Clothing

Clothing is closely linked to body image, having the potential to add glamour and attractiveness and also to conceal features that are not seen as desirable (Lox, et al., 2010). There is considerable evidence that clothing conveys numerous messages about the person (Johnson, Yoo, Kim, & Lennon, 2008; Lennon, 2012), with Lennon claiming that clothing and other adornment can be used as “appearance management” (p.4.) to give the impression that the person wants to portray. An important point raised by Lennon is the constructivist relationship between clothing as having a social role in identity formation. In other words, it is hypothesised that there is feedback between the appearance portrayed and the response from others that confirms or otherwise impacts on how identity is set; however, also important for such understanding, the identity cues must be chosen by the person and be consistent. This latter aspect may be particularly relevant when considering the impact of clothing on identity for a person with intellectual disability if they have not had a choice in their clothing, as McCarthy (1998) found to be common. Higgins (2000) considers there to be two aspects of reinforcement for the woman who considers she has chosen well. Firstly, she can see in her reflection that she looks good and, secondly, she gains satisfaction from having made a good choice. Thus, it would seem that having choice about clothing, in addition to giving one control over how one is seen by others, may also contribute to self-esteem when the person is satisfied they have made a good choice. In addition, from her literature review, Tiggemann (2004) suggested that clothing may become more important to women as they age, in that clothing and hairstyle continue to define who she is and may provide an active response to her limited ability to change the aging body, yet she may find it increasingly difficult to find suitable clothes that fit. Since that literature review, Tiggemann with others has explored clothing particularly in relation to self-objectification theory, identifying that there are links between women’s thoughts about clothing and their body image as well as demonstrating multiple functions of clothing and shopping (Tiggemann & Andrew, 2012a, 2012b; Tiggemann & Lacey, 2009).
With McCarthy’s (1998) findings in mind and the importance of clothing for identity and body image, two questions relating to clothing were included in the semi-structured interview outline. The first related to satisfaction with their clothes and the second to whether they were supported when making clothing purchases. However, clothing also came up in other parts of the interviews, indicating that it is an aspect of their appearance to which some women were particularly attuned. Thus, both responses to the questions and other relevant data are included in this section.

For a small group of women in the study identity and status could be seen to influence their choice in clothing. Tanya described her preferences as ...

Tanya: Jeans... and boots.
Interviewer C: ... if you were going out at night what sort of outfit would you like to wear?
Tanya: Tights and dress.
2/19

These would be typical clothes for young women of her age at the time. While she did not indicate any preferences for labels, Tanya’s response would suggest that she was at least conscious of the current fashion. Less concerned with fashion but aware that there are social standards, Ophelia noted the influence that her People First chairperson role had on her clothing ...

Ophelia: And I was going out to so many places I knew I had to look presentable to go to those sort of places.
Interviewer A: So did you choose your clothes when you were going out or when you go shopping do you choose your clothes?
Ophelia: Yeah I do and like most people have always said to me that I have always looked nice when I have dressed up.
2/14
In addition to recognition of a standard of dress, Ophelia's response also illustrates Lennon's (2012) point above regarding feedback. Ophelia was one of the few women who shopped for clothes independently, choosing items from within a range of shops that met her budget. She was therefore able to take credit for her choices, which she had interpreted as best to fit her role.

Poignantly, Vera reflected on the status she had felt in the past when she had a job, telling her interviewer ... “I used to like getting dressed up in the uniform.” (1/28). The uniform to which she referred was far from glamorous, being the white coat, hat and boots associated with factories producing foodstuffs; however, it represented the one time in her life when she had employment and was associated with happy memories of workplace relationships. As such, what the uniform looked like on her was less a concern than what it stood for. For most women in employment clothes are an important aspect of the identity that they choose to portray, however, few women were employed and therefore the opportunity to construct a body that aligned with a chosen identity for their workplace was not available to them.

Aside from the workplace, sporting codes commonly use uniforms to denote team membership. Nadia illustrated that uniforms are not necessarily going to suit all members, particularly when they might expose parts of the body the person prefers to cover. When presented with the new uniform for her sport team Nadia told her interviewer ...

Nadia: I thought: oh I’m never going to get in that [singlet top]. And so ... I actually told them if I could ... have a one with sleeves ... She said: yeah that’s fine. So I couldn’t believe my eyes, as soon as she told me: there you are there’s your t-shirt.

The impact on Nadia’s self-esteem was two fold in that she had an outcome with which she was happy in terms of her body image and by taking the initiative she gained confidence in her ability to make choices. This latter aspect being
further reinforced as other women in the team commented on her making a good choice and regret that they had not made a similar stand.

Overall the majority of the women were happy with their clothes, which were mostly tidy, comfortable and contemporary, possibly illustrating other studies that suggest women focus on these aspects rather than trendy fashion as they age (Grogan, 2008; Holmlund, et al., 2011). However, there were women within younger age groups that might be expected to take an interest in fashion trends and it was noticeable that none provided any evidence of such an interest. Barbara’s comment “I like sparkly things” (2/33) being the only indication of a desire that might be aligned to glamour and perhaps associated with power and sexual attractiveness (Higgins, 2000). As a component of identity, the impression was that clothing reinforced a relatively conservative view of self that considered the ideal body as neat and tidy, rather than sexually desirable.

An important consideration to such a construction of their body image is the influence of others on their shopping practices. While it was clear many of the women shopped for food with their support person, for four women clothes shopping provided an opportunity to shop with family. Mothers are generally implicated in teaching daughters about clothing, including both caring for garments and making choices (Lennon, 2012), however peers also become influential from adolescence. Quiana’s mother, Eva’s aunt and Patricia’s sister accompanied them shopping, which appeared to be an arrangement that they liked. Xena, however, relied on her brother and she was frustrated at the time because he had not made time to take her when she wanted …

Interviewer B: No. Are you happy with your clothes and what you wear?
Xena: I’d like to get new ones.
Interviewer B: You would. ... And why can’t you get new ones? ...
Xena: Oh I have to ask my brother to get me around town for things.

2/19
Families continued to control the savings of some women, making it necessary to involve them in their clothes shopping. This was the case even when they were otherwise independent as Tanya illustrates ...

**Interviewer C:** Yeah. So what if you want to buy clothes?
**Tanya:** I just get it out the bank. .... You know deposit slip forms?
**Interviewer C:** Yeah.
**Tanya:** Xxx takes one of them so I get it out from the bank.
**Interviewer C:** Yeah. And does someone else have to sign that or can you get it out when you want to?
**Tanya:** Someone has to sign it.
**Interviewer C:** Okay, and who usually does that?
**Tanya:** My step-dad.

Apart from a few women, like Tanya, Nadia and Ophelia, most others were assisted in clothes shopping, even when they were reasonably independent in many other aspects of their life. Most of the women appeared to welcome assistance, with either their family or support person perhaps fulfilling the role of friend that many women like to have with them when shopping for clothes (Holmlund, et al., 2011). Having someone available meant there was help available, such as Barbara explains ... “Pick out what I want and if it’s too small she [SW] just takes it back and gets me another one.” (2/33). The other person could also give an opinion about what suited them, with Sylvia providing an example of a time when she was encouraged to try on an item that she would not have chosen for herself. She was pleasantly surprised to find it suited her and bought the garment. However, it seems some support people are very careful not to influence decisions, as Hesta explained ...

**Hesta:** [support person] and I have a little look in the Miller’s shop, she goes: right you decide what you’re going to buy. Cos I decide ... she'll just stay there. We'll go and look in Miller’s.... But she says: it’s your turn to choose whatever you want to wear. (2/6)
In most transcripts, however, it was difficult to ascertain the influence that the support person or family member had when the women selected clothes to try. Carla commented that she sometimes went along with what her support person had chosen but most were clear they chose for themselves as Yolanda expressed when she was asked who chose her clothes “I do, of course, well I do wear them!” (2/8)

Whilst they believed they had choice, few women seemed aware that they were limited to a range of shops that would suit their budget, with shopping expeditions, as Hesta’s comment illustrates, limited to one or two shops. In this way the women were corralled into a “look” that excluded the high fashion of the more upmarket shops, or even the opportunity to shop around in a range of budget shops. Marika did show some insight into the limits of her budget when she proudly pointed out “I’ve got some new sandals too. ...Yeah, they’re expensive ones” (1/29), making it clear that she would not normally choose such a brand. While limiting in one sense, there may also be a benefit to the range of budget clothes that are available in that, in contrast to McCarthy’s (1998) findings, the women could make a choice not to shop in second hand outlets, with Barbara being the only person who liked to do so.

Further limiting the women’s choice was the need to arrange shopping in advance, also seen in McCarthy’s (1998) study. Organising both finance and support meant that most of the women could not buy clothes on a whim, possibly affecting the influence of media and marketing but also determining who would be with them and potentially able to influence their buying decisions. While peers are thought to be a major influence on clothing choices that women make from adolescence, it would seem that few women in this study shared their shopping outings with peers. Reliance on support people and family might mean generational differences, in either direction, that limit the woman’s opportunities in constructing a body image in keeping with her peers. From Freeman Watson et al.’s (2010) findings, caregivers are considerate of fashion, age, matching and tidiness when buying for people with complex needs, including intellectual impairment. While their findings might offer some reassurances regarding
appropriateness, they also suggest a conservative approach in keeping with principles of normalisation but not encouraging of self-expression. Despite these limits, however, that the women were happy with their choice of clothing might suggest it aligned with an identity with which they were comfortable. From this I would not want to imply that there have not been significant influences on their identity, a point that I will return to in Chapter Eight.

**Cosmetics**

Over twenty years ago, Wolf (1990) described the influence of cosmetics, such as beauty creams, as the magic treatment that will help women achieve the airbrushed image in the magazine, and in the process creating a multimillion dollar industry. For many years there remained ambivalence about the acceptability of make-up as evidenced in the employment court decisions from the United States, in which women were variably accused of wearing too much or insufficient make-up as reasons behind the termination of their employment (Wolf, 1990). Despite this difficulty, Wolf considered that the professional appearance expected of women meant that they had come to associate cosmetic use with high status employment, indeed occupational and income status have since been shown to also influence brand preference (Chao & Schor, 1998). There is a level of consciousness to Wolf’s feminist analysis, with most women in Western nations acknowledging the power of the cosmetic industry; yet, when asked, they will claim that they personally consider they make choices about their use of beauty products (Black, 2004; Muise & Desmarais, 2010; Stuart & Donaghue, 2011). Clearly many do make the choice to use cosmetics, including face creams and make-up, as their use is believed to be widespread among adult women as these and other authors note. Indeed, some women extend their beauty practices to cosmetic procedures, including surgery (Calogero & Thompson, 2010; Davis, 2008; Harter, 2012).

Given these broadly accepted positions it might be somewhat surprising that cosmetic use was not frequent among the women interviewed and, as noted in the previous chapter, Vera was the only woman to suggest a surgical intervention
to address a body image issue. Other more recently adopted practices of piercings and tattoos (Grogan, 2008) were absent, apart from some having their ears pierced. Grogan, however, notes that, in order to get these procedures, the woman requires the money and ability to free herself from authority figures, both of which are constraints for the women in the study. Of all the beauty practices, it might be considered that cosmetic use is a strong indicator of an understanding of the body as an object of gaze for other people and a means to influence how those others then see the self. I suggest this because it is a practice that is less obviously necessary than being dressed, or having tidy hair, for example. Whilst use of cosmetics, including the more expensive brands, has been linked to status, there is possibly less imperative for services that are influenced by normalisation and social role valorisation principles to encourage the women they support to use cosmetics. Indeed, while believed to be common and increasing, it is difficult to ascertain the use of cosmetics within the general population of women, as many of the above-mentioned studies have been focused on particular groups, with social role often associated in these cases with professional women.

The women’s comments about make-up and other beauty practices included in this section come from both their answers to specific questions and their wider narratives were relevant information was provided. The women were evenly divided between those who did or did not wear make-up; however, only Hesta claimed to wear it with any frequency “Yeah, I wear make-up. Especially when I’m going to work I put some make-up on.” Further, she illustrated the comparative influence of her family when she added “Cos my mother always says: oh you look pale. ...cos we never wear lipstick we always wear that lip balm/lip gloss. My sister’s the same. She said: you people look pale without lipstick. But we like the lip gloss.” (2/5). Calogero and Thompson (2010) suggest that conversations with peers about socially ideal standards have a higher chance of internalising appearance ideals and Hesta certainly made various comments that referenced her body against such ideals. For most of the women, however, make-up was limited to special occasions, as Diana commented “At the disco” (2/18), was a time to wear make-up. Those who did wear make-up at such times usually
applied it themselves, seemingly choosing from lipstick, blusher or eye shadow but rarely using all three together.

There is some suggestion that younger women are wearing more make-up (Coleman, 2009; Stuart & Donaghue, 2011; Swami et al., 2010) than was common in the past. Coleman’s (2009) young women participants (n=13) aged 13 and 14 years wore and regularly checked their make-up throughout the day. Stuart and Donaghue (2011) held focus groups with fifteen women aged 18 to 42 years and found that it was their younger participants who were reluctant to leave the house without their make-up. In Swami et al.’s (2010) study, among the range of variables that might influence cosmetic use (among other things), they found further evidence that younger age was relevant, along with a heightened tendency to objectify others, stronger sexist attitudes and more media exposure. However, this pattern of more cosmetic use with younger participants was not evident within the doctoral research. Indeed, in contrast to Hesta’s experience with her sister, one who had a beautician sister did not seem particularly interested in cosmetics, only occasionally wearing make-up.

Whilst there was little evidence of social pressure for the younger women, it was evident that the older women may have been influenced by conservative views about make-up held by previous generations (Black, 2004; Wolf, 1990) with Sylvia’s experience with wearing make-up illustrating how easy it has been to get it wrong. Some years ago, after enjoying the attention of pampering from a support person applying some make-up to her face, she went to her workplace and was told to wash it off. Such mixed messages make it difficult for women to negotiate the appropriate behavior; however, it is not uncommon for service industries to regulate the appearance of their workers in this way (Black, 2004). For Sylvia, the humiliation of that experience left her with little confidence and she now felt make-up drew unwanted attention, finding any compliments that she might receive when wearing a little lipstick uncomfortable rather than pleasurable, and certainly not enhancing her body image. It is interesting that Sylvia avoided make-up because she felt that doing so made her less susceptible to the gaze of others. As noted in the previous chapter, Sylvia was one of the women who were dissatisfied
with her overweight body, as was Vera. However, Vera utilized beauty practices as a distraction from her unhappiness with her global body image, enjoying having her nails polished and wearing jewellery; in addition, she also found these strategies beneficial to maintaining her mental health. A difference between these two women, would seem to be that Vera’s practices were about her own enjoyment, something that many women claim for using beauty products (Black, 2004; Gimlin, 2002; Muise & Desmarais, 2010; Stuart & Donaghue, 2011), whereas Sylvia’s were firmly positioned in a feminist view of the objectified body albeit one of resistance rather than compliance with the social mandates.

Few other women reflected on how their appearance when wearing make-up might be interpreted by others but, perhaps, that was in the mind of Nadia who commented “I don’t wear makeup, no, no I never ever did wear makeup cos I’m not very sensible with makeup” (2/39). In addition to deciding what is personally appropriate, Black (2004) suggests that women also need the skill and opportunity to engage in the ornamentation. Nadia’s comment is a direct illustration of that point, but it might also be the reason why many of the women only used one or two products when they were using make-up. Interestingly, none claimed to use mascara or eyeliner, both of which take some skill but, from observation, are commonly used by women in New Zealand today.

Another common practice amongst women is the application of face creams to protect and rejuvenate their skin (Muise & Desmarais, 2010). Despite their cynicism about the effectiveness of such creams, Muise and Desmarias found that even women in their twenties were using such creams. In contrast only a couple of the older women in the current study used face cream on a regular basis, with one of these women never wearing make-up and the other only rarely. Of these two women, Ursula alone mentioned a brand ...

Ursula: No, I don’t put makeup on.
Interviewer C: You’ve got lovely skin.
Ursula: I put that Olay on me.

2/7
Where Chao and Schor (1998) found the more expensive brand preferences to be associated with higher status employment, for Ursula, using a brand able to be bought at the supermarket was not an issue. Given that the women were on limited budgets face cream may not be an item deemed necessary; however, New Zealand has a high skin cancer rate (Ministry of Health, 2010) and using a cream that includes protection from the sun might be advisable. Indeed, from my observation, the sun protection factor is included in more recent marketing of face creams. With just two women identifying use of face creams, it seems that the marketing of these products is not yet influencing the beauty practices of the majority of the women in the study.

While beauty practices were not common, some women did discuss them as an entry to being pampered. Whilst this had ended unfortunately for Sylvia, more commonly it was enjoyed. For Ilona, having make-up applied was associated with the time that she spent with her volunteer friend. While Vera, in discussing her use of nail polish, inferred that part of the enjoyment for her was related to having her support person apply her make-up. Beauty practices are associated more widely with pampering (Black, 2004; Gimlin, 2002), with it becoming increasingly common for women to visit salons for this purpose. Although Black (2004) noted an age difference in terms of whether facials, nails, hair removal and other treatments in salons were seen as pampering or simply an extension of leisure pursuits, finding younger women more commonly seeing these practices as the latter. Interestingly, Wilma was one of the youngest women interviewed and, for her, attending a salon with her mother to “get a wax” or other treatment was a regular occurrence. The only other participant to mention professional treatments was Kura in reporting that “a podiatrist” (2/6) cut her toenails. The difference between the women and the other reported studies was that, aside from these two examples, people that support them or volunteer friends generally carried out their pampering. It was also support people that assisted with the more general grooming requirements including facial hair, finger and toenails, as specifically noted by Vera (2/21) and Kura adding “and my whiskers trimmed” (2/6) when detailing what she had help with. As mentioned above, removal of body hair is
commonly seen among younger women as routine and, while McCarthy (1998) has suggested that body hair and particularly facial hair can be sensitive topics for women with intellectual disability, for these two women, at least, it was simply included in the conversation about their grooming. Whether this is an influence of wider social acceptance of such topics or individual differences is not clear. Although not routinely included in the interview questions, Ilona, Nadia, Ophelia and Quiana indicated that they did not remove body hair, such as from armpits or legs, which supports McCarthy’s (1998) more general observation that women with intellectual disability are accepting of body hair.

Overall, the idea of making oneself more beautiful through taking special care of one’s skin, applying products that decorate one’s features or engaging in beauty treatments was not strongly held among the women interviewed. There is potentially a habit formed dimension to beauty practices, with Hurd Clarke and Griffin (2007; 2008) noting that older women tend to continue practices begun earlier in their lives. Many of the older women in the current study could thus be illustrating earlier attitudes towards their use of make-up, as seen with Sylvia. Interestingly, among the 50 to 70 year old women that Hurd Clarke and Griffin (2007; 2008) interviewed most related their beauty practices to remaining desirable, with four different motives: attracting potential partners (or keeping current), employment requirements, fighting the invisibility that they became aware of as they entered middle age and as part of a life-long investment in their appearance. The degree to which these would be motivators for the women in the current study is questionable given that most saw partners and employment as out of their experience and may well have felt invisible most of their lives.

Hair

Hair is one feature that can easily be changed through cuts, styles and colour to portray the image desired by the woman (Gimlin, 1996; Harter, 2012; Weitz, 2008). Whilst the women were not particularly interested in other beauty treatments, hair featured as an aspect of their body image that was important to them, with some implicating it in their identity. As noted in the previous chapter,
Hairstyles and colour were selected by a number of women as their best feature. Responses to specific questions about hair care, as well as the spontaneous information shared by the women throughout the interviews, contributed to the analysis reported in this section.

Hair treatments provide another opportunity for pampering but, as with clothes and make-up, they are also associated with status and a means to an image (Gimlin, 1996; Gimlin, 2002; Weitz, 2008). In her study of twenty women customers of a Long Island hair salon, Gimlin noted that most would decide for themselves the style they wanted, influenced by their social and occupational roles. Although the hairstylist would make recommendations, the women did not necessarily follow their advice, as they believed they knew best what would suit their social position, with Gimlin suggesting that they saw their social standing as different to that of their stylist. It was never clear how much influence the hairstylist had with the women in this doctoral study; however, both pampering and a means to an image could be seen in the women’s responses with Marika commenting, “I like getting my hair done to make me feel better every so often, you know” (2/20). Meanwhile for Ursula (who, at age 60 years, still had both parents living) her haircut provided her with an identity she could align with the rest of her family.

Intervener C: And do you like your hair a bit longer or a bit shorter?
Ursula: No, everybody in our family has got short hair, they don’t have long hair.
Intervener C: Right, and so you’ve got short hair too.
Ursula: And my parents have got short hair and everybody in the whole darn family have got short.

In a similar vein, Ilona’s hairstyle connected her with an image influenced by her mother who died many years ago ...
Ilona: When I was a wee girl in 1967 I had flat hair, in 1967 the Christmas holidays my mother took me to get my hair done for a perm when I was fourteen.

Interviewer A: You had a perm. And you’ve had one ever since?
Ilona: Yeah, I was fourteen.

Interviewer A: From when you were fourteen? So you get your hair permed...
Ilona: That was my mum.

Interviewer A: Your mum did it then.
Ilona: Yeah, with me.

Whilst this image was not tied to current trends, it was interesting to note that Ilona was less conservative with her choice of hair colour. Unlike earlier research where women want a “natural” look when they have their hair coloured (Gimlin, 1996), the women who coloured their hair seemed proud of the statement that the colour made about them. It was difficult to extract this sentiment in words from the transcripts, as often it was expressed informally even before the interview began. For example, following her proudly showing off her recent hair colouring before the interview, the best that could be achieved on tape with Rosa was ...

Interviewer A: Yeah. Is that foils you’ve had done?
Rosa: Yes.

Interviewer A: When were they done?
Rosa: Monday.

Interviewer A: Oh they’ve just been done?
Rosa: Yes.

Interviewer A: Oh well.
Rosa: [names other participant] goes to, I go to that one.

Interviewer A: Oh okay. Well they look very flash don’t they?
Rosa: Yeah.

Interviewer A: Are you happy with it?
Rosa: Yes.
Interviewer A: Yeah. You’ve got that lovely red and gold and all sorts of colours there haven’t you?
Rosa: Yeah. 2/13

A number of the women had their hair coloured, although there were clearly two viewpoints. Some of the women who did not colour their hair commented on their natural colour, as noted by Georgia in the previous chapter and also the eldest woman interviewed, Sylvia, who at 65 years of age retained natural brown hair, and commented that she “liked it natural” (from field notes of interview). Others more simply rejected the idea of having their hair coloured; for example, Quiana’s direct “no” (2/10) when asked if she would like her hair coloured. In these respects the women reflected other research that suggests hairstyling to be a purposeful decision related to the identity that women wish to convey (Gimlin, 1996; Gimlin, 2002; Hurd Clarke & Korotchenko, 2010; Weitz, 2008). In her interviews with 44 women in Arizona, Weitz (2001, 2008) focused on how the women’s hairstyle choices were used as a source of power, identifying that the women made conscious decisions about their hair with the intention that the style chosen would help them to achieve a personal goal. Some of the women in her study aligned with feminine values, whereas others purposely chose to use less feminised hairstyles, such as short or tied back, which they explained in terms of being seen as competent, more powerful or simply challenging of stereotypes. Interestingly, she found that women who belonged to minority groups, distinguished by facial features, skin colour or hair, were more conscious of their hair on a daily basis; for the other women, similarly to Gimlin’s (1996) findings, once their hair was styled they paid it little attention between hair appointments.

To explore the influences that there might be on the decisions that the women made about their hair it is interesting to consider who styles their hair and the role of support people as well as the affordability. The latter is identified as an issue in the United States, where there is significant variability in salon costs (Duesterhaus, Grauerholz, Weichsel, & Guittar, 2011) and, from the limited information that the
women shared, would seem to also be an issue in New Zealand, even within relatively small rural towns. Most of the women went to hairdressers within the shopping centres of their town for cuts, colour treatment and, in Ilona's case, her perm. As Eva expressed it “I can’t cut my own hair” (2/5) and Hesta reported, “A lady called [name] does my hair. Yeah I have my hair done now and again.” (2/5), and as part of the conversation about her six monthly perms Ilona noted, “Yeah, I have appointment next Friday.” (2/33). In addition to Hesta, Tanya was the only other woman to name her hairdresser, with most simply stating “At the hairdressers” as Patricia did (2/8) or “the lady in town” as Quiana (2/8) put it when asked who cut their hair. Responses did not suggest that status of the hairdresser was important to the women, as it had been to those in Gimlin’s (1996) research.

Aside from the women who went to hairdressers there were a few who had support people cut and/or colour their hair. It was difficult to conclude what that might mean for the women in terms of choice but they usually had stylish cuts and colours, which did lead the researchers to wonder about the support person’s previous experience. Vera was clear that “[name of support person] does it” (2/21) when discussing both her hair colour and cut, although it was not evident where the support person had gained experience. Francisca volunteered little information but agreed with suggestion of her interviewer ...

   Interviewer A: Do you go to the hairdresser? Who cuts your hair?
   Francisca: My care person.
   Interviewer A: Does she? She’s done a good job.
   Francisca: Yeah.
   Interviewer A: Yeah. Has she been a hairdresser or something?
   Francisca: Oh yeah.
   2/43

It is, of course, difficult to know whether Francisca is simply being agreeable, possibly not actually knowing whether or not it was true as, with other questions, she was more likely to disagree if she knew the answer. Although neither Vera nor
Francisca commented on the cost of professional cuts and colours, this was an issue for some of the women living independently. Nadia regretted her recent haircut stating, “I should have just left it. ...Yeah, for a wee bit longer. I’ve still got to pay her” (2/39). As Gimlin (1996) found, a few women planned their appointments with hairdressers around their ability to save. When their support person cut or coloured their hair at home it saved them money. For example, Ilona had identified that she had an appointment for her perm, but when asked if she would have her hair coloured at the same time, responded “Wait for more money” (2/33). In field notes her interviewer wrote that Ilona’s support person seemed influential in her choice of hairdresser and, interestingly, at her third interview Ilona had a different support person who had helped her to find a cheaper hairdresser for perms and they were now colouring Ilona’s hair at home, decisions that seemed to suit Ilona.

In constructing their body image, then, hairstyles provided a basis for the women to express themselves in a way that cosmetics did not seem to. At the same time their hairstyles did not appear to require daily attention, making them more manageable. Whilst the interviews provided limited insight into the influences on the women’s choice of hairstyle there is some evidence to suggest family and support staff had a role but as many went to salons, it is equally likely that their stylist would contribute ideas. As with cosmetics, there was no evidence that the women drew their ideas for hairstyles directly from the media, although some did appear to be following fashion trends with the way that their hair was coloured. For those women who did enjoy having their hair styled and coloured or could take pride in their natural colour, their hair contributed to a positive body image.

### Summary

The theme “tidy, clean and conservative” provides insight into how the women might construct their identity, including influences that shape their construction. Of note, few women appeared to use mirrors, or any other strategy, to try out different looks. Instead mirrors were a means to evaluate their appearance against socially prescribed standards of body shape and tidiness and, in a few cases,
appropriateness of clothing for the occasion. These findings contrast with the much more frequent use of mirrors seen in Coleman's (2009) study, and while that may be a function of age, it is notable that Black (2004) considers that the use of mirrors does not decrease significantly over time.

To control their identity and how it is portrayed to others women need to have choices about ornamentation items and practices. Clothes and hairstyles did provide the women with opportunities to make their own choices, with some actively encouraged to do so by the people accompanying them. However, whilst the women felt they were choosing freely, the limited range of clothes and reliance on family or support people for shopping and appointments meant that their choices were limited. Their emphasis on being tidy and the reasonably conservative shops to which they were taken suggest that ‘fitting in’ was more important to those accompanying them than an opportunity to express individualism. While hair colour might seem more ‘risky’, the women’s choices were still within current trends at the time.

Peers were virtually invisible as influences on the women’s construction of their body, contrasting with most of the research for women generally. As Hesta illustrated, peers might be particularly important for the adoption and choices of cosmetics. It is often in peer groups that discussion about preferences and opportunities to try out looks takes place (Coleman, 2009), with the findings suggesting that the women have had little opportunity to do so. The early influence of mothers may have been more important (Lennon, 2012; Rodgers, 2012), with Wilma illustrating current practices with her mother and Ilona the earlier influence of her mother. It should be remembered that 15 of the 25 women were over forty and have grown up in a time when mothers may have had more conservative views on both the use of make-up and the age at which it is appropriate. The evidence from other literature is that women often do refer back to these earlier influences for their construction of their body as they age (Grogan, 2012; Hurd Clarke & Griffin, 2007).
All women are constrained by the money that they have available to engage in ornamentation and other body practices they might choose to express their identity; however, for women on limited incomes constraints are tighter. Not surprisingly cost was a factor for a number of the women. Most evident with hair and clothes, it is also possible that cost was a factor in the use of cosmetics, including face creams. In addition many women did not control their savings, and had to plan shopping excursions in advance. Given that some of those with greater levels of support did not do weekly supermarket shopping either, for these women there would appear to be little opportunity to choose cosmetics. Seemingly the widely accepted influence of the beauty industry (Wolf, 1990) had little direct influence on the women’s engagement with, or selection of, beauty practices with only Ursula providing any indication of brand preference. The combination of various influences appeared to support the women’s construction of their body as neat and tidy, enabling them to feel comfortable within their social world. There was limited evidence of opportunity for creativity or interest in presenting as glamorous and fashionable in order to suggest a higher status to others.
Chapter Six: A fit and functional body

Introduction

Although body appearance is frequently related to the construction of women’s body image, the current research found that a number of the women were at least as interested in their fit and functional body. It was evident in the data collected that the women recognised the importance of their physical body both in terms of how it functioned and how it represented their ability to meet social standards. The previous two chapters might be seen as illustrating the emphasis that social standards had on their body image, whereas this chapter draws in the importance of internal bodily influences, as suggested by an understanding of embodiment, to recognise the interaction of multiple influences on the women’s perception of their body image.

This theme integrates the interview data that referred to self-perceptions of physical competence. In some cases physical competence was directly related to being active and healthy but in other cases it signified the impact of impairment on the physical body and what that meant for how they might be seen by others. Such impairment could be physical, cognitive or as a result of mental illness. As discussed in Chapter Two, it has long been recognised that higher order self-concepts, such as body image and self-esteem, are influenced by physical competence (Lindwall, et al., 2011) despite the relationship between these not being clear or consistent, it does make the women’s perceptions relevant to any discussion of their body image. Whilst there is one group of researchers working to develop greater understanding of interaction between physical self-concept and self-esteem with French-speaking adolescents with intellectual disability (Maíano, et al., 2009; Maíano, et al., 2011), these would appear to be the only studies with that specific focus. However, as indicated in previous chapters, other research with women with intellectual disability does infer a relationship between their thoughts about their body and their self-esteem (for example, McCarthy, 1999).
This chapter is divided into two subthemes, “being active” and “being competent”. The second of these subthemes is further divided into the influences on perception of the physical body, that is knowledge and understanding of how their body is affected by physical or mental health conditions; perception of social impacts, or influences, and the relationship between these and their body image; and finally how the women felt about receiving assistance with personal hygiene. This latter section draws on implications for the women that tie body image with self-esteem.

**Being active**

The subtheme of being active generally demonstrates a positive conception of body image for the women. It is widely accepted that there are many benefits to both having, and perceiving to have, a body that is physically active (Yeats, 2010), including independence with Activities of Daily Living (ADLs), mental wellbeing, higher self-esteem and awareness of functional aspects of the body. For example, in a meta-analysis of fifty-seven interventions, Campbell and Hausenblas (2009) found that exercise programmes, particularly those that were active as opposed to lecture-based, improved body image satisfaction. Interestingly, it did not matter whether there had been an actual improvement in the fitness measures. In a subsequent small study that attempted to control for such improvements, Appleton (2013) offered further support to the idea that exercise improves body satisfaction at least for some people. Carraça et al.’s (2012) findings, following an intervention with overweight and obese women, suggest that there is ongoing benefit in structured physical activity for body image, thought to be associated with shifting the women’s predominant focus away from their body appearance. There is also the thought that exercise benefits mental health, however Asztalos et al. (2010) and Harvey et al. (2010) suggest that social and contextual factors are likely to be implicated in findings that relate exercise to mental health. In Harvey et al.’s (2010) large population-based study (n=40,401) leisure time activity of any intensity was beneficial but this activity was also related to social support and engagement. Illustrating the difficulty that there is in making robust decisions about the benefit of exercise.
In contrast to the literature that espouses benefits to health from exercise programmes, there is a body of literature that questions these assumptions and also the potential for further stigmatisation of bodies that do not meet the ideal social standards (Mansfield & Rich, 2013). By promoting bodily perfection through exercise, the individual is considered responsible if they do not work to achieve the socially prescribed outcomes. As Mansfield and Rich identify, such a focus ignores the lived experience of individuals, who might for various reasons either choose not to, or be unable to participate. Furthermore, although it is generally accepted (even within this literature) that some activity is beneficial, isolating exercise from lifestyle is simplistic and not shown to have reliable health benefits.

It was interesting, then, that for a number of women in the study there was obvious pride in their physical fitness and participation in exercise, illustrating the relationship between perception of physical competence and self-esteem, as suggested in Chapter Two, and potentially identification with the health messages. Indeed, for a small group of women, some of whom struggled with the CDRS, as identified earlier, their focus on their physical competence may support Maïano et al.’s (2011) hypothesis that people with intellectual disability who have less inclusive lives, as it would appear that most of the women in residential services had, might be more positive about their body image. However, given that most of these women were involved in a number of activities it could equally support both Carraça et al. (2012), as above, and Martin Ginis et al. (2012) who, following their research with 88 overweight or obese women, also hypothesised that aerobic and strengths-based exercise shifts perceptions to functional rather than beauty aspects of the body. In addition, Levy and Ebbeck (2005) found that higher levels of exercise are related to higher levels of both physical competence and acceptance.

That over half of the women mentioned regular participation in sport or physical activity suggests that New Zealand women with intellectual disability may be more active than similar groups in the United Kingdom, with Emerson (2005) finding only 8% of the men and women surveyed meeting the measure of exercise believed to be necessary for health. However, the results also question the
Background Papers for “To have an ‘ordinary’ life” (National Health Committee, 2004) that suggested it was unlikely that New Zealanders with intellectual disability would be engaging in physical activity. Perhaps the best explanation is that the results indicate a change in behaviour, with the messages about the health benefits of fitness strongly represented at policy level (for example, SPARC, 2005 within New Zealand and Yeats, 2010 in Victoria, Australia). From the perspective of initial interest in bodyweight that led me to the topic of body image, this subtheme is also of interest owing to mounting evidence that regular physical activity may be a better predictor for preventing adverse cardio-vascular events than measures of obesity, meaning that a focus on an active body is more helpful to long term health than focusing on weight loss (Wessel et al., 2004), which often also leads to objectifying and devaluing people who are overweight or obese.

The results of the current study illustrate that having a body that enabled the women to be fit and active was important for various reasons. Even for those who had very little else to say about their body ...

Interviewer A: ..... have a wee think about what you like most about your body.
Rosa: It's healthy. ........
Interviewer A: And why do you like it cos it’s healthy?
Rosa: To be nice and fit ...
Interviewer A: Okay. And does that help you do things?
Rosa: Yes. .....With walking, yes.
2/7 (long hesitations removed)

Interviewer C: Okay. So would you say that you were fit?
Kura: Yes, fit as a fiddle.
1/7

The women focused on maintenance of fitness, rather than improving fitness, or, as seen in some of the self-objectification literature, improving physical appearance (Prichard & Tiggemann, 2008, 2012a, 2012b; Strelan, et al., 2003),
with none commenting specifically that they exercised to look good. Prichard and Tiggemann (2008) do, however, suggest that whilst most women will cite health and fitness as the purpose of their exercise, those spending longer hours at the gym, and engaging in more cardio workouts than other types of exercise, are more likely to score higher than other women on self-objectification measures. There was no suggestion that the women in this doctoral study were particularly focused on such workouts with a circular argument for being fit and active as much as some women could manage, in other words their liking for being fit and active was because it meant that they could be fit and active. Interestingly, however, even when they had physical restrictions, the women were generally positive, with some speaking with pride about their ability. For example Eva, with significant heart failure, commented:

Eva: My walking distance is quite good. ...
Interviewer C: Oh good. How far are you allowed to walk, do you know?
Eva: Just up and down out in this aisle.
Interviewer C: Oh okay.
Eva: Yeah, not very far.
Interviewer C: Right.
Eva: Yeah. It’s good for me.

13/9

Thirteen women provided examples of activities, such as swimming, bike riding, walking, horse riding and dancing. It seemed that for most of these women the opportunities to engage in sport and other activities came through the organisations that supported them, or special programmes such as Riding for the Disabled and Special Olympics ...

Interviewer A: ... You’ve been in the Special Olympics.
Ilona: Yeah, the first time 1985 I was there in the swimming.
Interviewer A: So 1985 you were swimming.
Ilona: Then in 1990 and ‘94 I was in the walking race.
Interviewer A: So '94 and '90 you were walking.
Ilona: Walking ... Now I play bocce.
2/22 (abbreviated)

Few independently sought out activities. Having readily available suitable activities has been identified as important for motivation to encourage physical activity (Lox, et al., 2010). In this respect, the activities provided opportunity and, for those that engaged in them, pride in their achievements, reinforcing the value to their self-esteem, such as Julia’s comment that was said with pride ...

Julia: I've done Special Olympics, I've done swimming.
Interviewer A: Oh okay. Are you a good swimmer?
Julia: Yep.
1/16

Others have suggested participation in such activities provide benefits to self-esteem and global self-concept for disabled children and adults (Martin, 2010; Martin & Whalen, 2012), in part because they have similar abilities, in contrast to the wider range of ability seen in more mainstream sporting activities, from which they commonly face exclusion anyway (Bucciere & Reel, 2010). However, the dependence on organised activities also makes their positive body image, implicating self-esteem and emotional wellbeing, somewhat vulnerable to the activity remaining available and there were examples within the research where lack of volunteer support had meant they ceased in that region.

Nadia, who was well integrated into her community, was the only woman that currently appeared to belong to a community sports team without requiring support to do so, although in the past Georgia had belonged to a local pony club. Indeed, Georgia’s understanding of her physical limitations might challenge the need to be in special activities for purposes of self-esteem suggested by Martin (2006) above. Although she was unable to compete at a higher level than a D Certificate due to her physical health she explained her success at pony club with obvious pride ...
Interviewer C: Okay. So what do you think are the best things that have ever happened to you?
Georgia: My family, my horses... I remember what it was now, my D certificate in the paper.
Interviewer C: What was that for?
Georgia: It was pony club.

Organised activities are generally associated with women from higher income brackets and levels of education, whereas activities of necessity, such as walking for transportation, feature for those of lower income (Yeats, 2010). From this perspective an interesting contrast was evident for the women in the study, as those living with greater levels of support were more likely to be engaging in organised activities, whereas, for those more independent, walking was the most cited exercise. Walking supported independence and as such their motivation for exercise was, in part, related to maintaining body function (Avalos, et al., 2005). Ilona illustrated the importance when reflecting on her life ...

Interviewer A: If you think back over your life what has been most important to you?
Ilona: Going for a walk to town. ...And sometimes some shopping.
Interviewer A: ..... Yeah, being able to do things, those are the important things in life are they?
Ilona: Yeah.
Interviewer A: And doing it by yourself or with other people?
Ilona: By myself.

Ten women specifically mentioned walking both in relation to transport and fitness. To some extent the outcome of the necessity to walk for transport provides the advantage of positive emotional benefits, as one Australian survey based on self-report of 3645 women aged 18-45 years who were living in disadvantaged neighbourhoods found lower odds of depressive symptoms were
associated with leisure time activity, including transport-related walking (Teychenne, Ball, & Salmon, 2010). As noted above activity and fitness has also been shown to reinforce a positive body image (Campbell & Hausenblas, 2009). Due to their limited income these women have little choice other than to walk if they want to get to places, as Ophelia points out ...

Ophelia: .... at the moment a lot of us ones who've been sort of, well, supposed to have been supported but we're supposed to have been independent on everything but I mean with there being no sort of proper transport in [town] there's not a lot of travel or anything that you can get to and from to places if you really desperate need to go in a hurry.

Further on in the interview ...

Interviewer A: Do you walk most places?
Ophelia: Yeah, most places I walk and I mean it’s easy accessible to the medical centre and up town, cos we’re so close to up town and that.
Interviewer A: Right, yeah. So there’s no bus service in [town] though is there?
Ophelia: No, there’s nothing like that here.
Interviewer A: So if you’re out at night how would you get home?
Ophelia: Well by a taxi but I mean most of the time me and [flatmate] walk together.
Interviewer A: Right. So if you were out at night you’d just make sure you walked home together.
Ophelia: Yeah.
Interviewer A: And you feel quite safe?
Ophelia: Yeah, because we sort of make sure we don’t go out too late at night.
Interviewer A: And that’s because of safety is it?
Ophelia: Yeah.

1/8-9
It was noticeable that being able to walk where they wanted to go was more significant for those who lived independently. Typical of residential support in New Zealand, homes that had 24-hour supervision included a vehicle at the disposal of the residents, with a driver’s licence a requirement of employment as a support person. While those who were supported in residential care did, therefore, have shared access to a vehicle and a driver, it was more difficult for those living independently to access transport owing to cost and poor or non-existent public transport services. A number of the women interviewed, as seen with Ophelia, lived in provincial towns with no service; however, even in some of the larger towns that have a service they can be quite limited in frequency. Thus, walking becomes the only alternative but does have the advantage of being a readily available form of exercise even if it has to be carefully planned to ensure safety.

While the availability and affordability of transport were clearly a problem, the women in provincial towns did appear to benefit from the relative size of their town, which meant that most places they wanted to go were within walking distance. However, that was only available to them whilst they were physically able. The eldest participant, Sylvia, was very aware of the importance of remaining active enough that she could stay in her own flat. Whilst the physiological effects of Sylvia’s body size and history of smoking, such as breathlessness, made it difficult for her to engage in exercise, like other women with physical impairments (Chrisler, 2007), she was conscious of the impact on her life overall if she could not maintain sufficient activity to be independent. Interestingly, as noted in Chapter Four there had been repeated attempts for dieticians to assist her with weight reduction; however, an approach to her overall health from the perspective of increasing activity did not seem to have been considered, yet may have been more fruitful and practically useful to her. As Wessel et al. (2004) noted, following their longitudinal study of 936 women over four years, higher self-reported physical activity is independently associated with fewer coronary artery disease risk factors, with measurements including angiographic evidence, whereas obesity was not shown to be independently associated with such factors. From other limited research, as discussed in Chapter Two, regular activity has been shown to enhance self-perception of physical condition among women (Elavsky & McAuley, 2007;
Levy & Ebbeck, 2005), with Levy and Ebbeck also noting that exercise self-efficacy is more likely when the woman perceives she is physically competent. These were clearly concerns for Sylvia, who spoke at some length about what her independence meant to her as she reflected on previous experience of living within a supervised setting.

For the women who relied on walking as a way to be independent there was little need for additional motivation and, with regard to their body image, it appeared to be related more to maintenance of fitness and health than achieving the slim, ideal body seen in those who spend hours in a gym (Prichard & Tiggemann, 2008). Although the interviews provided insufficient information to draw out motivation with many of the women who participated in organised activities, given the emphasis on physical activity in their weekly plans, it is likely that the positive responses of significant others were implicated (Avalos & Tylka, 2006; Pelican, et al., 2005). Pelican et al. found that influential people, such as family, teachers or coaches, tended to make the person more confident both about their body image and physical ability while negative responses, even years after they had been experienced, impacted in terms of lowering body image and confidence with physical ability. As noted above, Rosa was proud of her physical fitness, which was maintained by a weekly programme that included swimming, yoga, gym activities, basketball and snooker. Although she was probably the extreme end of multiple activities, it was not uncommon for the more active women to mention three different forms of sport or exercise that they did each week. Given the emphasis that some women (for example, Rosa and Barbara, as indicated below) put on being active as the most valued self-perception of their body, it is possible that they have internalised motivation to the point that they see themselves as ‘an exerciser’ (Lox, et al., 2010).

Whilst participation in organised activities was more likely for those living in residential support, some who lived independently also took part in these programmes. As suggested above in regard to health policy, there appeared to be an emphasis on healthy living for many of these women, with some women identifying reasons for being active, including weight control and improving
measures of health such as blood pressure recordings. This emphasis on being active (and following healthy eating habits) was reflected in the women’s responses to questions about their body, as illustrated in the following dialogues:

Interviewer A: Are you happy with your weight? ...
Marika: Yeah, I’m doing some good exercise.
2/21

Interviewer A: And what do you mostly eat? Do you mostly eat what you like or?
Marika: Yeah, just small meals now it is, yeah.
Interviewer A: Small meals. Whose idea’s that?
Marika: Oh that’s everybody’s for fitness, for healthy living, you know sort of thing, yeah. ... Go for walks every day.
2/23

Whilst in response to the question of what she liked best about her body Barbara responded:

Barbara: It’s special to me. ...
Interviewer A: In what way is it special to you?
Barbara: To keep healthy...
Interviewer A: Yeah...anything else?
Barbara: ...and I keep active every day ... see the doctor for my chest and for my back and then sometimes he takes my blood pressure to see if it’s going all right.
2/26

Whilst being active was generally seen as related to using their body as a means of activity, it is important to note that Yolanda, the one woman who used a wheelchair constantly, incorporated her electrically controlled chair in her body image for the purpose of independence and activity ...
Interviewer C: ...Now what else was it that you told me was one of your hobbies
Yolanda: Going for walks
Interviewer C: Going for walks. Do you go by yourself sometimes?
Yolanda: I go in my wheelchair
Interviewer C: Yeah. And do you go by yourself in your wheelchair?
Yolanda: Yes
Interviewer C: Yeah. Do you prefer it that way?
Yolanda: Yes

In summary, having a body that was fit and enabled activity was a key component of the women’s body image. The responses that have been interpreted as relevant to this aspect of the theme were mostly suggestive of how the women saw their body as a whole. Despite their mostly positive responses, many of the women did have significant health or physical disability issues that limited their mobility and/or their independence. Understanding how their body contributed to a sense of competence provides further insight into influences on their construction of their body image.

**Being competent**

Being physically active provided satisfaction with their body for a number of the women, however the physical body and ability had other meanings in terms of body image. A number of the women had a physical impairment in addition to their intellectual impairments or were vulnerable to mental illness, with each of these situations interacting with body image. Physical impairment, as seen above, influenced activity, however it also provided insight into how the women understood their embodiment, including relationships between physiology and symptoms, along with the personal and social consequences, including stigma. Although implicated in social consequences, intellectual impairment and mental illness led some of the women to view their body in terms of what it signified in relation to their impairment. In particular, competence with ADLs that related to
body were important evidence of either intellectual or mental functioning. Each of these aspects is discussed separately below, although, as with other sections, in understanding each woman’s global body image they are related.

**Understanding the body**

For half of the women interviewed, questions about how they saw their body drew responses about some component of their body that did not function in a way that they perceived as normal or healthy. It was not uncommon for these women to emphasize their ability despite their physical impairment, such as seen with Eva above in relation to her walking distance, or Nadia, who had multiple physical challenges mostly related to her spine and complicated by her obesity, commenting ... “Yeah. At the moment. I’m not falling to bits.” (2/30). Physical limitations related to previous injury and conditions, such as arthritis, brought out general complaints about sore knees, backs and other joints, more commonly from the women in their forties to sixties, but both Quiana and Wilma also commented on painful joints. Some women stated frustration that the joint did not work as they felt it should, with Ilona and Marika identifying that they sometimes fell when their joint “gave way”. Although there was the potential that pain might limit activity for these women, a number of them did persist with attempts to be as active as possible. Some had regular medication to help with their pain but alternative therapies, such as physiotherapy, seemed rarely to be offered. Whilst many provided little description of their condition, most of the women with significant physical impairments provided insight into their understanding of their condition. In some cases understanding drew on objective knowledge of anatomy and physiology, which they then related to the subjective, through their symptoms and implications. For example, Georgia explained the work that had been done to date to correct her congenital dislocated hip that had been untreated in infancy ...

Georgia: Yeah, what they’re trying to do is when they first found out my condition they made the socket a bit rounder so my ball would kind of fit. ... And then what they were doing is they had a special plate in my leg and it was like a thing that you can shorten and lengthen. ...
And they used to cut my bone, lengthen that out, force my bone to grow, [stretch] my legs inside, but it didn't work.

2/3

Furthermore she understood that all this surgery had implications for her body beyond her hip ...

Georgia: Sometimes it is but except for when I get sick because of me having a bad hip and that and I've had so many operations on it my immune system – they've said my immune system's got worse and it's deteriorating so I get very, very sick.

1/9

Whilst Eva had a more difficult task in trying to explain to the researcher why she needed oxygen as a result of her end-stage heart disease, she was clear what it was not related to ...

Eva: Yeah. Sometimes I use that oxygen out there and...
Interviewer C: And why is that Eva? Why do you have to have oxygen?
Eva: Because it helps me breath properly.
Interviewer C: Okay. Do you have asthma?
Eva: No. ...
Interviewer C: So do you know why you have to have oxygen?
Eva: Cos I get short of breath. ...
Interviewer C: Okay. So is that something that might be wrong with your lungs or?
Eva: No, it's not.
Interviewer C: No.
Eva: And I use that other concentrator at night. ...
Interviewer C: So you have that on at night.
Eva: During the night, yes. ...And it keeps me right.

1/7-9
Interestingly, Eva took the whole body experience in a different direction to Georgia ...

Interviewer C: So when you’re feeling unwell ...
Eva: Yeah, but my whole body knows what I want.
Interviewer C: Right, so you don’t feel bad about your body when you’re feeling sick?
Eva: No.

The idea of the body as a whole interacting and providing information back to the self, or to others when the self is struggling to make sense of what is happening, is seen with those experiencing mental illness. Marika explained how she behaved prior to a hospital admission, which she hypothesised as her body and mind working together to express her need for help ...

Marika: Like one time I lied down on the floor at the centre ... and [support person] said to me: get up, get up. You know I even packed my bag for a couple of times ... So I must have known I need to go to the hospital.

Being able to make sense of what is happening to their body might have gone some way to helping the women accept changes to their life, but it was clear that for some the social impact of their disability was more difficult to accept.

Social impacts

Physical impairments mark the body as ‘other’ in a way that intellectual may not so readily. However, attention to physical presentation, which may be influenced by either intellectual or mental function, can make a person stand out in a social setting. While the influence of beauty standards (Grogan, 2008), other than weight, had limited effect on most of the women, there was no doubt that a
number of the women reflected on how they could meet social standards of hygiene. Although none of the women used the word, essentially what they were wanting was not to be stigmatized or excluded on the basis of their impairment. The body that was visually ‘other’ was at risk of being so and, for those with an obvious physical impairment, difficult to avoid, whereas those with an intellectual impairment or history of mental illness could use their well-presented body as evidence of their competence and therefore of being worthy of inclusion.

Among the women most vulnerable to stigma, owing to the obviousness of their physical impairment, there were variations in how that affected them. Young people with congenital heart disease have been shown to use their knowledge of their physical capacity to try to minimise their breathlessness in the hope that they do not stand out (Claessens, et al., 2005; McMurray et al., 2001), however both Amelia and Eva were experiencing illness that was beyond such measures. From their various responses it could be interpreted that Eva understood her condition was one that would not markedly improve and had come to accept her social limitations, which were significant in terms of previous years. Amelia did suggest some understanding that her condition was limiting her opportunities, for example, she had recently given up a treasured job because of her health. However, she remained optimistic suggesting to the interviewer that she would be able to travel overseas later in the year because “No. I’m much better then.” (1/22). In other words, she could see the immediate implications for her socially but had less understanding of the wider issues that such travel arrangements might raise for someone with a major medical condition. As indicated above, Georgia had a good understanding of her physical limitations and she had over the years attempted to minimise these in order to remain socially engaged. However, she had reached the stage whereby that was no longer possible, as she described when asked about friends ... 

Georgia: Not really, as I said the other day when you talked to me about my friends, half of them don’t want to be my friend anymore cos of my disability.

Interviewer C: Okay, because you can’t go out and do things with them.
Georgia: Can't do things with them at all.
2/5

Thus, all three comparatively young women were experiencing changes in their social milieu, including becoming more isolated. Whereas for Eva and Amelia it might be considered an inevitable consequence of their terminal illness, something Eva had incorporated into her body image, Georgia’s situation was different. As indicated above with pony club, Georgia was used to participating at the level she could achieve and accepted her body in those terms. Being totally excluded, as was happening with friends, made it much more difficult for her to accept her physical deterioration.

A similar response could be seen with Ursula in relation to her recent seizures that resulted in a head injury. A major concern to her was the protective helmet she was now expected to wear and which she felt made her more obviously ‘different’ as well as limiting her social opportunities. Whilst seizure patterns can change throughout life, for people with epilepsy social stigma may well be a reality that they have felt for years (Hermann & Jacoby, 2009; Smith et al., 2009). Ophelia explained how she saw safety as having a social impact ...

Interviewer A: So how have your seizures affected your life? ...
Ophelia: Well probably only in different ways but like I mean especially in the way some might say: oh why don't you go swimming or something? Like I mean for one I don't like going swimming on my own because you never know when they'll come and like that’s the only reason I don't go swimming on my own.
Interviewer A: Right.
Ophelia: And when they say: well you're independent. I mean I still think: well you still need that bit of support.
Interviewer A: Because of your seizures.
Ophelia: Yeah.
1/25
None of the women reported that they have a warning, thus, they were not able to take themselves to safety prior to a seizure therefore it is likely they have experienced a seizure in a public place at some stage. In terms of stigma, interestingly, none suggested they were particularly worried about how they were perceived by those around them at the time of their seizure. Although this might be questioned for Ophelia as her response above does indicate seizure worry, which has been associated with people with epilepsy having a higher stigma score (Smith, et al., 2009). What is more Ophelia’s behaviour with regard to ensuring she looks neat and tidy might suggest that she is conscious of needing to minimise her potential to be stigmatised further ...

Interviewer A: ... Do you look at yourself in the mirror?
Ophelia: Yeah, I do at times, like especially if I’m going out anywhere and I’m dressing up for anything in particular. I mean, yeah, I don’t always do it but only when I’m sort of going out and I’m trying to make myself look nice and tidy to go out to people’s places and that, so I know I look presentable to go out to each other’s place and that.

2/13

Smith et al. have suggested that the combination of epilepsy with disability is implicated in greater stigma scores.

However, Ophelia was not alone in recognising the importance of physical presentation in reducing stigma and enabling social interaction. Intellectual impairment in itself was seen by some women as reason to be extra vigilant if they wanted to be seen as socially competent. Sylvia, having received previous feedback that she “smelt” was now careful to maintain her personal hygiene, including carefully washing her clothes. As with her desire to remain active, she associated the need to meet social standards with remaining independent. Being able to take care of one’s own hygiene needs is an expectation of most people; however, for people with intellectual impairment it may take longer or not ever be achieved (Boulet, Boyle, & Schieve, 2009; Woodward, Swigonski, & Ciccarelli, 2012). Two of
the women identified particular pride in their body as representing their ability to meet the basic social standards ...

Interviewer A: ... What do you like most about your body?
Patricia: I have showers.
Interviewer A: Yeah.
Patricia: Keep clean.
Interviewer A: You like to keep clean.
Patricia: And wash my hair.
Interviewer A: Yeah, and that’s how you take care of your body.
Patricia: And clean my skin. ...
Interviewer A: And is there any part of your body that you really like, that you think looks good?
Patricia: Clean clothes.

2/5

Although particularly difficult to understand, Dianna was persistent with making sure that the interviewer understood the importance to her of cleanliness when asked about her body. She first explained how she took care to wash carefully, including removing the soap, and then identified the routine for putting out the dirty clothes. This following excerpt picks out the thread of her statement including the verification that she sought from the staff member present ...

Dianna: Well take underpants put them in a bucket. ... Put my socks, pants... Isn't that right staff?
Support person: Yeah. ... Oh yes, she puts her knickers in the bucket.
Dianna: Yeah.
2/13 (edited)

Unlike Sylvia and Ophelia, Patricia and Dianna were supported 24 hours a day, however their contributions illustrate that, even at their more limited level of independence, the body and associated practices can represent competence and provide social approval.
In terms of their intellectual impairment, although competence in hygiene may take longer than for other people, once achieved it is likely to be reasonably stable, whereas for the women who experienced mental illness, hygiene practices and thus appearance could fluctuate. Vera explained both how her attention to personal hygiene was affected by her mental health and how her support worker has helped her to identify her change in behaviour in the past ...

Interviewer A: ... And if you're not feeling so well mentally, you know, when you're feeling a bit upset, do you find it is easy to look after yourself like that?
Vera: No. My personal health goes down.
Interviewer A: Does it?
Vera: Yeah.
Interviewer A: Can you tell me a wee bit more about that?
Vera: It goes down with my hygiene.
Interviewer A: Hm.
Vera: And I don't want to have showers and things.
Interviewer A: Right.
Vera: And I don't care what I look like and I get a bit not caring.
Interviewer A: Right.
Vera: Not caring what I look like and – not what I look like – well actually now I get all dressed up and stuff but those times I just couldn't care less what I look like and – you know.
Interviewer A: Right, yeah.
Vera: Couldn't care less.
Interviewer A: Yeah. So do you think that's a warning sort of thing for you?
Vera: Yeah, it's a warning. And I go very quiet.

2/24

Vera: It happened about five months ago.
Interviewer A: Did it?
Vera: Yeah.
Interviewer A: And what did you do?
Vera: I went downhill. I didn’t care for a while.
Interviewer A: Right.
Vera: And I wasn’t having showers and stuff.
Interviewer A: Oh okay.
Vera: And I went down a wee bit and then I started talking to [support person] and I had help from [support person] and [support person] pulled me through it.

2/29

Interviewer A: ... So what made you go and talk to [support person]? Or was it you went and talked to [support person] or [support person] came and talked to you?
Vera: Yeah, [support person] came and talked to me.
Interviewer A: Okay, so she saw that there was something going on.
Vera: Yeah, she saw me go quiet and that. She saw me going downhill a bit. And I started to get in bad moods and getting angry.

2/30

Thus for women with intellectual disability with or without mental health concerns, the care that they take of their body can demonstrate their competence to other people. Being competent is valued for the social approval that it brings as well as providing some independence and privacy. Competence with ADLs has also been linked to self-efficacy for people with disability (Nuñez, Keller, & Ananian, 2009; van der Slot et al., 2010) providing a basis for the women to have a sense of control in terms of what happens to their body. As Diana and Patricia demonstrate, personal hygiene practices provide an opportunity to develop self-efficacy. In addition to their comments, a few other women provided insight into how they felt about being assisted with personal hygiene. Requiring such assistance means that the control of their body in these matters is dependent on the support they receive.
Accepting personal hygiene assistance

Given the emphasis on independence with hygiene, it is not surprising that among the few women who relied on assistance for showers some found it difficult to accept. Various factors appeared to influence acceptance, including the reason for the need and the relationship between the person receiving and the person providing support. As suggested above, greater levels of independence with personal hygiene can influence self-efficacy and therefore it might be expected that would also be seen in other situations whereby the women could be expected to have some control.

Although other research suggests that people who have always had assistance with personal hygiene find it easier to accept (Nair & Wade, 2003; van der Slot, et al., 2010), the one woman in the current study who is in this position illustrated the discomfort of such vulnerability remains ...

Interviewer C: ... is there anything you dislike about your body? ...
Yolanda: Yes, when the staff have to wash me occasionally
Interviewer C: Yeah. So do you ... have a shower by yourself? ...
Yolanda: No, staff have to do it, help me with a shower
Interviewer C: Right. And you'd rather do that by yourself?
Yolanda: Mmm.
Interviewer C: Mmm. So are they good about helping you in the shower?
Yolanda: Yes

Most research that considers personal hygiene in relation to increasing disability suggests that independence with ADLs are among the desirable goals to continue to meet (Drageset, Eide, & Ranhoff, 2011; Nair & Wade, 2003). Aging is a factor in acceptance, with younger people less accepting than older. Throughout Ursula’s interview her vulnerability to changing ability was evident and particularly clear in the following excerpts ...
Ursula: But I didn’t used to have my down there but I’ve got to now. I don’t know.

Interviewer B: You’ve got – so what have you got down there? ...

Ursula: The pads and I’ve got to have… But I can’t put them in other people have to put them in.

2/5

To be clear, the pads that she speaks of were hip protectors designed to prevent hip fractures. In addition to recognising that she needed more assistance she had insight into her changing cognition, which she interestingly related to “a boy” whom she clearly sees as more intellectually impaired than herself ...

Ursula: And another person in this house that – a boy – can hardly talk at all and he gets – doesn’t know where he’s going, he gets into my room half the time and yet this morning I nearly went into his room. I didn’t know. … I can’t remember. I don’t know what it is.

You can’t really – some things get wrong and some things get right.

2/12

At sixty years of age Ursula fits with the younger people in Dragaset et al.’s (2011) study. However, younger than Ursula, Vera illustrated the impact long-term dependence on others for personal hygiene needs can have on self-efficacy within the context of her long history of mental illness. Vera spoke of the horror that she had experienced when first acutely unwell and staff in the psychiatric hospital had left her in “wet” clothes when she was incontinent of urine. It would appear, however, that on discharge she was provided with support to shower and dress and that had continued throughout the subsequent years (approximately 20), including moving from one town to another and back again and also through her being involved in some intimate relationships.

Vera: I get helped by the staff members.

Interviewer A: Do you need helped to get dressed?

Vera: Yeah, I need help to get dressed. ...
Interviewer A: So what do you need help with?
Vera: Putting my pants on and putting my trousers on and that and my clothes on.
Interviewer A: And is that because of your size ... or is that just because of...?
Vera: Cos that’s with my mental health.
Interviewer A: With your mental health?
Vera: Yeah, I’ve always had people helping me.
Interviewer A: Have you?
Vera: Yeah. When I was in hospital I had people helping me as well.
Interviewer A: Yeah. When you were twenty-one...
Vera: Yeah.

Then further on in the interview ...

Interviewer A: Did your mum help you when you were younger or did you dress yourself...?
Vera: No, I used to dress myself when I was younger. Yeah.
Interviewer A: So it was only after you started...
Vera: Yeah, mental health problems.
Interviewer A: Right.
Vera: I used to be in – when I was living in [town] I used to have a lady coming down and helping me shower and that.
Interviewer A: Oh okay.
Vera: Yeah.
Interviewer A: So you went to [Town] to be with a boyfriend?
Vera: Yeah, my boyfriend.
Interviewer A: And how old were you when you went to [town]?
Vera: I was about thirty odd.
In reality her current body size and a poorly healed fracture to her arm would make it difficult for Vera to be independent now. However, Cameron and McGowan (2013) have expressed concern that traditional psychiatric medical responses may foster dependence. What was of interest in terms of a relationship between such dependence and self-efficacy was her seeming lack of self-advocacy as she accepted what appeared to the interviewer to be poor treatment ...

Vera: Yeah, cos I broke my arm a long time ago.
Interviewer A: Has it never been properly fixed?
Vera: No. ...
Interviewer A: So why didn’t you get it fixed?
Vera: Cos I went to a physio and they didn’t fix it.
Interviewer A: So did someone miss the fact that it was broken or?
Vera: No, they knew it was broken...
Interviewer A: Yeah.
Vera: ...but they didn’t fix it very well.
Interviewer A: Were you not in plaster at some stage?
Vera: Yeah, I was in plaster.
Interviewer A: Right. Yeah.
Vera: Yeah.
Interviewer A: And how old were you when you did that?
Vera: That was about – must be about four years ago.
Interviewer A: Quite recent then.
Vera: Yeah.

2/22

It has been suggested that consistent nurturing relationships developed through the provision of personal care may provide people who are depressed with social connections (Drageset, et al., 2011). While it is concerning that such assistance with personal hygiene might lead to what could essentially be seen as learned helplessness, it is important to note that it can provide a legitimate source of touch that many women with intellectual disability might not receive, as Barbara illustrated ...
Interviewer A: And in terms of showering and all those sorts of things you do all that yourself?
Barbara: Yeah, I do all that myself.
Interviewer A: Yeah, do you like to keep yourself nice and clean or how often do you shower, you know?
Barbara: Oh every week. I get [support person] to do my hair. ... 
Interviewer A: You don’t do that in the shower yourself?
Barbara: No, I call out to [support person] and she does it.
Interviewer A: ... Is that cos you just like someone to come and do it for you or do you really need her to help you?
Barbara: To help me.

Barbara inferred that she needed help with her hair, however her relative independence in other matters would suggest that she could manage if that was her preference. Field notes written at the time of the interview identified the special relationship that the support worker had with the women in the house. Previous research has indicated the pivotal role of the support person, especially their sensitivity, when providing intimate care in the relative acceptance of receivers of such support (Conder & Mirfin-Veitch, 2008; Twigg, 2000).

To summarise this subtheme: competency could be understood as relative for women with physical illness or disability; however, how they felt about their body, as their social world was changed by that illness/disability, varied. Not surprisingly, recency was a factor as the person adapted to their revised body image, with knowledge and understanding of what is happening possibly facilitating adaptation. However, perhaps equally important was their social world that appeared to contract when it need not do so if appropriate support were provided. In contrast to the women with deteriorating physical health, the focus on competency for some women related to their intellectual impairment and social standing. Personal hygiene becomes an important marker of competence, as was seen with both those women who emphasised their independence in these tasks and those who expressed discomfort with their need for assistance. Thus, the
women who shared information relevant to this theme illustrated an understanding of social implications associated with their physical body.

Summary

Combining the various aspects of the women’s self-perception of their physically active and competent body, the chapter demonstrates the complexity of body image. The emphasis that the women placed on their fit and functional body was initially a surprise but perhaps reflects a shift to function over beauty as women age or develop illnesses. Where they struggled to identify separate aspects of their body that they liked, or reflect on beautifying practices, they recognised their body as representative of their conformity and competence. What is more, for the women who lived independently, their body was their mode of transport. There is something of a mechanical, objectified body within these conceptions; however, for a number of the women embodiment and subjective sensations were also evident. Embodiment came to the fore when the woman reflected on the impact of her mental or physical fragility.

Understanding the limitations of their illness or physical disability provided the women with comparisons that were more realistic for them than a comparison with an idealised ‘norm’. As illustrated above, acceptance of these limitations differed depending on various factors. Of interest is the evidence that others had taken the time to explain something about the condition to the women, yet, as will become evident in the next chapter, the ordinary, that is, the sexual, reproductive body has, for many women with intellectual disability, been left unexplained.
Chapter Seven: A gendered body

Introduction

Whilst not the specific focus of the research, consideration of the women’s perception of themselves as sexual and gendered beings is relevant to the construction of their body image. Social constructionist approaches to understanding body image rely on women internalising implications for their gendered body. The gendered body has been a significant focus for feminist writers, often associated with reproductive functions. Ussher (2006) suggests that the cultural positioning of the reproductive body has seen it as both “dangerous and defiled” yet also capable of provoking “adoration and desire, enthralment of the mysteries within” (p.1). Both positions have implications for the bodywork women then engage. Disabled women, however, may experience neither within a society that simply denies their sexuality (Shildrick, 2009). Schildrick’s focus is on physically disabled women and she acknowledges the potential for yet another discourse for women with intellectual disability. Of interest for the women interviewed in this research was how society’s positions played out in their interpretation of their reproductive, gendered body. Whilst recognised as simplistic, for the purposes of this theme, gender is understood as the social construction of the physical sex differences (Butler, 1990).

Although self-surveillance becomes sufficient for most bodywork, rendering it invisible, with regard to the reproductive body there remains external surveillance and control that differs across cultures (Ussher, 2006). The findings of the current research might suggest that women with intellectual disability are a cultural subgroup that experiences greater control than is seen with other women in the New Zealand context. Among the signifiers of adulthood, such as having a partner, being able to protect oneself and make choices about sexual activity, there was limited evidence. There was a comparatively high incidence of sexual violence; few of the women had experienced an intimate relationship and the use of a long-term contraception seemed to have a limited connection with sexual activity. Interviews did differ in terms of the depth of exploration of these topics; for some
women they were a major component of the interview whilst others provided straightforward answers seemingly having little experience to share. Both extremes are of interest in this theme. However, a limitation for this theme is that the women were only questioned about sex, sexual health or contraception if the woman first raised an associated issue. This decision was based on the limited contact that the researchers had with the women and that the topic of sexuality was not specifically identified in the information sheets or consent process. As noted by McCarthy (1999), sensitive topics require multiple interviews and it should be clear to participants what they are consenting to prior to discussions taking place.

While the current study did not set out to explore gender, inevitably, when considering body image and, through the wider study on mental health, the women’s perceptions of their body as gendered formed part of a number of interviews. This chapter focuses on the data that provided an insight into these perceptions. Three subthemes are used to illustrate the role that identity with gender has developed in the women who chose to share information, with these subthemes being 1) a reproductive body, 2) Boyfriends and marriage and 3) experience of sexual violence. There was no doubt that all participants understood sexual difference, including experience of the male gaze, such as Ilona “sometimes the boys were trouble” (2/7) when they peeked through a gap in the girls’ bathroom at her boarding school. While for Georgia helping out with her father at her brother’s school drew the comment “all the boys looked at you...cos I was the only girl there” (1/6), Wilma emphasised difference through her comment “And like me on my own, the only girl, it’s just lonely.” (2/3), when describing her current living situation. The following subthemes incorporate the meaning made of sexual difference.

A reproductive body

One of the things that struck me when first reading the transcripts and field notes was that a number of women were hesitant to speak about their bodies, particularly in relation to more intimate aspects such as they might perceive...
menstruation, contraception or menopause to be. The overall sense that the body is “private” is echoed in other research that has specifically asked about these issues with women with intellectual disability (for example, McCarthy & Millard, 2003; Rodgers, 2001) but as Ussher (2006) notes, women without disability are also reticent about discussing menstruation. Indeed, it was only through conversations about contraception and sterilization that attitudes towards menstruation were exposed in the current study. Experience of menopause was not discussed, although two of the older women identified that they had ceased menstruation and, as will be seen below, another woman in her late forties had no idea whether or not that might be the situation for her as she was using hormonal contraception. As research that has specifically explored menopause has found, women with intellectual disability are not particularly knowledgeable about menopausal symptoms. For example, McCarthy (2002) found that women were more likely to understand an end to menses if they had experienced menopause than those yet to reach that stage in their life; while Willis (2008), in contrast, found five of the ten women in her study identified that they still menstruated when others reported them as having ceased menstruation. Hot flushes are as likely to be understood as environmentally caused as related to the changing nature of their body (Brown & Gill, 2009; Willis, 2008; Willis, Wishart, & Muir, 2011). Overall, these and other physical changes do not seem to be seen as particularly remarkable by the women (McCarthy, 2002), with Willis (2011) and McCarthy both noting the difficulty they had in teasing out menopausal symptoms from other issues that the women reported.

Attitudes to menstruation and contraceptives provide insight into wider social attitudes towards the bodies of women with intellectual disability, thus findings related to either provide potential for understanding their body image and associated behaviours discussed in previous chapters. Other research has suggested parents, medical professionals and support services influence prescribing of contraceptives. For example, Hollomotz (2011) describes how mothers insisted that their daughters used contraceptives whether or not they were sexually active. McCarthy (2009, 2010) found that most of the 23 women she interviewed thought that either their general practitioner, staff or parents made
the decision, while the general practitioners (n=162) that she surveyed, as part of the same study, had little experience of working with people with intellectual disability and were inclined to seek guidance from staff or parents, seemingly confused about who could legally consent to treatment. In Servais et al.’s (2002) study of contraceptive use within Belgian institutions for people with intellectual disability, factors associated with contraceptive use were associated with the policy of the facility, more so than factors associated with the individual woman. Thus, although overall use of contraceptives is lower in the population of women with intellectual disability than it is in the general population, others often control its use in a way that would not be considered appropriate for most women.

Entry into conversations about menstruation and contraception did not necessarily follow from questions about sexuality, as might be expected, instead it was drawn from conversation about health, medication or boyfriends. Menstruation was generally referred to as ‘period/s’, this being a term that generally has shared meaning for women in New Zealand. For example, Barbara “No, I have needles for that” (1/27), when asked if she used paracetamol should she experience pain with her periods as a way to explore medication use. All three researchers were aware of controversy about the use of depot medroxyprogesterone acetate (Depo Provera) for women with intellectual disability, which meant they were more likely to encourage or seek further detail. The wider literature would suggest that regulation of periods is often the stated purpose in medical records, with a number of women administered contraceptives not being necessarily sexually active (Paterson, Ashton, & Harrison-Woolrych, 2009; Servais, et al., 2002; van Schrojenstein Lantman-de Valk, Rook, & Maaskant, 2011). These medications are often started before the young woman is deemed competent to provide consent; however, the pattern of passive acceptance noted by McCarthy (2009) would suggest that it continues well beyond that stage. While some argue that long term use of Depo Provera may be harmful, many women with intellectual disability appear to be on it throughout their reproductive years and, seemingly, beyond (McCarthy, 2009, 2010; van Schrojenstein Lantman-de Valk, et al., 2011).
Use of Depo Provera within New Zealand has been reasonably common within the general population, with one study indicating that 13.7% of women aged 25 to 54 years reported use at some stage in their life (Paul, Skegg, & Williams, 1997). However, only 53% of these women reported use for more than one year and these were generally multiparous women (that is women who have had more than one baby); for many other women it had been a single use. There is, therefore, a different pattern of use seen for the four women in the current study that identified that they were using Depo Provera. For three of these women the purpose was not identified as a contraceptive, but rather a way to control menstruation, in line with the research mentioned above. Given that Barbara was in her late forties it was interesting that she was still using Depo Provera; however, unlike the short term use seen in the general population, the women in the study, like other women with intellectual disability, appear to be on it throughout their reproductive years and, given Barbara’s age, possibly beyond as McCarthy (2009, 2010) suggests.

How the women saw Depo Provera and the control that they had over its use are also telling of their attitude to what might be seen as a normal female function (menstruation) and their autonomy over their body. In regard to the effectiveness of Depo Provera for period control, the women reported different experiences, including Francisca who responded “I love it too” (1/7), interpreted from the surrounding conversation to be because it stopped her periods; while Lynda noted “the injections don’t seem to work for me” (2/9). Lynda wanted it to stop her periods, which it hadn’t, and subsequently had been trying to get changed back to oral contraceptives, which she found more effective. However, her doctor didn’t seem to listen, telling her to “just give it a go”, even though she had been on the injection for some years. It has to be questioned whether there was an agenda related to the contraceptive function of the medication and perceived reliability of Lynda in taking the oral contraceptive that influenced the doctor’s response. By presenting menstruation as the issue, as would seem to be the case in the current research, the focus is on preventing mess and pain, with the contraceptive function possibly not even mentioned or, if it is, not emphasised or explained. In contrast, Georgia, the one woman who clearly understood a contraceptive action, did have
her Depo Provera stopped between her first and last interviews, citing weight gain, interaction with other medication and not being sexually active as reasons. Knowledge and a more responsive general practitioner giving Georgia control of her body that appeared to be missing for Lynda.

Hysterectomy is the more permanent answer to both periods and contraception. Two of the women spoke of having hysterectomies for medical reasons and a third in her youth, which she explained as having been done before she was old enough to make a choice. New Zealand does have a history of sterilization of women of intellectual disability meaning that it is likely more women may have had hysterectomies. While hysterectomy in this population is thought to be declining (Hamilton, 2012), that may be because of alternatives that are not as permanent becoming more available, rather than a change in perception of the bodies of women with intellectual disability. Of interest, Paterson, Ashton and Harrison-Woolrych (2009) identified 19% of the 133 New Zealand women aged 11 to 19 years that were using Levonorgestrel interuterine system (LNG-IUD) had intellectual disability identified as a reason for its use. Of some concern, three of these young women had LNG-IUD inserted before menarche and for five the option had been offered following presentation for hysterectomy. The benefit of this option, however, might be that women, unlike the participant mentioned above, might have the option of parenting available to them as they mature. The participant was asked whether she would have liked her own children within the context of her talking about caring for younger family members. Her response was that she accepted what is rather than dwelling on what she has missed, suggesting a coping strategy (this information is taken from field notes).

Ilona, however, illustrated attitudes that are not uncommon in regard to choosing hysterectomy when she commented about menstruation “All gone. ... I didn’t like the smell ... I don’t like periods” (2/23). In one of the first studies to directly ask women with intellectual disability about their experience of menstruation, negativity was found to be common (Rodgers, 2001). Subsequent studies have simply reinforced that tendency (Ditchfield & Burns, 2004; McCarthy & Millard, 2003; Willis, 2008; Willis, et al., 2011), with Chou et al. (2008) an
exception in suggesting that their Taiwanese participants may be less negative than the, generally British, participants in the other studies. Ilona’s answer to her dislike of periods had been a hysterectomy in her mid-thirties, associated with surgery for her bladder, about which she was very vague. As with the women on Depo Provera, her focus was on menstruation with fertility not mentioned. However, her response to being asked whether she would have liked to have had children drew a long period of silence, broken only when the researcher asked if the question was “too hard” to which she agreed.

The third woman, Sylvia, was diagnosed with cancer of the uterus and had had a total hysterectomy to prevent spread of the disease three years before the interview. At the time she was well past menopause and accepted that the surgery was appropriate. As the women were not asked directly, it is not known whether there were others who have had hysterectomies.

For the one woman who stated she was sexually active, contraception was clearly identified for that specific purpose and not to control menstruation. Tanya, in her late twenties, despite some difficulty with terminology, demonstrated understanding of her contraception. As such Tanya fits (as did Georgia) with both McCarthy’s (1999) and Hollomotz’s (2011) findings that younger women are more knowledgeable about contraceptives. In addition, McCarthy (2009) predicts a rise in alternatives to Depo Provera, which can be seen both with the increased use of LNG-IUD in New Zealand and Tanya’s use of a Jadelle implant. These implants ensure a reliable and medically controlled contraceptive, as Tanya explained in the following way:

Interviewer B: Yeah. So do you use contraceptives - which is something to stop you getting pregnant or?
Tanya: Oh I went to the doctors...
Interviewer B: Yeah.
Tanya: ...and I got one of them IVs.
Interviewer B: IUDs?
Tanya: Yeah.
Interviewer B: Yeah.
Tanya: In my arm so I don’t get pregnant.
Interviewer B: Oh right. So it’s something that – is it Depo? Is it an injection in your arm?
Tanya: It goes into like a V-shape.
Interviewer B: Oh right.
Tanya: I’ll show you. I just got it in my arm. It really hurts.
Interviewer B: When you get it in?
Tanya: Yeah.
Interviewer B: And how often do you get it in?
Tanya: It stays in there for five years.
Interviewer B: Oh really?
Tanya: Yep.
Interviewer B: It just goes there?
Tanya: Yep.
Interviewer B: Right. And so they just inserted that in there?
Tanya: Yeah.
Interviewer B: Okay.
Tanya: What they do is they numb it first, then they put like the injection in and if it doesn’t go in they cut it a wee bit so it can go in and they’ve got like a wee – it’s basically like a V-shape but I can’t feel it.
Interviewer B: Right, so that’s in there for five years.
Tanya: Yeah.
Interviewer B: Yeah, and so you can have sex with your boyfriend...
Tanya: I have sex with my boyfriend but I can’t get pregnant.

The interviewer followed up the conversation about contraceptives by asking Tanya if she would like to have children ...

Tanya: Yeah, I’d love children.
Interviewer B: Yeah. Have you ever talked to anyone about the fact that you’d like to have children?
Tanya: Not yet but...
Interviewer B: What do you think other people would think about that?
Tanya: They’d say no.
Interviewer B: Why do you think they’d say no?
Tanya: I don’t think I could handle it.
Interviewer B: Do you think you couldn’t handle it or do you think other people think you couldn’t handle it?
Tanya: Yeah, I think I could handle it but I just can’t remember, I don’t know.

This excerpt from the data illustrates the conflicting messages for women with intellectual disability, that suggest greater acceptance of sexual activity than in the past but only provided that it will not result in pregnancy and parenting. For example, an Australian survey, with a convenience sample of 261 adults in the general population, found acceptance towards people with intellectual disability having greater rights to sexual freedom (Cuskelly & Gilmore, 2007). Two more recent studies offering further perspectives, one from professionals (Parchomiuk, 2012) and one from mothers (Pownall, Jahoda, & Hastings, 2012), would suggest that there is openness to people with intellectual disability enjoying the benefits of friendship and love; however, within these studies it is evident that there remains caution with matters such as sexual relationships and parenting. As we have found in earlier research (Conder, Mirfin-Veitch, Sanders, & Munford, 2010), Tanya demonstrates the lack of conversation about what parenting might mean for her whilst also showing insight that such a conversation could be uncomfortable both for her and others.

Whilst Barbara’s age meant that she was unlikely to be fertile at the time of the interview, her response to whether she would have liked to parent indicates
poor knowledge but also, similarly to Tanya, a lack of anyone willing to enter a discussion.

Interviewer A: ... And when you were younger ... Did you ever think about becoming a parent at all?
Barbara: Yeah, I see kids in the thing, I said: I wish I had a baby then they’d say I look like them. ...
Interviewer A: Did anyone talk to you about that at all Barbara?
Barbara: No.
Interviewer A: No. So did you talk to anyone about it?
Barbara: No.
Interviewer A: You just thought it to yourself.
Barbara: Yeah, thought it to myself.
Interviewer A: Do you know about how babies come about?
Barbara: Yeah.
Interviewer A: You’ve had some sex education talks have you?
Barbara: No.
Interviewer A: No. Do you know how babies are made?
Barbara: No.
Interviewer A: No. So you don’t really know about sex at all?
Barbara: No. No one talked about that before.

2/18

Despite her limited knowledge, holding a desire to reproduce self is evident in Barbara’s response. Barbara’s positive recounting of her early life and ongoing connection to her siblings, evident throughout her interviews, contrasts with Francisca, who implied major conflict within her family, further reinforced through a workplace that displays photographs of family violence. When asked if she would like to have children her reply was ...

Francisca: No, I don’t want any kids.
Interviewer A: No. Any reason why you don’t want them?
Francisca: They’re noisy. (2/29)
Francisca’s belief that they “usually get bashed up, little kids” also demonstrates the influence of media which, in this case, has been taken beyond context, social support for, and education about, family violence being the focus for her workplace. Whilst Francisca’s response to children may simply acknowledge her preference for solitude noted at other points in her interviews, a deeper analysis might question the impact of her earlier life on her understanding of childhood and her current situation of living amongst a group of men, none of whom she appeared to like, on her preference for solitude. Although, as noted previously, Francisca took delight in her recently coloured hair, there was little in her interview or appearance to suggest that she wished to express her femininity in the way that Barbara so clearly did, providing an illustration of variation in the way the women embodied gender.

Although Francisca was not asked whether she had discussed parenting with anyone, that the others had not suggests those people who may have had these conversations with them preferred to use external control of contraception to prevent pregnancy rather than empower the women through knowledge, including implications of their choices. That parenting is challenging cannot be ignored. The two women who were parents, Carla and Marika, had broken relationships with their children. However, their challenges seemed most closely related to their mental illness and not their intellectual impairment. Their choice to have children was not discussed, however. Although Marika had attended special class, she was not aware that she had an intellectual impairment until more recent admissions for mental illness, suggesting that she may have been subjected to less external control of her body. Interestingly her more recent diagnosis also illustrates the social construction of intellectual disability, whereby the person only has the ‘condition’ once labelled (Goodley, 2001). However, once admitted with mental illness, she experienced others controlling her access to her children, explaining her husband’s response ...

Well he would never bring the children to – especially the youngest one, the other two were grown-up – to see me and look back on that’s pretty hard. Even when I was in hospital he wouldn’t let the kids ring
me up cos they’d have to pay for the toll call. I said: well how can they pay for it when they’re only children? You know.

Although she had more recently reconnected with two of her three children, there was limited contact; interestingly, it is the youngest to whom she is closest. Being geographically distant from her children did not facilitate contact. Carla, however, lived in the same town but at the time of the first interview struggled with her relationship with her child “Yeah but x doesn’t like me because I cut myself ... and I overdosed ... many times”. (2/11). Before the final interview, however, Carla had moved from her flat into a more supportive environment and was seeing her child regularly, reporting a positive relationship. While both of these women and their children have had significant challenges, that more positive relationships can be developed with appropriate support raises questions for the positioning of women with intellectual disability as parents that is suggested by the control of their fertility. As this research confirmed, support to actively parent makes a significant difference to the outcome for both parents and children, particularly in terms of children remaining with their parent/s or, if removed, having a meaningful relationship (Booth, Booth & McConnell, 2005; Conder, et al., 2008, 2010; Mirfin-Veitch, 2010).

Attitudes to parenting by women with intellectual disability may appear somewhat removed with respect to the process of developing body image, however, as Chodorow (1978) opened the introduction to her book, “Women mother.” (p.3), identifying that in our society being a mother is considered a fundamental position for women and is intertwined with the capacity of their body to perform the functions of childbearing and lactation. That the idea of becoming a mother was treated with such uncertainty and lack of knowledge by those directly asked and did not come up in any interviews where women were asked about such things as future dreams, all this would suggest that most women in this study did not relate themselves to other women in this regard. How such a position plays out in their life might well have implications for their body image, including beauty practices seen in Chapter Five.
Boyfriends and marriage

Whilst few women discussed their reproductive body, it was more common for the women to aspire to or have a boyfriend, although with significant variations in how they saw these relationships. Just one woman indicated that she had had a lesbian relationship in the past, although it is possible that among the other women who did not elaborate about why they didn’t want a boyfriend, there may have been some that would prefer a same-sex relationship. Of note, women with intellectual disability generally report heterosexual relationships (Bernert & Ogletree, 2013; Dotson, Stinson, & Christian, 2003; McCarthy, 1999), if acknowledging that they are sexually active at all, with same sex relationships being rarely reported. For example Dotson et al. (2003) noted that one woman in their study was known to be bisexual but withheld that information. There is some evidence that attitudes towards lesbian relationships are changing, with isolated studies considering sexual relationships for people with intellectual disability who identify as gay, lesbian or bisexual (Abbott & Burns, 2007) and Eastgate et al. (2011) having two participants that identified previous same-sex relationships. However dominant social attitudes that stigmatise homosexuality may still account for hesitancy of participants to identify their interest in same sex relationships. It is acknowledged that gender-specific language such as ‘boyfriend’ also presents a barrier to women identifying a preference for a female partner, however the more gender-neutral word ‘partner’ did not seem to be readily understood by many of the women.

At the time of the first two interviews eight of the twenty-five women were dating a man. Whether because the women chose not to share details, or because they struggled with the language necessary, the exact nature of their relationship was not always clear. Two women provided reasonably direct answers to whether they had sex with their boyfriend. As noted above, Tanya was clear that she was sexually active with her boyfriend while Barbara, when asked if they slept together when she stayed at his place responded ...
Barbara: Oh I sleep in the – they've got sort of a craft room. ... Yeah, I stay in there.

Interviewer A: Okay. But you don't sleep together then?
Barbara: No, we can't till we’re married.

Given her long-term use of Depo Provera, this response from Barbara was somewhat surprising; however, it does illustrate the comparatively conservative opinions of women with intellectual disability seen in other research (Bernert & Ogletree, 2013; Healy, McGuire, Evans, & Carley, 2009). For example, a number of the 14 women interviewed in Bernert and Ogletree’s (2013) study identified sex as appropriate once married and primarily for the purposes of having children. There were two women in that study whom expressed similar pleasurable relationships with their boyfriend to that expressed by Barbara; however, as also among Hollomotz’ (2011) interviews with 17 women, it would seem that just a few women do recount such relationships.

Whilst, as indicated below, Barbara seemed certain about her relationship with her boyfriend, Tanya’s relationship was more tenuous ...

Interviewer B: Yeah. So do you guys talk about getting married?
Tanya: Oh he does.
Interviewer B: To you - but do you talk to other people about the fact that you might want to get married?
Tanya: Yep.
Interviewer B: And what do people say?
Tanya: When he’s been good, has dropped the alcohol, then we’ll get married.
Interviewer B: So does X drink alcohol?
Tanya: Yeah.
Interviewer B: Yeah.
Tanya: Oh not like – oh sort of if he’s upset and things.
Interviewer B: He might drink, yeah.
While they had dated for seven years, by the third interview the relationship had ended and Tanya had a new boyfriend. Although not captured on tape, the researcher noted in field notes some surprise at the relative matter-of-fact way with which Tanya reported the ending of the old relationship and beginning of the new. Also of note in Tanya’s transcript is the influence of others on her relationship, with it being her boyfriend that initiated conversations about marriage, while ‘others’ tempered the prospect and applied conditions. Whilst Barbara’s experience reflects the more recent research that indicates a positive picture for some individual women in relationships (Bernert & Ogletree, 2013; Hollomotz, 2011), Tanya’s appeared more closely aligned to the women who had less positive experiences seen both in these studies and Dotson (2003) and McCarthy (1999). In each of these studies it was common for women to report that their boyfriend controlled their relationships, including sexual activity.

The other women were not asked directly whether or not they had sex with their boyfriend but it is likely that at least some were judging by the way that they talked about their relationship. That they did indicate a heterosexual relationship and freely spoke of intimate aspects, both of these do suggest that they, unlike women in some previous studies (Bernert & Ogletree, 2013; Fitzgerald & Withers, 2011; Healy, et al., 2009; Hollomotz, 2011), felt comfortable to express this aspect of their gendered being. In these other studies sexual relationships have been kept secret for fear that they will be stopped by parents or services; however, it would seem that this is less of an issue for these women in New Zealand. For example, Yolanda was happy to share how she and her boyfriend enjoyed intimate cuddles.

Yolanda: Yes, very much so.
Interviewer C: So how does he make you feel?
Yolanda: Very good
Interviewer C: Yes.
Yolanda: Very good in fact (1/7)
Although these intimate moments appeared to involve only kisses and cuddles, it was not established whether that was the limit of their privacy and thus affecting their choice. However, Yolanda’s attitude to her sister having sex, which she overheard while staying with her “She was doing something rude in her room every time she was looking after me.” (1/6), might suggest an attitude that sexual activity should be limited to particular relationships, as illustrated above by Barbara. Whether or not sexually active, the other women who placed significant importance on their relationship with their boyfriends, like Barbara and Yolanda, emphasised pleasure, feeling special and a sense that there was reciprocity. For example, referring to her illness, Eva stated ... My boyfriend cares about me. That’s X ... he wants me well. (1/5).

Having a partner can be seen as a mark of adult life and for the above women such social expectations do appear to be implicated. For some of the women who did not currently have a partner there was less interest in identifying but, perhaps, also less need to identify, with this marker because they had had previous relationships that already marked their adult status. Eight of the remaining women had previously had partners, this included Marika who was divorced, Vera who had two broken engagements in her past and Carla. Of the eight women only Ilona was clear that she had not wanted another boyfriend in the many intervening years, although she did not state why she made that choice. For the others having another boyfriend did not seem to be particularly important to them but they were open to the possibility. However, for the remaining group of women social expectations related to their intellectual impairment may well have over-ridden social expectations for women in the general population. Three simply did not want boyfriends, but provided no further insight into their reason for that choice. Two others, Dianna and Quiana appeared to understand that having a ‘boyfriend’ was a socially desired state, with Diana naming a local football hero, which Hollomotz (2011) suggests is not unusual. Quiana identified a person that was more realistic, suggesting a man from her day-base. As various authors suggest (Bernert & Ogletree, 2013; Fitzgerald & Withers, 2011; Healy, et al., 2009; Hollomotz, 2011; McCarthy, 1999), services are an obvious origin for relationships,
however Quiana seemed unable to extend the relationship beyond as she hesitantly explains in the following abbreviated transcript

Quiana: He’s nice.
Interviewer A: He’s nice. So do you go out with him sometimes?
Quiana: Xxx one night. [difficult to hear but seemed she would like to rather than does]
Interviewer A: Okay. So do you just see him here really?
Quiana: Yeah.
Interviewer A: And has he been your boyfriend for long?
Quiana: Yeah.
Interviewer A: Yeah. So he’d call you his “girlfriend” would he?
Quiana: Mm.
Interviewer A: But you don’t go out to the pictures together or anything like that?
Quiana: No. No, not yet.
Interviewer A: Not yet.
Quiana: No.
Interviewer A: Are you going to work on that are you?
Quiana: Yeah.
Interviewer A: Would you like to go out with him somewhere just the two of you?
Quiana: Mm. [nodded]

2/3

The active engagement of services in supporting relationships differed, with some aligning with conservative approaches that might see mostly risk associated with encouraging women with intellectual disability to have partners, while others appeared to draw on human rights and normalisation principles to facilitate such relationships. At times it seemed that the service vacillated between accepting normalisation principles whilst also worrying about risk. This was most evident in the comparison between Barbara and Amelia. Barbara had been engaged to her partner for a number of years and, at the time of the first two interviews, Amelia
was about to be engaged to her boyfriend in the next few weeks, following a year of dating. At the time of the third interviews both remained engaged, with Amelia anticipating a wedding, while Barbara had no set plans. Amelia and Barbara relied on their support services to facilitate time with their fiancés. For Amelia that included dates, although it was not clear that they shared intimate private time together. Amelia and her fiancé had daily contact through their support service. Barbara, on the other hand, required assistance with transport to visit her physically disabled fiancé, with it clearly not being acceptable for him to visit her. “No, he’s not allowed to. ... Because [support person] said you can’t have him here cos you know what the other girls would say.” (1/21). A comment clearly imbued with meaning about the appropriateness, or otherwise, of her relationship. While weekend visits were supported, there was little encouragement for the couple to marry. In her late forties Barbara dreamed of the day that would happen ...

Interviewer A: So if you had a dream ... what would your dream be?
Barbara: Get married to X.
Interviewer A: Yeah.
Barbara: And get my whole life started and get the job done.
Interviewer A: So getting married to X is going to bring – why do you see that as important?
Barbara: Because we want to live together and sometimes it’s a bit awkward for him and I if we can’t get a little flat of our own.
Interviewer A: Yeah.
Barbara: Yeah.
Interviewer A: And if you had a little flat of your own you feel that would give you a sense of what?
Barbara: Feel more secure, more happier.

Despite living with mixed messages from her support service, both in this respect and as seen in previous chapters, Barbara clearly identified with cultural constructions of womanhood including having a long-term heterosexual relationship as well as an interest in glamour and beauty practices. Yet, her
hesitancy about the questions related to parenting possibly illustrates a naivety of the influence of social attitudes on her achieving her dream. Although not always so clearly identifiable from their transcripts, a number of the other women shared similar experiences whereby they were encouraged with feminine practices in relation to their body image whilst controlled in their expression of their sexual body either through limited opportunity to have a partner or contraception that ensured they did not parent. As Hollomotz (2011) has suggested both of these latter points have been influenced by a perception that women with intellectual disability are at increased risk of sexual assault.

**Experience of sexual violence**

Experience of sexual violence or unwanted sexual attention, not surprisingly, affects the way in which women with intellectual disability perceive their gendered body including lowered expectations of sexual enjoyment, avoidance of sexual relationships and denial of their sexuality, as expressed by a number of women interviewed for the qualitative studies mentioned in the previous sections (Bernert & Ogletree, 2013; Eastgate, et al., 2011; Hollomotz, 2011; McCarthy, 1999). Definition of sexual violence to include harassment, assault and rape (Hollomotz, 2011) is adopted for this subtheme. Although it might appear to be a very sensitive issue, requiring a trusting relationship developed over time, many of the women in the current study brought up their experience of abuse or harassment before questions were posed. The women who experienced interfamilial abuse are written about in general terms, as connection to their pseudonym used in other sections may make them identifiable within the relatively small community.

As a group the women in the current study reflected previous research in terms of prevalence of abuse and identity of perpetrators. As Hollomotz (2011) suggests it is difficult to get clear data on prevalence. McCarthy (1999) makes the point that research methodology has implications for reporting of sexual violence, believing that qualitative methods, where the women see the interest as benefitting, will expose abuse that might not otherwise be shared. In her study 14
of the 17 women believed that they had been sexually abused (McCarthy, 1999). In Johnson et al.’s (2001) project, 11 of the 13 Australian women had experienced some level of sexual violence, whilst it would seem from the data that at least six of the nine Australian women interviewed by Eastgate et al. (2011) had been sexually abused. With sexual violence recognised as more prevalent within the population of women with intellectual disability there is little surprise that eleven of the twenty-five women indicated that they had been subject to sexual violence, whether abuse, harassment, or otherwise made to feel uncomfortable. Commonly, assailants in previous research are identified as family members, fellow (male) schoolmates or service users or neighbours (Eastgate, et al., 2011; Hollomotz, 2011; McCarthy, 1999) and for the women in this study this also held with the person known to them either as family, family friend, neighbour or teacher. Three women (names withheld) had experienced sexual abuse within their family, seemingly none of the perpetrators were charged and in the case of two their mothers appeared to be complicit in the abuse. Contrary to the more usual underreporting of abuse, another woman accused her father of sexually abusing her when she was annoyed with him, seeing it as a way to punish him. Not surprisingly, the accusation had caused distress and, when she admitted lying about it, she was alienated from the family. However, this illustrates that she saw a way to use her gendered body to achieve some power in a situation in which she otherwise felt powerless.

Embodied responses to sexual violence can be seen in the women who experienced interfamilial abuse and subsequent mental illness (Colangelo & Keefe-Cooperman, 2012). For one of these women physical presentation included bedwetting in her late teens, although as she noted … “Yeah, they knew something was wrong. Cos I didn’t used to wet the bed so – for ages – and then I started wetting the bed again and that’s when they started to realize something’s going on.” (2/14). Although widely recognised as a defence mechanism (Chodorow, 1978), it was not until her mental health deteriorated much further that the cause of her change in behaviour at that time was identified. Another participant illustrated the impact on later body image when abuse happens during adolescence, commenting …
Respondent: I did at times but I mean when I had that thing done to me when I was about sixteen and then like later on my other - who would have been in a sense my stepfather - like I mean and he sort of used to always talk sweet talk to you and he used to do it with one of his younger kids as well. And I knew I had to be careful then like cos both me and this younger girl used to tell mum about things on our own and yeah like and of course that’s what sort of, for me, put me off really any other relationship.

Interviewer A: Right.

Respondent: Because like I mean I always thought well when something like that happens like no other guy or that who you have a relationship with would want you with you yourself feel like you're dirty and that like no other person would want you because of what had happened to you.

The first experience of abuse referred to as “that thing done to me” was by a neighbour who, though charged, was acquitted. The respondent’s response to feeling dirty is well recognised in the literature (Bordo, 2003) and also reflected in Nadia’s experience below. These above examples occurred some years ago and provide a contrast for the responses to change in behaviour seen in some services and from the police more recently. Importantly prompt responses that take the woman’s concerns seriously appeared to provide women with greater feelings of self-worth and confidence to keep safe, a situation that supports Holomotz’s (2011) ecological model.

For example, Nadia had the frightening experience of a man coming into her home and ...

...well he didn’t touch me but he asked me if I wanted a sexual relationship and I said: no. And he went on and on and on like that. And how he got my phone number and my address I’m blowed if I
know. But I wouldn't go out on the street. I wouldn't go out anywhere afterwards. 2/19

At the time Nadia managed the situation in terms that the man left, however she was unable to initiate a strategy to protect herself from future approaches by the man and remained fearful. It was an astute support service that noted her change in mood and once questioned she opened up to them, setting in process police action. The police initiated protection orders through the courts to serve on the man so that he was warned to stay away from her. Now she is very clear and confident about what action she can take if he, or any other person, harasses her in future. Although reflecting commonly held perceptions by women who somehow fear that they may be to blame, she initially resisted telling her parents, however the consistency of responses provided her with new found confidence ...

I was just too scared to tell her [mother]. Yeah. But then as soon as mum found out she said: don't be so scared. And said: you've done the right thing and then the constable in [regional city] said that you've done the right thing too, you went to the right person. Yeah. But if anything happens to me again I'll go straight – I'd definitely tell my parents. Yeah. 2/14

Others had used educational institutional policy with suitable responses following up their complaint of sexual harassment. Indeed experience of these processes meant that women, such as Georgia, who had a protection order following reported rape by her boyfriend, utilised their new knowledge of protection orders to educate friends that they perceived to be at risk. Furthermore she quickly sorted out that she didn't like what was happening when, in a recent trial of flatting, her flatmate had men visiting stating “But it wasn't good there cos she kept bringing guys around. ...So I wanted out. I didn't want them round me twenty-four-seven.” (1/2).
As an aside, judging from the experience of the women in this study, police response and court results in New Zealand would seem similar to other countries where it has been difficult to get convictions for sexual abuse of women with intellectual disability (Eastgate, et al., 2011; McCarthy, 1999). In the current study, there was just one woman who had successfully charged a man who had sexually assaulted her. The recent accounts of abuse outlined above would suggest that police might currently be using Protection Orders as a way to manage situations where evidence is deemed insufficient to bring about convictions.

Clear, well-explained strategies for either preventing sexual violence or responding when it occurs appeared to strengthen the women's self-concept, whilst providing them with confidence to manage relationships. However, not all services seem to be ready to provide such clarity and the confusion, for the women concerned, can be seen in Hesta's struggle to understand why there might be a change in policy ...

Hesta: We had a massage class with K.
Interviewer C: Right.
Hesta: And she taught us how to do a massage. We did it at our old workshop in T. But that's all changed now.
Interviewer C: Okay. So you're not allowed to do it anymore. That's a shame.
Hesta: No, cos J put a stop to it. ... they're not allowed to massage.
She's got something against that.
1/10

There may well have been good reason for stopping the class but for Hesta it only caused confusion, missing an opportunity for learning about safe touch. Whilst Hesta's confusion lay in absence of an explanation, Rosa appeared to have been given the message of safety some time ago but no longer had a context for her avoidance of strangers ...

Rosa: I don't talk to strangers either.
Interviewer A: Why is that?
Rosa: You don't know them.
Interviewer A: Yeah, you don't know them and why would you not talk to them because you don't know them?
Rosa: They're strangers.
Interviewer A: Yeah, so you don't talk to strangers...
Rosa: No, I do not.
Interviewer A: No. Would you be worried they might hurt you in some way?
Rosa: No.
Interviewer A: No? So you just don't talk to them...
Rosa: No.
Interviewer A: ...cos they're strangers? Is that right Rosa?
Rosa: Yeah.
Interviewer A: Who told you that?
Rosa: Don’t know.
Interviewer A: Have you always known it or?
Rosa: Yeah.

Whether at a conscious level or not Rosa’s attitude to most questions about body image that might relate to gender, for example having a partner, colouring her hair or wearing make-up, would suggest that she has developed a sense of self aligned with Shildrick’s (2009) point that for some disabled women sexuality is simply denied by society. Interestingly Rosa was positive about her physically fit body.

This subtheme illustrated that some of the women were clearly aware of social messages that might be interpreted as women having dangerous and defiled bodies (Ussher, 2006), such as the young woman who worried that her body might be seen as “dirty” to future partners following abuse. Nadia, too, illustrated these beliefs in her concern that she might be blamed for the man entering her house without invitation. Such messages may well be reinforced, albeit unintentionally,
by ceasing massage classes as Hesta reported, or in Rosa’s avoidance of strangers. As Calogero and Thompson (2010) note, many women have a high level of anxiety about their bodily appearance as they work to achieve the right balance between desirability and personal safety, for women with intellectual disability the mixed messages to which they are exposed only makes it more difficult to achieve a balance.

**Summary**

The limited data available from this research would suggest that attitudes to the women’s sexuality included denial (Shildrick, 2009) or, when acknowledged, risk (Ussher, 2006). The importance of these attitudes for the current research is in how they played out in terms of the women’s body image. A social constructivist interpretation of body image acknowledges the role of gender construction. Whilst all the women identified with female gender, there was considerable variability in their understanding of, or expectations for, their sexual body. Overall the women appeared to be conservative in their attitudes to sex with a number not currently sexually active. Barbara’s particularly poignant story, illustrates the multiple and mixed social messages that have influenced the embodiment of women in middle age. Most of the women seem to have grown to adulthood amidst a social network of people who talk about menstruation as a nuisance, not celebrating it as a mark of womanhood as other young women might. Building on the nuisance theme, contraceptives are positioned as beneficial in controlling their period and conversations about sex and pregnancy avoided.

On a positive note there was evidence of a generational shift in terms of knowledge and practice within services that may impact on younger women’s perception of their body. In addition, the more active response to sexual assault within wider society has possibly had an impact for women with intellectual disability. For those able to report incidents being listened to and assisted with taking action appeared to result in greater confidence, however it is concerning that lack of knowledge is evident, suggesting there is little preventative education available which inevitably leaves women at risk.
In conclusion, the sexual body of women with intellectual disability would appear to often be in the control of others, be they partners; protective, perhaps uncomfortable, and sometimes abusive, family; or support services. Power over decisions that most adult women in the West would take for granted, such as choosing whether to control menstruation, contraception, sexual preferences and being able to engage in sex in a safe and private space, is often denied to women with intellectual disability. Although this research suggests greater awareness and higher expectations for expressing their sexuality and gender among younger women, it is not consistent.
Chapter Eight: Discussion

Introduction

The previous four chapters have provided evidence for how the women constructed their body within areas of interest, that is, their body and beauty, functionality and gender. My intention with this chapter is to shift the focus back to their “whole” body and through my interpretation construct a whole of body image. From the previous chapters it can be seen that the women’s construction of their body was influenced by internal factors, such as cognitive understanding and perceptions (for example, pain, breathlessness), as well as socio-cultural factors, including their exposure to media and the people who provided their support. Within this chapter I will explore the meaning of these influences for the development of the women’s body image. The findings so far indicate a body image that is fluid; in other words, for the women in the study it was possible to be both satisfied and dissatisfied with their body, depending on the focus they took and, as some also acknowledged, how they felt at the time. Overall there is a sense in which the women saw their body as representative of their ‘goodness’, either through their adherence to diet and exercise or their cleanliness and tidiness. For many of the women it was evident that they had limited control over practices that impacted on their body image including construction and expression of gender. As the component parts of their body image come together, a critical lens, drawing on the background information in Chapter Two, will add another level of analysis to the data presented in the last four chapters.

An initial impression from the results of the research is that a number of the women expressed satisfaction with their body. Whilst research on body image tends to focus on dissatisfaction, it is evident that there is always a minority of women who are in fact satisfied (Wood-Barcalow, Tylka, & Augustus-Horvath, 2010). Within the broader research these women were the same ones who expressed overall happiness with their life, emphasising the relationship between body image and other aspects of self-concept, including self-esteem (Harter, 2012).
Aside from the possibility of acquiescence, which will be discussed later, other authors might offer suggestions for this positive finding. Cognitive ability may be implicated with Harter's (2012) synopsis of both her own and other research suggesting that the ability to express both positive and negative features of self is related to development and that, in general, being positive comes first. Maiano et al. (2011) suggested that people with intellectual disability who have less inclusive lives might be more positive about their body image. However, I would suggest caution in applying such rationale as the findings of satisfaction are not particularly different to those of Avalos et al. (2005) when they developed their questionnaire that focused on body satisfaction among young women without intellectual disability. In addition, while mostly positive, many of the women also confirmed a plurality in their body image (Pruzinsky & Cash, 2002), with multiple and, at times, conflicting messages of satisfaction according to the aspect being discussed. For example, a number of the women expressed dissatisfaction with their body weight, either through their response to the CDRS or to specific questions, whilst expressing satisfaction with how their body provided a means of independence or their current level of fitness.

As might be expected, individual differences mean that generalisations about the women's body image need to be contextualised, including examples that both confirm and challenge the themes. However, these individual differences also support active construction that is influenced both from within and through the social world as suggested by Lacan's (2002) theory of ego development. Reliance on the social model of disability or feminist social constructionism with their emphasis on the social world would ignore the embodied experience of being a woman (Butler, 1990) and having an impairment (Goodley, 2011; Simpson, 1999; Watson, 2004). Whilst processes affecting the individual’s construction of their body image are interactive, this discussion will firstly consider the embodied body before examining how political and sociocultural influences might have shaped the women’s body image. Ultimately recognition of the interaction is important if the research is to provide advocacy and bring about change in the opportunities for women with intellectual disability (Björnsdóttir & Traustadóttir, 2010; Moore, et al., 1998; Walmsley, 2001), as suggested in Chapter Three.
Although there were discrete questions within the semi-structured interview guideline, having the data collected for the wider study available has been important for understanding how the women constructed their body image. Thus, the relatively straightforward answers to questions became a starting point for analysis that drew on constructivism overlaid with the fundamentally critical lenses of feminist and disability research approaches. Both Harding (2007), from a feminist perspective, and Patton (2002), in writing about constructivist approaches, suggest exposure of participants’ reality and understanding is fundamental. Furthermore a narrative approach, such as taken through the women telling something of their life story, assisted with understanding and illuminating “the life and culture that created” (Patton, 2002, p.133) their body image. Ultimately my approach to this research was to view the women’s body image as a result of active construction (Butler, 1990; Grosz, 1994), recognising, as Butler suggests, social, political and cultural influences interwoven with the natural body.

Consideration of the various factors that influenced the women’s body image is followed by an analysis of what these findings might contribute to opportunities for change within a framework that sees a person’s body image as always ‘becoming’ and never final. Furthering the call to provide advocacy, the implications for policy and practice are outlined within the context of the UNCRPD (United Nations, 2008). Towards the conclusion of the chapter, I reflect on the research process, including ethical challenges and then the limitations of the study and suggestions for future research.

**The embodied body**

The embodied body recognises the influence of internal sensations, and physical and cognitive ability on the development of body image. From a feminist perspective, important aspects of such embodiment are the sensations associated with having a female body, including reproductive functions, such as menstruation, menopause and sexual activity. For the disabled body, there may be pain, physiological and physical impairments that cannot be ignored in understanding construction of the body. Whilst in reality quite complex, in the most simplistic
terms, some of the women indicated their sense of embodiment through their responses that it was their physically fit body, that is, how their body felt to them, that they most liked about their body. Remember that many did not look at their reflections in a mirror very often. Illustrating a greater complexity a number of the women spoke of their body within the context of physical illness or disability as well as mental illness, with body image for these women often shifting from negative to positive depending on the focus they chose to take at the time. To ignore the impact of their impairments on their body image would miss crucial information (Goodley, 2011; Simpson, 1999; Watson, 2004), including how their cognitive impairment might be relevant (Harter, 2012).

Fundamental to a constructivist understanding of body image is the process of internalisation of the constructs of the social world. Whilst the exact mechanism may be elusive, both Lacan’s psychoanalytic perspective and Harter’s social cognitive perspective infer a developmental component that includes the individual understanding the social messages that ultimately shape the direction of self-concept (Goodley, 2011; Grosz, 1994; Harter, 2012). The primary focus for psychoanalysis is the internalisation of gender but, as Shildrick (2009) suggested, disabled women might have a different experience to other women if their sexuality is simply denied. As noted in Chapter Seven the data extracted from the interviews suggested an embodied sexuality was limited to some of the (participant) women and more likely to be associated with control and risk than it might be for other non-intellectually disabled women (Lupton, 2013). For another group of the women it was more difficult to identify their construction as female gender beyond recognition that they were physically different to men. Embodied sexuality cannot be ignored in terms of the potential that it has to influence body image and the practices that women might engage, to shape or otherwise beautify their body to align with social expectations. As Braidotti (2006) suggests, it may not be useful to accept as inevitable the psychoanalytic interpretation of gender development but it is helpful in explaining the current position of women and their body image. Following consideration of socio-political influences on the women’s body image, I will return to the interaction between their embodiment and the messages to which they are exposed. However, it is important to keep the degree
to which the women had internalised gender roles in mind, as I turn to discussing other internal influences on their embodied self. For this section I will draw on the drive for an Ideal-I as interpreted from Lacan's work and the similar interpretation that Harter suggests of an ‘I self’ and ‘me self’, both of which were described in Chapter Two.

Language plays a pivotal role in internalisation of constructs in terms that it provides the symbols, which in turn give meaning to the social world of the child. From the perspective of people with learning impairments who struggle with both receptive understanding and expressive language, this might seem to be a critical consideration for their development of a self-concept and ultimately body image. As noted previously, the women in the study differed in both their receptive and expressive language skills, therefore differences in construction of body image are not surprising. However, as will be discussed further later, such differences should be viewed cautiously and not assumed predetermined as a result of their intellectual impairment per se. Acknowledging the interaction of social messages received when one’s impairment includes difficulty with forming clear words (as was common to some of the women) might suggest that, for these women, a component of the constructed ‘me’ self (Harter, 2012) was as someone who should be silent unless addressed and at such times offer simplistic responses to assist the listener to understand; this latter being a requirement of being a ‘good’ woman (Bordo, 2000; Brand, 2000; Carroll, 2000). For most of these women it was likely that they had had a lifetime of being asked to repeat themselves and understandable that they might be choosing not to offer complex sentences because that provided a more comfortable social engagement. That most of the women, who appeared to have difficulty answering open questions, were able to clearly state when they disagreed with something we suggested, infers understanding when there are co-operative partners in the conversation. It would therefore be inappropriate to draw conclusions from expressive language alone, the degree to which the women have internalised social expectations that might influence their body image and understanding of an Ideal-I.
For most of the women, however, their body image was influenced by their self-perception of either their physical or mental ability to take care of themselves and their view of their body as ‘fat’ or ‘trim’. Just as the physically fit and trim body was appreciated for how it felt to them, some women took pride in their cognitive competence as represented in being clean or independent with personal hygiene. The ‘I self’ and the ‘me self’ (Harter, 2012) might be useful for considering the differences in how the women valued these aspects of their body. For a number of the women cleanliness, maintaining social standards of tidy presentation and needing help with personal hygiene clearly came from an understanding of the drive inferred by the concept ‘Ideal-I’ (or ‘I self’). As Goodley (2011) notes, the Ideal-I sets up the drive to achieve social standards which, Harter (2012) suggests, requires a recognition that others have a perspective on them. It could be seen in responses such as Ursula’s, who now needed extra help, or Ophelia’s, who looked in the mirror before going out, that most of the women knew that others were watching and potentially judging them. Similarly most of those who were overweight understood their body from that perspective. It was more difficult to ascertain the degree to which some women were aware of wider social scrutiny driving an Ideal-I; however, when their response seemed more closely related to a ‘me self’ that valued cleanliness and independence for the immediate reinforcement they received, such as was seen with Diana asking her support person to confirm what she had said. Of course an explanation for their limited understanding of wider social scrutiny might be that the social world of the women living in residential support settings was comparatively restricted (Maïano, et al., 2011; Martin, 2010). That is, their days seemed to revolve around day services and segregated activities, whilst their evenings were spent with their flatmates who were also supported by the service. As such independence with personal hygiene was valued for the implications it had within their social world, that is, it inferred a degree of intellectual competence that could be compared against others in their midst.

In addition to consideration of how their cognitive limitations might affect the construction of their body, other sensations such as physical pain, breathlessness, and symptoms of mental illness were daily or frequent experiences
for some of the women. These and physical impairments provide further chances for their body to be constructed as ‘other’ or ‘risky’ (Goodley, 2011; Shildrick, 2009). Both Goodley and Shildrick suggest that a Lacanian perspective would identify two implications for disabled people; one being the influence this has on the embodied experience of the person with the disability and the other the influence on people without disability who might compare themselves favourably and thus imply these other bodies as ‘risky’. Whilst all the women were potentially ‘othered’ by their intellectual impairment, those with a physically disabled body, or mental illness presented additional differences through their ‘risky’ body. Having a chronic illness, such as Eva’s heart condition, which meant that she became breathless very easily, inevitably impacted on her construction of her body. Conscious that she was ‘othered’ by people around her, she chose to construct her body image within the constraints of her illness to arrive at a positive sense of self, similarly to how Madjar (1997) described for some of the people who were experiencing illness in her research. However, as with Ursula, Amelia and Georgia, who also experienced physical symptoms and bodily limitations, Eva understood that her body was seen as ‘risky’ to others and was the basis for the way that others were responding to her changing health needs. In contrast to Eva’s construction of her body, Ursula, Amelia and Georgia were less positive about their ‘othering’, with their more recent experience providing the main focus for frustration in the construction of their body, again reflecting Madjar’s (1997) findings, which also had this variability in responses and which she put down to being able to have some hope or optimism about the future.

The women who experienced repeated episodes of mental illness similarly indicated recognition of being ‘othered’ while also drawing on the embodied experience of symptoms to illustrate the impact on their body image. In common with other people with mental illness (Cameron & McGowan, 2013; Todd, Simpson, & Murray, 2010), they expressed a loss of a sense of control of their body at such times. As Vera identified, the drive to achieve an Ideal-I in relation to personal hygiene became lost as she simply struggled to survive through her depression. With repeated episodes of mental illness the women had come to the point where feelings of vulnerability remained within their construction of their body.
However, while Marika expressed this vulnerability as the most disliked aspect of her body, she also saw that being cognisant of bodily changes at the onset of deterioration in her mental health might be useful for knowing when to seek help. Furthermore, she illustrated her understanding of embodiment as she emphasised the role that physical exercise and relaxation techniques were having in keeping her mentally well.

Recognising their embodied self redirected their drive towards a construction of their body that was achievable for some of these women, providing support for the concept of multiple body images. For example, despite Eva’s significant illness she expressed pleasure in her body, while Vera emphasised the way that she could decorate her body. In this way the women’s ‘risky’ body, while potentially a source of stigma and social exclusion, could also provide a source of pride in abilities when considered within the limitations that they or others imposed. However, just as the research outlined in Chapter Six showed for people with a range of limitations/disabilities (Cameron & McGowan, 2013; Claessens, et al., 2005; Drageset, et al., 2011; McMurray, et al., 2001; Nair & Wade, 2003; van der Slot, et al., 2010), variables included time and support available. As indicated above, Ursula, Amelia and Georgia were struggling with their changing Me Self, reflecting Morris’s (1991) experience as she adapted to her newly disabled body at the same time as coping with unfamiliar responses to her ‘self’ from others. In other words, those who had lived with their physical or mental disability for longer were more likely to draw on other positive aspects of their body, whilst those with more recent changes found it difficult to shift their attention from the impact that their impairment was having on how they had constructed their body (Madjar, 1997).

In summary, findings from the research support that the women construct their body image within their cognitive understanding and influenced by their physical and mental sensations. Gender construction was limited, as embodied sexuality seemed to be discouraged. For many the focus appeared to be on the ‘me self’, that is, this is who I am and I am happy with that being. Their satisfaction in these situations was based on a view of an ‘I self’ that was drawn from a limited
worldview of possibility. However, some of the women certainly understood that their potential was constrained by their weight, physical or mental health and satisfaction with their ‘me self’ was dependent on being able to select other features of their body or through the use of enhancing beauty practices that provided them with feelings of satisfaction. From a constructivist position, their understanding of embodiment provides a basis for exploration of the social influences interacting with the self.

**Socio-political influences on the women’s body image**

From a social constructionist viewpoint the social world is deemed to be the basis of body image including how all women come to be ‘othered’, within a male:female binary (Butler, 1990; Ussher, 2006) and for those with disability further complicated by an able:disabled binary (Clapton, 2009; Goodley, 2011), as indicated above and discussed in Chapter Two. Furthermore, internalisation of social constructs is crucial to determining how women might understand their body as ‘othered’. In bringing a social constructivist lens to this research, my intention is to incorporate the above sense of embodiment with the political and sociocultural influences that shape body image as they inform the Ideal-I and consequently the drive to meet perceived expectations. Whilst family provide the context for early childhood expectations, as the child ages it is anticipated that influences will broaden to include social networks and cultural context. Of course, each of these interacts with the other within a political sphere. For example, parents of a child with an intellectual disability will receive messages about what they should expect for their child from various sources such as, medical professionals, policy makers as well as the sociocultural values that are expressed by people around them. These influences may have an important effect on the body image of the growing child if expectations for their adult lives are different to those held for other children. From the current research, I suggest that there is evidence that the women have been subjected to more limited expectations. As with all women, the participants’ responses suggested that their bodies were perceived by others as ‘risky’ and they were encouraged to use body practices that would conform to the ideal ‘good woman’ (Black, 2004; Bordo, 2000; Grosz, 1994;
Ussher, 2006). However, these women were also subjected to a number of controls on practices that might be used by other women to shape and construct their body, limiting their choices but also their Ideal-I.

**Politics and policy**

Following deinstitutionalisation the New Zealand government stated the direction that was expected from NGOs supporting people with disability within the Disability Strategy (Ministry of Health, 2001) and then, later, the To Have an Ordinary Life document (National Health Committee, 2003). More specific outcomes for operationalizing these policies are contained within various contractual arrangements. The political agenda is important to the findings of the research in terms of how it impacts on the body image and body practices of the women. Being clean, tidy, fit and not overweight could be aligned with social standards that facilitate integration, a key outcome required of the NGOs providing support services. In addition, the National Health Committee (2003) document, in expressing concern for the poor health of people with intellectual disability, potentially alerted support services to the mainstream health messages coming out of the Ministry of Health (Burrows & McCormack, 2013; SPARC, 2005). However, while the current policy is important, given the age range of the women, it should also be remembered that many have lived through changing political positions and social attitudes to people with intellectual disability within New Zealand. Normalisation, social role valorisation and the social model of disability have influenced more recent policy but the medical model remains influential, including in providing access to services. The findings from the research illustrate the tension that exists between these different positions and the implications for the women’s construction of their body.

Although none of the women experienced the long years of institutionalisation common to many people with intellectual disability within their age range, the older women grew up in a society that chose to seclude a number of their peers within large specialised hospitals. The medical model was dominant at this time and it contributed to labelling through identifying a
diagnosis and assessing IQ. In choosing to participate in the research, all the women had indicated that they had an intellectual impairment, although not all recollected having such a label as they grew up. However, while most of the women in the study were educated in special schools or satellite classes sited on regular school grounds, some couldn’t remember school and, given their age, may never have attended one. Prior to the Education Act 1989 children with intellectual disability could either have no formal education or be required to attend special schools, with the obvious outcome of being ‘othered’ and separated from their age peers from a young age. The medical model was, and remains, influential in providing a diagnosis and IQ testing, which together direct where the child might receive their education. For those women with a memory of schooling, being seen as different made them vulnerable to bullying, with various body features providing the focus, such as Vera’s body size, Tanya’s ‘lazy eye’ operation and Yolanda being put in front of the school, which from her perception, was as an example of disability. Whilst the two younger women were at school through a time of change at a political level, with the 1989 Education Act requiring local schools to accept all children in their area, the reality of being seen as ‘other’ remained. Many of the secondary schools maintained a special class and all of the younger women in the study appeared to have had at least some of their secondary education in one of these classes although their earlier education was in the mainstream. For most women schooling provides the opportunity to establish relationships with peers who might ultimately be influential in the construction of their body image, however, with a few exceptions, friendships did not focus strongly in the women’s memories of school. Separation into special schools and special classes has long been identified as socially isolating for disabled adults and was one of the impetuses for the 1989 Education Act. However, it would seem that despite the intentions of the Act, the reality for the younger women in the study would suggest that developing peer group relationships remains challenging whether in their integrated primary years or their segregated special class at secondary school.

Whilst Marika could reflect that her education had been in a ‘special’ class at her local primary school, she had grown up unaware of having a label that might
exclude her from the gendered role of motherhood. However, for others their label, whether they were aware of it or not, provided a reason for control of their sexuality through medicalization of reproductive processes to an extent not usually seen amongst other women in New Zealand (Paterson, et al., 2009; Paul, et al., 1997), but that did mirror studies with women with intellectual disability in Britain (McCarthy, 1999, 2009). Furthermore, as predicted by McCarthy (2009), although Tanya’s use of a Jadelle implant might suggest that the form of contraception will change, the idea that their fertility should be medically controlled remains. The Contraception, Sterilisation and Abortion Act 1977, despite subsequent amendments since originally passed into law, continues to sanction such control by medical professionals as well as parents or guardians, with the stated purpose being protection of the women from exploitation. It is difficult to understand how contraception is supposed to have that outcome, without also drawing the implication that the woman’s appetitive body remains a risk in terms of questioning her ability to make decisions about her fertility, as commented upon by a number of feminist writers (Black, 2004; Bordo, 2000; Grosz, 1994; Ussher, 2006). With a number of the women having experienced sexual violence it is not surprising that many did feel vulnerable but some also demonstrated that they were able to make choices about what they wanted for their body. Such developments support Hollomotz’s (2011) contention that empowerment of people with intellectual disability is the more effective response to their vulnerability than long-term use of contraception or constant surveillance. At a policy level, changes to the Police response in New Zealand (New Zealand Police, 2014), with the availability of both short term Police Safety Orders that can provide immediate protection, and longer lasting Protection Orders, have meant better outcomes for those women who reported sexual violence. Interestingly, this policy change in response to the Domestic Violence Act 1995 provides a benefit to all women and is not specific to women with intellectual disability, unlike the sections of legislation above. However, that the police chose to use this strategy rather than charge perpetrators suggests legislation that has been intended to provide greater support to victims of sexual violence is still not meeting the needs of women with intellectual disability by bringing about successful prosecutions (Mossman, Jordan, MacGibbon, Kingi, & More, 2009).
Other policy influencing the population as a whole comes from the Ministry of Health who are driving the message for control of overweight and obesity (for example see, Health improvement and innovation resource centre, 2010-2014). Closely aligned with the medical model that positions weight as a significant contributing factor to disease, there is also the underlying paradigm that positions the body as appetitive and in need of control. Amongst the women’s responses to questions about their body size, diet and exercise, health was positioned as a dominant influence on their attitude and behaviour. Furthermore, their pride when they saw themselves as an ideal weight and their dissatisfaction when overweight were suggestive of understanding their body in terms of self-control. The influence of the people around them will be discussed in the next section, but contributing at policy level to the variations in self or other control of eating and exercise was the interpretation of the New Zealand Disability Strategy (Ministry of Health, 2001) and the To Have an Ordinary Life document (National Health Committee, 2003).

It might be supposed that the Disability Strategy (Ministry of Health, 2001), and the To Have an Ordinary Life document (National Health Committee, 2003), with their basis in movements such as normalisation, social role valorisation and the social model, would be driving changes in the way that the bodies of women with intellectual disability might be perceived as ‘risky’. With these documents the goal was clearly social inclusion but, as Ikäheimo (2009) suggests, even in situations where there is to all intents social inclusion, the attitude of others towards recognition of full personhood can be a limiting factor. Within the research there was no doubt that many of the women experienced mixed messages about their ownership or control of their body and these were reflected in their various body images. Autonomy depended on others’ perceiving risk. In other words the ethical principles of autonomy and best interest (Beauchamp & Childress, 1989) were variously applied according to the social importance of the practice. The medical model, eugenics, normalisation or social role valorisation could all be seen to underlie the behaviours in which the women had least control. While legislation and policy provided a background to the social messages that
were influencing the women’s perceptions of their body, the more immediate influences came from the people around them.

**The women’s social world**

While the move to deinstitutionalisation progressed relatively slowly, as outlined in Chapter Two, an alternative support service had begun to provide short stay homes in the mid 1950s. For a number of the women, both this original service and other smaller services that developed, provided their home as they grew older and moved from the family home. The Intellectually Handicapped Children’s Parents’ Association had become a major player in adopting human rights and normalisation perspectives. As such, it is likely that this association and other smaller but similar NGOs have influenced the values that some of the women in the study were exposed to, through their family and support staff. Following the politically led deinstitutionalisation, NGOs grew in number and, while normalisation or the later social role valorisation principles remained relevant, as providers of essentially adult support a difference detected within the current research is that they appear to lean more towards human rights based on the social model of disability.

For most of the women, their social world revolved around their association with these support services, family and volunteer organisations. Some of the more independent women belonged to church groups, clubs or had part-time employment and through these venues mixed more widely with a range of people but, for most, opportunity for contact with people outside of services was either through family or their few hours a week of work experience. It is not surprising that families and support people had the most overt influence on the women’s body image. While there was some evidence that their bodywork was influenced by fashion trends, I suggest that their reliance on others meant that trends were often interpreted and weighted as appropriate or not by these others. In this study these people were not interviewed and therefore their approaches cannot be assumed; nevertheless, it is likely they would be influenced by social attitudes that
consider women responsible for controlling their appetitive body, as suggested in Chapter Two (Bordo, 2000; Grosz, 1994; Ussher, 2006).

Within this doctoral research the women’s families had both an historical and current impact on their body image and bodywork, reflecting the expectations of a constructionist approach, which generally places the family as the first influence on body image and bodywork (Calogero & Thompson, 2010; Hurd Clarke & Griffin, 2007). A psychoanalytic approach to body image would position the family as crucial to forming the Ideal-I and there is some evidence of this in the data, but questions about the nature of family influence remain. For example, the women who had experienced sexual abuse within their family were those most at risk of mental illness and obesity, outcomes that might not be too surprising (Colangelo & Keefe-Cooperman, 2012) but from which it is difficult to infer anything, beyond that they follow a typical pattern of low self-esteem and negative body image. For the one woman who identified having had a hysterectomy at a young age, from her unwillingness to discuss the decision it could only be inferred from her age at the time that her parents had taken a lead role, for which there is clearly legislation to support their decision. On a more positive note, none of the women had been institutionalised at a young age, suggesting that they had exposure to learn their body practices from their mothers. Mothers had in the past or currently, accompanied their daughters shopping for clothes, to hairstylists and, in the one case of Wilma, to the beauty therapist. Furthermore, it seems likely that family had influenced Sylvia’s belief that the body needs fat reserves and Ursula’s that her size reflected her being the “biggest one in the family” and wearing short hair because that was how people in her family had their hair styled. As older women, both Ursula and Sylvia are, perhaps, illustrating a commonly seen reference back to earlier standards for women as they age (Grogan, 2012). Family were also notable as having control of the women’s discretionary money, possibly restricting their freedom to buy clothes or cosmetics but also to engage in more trendy practices such as tattoos, body piercings or cosmetic surgery. However, as only two women lived at home with their parents, daily living choices such as food and exercise patterns sat with either the women themselves or their support service.
Where family influence is most likely embedded in their sociocultural milieu, including exposure to media, support services are, in addition, expected to meet legislative and policy requirements to secure funding and these could be seen to influence the body image and body practices of the women. Women who were living with higher levels of support were more likely to have their identity shaped by the interpretation of government policy by their service; however, all the women were exposed to these values to some extent. For example, the emphasis that many women placed on being clean and tidy, including being presentable when going out, suggests that the influence of normalisation or social role valorisation principles (Caruso & Osburn, 2011) persist at least to some extent. Support staff monitored and told the women when they did not meet an appropriate standard, as evidenced in Sylvia reporting that she had been advised when she “smelt” or Diana emphasising that she knew what to do with her dirty clothes while seeking confirmation from her support person who was in attendance at the interview. Amongst the various studies exploring the body image of women without disabilities I do not remember any emphasis on basic hygiene, most likely because it is assumed; whereas, for some women in the study, this was their main focus when asked about their body, in part because it demonstrated their competence. Although the data are not sufficient to be certain, they suggest that the women are exposed to regular messages about meeting these standards of hygiene, a point supported by Freeman Watson et al.’s (2010) findings that caregivers emphasised the need to ensure tidiness of clothing to facilitate social acceptance. In other words, the emphasis was on ‘fitting in’ with social standards as a way to facilitate inclusion, that is, to decrease ‘othering’ by society. Whilst it might seem to be a worthy goal, there is, however, a risk that it simply perpetuates a sense of ‘other’ for the woman herself and limits her opportunities to develop self-expression as she conforms to the group identity.

Furthermore, many of these same women were those who took great pride in their trim body weight and fitness. Perceptions of body size and associated pride in being trim and fit provided contrast between services. Given the findings of other studies that have identified variables in relation to body weight for people with intellectual disability living in residential as opposed to independent flats
(Bhaumik, et al., 2008; Rimmer & Yamaki, 2006) this finding might not seem unique. There was, however, a difference within the residential services that led me to question whether they were drawing on various interpretations of human rights. Living in a flat that was staffed and attending a day service with a regular programme of activities meant that some women had limited control of their diet and the potential for easy access to exercise if their day programme offered such. The women within this study did not question this degree of control but, then, for those who were forty or fifty, it had been their way of life for some years. Again, the principles of normalisation, particularly having a regular rhythm to the day (by moving from residence to ‘workplace’, which is considered to reflect the lives of most people in society) (Culham, 2003), overlaid by medical model health messages about diet and activity, provided a basis for the women’s positive body image. As discussed in Chapter Two, in their own way, these women could be seen to be accepting that their own best interests were served through acquiescing to the practices expected of them by those that they perceived to have the power within their world (Bartky, 2008; Sentilles & Callahan, 2012). In other words, they were being ‘good’ women within their particular social world of services.

In contrast, where the women lived independently with family, or in the residential services which put a greater emphasis on the people that they support choosing their own weekly menus, weight management appeared to be more difficult for the women, making them less satisfied with their body size. In these situations services would appear to be influenced by the broader Disability Strategy (Ministry of Health, 2001), which emphasised personal autonomy. Empowerment had, in this situation, the interesting effect of increasing dissatisfaction with their body weight for many of the women, thus making it a challenge for them to be ‘good’ women within the context of a society that valued a trim body. At the same time the women’s dissatisfaction reflected a more common perception of women in that society, where both being overweight and being unhappy about that, are not uncommon (Bulik, et al., 2001; Chrisler, 2007; Tiggemann, 2004).
Within the theme of gender, the variable influences between policy and practice became even greater. The reproductive body was clearly the more 'risky' and, while not explored in depth, women provided examples both in terms of others controlling their fertility and in that a number had experienced sexual violence. This research supported other studies that identify comparatively high rates of sexual abuse (Hollomotz, 2011; Johnson, et al., 2001; McCarthy, 1999) and from that perspective it is not surprising that the women themselves saw their body as somewhat 'risky' (Lupton, 2013). Furthermore, some of the women were clearly aware of social messages that might be interpreted as women having dangerous and defiled bodies (Ussher, 2006), such as the woman who worried that her body might be seen as 'dirty' to future partners following abuse that had occurred some years previously. However, it was also clear that some women were aware of changing attitudes and felt supported by the legal system or educational institute policy where these had enabled them to take more definitive action. Support services and then police taking action had been pivotal in these more recent events and such responses appeared to shift the sense of responsibility clearly to the offender in the woman’s mind. In being so vindicated these women did not carry the burden of the woman with the earlier experience of seeing their bodies as defiled.

As Chodorow (1978) suggested some years ago, women's body image is aligned with mothering. However, for most of the women, mothering was not even considered a possibility. Services appeared to support the social mandate that excludes women with intellectual disability from expressing their sexuality through reproduction. In this respect they were in collusion with medical professionals and quite possibly parents who may have initiated contraception for the women. If I leave aside the reproductive component of sexuality, I found that services also differed in the extent to which they supported the woman’s right to have enduring personal relationships, and to give and receive love (National Health Committee, 2003). Although half of the women said that they had a boyfriend, encouragement of these relationships ranged from invisible to proactive, with Amelia’s experience of her engagement and plans for a wedding illustrating a supportive service.
Where there did seem to be general agreement across services was in the women’s rights to make decisions about the less ‘risky’ aspects of body image, as seen in the data relating to clothing, cosmetics and hairstyles. Most of the women felt able to make choices within what was offered and that they did so, reflects similarity with other women for whom the influences on beauty practices play out differently with each individual (Black, 2004; Dellinger & Williams, 1997; Gimlin, 2002; Lennon, 2012; Sentilles & Callahan, 2012). Individual support people were particularly important in the opportunities provided to the women. The women often saw these individuals as friends as they fulfilled many of the roles usually associated with peers; a role that Holmlund (2011) identifies for most women. These were the people who accompanied them on shopping trips (when family were unavailable) and to hairstylists, or cut and coloured their hair, or took time to apply makeup, paint nails and so on. Whilst the women were generally very happy about the opportunities such relationships offered, I reflected on what the relationships meant for their body practices. Although it appeared that the women had choices about their clothing, cosmetics and hairstyles, the group who were dependent on others facilitating their choices were, in fact, limited by the decisions of these others regarding where they shopped and, in some cases, where and whether they had their hair cut and coloured. I would suggest that few women would want or accept that degree of input from friends, even though many women do value friends accompanying them shopping (Holmlund, et al., 2011).

In summary, both political and sociocultural positioning of the women would suggest that their body image is subject to multiple influences, each of which contributes to the Ideal-I. Underpinning these influences is an interpretation of women with intellectual disability as having a body that is both ‘risky’ and ‘othered’. Policy that is aimed at producing an inclusive society seeks to reduce the degree to which the women are ‘othered’ and encourages practice that assists the women to achieve a look that will be socially acceptable. Such values are embedded within daily interactions that support staff had with the women to the extent that the women have internalised or at least learnt to comply with the rules. Where their body fits within these rules, they are satisfied with their body. Experiencing their body as risky are those women who do not meet the ideals of
body shape and size and those who are concerned about their ability to meet standards of hygiene. In addition, for many women, their sexuality made their body risky, recognised by most in their anxiety that they may be abused or their responses when they had been abused. However, attitudes to menstruation and the influence of medicine on controlling their reproductive body would suggest to some of the women that others also considered their body ‘risky’. As Calogero (2010) notes, many women have a high level of anxiety about their bodily appearance as they work to achieve the right balance between desirability and personal safety; for women with intellectual disability the mixed messages to which they are exposed only makes it more difficult to achieve a balance.

**From research findings to making meaning**

The methodological considerations for this research included the ability for the data collected to provide insight into the ways in which the women constructed their body. By bringing my interpretation of their construction to the attention of others the hope is that social change, including removal of disabling barriers, will eventuate, as others have suggested should be the goals of disability research (Björnsdóttir & Traustadóttir, 2010; Moore, et al., 1998; Walmsley, 2001). A feature of the literature that presents ways to challenge the positioning of people is that these authors are not averse to melding ideas from a number of sources. For example, Van der Tuin (2011) suggests that, rather than critique philosophy, it can be more useful to develop ideas and Shildrick (2009) openly states “I have no compunction in raiding the theoretical toolbox to assess whether the Deleuzian analytic offers any insights that might be adapted to the end of further queering the problematic of disability and globalisation” (p. 156-7). If we follow in the path of Grosz’s (1994) writing on corporeal feminism, we find there is a general pattern among the more recent writings on disability to consider interpretations of Deleuze and Guatarri along with other philosophers. Whereas a concern that postmodern and poststructuralist approaches might, through an emphasis on deconstruction, have little effect on change (Thomas, 2004), a primary appeal of these theorists is that they provide a way to move understanding beyond the critical and open up possibilities for change. Indeed, this was a primary reason for
the initial choice of theoretical perspectives taken within this thesis. While an interpretation of Lacan’s mirror stage might also suggest that the drive for an Ideal I indicates that there is no natural body (Goodley, 2011), making any division between able/disabled bodies artificial.

The mirror stage, melded as it is to language and sociocultural context, provides an interpretation of how the women came to have an understanding of their embodied self and where that self fits within their social world. However, the themes from this research illustrate that body image is neither static nor singular. As Coleman (2009) found with the young women in her study, there was a relational component to the body image that the women shared with their interviewers, suggesting fluidity and possibility. Featherstone (2006, 2010) discusses the idea of body without image, that a reliance on body image as a means to understand bodily perception is flawed. Here he is drawing on Massumi, to suggest that the concept of body without image might better explain the proprioceptive and intense bodily response identified when people talk about their bodies or those of others. Indeed, in the later article, Featherstone draws on the work of Coleman and Shildrick to illustrate this alternative concept. According to Shildrick (2009), the power to affirm life, recognition that potential is never reached and being open to opportunity, as she borrows from Deleuze, can be used effectively in repositioning attitudes to disability. If instability is unexceptional, disability should be seen “as just another variant on the infinite modes of becoming” (p.173). In particular it is Deleuze and Guatarri’s use of rhizomatics that is seen as most useful, alongside their concept of body without organs (BwO) in terms of bringing about change. Authors, who write from either/both feminist and/or disability positions, have contributed to interpreting the concept of BwO (Braidotti, 2003; Coleman, 2009; Goodley, 2007a, 2007b; Grosz, 1993, 1994, 2011; Hickey-Moody, 2009). However, it should be noted that BwO has created some concern for Grosz (1993), Butler (1990) and Braidotti (2003) in view of the risk to making invisible the very real differences in the way that they see men and women constructed. However, both Grosz and Braidotti are prepared to put such concerns aside to adapt that which is useful for the purpose of exploring an alternative conception of identity. The rhizome is a metaphor, contrasted with the tree, which
is seen to be hierarchical and the metaphor for the current stratification, ordering and dichotomising of beings (Grosz, 1993). In contrast, Grosz (1993) describes rhizomes as a “... network of multiple branching roots and shoots, with no central axis, no unified point of origin and no given direction of growth – a proliferating, somewhat chaotic and diversified system of growths” (p.174). In addition to the above-mentioned connection, heterogeneity and multiplicity, Grosz notes that rhizomes are “capable of being severed or disconnected, creating the possibility of other, different connections.” (p.174). A related concept is that they are seen as map-making with the focus on what the body can do (the possibilities) as suggested by Grosz (1993) and illustrated by Hickey-Moody (2009) through her research with a mixed abilities dance group.

Grosz (1993) describes the BwO as “... the body disinvested of all fantasies, images, projections, a body without a psychical interior, without internal cohesion or latent significance.” (p.174). It should be noted that it is never meant to be totally disinvested but rather partially, in order that it is open to possibilities. Thus the BwO provides the field for becomings. It has to be acknowledged that these ideas may be somewhat utopian (Braidotti, 2003), however that should not prevent consideration in terms of possibilities and limitations that might influence change in society. In other words by changing the perceptions of others, whilst working with any cognitive limitations the person might have to internalise concepts, it should be possible to remove current barriers to the women’s construction of their body. Both the medical model and the social model, as they have been critiqued, offer insight into how the women have come to be ‘othered’ but, as Hickey-Moody (2009) suggests, the challenge now is to open up the possibilities.

Consistent with attitudes to disabled female bodies in the past (Shildrick, 2009), the limited evidence in this research suggests that others may interpret the women’s female body as ‘risky’ from an early age. Thus few of the women appeared to grow up with a sense that their gendered body might be attractive or desirable in a pleasurable way; rather their body seemed to represent an ascribed status with opportunities for personal expression to be controlled. My thought is
that the overriding influence of risk, coupled with the need to demonstrate cognitive competence through compliance with standards of hygiene, limited their internalisation of an Ideal I to that of ‘being good’ as judged by others. For a number of the women, their body represented their ‘goodness’ through cleanliness, fitness and being an ideal weight, rather than through a beauty standard considered to represent the ideal body. Where cosmetics, stylish and fashionable clothing, hairstyle and surgical interventions are believed to provide women with the tools to indicate through their body such things as income and importance, for the women in this study, status was more closely aligned to competence. Indeed, as was seen with Nadia choosing not to wear makeup, some beauty practices were avoided so attention was not drawn to their competence or lack thereof. Thus either the woman herself, or others, set limitations or closed off possibilities in constructing body image.

Shifting the interpretation of the women’s body as ‘risky’ then becomes a starting point for change. Eva, with many health concerns in addition to her intellectual impairment, demonstrated that it is possible for a different representation. Eva and Amelia were supported by the same service and whilst both were only able to contribute in a small way to the research because of their health, they were two of the more ‘gendered’ women, in terms of relationships and interest in beauty practices. In their service it would seem that there is potential for map-making (Grosz, 1993; Hickey-Moody, 2009), that is, fewer predetermined pathways for the women and their body practices. The rather paradoxical difference noted between hairstyling and other beauty practices suggests that there might also be tentative changes happening within other services. Whilst most practices were aimed at ensuring the women did not stand out, hair colour made a statement. It was difficult to ascertain the woman’s motivation for colouring her hair, it may have been as straightforward as finding pleasure in the comments of others and/or the one-to-one attention and pampering. Some women may have seen it as their one opportunity to express some resistance to their otherwise rule-bound body practices. From a service perspective, situated, as it was, within a time whereby such activity was fashionable amongst other women, it may simply be understood within a context of normalisation or social role
valorisation, rather than risky behaviour more commonly associated with the sexuality of women with intellectual disability. However, whether or not consciously done, such practices might serve the purpose of making other connections for the women, for whom other possibilities might emerge.

As suggested above, services appear to struggle with which policy or principle should drive their support, with autonomy and beneficence generally the underlying ethical positions that are in conflict. In reality these positions perpetuate limitations as their interpretation is tied to assessments of competence and labelling. Other models for service provision drawing on rhizomatics have been suggested, such as Clegg and Lansdall-Welfare’s (2010) conceptual model for services for people with intellectual disability that would be open to exploration and innovation, based on relationship and respect for differences. Feminist ethics of relationship and reciprocity are gaining the attention of various authors writing within the field of intellectual disability, with Goodley (2007b) suggesting that the appropriate approach might be “becoming-care” (p. 325), by which I take to mean supportive but open to possibility. Clapton (2009) also emphasises a shift away from traditional ethical approaches in her call for a “Fabric of Integralty, by which the whole structure and texture is changed: confronted by difference, enlightened by imagination and ruptured for transformation” (author’s original italics, p.232). Feminist ethics provide the key to bringing about such change, with Clapton placing particular emphasis on friendship models of relationship as appropriate to consider for a way forward. These models include elements of respectful relationships, filial love, companionship and mutuality. Whilst some of these elements were evident within the relationships that the women identified as pivotal to their body/beauty practices, they differed in degree. A key ingredient of such relationships is reciprocity, which might usually be found in friendships and, in the construction of body image, is often most evident in peer relationships, with Coleman (2009) showing that it was pivotal in how the young women in her study viewed their immanent body. Indeed, most of the literature reviewed for body practices considered peers to be important in guiding women’s decisions (for example, Calogero & Thompson, 2010; Grogan, 2008; Lennon, 2012; Stuart & Donaghue, 2011). Such peer relationships were absent in this research. Whilst a
model of friendship for service provision might be ideal, it would be naive to ignore the challenges that such a model would pose. At the most fundamental level, support people are employed to provide a service. In contrast, peers are not employed and the informality of the relationship is part of the value they may have in helping shape self-identity and body construction. Peer relationships generally develop naturally; however, it might be that young women with intellectual disability are not getting sufficient opportunity to meet and spend time with peers and/or might need some scaffolded support to build such relationships (Harter, 2012).

As discussed in Chapter Two, the diagnosis of intellectual disability, with the associated implications of classification, meant that once a person was classified their opportunities were determined accordingly (Simpson, 1999). For the women in this study such limited opportunities could be seen to be relevant to their body image. There were many ways that their body image could be seen as relational, such as the differences that appeared to exist between the influence of services, the variability in access to money that impacted on independence when shopping and how they had been positioned by others throughout their lives. By removing the positioning of women that classifies them according to their intellectual disability and therefore ‘risky’, the BwO offers an alternative, shifting the focus from limitations imposed by others to ‘protect’ and bring about conformity, to seeking possibilities. Becoming means that at no age is the body image final; as others change their ‘being in relationship’ with women with intellectual disability possibilities open for the woman to make different connections, that is, change her body image.

**Implications of the research for policy and practice**

Before I turn my attention to the implications for policy and practice that directly relate to body image, it will be evident that a major influence on the findings of this research has been the variability in the women’s expression of ideas. Communication is such a fundamental component of social interaction that I believe we have an ethical duty to make every effort to provide suitable means for
people to communicate their thoughts. Furthermore, as a signatory to the UNCRPD (United Nations, 2008), New Zealand is obliged, according to Article 21, to provide the means for people to communicate and through Article 26 provide the necessary habilitation measures, which would include speech language therapy. The difficulty that a number of the women in this study had, when they otherwise appeared to understand the question, may well reflect an historical position; however, it reminds of the importance of communication and need to provide the support necessary from childhood to assist people with intellectual disability to find effective methods to communicate. The following points all relate back to communication and being ‘in relation’.

As with other studies, memory of past events was variable amongst the women. Those who could produce photographs, or had frequent contact with their family and opportunities to rehearse memory, appeared better able to recount events. Memory aids the sense of continuity, important for both self-concept and body image.

Body image is fluid and related to both opportunities and limitations. Article six of the UNCRPD (United Nations, 2008) specifically recognises women with disabilities and that they are often subject to multiple discrimination, while Article 23 of the same convention recognises disabled women’s rights to family, including becoming a mother. This research demonstrated that women with intellectual disability do not have the same opportunities as other women, most significantly seen in attitudes of others towards their sexuality and having the consequence of limiting their gender identity. There was some evidence that younger women better understood gender identity and were more empowered to control their own sexuality; however, these women were also more likely to be living independently. Together with the modestly better outcomes seen for the women who had more recently experienced sexual assault, it could be suggested that small shifts have occurred regarding evaluation of risk for some women with intellectual disability. Policy and practice should respond to these positive examples by extending education about relationships and sexuality to all young women with intellectual disability in a way that is meaningful to them.
The lack of peer relationships was a limitation for the women’s body image and body practices. Opportunities to develop and maintain peer groups from an early age should be supported. Family, education and adult support services all have a role in facilitating peer relationships.

For the women most dependent on services there were various limitations to how they could express their personality through body practices. Rules can provide some security and reassurance; however, there was evidence that the women used these to conform and be seen as ‘good’. Furthermore, for many of the women, there were few opportunities to learn about nutrition and cook, choose clothes from a range of shops, or engage in activities that were not service-led. Given the variation seen, all services might consider how they could expand the opportunities for women to make choices and learn new skills. Developing consistency between legislation and policy, at both governmental and service level, might assist services to meet the requirements of their contracts. Taking a view that body image is always becoming, there is much that services could do to provide opportunities and respond to the above limitations. It could be argued that these limitations contravene Article 19 of the UNCRPD (United Nations, 2008), which requires that disabled people be offered choices equal to others within their community.

Whilst the focus above is on services, family and education, as the groups that have day-to-day contact, health professionals with more intermittent contact also need to take heed and consider their assumptions about opportunities that should be available to women with intellectual disability. The medical model underpins many of the limitations on the women's body image that were seen in the research. The UNCRPD in article 25 requires health professionals to provide health services consistent with that provided to other people in their community with specific mention of sexual and reproductive health and free and informed consent (United Nations, 2008).
The research method

The choice of a constructivist approach for this doctoral study was led by my desire to consider the body image of the women from their perspective. As highlighted in the methodology section, there were a number of considerations that were important to the methods chosen for data collection. Reflexivity is a crucial element of any constructivist study, thus I offer my reflections on how constructivism benefitted my understanding of the women’s body image. Within the actual methods chosen for data collection there were both strengths and weaknesses. The interviews, including the interview schedule and CDRS and subsequent data analysis are considered first in this section. The ethical issues for research that engages people with intellectual disability are well documented and were introduced in the methodology chapter. My reflection on ethical issues that arose within this study provides the second part to the discussion on the research method.

An important consideration for constructivism is whether the method has answered the research questions (Patton, 2002) and I believe that the previous sections of this chapter would confirm that it has provided some answers. Further, Patton (2002) suggests that a constructivist approach allows for particularity, the exposure of unique cases, differences and similarities, which were seen amongst the women’s expressions of their body image, supporting my understanding of body image as contextual and fluid. There was an advantage to having the body image questions situated within the wider research that had been influenced by narrative and life history approaches (Goodley, 2001; Hardy, et al., 2009; Somers, 1994), as understanding of the women’s construction of their body was ultimately drawn from their full transcripts and not solely the questions added for this doctoral study. Through taking a broader approach to studying body image, I believe I have avoided many of the criticisms of quantitative studies that interpret women’s body image from singular or very specific aspects (Somers, 1994). Instead, what has been shown is that a woman’s body image might differ according to her focus at the time; for example, while she might be unhappy with her weight, she can be proud of her hair and her overall evaluation might be positive. Utilising
both interviews and the CDRS as a method of triangulation was also helpful in drawing out these aspects of the women’s construction.

**The usefulness of the CDRS**

Whilst it might seem contrary to the generally qualitative approaches that I prefer for research, a rating scale was included in the method of this study for two purposes. Firstly, from the perspective that there may be a relationship between how people perceive their weight and the likelihood of losing weight (Lynch, et al., 2009), it could be useful to know whether such a straightforward tool would have value for health promotion practice with women with intellectual disability. Secondly, the tool provided a different strategy to the interview and by using a pictorial presentation of size, I thought that it might aid contributions from those women who relate better to pictures than words. The small number of women in this study always meant that indications of utility would need to be seen conservatively; however, the majority of the women were able to view the rating scale and make an assessment of their current size that was considered by the researchers to have reasonable accuracy, consistent with most other research using such tools (Bulik, et al., 2001; Napolitano, et al., 2012; Sanchez-Villegas, et al., 2001). A small group of women appeared to have difficulty perceiving the very thin presentation of the figure to the extreme left (that is, figure 1) which could be explained as simply a preference that has been shown for left-hand options on Likert-type scales. Other ways of presenting figures have been trialled and demonstrated that the method of presentation may affect choice (Doll, Ball, & Willows, 2004). Using Doll et al.’s approach the figures would be presented one at a time and it might be interesting to see if that would make a difference to accuracy.

Among other criticisms of figure rating scales, a range of authors suggest that the participant might have difficulty relating to the drawing (for example, Gardner & Brown, 2010; Pruis & Janowsky, 2010; Sanchez-Villegas, et al., 2001; Thompson & Gray, 1995). As a group the results would suggest that this was not a concern for the majority of the women; however, it may have been for some
individuals. The one woman who did not freely stand refused to complete the scale. There are a number of more sophisticated scales that have been developed over recent years (Heuberger, Domina, & MacGillivray, 2010; Pruis & Janowsky, 2010; Swami, Salem, Furnham, & Tovée, 2008; Swami et al., 2012) that might overcome difficulties people have relating to drawings; however, aside from Swami et al.’s (2012) Photographic Figure Rating Scale (PFRS), the others require specialist equipment. Choice as to which scale to use might be driven by the purpose. For research, greater accuracy might lead to a choice of the more sophisticated tools, but, for clinic purposes, the CDRS or the more recent PFRS would be adequate to facilitate a health promoting conversation.

Reflexivity

Whilst reflexivity is fundamental to a constructivist approach, with this doctoral study focused on others’ bodies, it was crucial to remain conscious of the influence of my own body image throughout data collection and analysis (Heyes, 2007; Tracy, 2010). Finding that many of the women struggled to identify specific features they preferred or disliked led me to reflect on how I would respond to such a question. Recognising that most of my thoughts were bound in my younger self and that strength of feeling had lessened with age, I tried asking other women that I knew how they would answer such questions. Most acknowledged it was not as straightforward as it might seem and that it took some thought. Similarly with use of make-up and clothing choices I found myself asking whether the women’s responses were significantly different to what I might provide, or what I saw around me. Other literature was not particularly helpful with these points, as the limited research that has been done was often related to women younger than the majority of the participants.

Intrusion of my own and my colleagues’ body image within this research were also evident in the transcripts. All three of us were familiar with the need to balance self-disclosure within the research relationship (Hesse-Biber & Piatelli, 2007; Reinharz & Chase, 2003); as well, we were aware that there might be challenges in interviewing people with intellectual disability (Booth & Booth,
At times our own body image guided the questions that were used to assist the person to think about their self but, as was shown with Amelia's feet, may have also led to the response that was given. During coding it was thus important to keep the context with the coded data, so that my analysis could take that into account.

Amongst the challenges for standpoint researchers using constructivism is the potential for the participants to have a different point of view (Larner, 1999; Olesen, 2005). As a feminist and disability researcher with a strong belief in respect for persons, it was important that I remained true to the data that indicated the women who I saw as being the most controlled by others, were essentially happy with their bodies and, indeed, their life in general. Clearly these women did not hold my feminist views, yet their positive construction could have held promise for my health promoter self. Given that current practice towards obesity management within the general literature is based around diet and exercise (Health improvement and innovation resource centre, 2010-2014; SPARC, 2005), it would seem that the women best able to meet these objectives were those with least control in their lives. One of the goals of good constructivist disability research is for it to be translated into practice; however, as Lather (1997) and Olesen (2005) both suggest, this can be difficult if the construction is at odds with the researcher’s beliefs. On the one hand, as a health promoter this research finding might lead me to consider that the best way to manage the high levels of obesity amongst women with intellectual disability would be to encourage greater control over their access to food and increase their opportunities for exercise; however, such control is counter to my beliefs about respecting persons. Thus, in constructing my view of their body image it was important to elaborate on the wider context that might be influencing the women’s perceptions (Howell, 2013; Moore, et al., 1998; Walmsley, 2001) and challenge the barriers that I saw as limiting for the women’s body image. Nevertheless, by adopting a reflexive position it remained important to give voice to those perceptions.
As Lather (1997) and Olesen (2005) are suggesting, reflexivity inevitably results in the researcher weighing up values that may conflict. Braidotti (2006) succinctly states how I felt at times as I tried to balance the competing interests in this doctoral study ...“Thinking is a nomadic activity, which takes place in the transitions between potentially contradictory positions.” (p. 199). The contradictions in this case are not unique when considered within the field of intellectual disability research, particularly where the aim is to raise awareness through people with intellectual disability having a voice (Goodley, 1996; McDonald & Keys, 2008; Nind, 2008; Walmsley, 2001; Walmsley & Johnson, 2003). At the most fundamental level, these contradictions involve balancing ethical principles. Reflecting the notion of ‘becoming’ is the research process, for while planning can aim to lessen ethical challenges, the reality of application is that the real world disrupts those plans. One value of having an advisory group is that while the process might feel nomadic at times, it is not solitary.

**Ethical challenges**

Inevitably there is a relationship between ethical and theoretical challenges. Thus, while I am positioning the following within ethics, the overlap will be apparent. A priority for this research was that any conception of their body image should come from what the women could tell us; in part this influenced the choice of a constructivist approach. However, as explained in the methodology, hearing from the women also aligned with my belief that people with intellectual disability should have the opportunity to participate in research that was about them (Booth & Booth, 1996; Goodley, 1996; Mirfin-Veitch, 2010). People First was chosen as the organisation through which we would recruit as it was seen to broaden the field of potential participants in a way that recruitment through selected services might not; however, most of the women required the assistance of their service when it came to arranging interviews. Indeed, owing to lack of volunteer support, smaller towns did not have regular People First meetings and in these regions the local services stepped in to arrange a special meeting for women to hear about the research. Thus, services became involved in the research and while they were
often very helpful they were also the source of some of the methodological and ethical challenges.

As noted earlier in this chapter, service providers are expected to incorporate inclusive principles into service provision within New Zealand. The research was seen by some to be well positioned in support of both their aims, and the aims of People First, for inclusion. Thus, support people were very encouraging of women taking part, to the extent that I sometimes wondered, as Walmsley and Johnson (2003) have in the past, whether they saw the act of participation as the primary purpose of the research. As we went around the country recruiting women into the study, we faced the dilemma of whether or not to include women, who for all intents and purposes seemed to be able to provide consent, but who struggled to have a conversation with us. As we did not wish to disappoint the women they were often included. What this meant for the construction of body image, where cognition and language are important components of theorising (Harter, 2012), is seen in the variations in the contributions of the women. Ultimately the variation has meant that some women’s voices are stronger than others. I have taken care to include quotes that illustrate the range of opinions and the depth of response to questions (Guba & Lincoln, 2005). However, aside from the methodological challenge presented by choosing to include all women, there are clearly ethical issues both in accepting the women into the study and the involvement of their service in the research process.

Juggling the desire to give people a voice, with the very real concerns of truly informed consent and contribution, is a struggle (McDonald & Keys, 2008; Walmsley & Johnson, 2003). Careful thought had been given to how we would ensure informed consent with the women, including recognition that, for our participants, it is not a one-off procedure but should be revisited throughout the research relationship. Fundamentally the relationship that we each developed with the women guided our decisions about the soundness of their consent to continue. All three researchers chose to stop interviews, at times checking consent and then continuing but at other times terminating the interview. Based in the ethical principle of autonomy and the rights of persons to make their own
decisions (Beauchamp & Childress, 1989), it is through relationships that people come to know about the research and ultimately choose to participate (DeVault & Gross, 2007; Oakley, 1981; Olesen, 2005; Reinharz & Chase, 2003). While there are various methods suggested for identifying capacity to consent and contribute meaningfully to research (Nind, 2008), it was while reflecting on our recent interviews that we noted the importance of the interactions both prior to and at conclusion of the interviews. Although there were some exceptions, it was the women who engaged at a social level, either through offering hospitality or showing an interest in us as people, who contributed most meaningfully within the interview setting. These might be important cues to consider when making decisions about the person’s capacity to consent and contribute. I do not mean that those people who do not display the social skills should be excluded from the research but that they might need a different approach to the traditional interview or, perhaps, just the opportunity to learn what is expected of them in an interview (Reinharz & Chase, 2003; Walmsley & Johnson, 2003).

Another ethical challenge that arose owing to the women’s reliance on support from services was management of confidentiality and anonymity (Walmsley & Johnson, 2003). According to our protocol the woman was to choose the place where she was interviewed; however, we found that some services were not willing for women to remain at home, even if that had been their choice, unless a support person was able to be present in the home. What was never clear to us was the rationale behind these decisions, but it is difficult to avoid the conclusion that there had been some analysis of risk, real or otherwise (Hollomotz, 2011). Interestingly, the decision was usually relayed to us at the last minute and the unavailability of a support person used as the reason for the interview to take place at the day base instead. Choosing not to do the interview was complicated by the fact that these women were living in different parts of the country and we had travelled to meet with them, otherwise rescheduling would have been the obvious option. Although all the services provided a separate room, the woman could not keep private her participation in the research. Reflexivity in this case meant recognising a heightened risk of people knowing the woman had taken part in the research making it more likely she could be recognised in reports. Thus, in writing
up the study consideration was given as to the detail provided about participants and pseudonyms were not used with particularly sensitive information. Whilst much could be learnt about the construction of their individual body image from each woman, prioritising a collective construction within the themes makes it less likely that women will be recognised.

Reflexivity inevitably leads to consideration of what would be done differently. It is clear from the above that my colleagues and I had challenges, which have meant some limitations for the research. Although the research has provided some understanding of the construction of the body image of the women interviewed, it also raises a number of questions. In the final sections of this chapter implications for policy and practice are summarised, limitations of the research and possibilities for future research are considered.

Limitations of the research

Qualitative research is always contextual and limited and this doctoral study is no exception. A hope for this research was that the findings would open opportunities for women with intellectual disability in terms of their body image and body practices. For this outcome, the research needed to tell compelling stories, however it is equally important to be honest about the limitations.

The decision to be inclusive of women, who chose to participate, meant that some interviews did not provide the depth that is usually expected of qualitative interviews. An alternative data collection method might have suited these women better and would be a consideration for future research. In her research with younger women, Coleman (2009) interviewed two girls together and also used focus groups. Whilst such strategies might be less likely to draw out sensitive issues, for some aspects of body image women might find it helpful to be able to share stories. In addition, taking an approach more akin to ethnomethodology, that is spending time with the person within their usual environment, might make the process of data collection more ordinary to the women, and facilitate communication as the researcher becomes used to the rhythm of the woman's
speech and provide opportunity to develop the relationship for more sensitive questions (McCarthy, 1999). Indeed, any attempt to provide a more in depth critical analysis of the women’s lives would also demand longer and more frequent visits in order to gain a more comprehensive understanding of their lives.

The age range of 18 to 65 years was, for a comparatively small study, possibly too large. Older women had vastly different experiences to the younger women. Although these different experiences provided a construction illustrating variability in the women’s body image, there may have been value in choosing a narrower age band. If variability of social experience were found within a narrower age band it might be considered stronger evidence of the role of opportunities and limitations in the development of body image.

The twenty-five participants were all from New Zealand and most identified as Pākehā. Women from other countries or cultural groups might have quite different perceptions of their body. Satisfaction with body size, ideal body size and body practices have been shown to differ across cultures (Becker, 2004; Black, 2004; Latner, et al., 2011).

Although having body image nested within the wider research was beneficial for understanding the women’s contexts, it meant some limitations for exploring their body image in more depth. A more consistent effort to explore gender-related aspects, such as attitudes to menstruation, contraception and sterilisation, would provide a stronger basis for the relationship between gender construction and beauty practices.

Recruitment through People First meant that all women identified with, and were active in, intellectual disability services; thus, there might be little surprise that being ‘other’ contributed to their body image and predetermined some limitations. It might be that women with intellectual disability who do not position themselves thus have a different interpretation of their body and are open to more opportunities for body practices.
The results from the CDRS should not be used beyond the limited application in this study, as the tool was simply a strategy for introducing the topic of body image with the women. Collection of accurate weight and height would be necessary were it to be used to assess accuracy of women’s perception of the body size.

**Future research**

As a first study of body image with women with intellectual disability in New Zealand the research provides a starting point from which to explore the topic in greater depth and from different perspectives.

Further study of how possibilities and limitations interact to determine body image might ultimately increase opportunities for social integration for women with intellectual disability. Of particular interest would be a study of young women who are growing up within the more integrated setting of regular schools and with greater levels of participation in social media. From personal observation, it would seem that younger women are engaging in more beauty practices, although the evidence from the current study was mixed with the under thirty year olds. As both Becker (2004) and Latner et al. (2011) have found, exposure to media has had an impact on the body practices and satisfaction with body image for young women without intellectual disability. The World Health Organisation, Europe, has identified the importance of empowering young people with an intellectual disability to make decisions about their lives as a priority for future research (World Health Organisation, 2012). They include within this priority the need to “examine the impact of socio-environmental variables on self-determination and quality of life” (p.9).

In addition to social and other media, the influence of peers on body image needs further study with women with intellectual disability. Although the women did not speak about peer relationships, as such, it may be that they simply did not think to do so. In addition, evaluative research of strategies to enhance the
development of peer relationships would assist with development of evidence-based policy and practice.

Widening participation so that women participants take a greater role in the research to understand their construction of their body would give authenticity that might not be evident in the researcher-constructed approach taken for this doctoral study. Whilst such research might be challenging for the women (Harter, 2012; Walmsley & Johnson, 2003), a participatory action approach, and/or using multiple methods, such as Coleman (2009) used in her study with young women, is worth consideration.

Both this research and previous research (Conder, et al., 2010) suggest that women with intellectual disability in New Zealand would benefit from more opportunity to learn about their sexuality and reproductive health. Specific research exploring these aspects of the lives of women with intellectual disability would add to the international research that does support these findings. There is a range of sexuality and relationship education approaches (for example, K. L. Johnson, et al., 2001) and evaluation research within the New Zealand context would be useful so that evidenced-based recommendations could be made to inform policy and practice.

This doctoral research began with an interest in women with intellectual disability and weight management. The evidence from women who had experience of weight reduction in this study would suggest that current strategies are not successful. There would appear to be no research that has looked at motivational interviewing as a strategy for supporting health behaviour with people with intellectual disability. There is literature that supports motivational interviewing with other populations (for example, Folta & Nelson, 2010) and it therefore might be interesting to consider this approach with people with intellectual disability so that they can feel more in control of their own health. Appropriately conducted motivational interviewing is respectful of persons and choice.
Conclusion

From the findings of this doctoral study it is clear that the body image of women with intellectual disability is not static, nor a singular concept. As with other women, the women in this study were satisfied with some aspects of their body but not others. Body size satisfaction most closely reflected the perception of other women and the social influence of the thin ideal. In contrast the women's body image aligned less with other women in terms of gender roles and beauty practices. Whilst all the women identified their body as female, few saw themselves as potential mothers or engaged in beauty practices such that other women might use to attract a partner. For many of the women, their body practices, such as being clean and tidy, were more closely aligned with a desire to be seen as competent. Competence was aimed at presenting a body that ‘fitted in’ with social expectations. Challenges to competence included the women's perception of their cognitive, mental or physical impairments and, as such, demonstrated a sense of embodiment, illustrating that the women’s body image was influenced by more than sociocultural factors. In addition to fitting in, having a physically able body was valued by the women who enjoyed activity and/or relied on their fitness to independently access their community.

The absence of peer relationships, within the context of learning about and engaging in beauty practices or discussing sexuality, was a major difference in the lives of these women and that of other women. Services might consider how peer relationships could be supported and conversations facilitated. As more young women with intellectual disability grow up in their family’s community it is likely that they will encounter social messages that are more in line with their peers, ultimately changing their understanding of their body and body practices and ideally presenting them with more choice.

Throughout the three themes there was evidence of the women having their body and body practices controlled by others. For the women living with close supervision, control was illustrated by their limited choices about their diet, activities and shopping. In contrast, those women who lived independently were
more likely to be controlled in the expression of their sexuality. Both feminist and
disability perspectives would see such control as undesirable and limiting. In
addition, the UNCRPD indicates that policy and practice should address
opportunities for women with intellectual disability to make autonomous choices
and express their sexuality. Within this study there were various opportunities
that could be developed. For example, many of the women living with high levels of
support could be involved in shopping for food and preparing their meals.
Opportunities for understanding their body, including sexuality education, should
be maximised for all women. As the women who explained their physical health
conditions demonstrated, effective communication aided comprehension of their
body. Furthermore, learning about their body is one strategy that has been
considered important for preventing sexual violence. I have no doubt that more
could be done to help women with intellectual disability learn about their body
and thus have greater control over their lives and participate meaningfully within
their community.
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Appendix 1

Contour Drawing Rating Scale

Figure: Rating Scale
Mark "current" and "preferred" in response to questions on interview framework.
Appendix 2

Abstracts


Aim
The research explored how women with intellectual disability perceived their body and understood the relationship between their perception and strategies for weight control and nutrition. This paper reports on initial findings related to the women’s responses to questions about their body image and a data collection tool of a scale drawing of body shapes.

Methods
Semi-structured interviews were conducted with twenty-five women. In addition to responses to questions the women also completed the task of identifying the shape most like them and the shape they most desired to be from a series of drawings. A general inductive approach was used to analyse the data.

Results
While some women could accurately choose their current body shape, a number struggled with the task. Most women had a positive view of their body, linking it to function more commonly than aesthetic properties. However, asked if there was some part in particular that they liked, a number could identify a feature. For those women who were dissatisfied with their body, weight or mobility were implicated.

Conclusions
These early findings warn of the necessity to explore with individual women how they see and understand their body when discussing health implications such as weight control.


Background
Under the social model of disability disabled people themselves have a crucial role in research that is about them. One aim of a recent study that explored mental health with women with intellectual disability was to maximise opportunities for involvement in the research.
Method
Regional People First groups provided advice and assisted with recruitment of participants. The researchers presented the research to women members at local meetings. Plain language forms assisted the women’s understanding of the purpose and participation requirements of the research.

Results
Twenty-five women were interviewed for the study. The method of recruitment achieved the aim of providing an opportunity for women with intellectual disability to independently participate in research. However, although all women appeared competent to provide consent, a number found it difficult to express in depth opinions when interviewed. Adjusting the questions and working with the women’s understanding made it possible to gain insight into their life and thoughts about the issues covered.

Conclusions
Women with intellectual disability will choose to participate in research when invited and can meaningfully engage in qualitative processes. While in depth interviewing may provide challenges, by working with women with limited expressive language it is possible to gain an insight into their lives and value their contribution to the understanding of others.


Aim
Using a qualitative approach the research aimed to explore how women with intellectual disability perceive their body.

Methods
Following Multi-region Ethics Committee approval, semi-structured interviews were conducted with twenty-five women aged between 20 and 65 years. Interview questions included how they viewed their body, their choices in clothing, make up and hairstyle as well as whether they had a partner and, if appropriate, sexual activity and contraception. A general inductive approach was used to analyse the interview data.

Results
Thematic analysis found the women held both functional and aesthetic perceptions of their body. Current strengths as well as some weaknesses were identified in the way that women are supported to express their sexuality and femininity. Most felt that they could choose their own clothes and hairstyles. More varied was their understanding and the language that the women used when discussing sexuality and in their adoption of adult gender roles, such as being a partner in an intimate relationship.
Conclusions
This paper focuses on the gender-related concepts of sexuality and femininity. The diverse responses of the women interviewed would caution against any assumptions about individual women and the knowledge that they might have about their gendered body. There would seem to be opportunities to build on the choices that women are making about their dress and hairstyles to include other concepts that are relevant to their sense of femininity and sexuality, including their sexual health knowledge.


Why this topic is important
Mental health has been described as consisting of both the presence of personal contentment and the relative absence of psychological distress. Problems with maintaining mental health are often associated with particular life-events or periods of transition. For women with intellectual disability there can be increased susceptibility to mental illness, including depression, than for women in the general population. Such women also have poorer mental health outcomes due to difficulties achieving accurate diagnosis and appropriate treatment of their mental health illness.

What people attending can expect to learn
In this paper the authors will present preliminary findings from a qualitative study in which 26 women with an intellectual disability were interviewed about their mental health and wellbeing. Participants included women who have experienced mental illness as well as women who have maintained good mental health. Initial findings point to the importance of a broad base of support in negotiating critical transitions through the life of the women.

How this information will be of use to others
Mental health is important to the general health and wellbeing of women with intellectual disability. Raising awareness of the vulnerability of women to mental ill health may lead to early and more effective intervention. Assisting women to negotiate critical life transitions is a key role for those who support them.

How the paper relates to the conference theme
There is strong evidence that the mental health of women relates to life experiences, the resilience of individual women and the support that is available to them to navigate through life events.
Appendix 3

WOMEN’S MENTAL HEALTH: “HOW I THINK AND FEEL”

INTERVIEW FRAMEWORK: WOMEN WITH LEARNING DISABILITIES

Participant:

Age:

Living situation:

Interview One Date:

Interview Two Date:

Sections 1, 3 & 4 to be completed for all participants.

Section 2 (to be completed for participants that identify as having a history of mental illness).

Interview Three Date:

The interview framework is indicative of the subject matter to be covered. While this framework includes the intended topic areas for interviews 1, 2 and 3, it must be noted that the researchers will be responsive to additional or unanticipated topics that participants may raise.

Interview 2 will ideally be the day after interview 1.

Interview 3 will be within 3 months of interview 2. Interview 3 is planned for verification of the information that the participant shared at the earlier interviews and to seek additional information where necessary.
Interview One.

Interview One will focus on the collection of demographic information from each of the participants.

Collecting specific information about their disability status (e.g. related health and/or disability issues, educational placement and attainment; use of services; employment experience; family and community involvement; and income and living situation) will be the focus of this interview. Include a question about welfare guardian.

Childhood/Early Life
Tell me about you and your family
• Where did you grow up?
• Did you always live at home?
• Did you ever live somewhere other than home?

Can you tell me about school?
• Where did you go to school?
• Were you in a special class or school at any time?
• When did you leave school?

Adult/Current Life
Tell me about your life now
• Where do you live?
• Who do you live with?
• Do you use a disability support service?
• Do you have a job?
• Are you on a benefit?
• How is your general health?
• Do you have any hobbies, sports or special interests that you can tell me about?
Towards the end of the interview include questions about alcohol and drug use, medications, including over-the-counter and prescribed, smoking. Where indicated these can be followed up in more detail with the next interview.

**We have some specific questions to ask today**

- Do you have a welfare guardian?
- Have you had counselling or been admitted to hospital because you were mentally unwell?
- Do you now (or in the past) drink alcohol?
- Do you take medication? (check whether prescribed, over the counter etc)
- Do you now (or in the past) take drugs?
- Do you smoke?

This type of demographic information is important to later analysis processes. It is also an appropriate way to get to know each participant so that in future more sensitive interviews are able to occur with maximum comfort for the participant. This again assists with creating a positive research experience for the participant.

**Notes from interview one**
Interview Two:
In this interview the emphasis will be on exploring each woman’s own life story so that the researcher can gain an understanding of the subjective realm of each woman’s life and their ways of structuring their social world. It will also seek information about specific issues related to mental health and wellbeing. While the general interview framework will be used with all the women, only women who identify as having a history of mental illness will be asked a specific subset of questions (clearly indicated in the following framework) relating to their experiences of diagnosis, treatment and recovery.

Section 1

Childhood/Early Life

What is your relationship with your family like now?
- Mum and Dad
- Grandparents
- Siblings
- Other important extended family members
- Do you see your family?
- Do you support each other?

Can you tell me about your experiences at school?
- What was school like for you?
- Were you happy?
- Were you ever bullied?
- Did you feel as though you learned a lot?
- Who did you play with?

Young Adulthood
- What were your plans or goals when you left school?
- What did you do when you left school?
- Did you enjoy your work / training?
- Did you have many friends?
- What did you do for fun?
- Did you have a relationship?
- When did you leave home?
- Where did you go to live when you left home?

Adulthood

What do you do in a typical day/week (discussion to cover areas listed)
- Work (redundancy, job-seeking, feelings when rejected for jobs, volunteering).
• Relationships (friends, family, partners – attending events, closeness, management of conflict).
• Community involvement
• Exercise
• Recreational activities
• Sex, sexuality and parenting

What makes you feel good?
• Are there times when you are unhappy or not feeling good?
• If you are not feeling good, what do you do? (looking for resilience factors)

Do you manage your own money?
• If no, who does?
• Have you ever been financially abused (had money stolen from you or been used in a way that you didn’t want)?

Physical, sexual, verbal, emotional abuse
• Have you ever had any experience of being abused (verbally, physically, sexually?)
• Have you talked to someone about this?
• How do you feel about it now?

Experience with the court / justice system
• Have you ever had to go to court – as a victim, witness or perpetrator?
• What was it like for you?

Alcohol & Drug Use (If relevant from first interview)
In the first interview you told us that you smoke/drink alcohol/use drugs.
• How many cigarettes do you smoke a day?
• Are there times when you smoke more/less?
• Have you tried to stop smoking?

• When are you most likely to drink alcohol or use drugs?
• Has anyone ever told you that they are concerned about your drinking or drug use?
• Have you ever felt bad or guilty about your drinking?
• Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover?
• Have you ever felt you should cut down on your drinking?
• Did you do anything about it?

Section 2
Mental Health Section
(To be completed with women who identify as having experienced mental health problems)

History
When did you first have mental health problems? (what age?)

Have you ever had an emergency admission to a psychiatric service?
- Why? What led to it?
- What was it like?
- Why were you admitted?
- Did you want to be admitted?
- What were you scared about?

Experience of mental health issues
- When have you been most happy?
- When are you most likely to feel unwell?
- What do you do when you have bad days?
- Are there any things that have happened to you during your life that have made you depressed/angry/upset?
- Have you noticed that your mental health has been a problem at certain times of your life?

Experience of seeking non-urgent help/treatment
- When you feel mentally unwell do you go to your GP (or other if not GP)?
- Do you feel comfortable to talk to your GP when you are very sad/angry/depressed/nervous?
- Do you feel you have enough time to talk about all the things you need to say?
- Do you feel you are listened to when you give a history of your life experiences and your symptoms?
- What makes you feel as if you are being listened to?

What helps your recovery?
What do you think has been the most help in recovering from mental illness?
- GP, psychiatrist, counsellor, psychologist, support worker or other specially trained person
- Medication
- Support programmes designed to help people with mental ill health
- family, friends
- work (meaningful activity)
- doing things I like to do (exercise, hobbies, keeping busy) myself

Section 3
How I think and feel about my body

- What do you like most about your body?
- What do you dislike about your body?
- How do you feel about your body when you are feeling unwell (those with identified mental health problems)?
- Are you happy with your weight?
- Look at these pictures (use the Figure rating scale): which picture do you think is most like how you look now? Would you rather look like one of the other pictures? Which one?
- Do you look at yourself in the mirror?
- How do you feel when you look at yourself in the mirror?

Choices related to body image

- What do you like to eat?
- What do you mostly eat?
- Who decides what you eat?
- Do you have special things you do to make yourself look nice (e.g. haircut, make-up, personal hygiene, shaving etc?)
- If you are feeling mentally unwell, do you still do these things?
- Are you happy with your clothes and what you wear?
- Who chooses your clothes? If appropriate – Why don’t you wear what you want?

Section 4

Reflecting on life

Do you ever feel as though no one likes you or no one cares for you?
- When are you most likely to feel this way?

Can you tell me about the important things that have happened in your life?
- What things “stick” in your mind?

What things have you done in your life that you are proud of?

What are the best things that have ever happened to you?

Notes from interview two
Appendix 4

27 October 2009

Dr Bridgit Mirfin-Veitch
PO Box 6189
Dundin 9059

Dear Bridgit

MEC/09/09/054
Mental health and wellbeing for women with an intellectual disability

Thank you for your letter dated 15 September 2009 enclosing your updated documentation for the above study. This information has been reviewed and approved by the Chairperson of the Multi-Region Ethics Committee under delegated authority.

Approved Documentation

- Participant Information Sheet including information concerning Jenny Conder’s research project, a section entitled ‘What will happen to the information I tell you?’ and a section entitled ‘Who can I contact if I need independent advice about taking part’.

- Interview Schedule including questions on the use of alcohol, tobacco and other drugs

If you have any further queries please do not hesitate to contact me.

Yours sincerely,

[Signature]

Rebecca Stewart
Multi-region Ethics Committee Administrator
Women’s Mental Health Project: “How I think and feel.”

Study Information Sheet

You are invited to take part in a study about mental health and wellbeing for women with learning disabilities. The study is being carried out by a research team who are from the Donald Beasley Institute. The Donald Beasley Institute is a disability research institute that is based in Dunedin.

What is this study about?

Women with learning disabilities often have mental health problems like depression and anxiety. Sometimes it is hard for women with learning disabilities to find the right treatment or support for their mental health problems. In this study we want to talk to women themselves about the things that have happened in their lives that might have affected their mental health and wellbeing.
We would like to talk to women who have had mental health problems.

We also want to talk to women who have never had help with their mental health.

At the end of the study we will be able to give mental health professionals some good information about how to meet the needs of women with learning disabilities.

**Who will be doing the research?**

Researchers from the Donald Beasley Institute working on this study will be Brigit Mirfin-Veitch, Sue Gates and Jenny Conder. We have all worked with women with learning disabilities for a long time.

Jenny Conder will write about some of the information that we learn from you as part of her university study for a PhD.

**What will I have to do if I choose to take part?**

If you choose to take part in the study you will be interviewed three times.
Interview 1: We will make sure you really want to take part, and will ask you some questions about your childhood, and your life now. The first interview will take 1 hour.

Interview 2: The next day we will meet with you again and talk with you about all the things that have happened to you during your life. In this interview we will ask you questions about your mental health and wellbeing – how you think and feel about yourself.

We are also interested in what helps you to feel good about yourself and your life. We would also like to learn about the things that can make you feel bad about yourself and your life. The second interview will take 1-2 hours.

Interview 3: We will meet with you a third time about two months later. Before this interview we will write up all the information you have given us into your life story. During this last interview we will read through your life story with you. At this time you can add any new information, or change your story. The third interview will take 1-2 hours.

**What will happen with the information that I tell you?**

We will keep your information private. No information that could personally identify you will be used in reports on this study.

If we are worried about your health or safety we will talk with you. We have a psychologist to advise us if we need to discuss our concerns. The researchers will not talk to any other person about you, without your consent, unless they are legally required to do so.

**What else will happen?**

All of the interviews will take place where you are comfortable. This could be your home, or another place where you can talk in private.

The interviews will be tape-recorded but you can turn the tape off whenever you want to.

The researcher might write down some notes during the interview and after the interview ends.
Who can be in this study?

If you are a woman with learning disabilities, and you are over the age of 18, you can take part in the study. It doesn’t matter if you have ever had mental health problems or not.

What do I do if I want to take part?

If you want to take part in this study, you can phone us at the Donald Beasley Institute (0800 878 839). We can help you fill out the Participant Interest Form. If you are able to fill out the Participant Interest Form yourself please do so and send it to us in the stamped and addressed envelope attached to it. You can ask a friend, family member or support person to help you fill out the form if you want to.

After you have filed out a Participant Interest Form the research team will contact you and talk to you about the study again, just to make sure you really want to take part. If you still want to take part the research team will help you fill out a Consent Form.

What happens if I don’t want to be part of the study?

Nothing. If you don’t want to take part it is OK. No one can tell you that you have to take part in research.

Is it safe for me to take part in this study?

This study has been approved by the Multi-region Health and Disability Ethics Committee. This means that a special group of people have made sure that the study is safe and that we will work with people in a respectful way.

What do I do if I want some more information?

Call the research team, Brigit, Sue or Jenny on 0800 878 839. The call won’t cost you any money.

Who can I contact if I need independent advice about taking part?

If you would like to know any more about your rights as a participant in this study you can call a Health and Disability Consumer Advocate. The phone number is 0800 555 050.

Thank you for thinking about taking part in this study.
Women’s Mental Health Project: “How I think and feel about myself.”

Participant Interest Form

If you would like to take part in the Women’s Mental Health Project please fill out these questions. Ask a friend, family member or support person to help you with them if you need to.

1. Name:

2. Address

3. Ethnicity: □ Pakeha/NZ European  □ Maori  □ Pacific Island  □ Asian  □ Other

4. How old are you?

5. Have you ever talked to a specially trained person about your feelings? That person could be a counsellor, a psychologist or a psychiatrist. Yes □ No □

6. Do you take any medication for your mental health? Yes □ No □
Women’s Mental Health Project: “How I think and feel.”

Consent Form for Women with Learning Disabilities

If you want to take part in this study please read this form, or have someone read it to you.

It tells you what your rights are as a research participant. If you sign the form you are saying that you want to take part.

1. I have read (or had read to me) the information about the study.
2. I understand the information I have been given.
3. I have had a chance to talk to a researcher about the study.
4. I have been able to ask questions and I have had all my questions answered.
5. I have been able to have a friend, family or whanau member, or support person with me when I have learned about the study.
6. I understand that taking part is my choice.
7. I understand that I don’t have to take part.
8. I understand that I can stop taking part at any time I won’t be affected in any way.
9. I understand that my participation is private. When the researchers write about me they will change my name so that no one else will know that it is me.

10. I understand that my personal information is confidential. The research team will not talk to any other person about me unless I am in danger or someone else is in danger.

11. I have had read to me the study protocol about responding to danger. I understand that the research team may need to tell someone else if I am in serious danger, or someone else is in danger.

12. I have had enough time to decide whether or not to take part in the study.

13. I understand that I will be interviewed.

14. I understand that the interviews will be tape-recorded.

15. I know that I can ask to have the tape recorder turned off at any time during an interview.

16. I know that the researcher may take notes during the interview and will take notes after the interview.

17. I know that I will have the chance to go through my “Life story” with a researcher and to make changes if I want to.

18. I understand that I will get a final report at the end of the study. I know there will be a delay between my taking part in the study and getting the final report.
19. I understand that I can contact a Health and Disability Consumer Advocate if I want to know more about my rights as a research participant. The number is 0800 555 050

20. I know I can contact Brigit Mirfin-Veitch, Sue Gates or Jenny Conder at the Donald Beasley Institute (0800 878 839) if I have any questions.

21. I know that Jenny Conder will write up some of the information from the study for her PhD project. If I have any questions about her project I can contact Jenny or Brigit (0800 878 839) or Marie Crowe (03 364 3858). Marie Crowe is Jenny’s university supervisor.

I give my consent to take part in this research project.

Participant Name__________________________________________________

Signed ______________________ Date ________________________________

Researcher Name__________________________________________________

Signed ______________________ Date ________________________________
Women's Mental Health Project: “How I think and feel.”

Rationale for the management of unmet health need

People with learning disabilities are consistently reported as having a high level of unmet health need. This unmet need is also present in the area of mental health. Previous experience with women with learning disabilities has made the team very aware that unmet health need often becomes apparent as more is learned about an individual’s life. For this reason it is appropriate to have a procedure for responding to unmet need in the area of mental health.

Procedure 1: If it becomes clear through the interview process that a participant has unmet health need in the area of mental health the researcher will take the following action.

1. The researcher will bring the issue to supervision with the other team members and the specialist psychologist.
2. Referral options will be determined.
3. The referral options will be communicated to the participant. These options will also be disclosed to family/whanau or support staff should the participant wish for this to happen.

Procedure 2: In the case of acute mental ill-health an alternative procedure will be followed:
1. Contact will be made with the team’s specialist psychologist adviser immediately.
2. Contact will also be made with family/whanau or the participant’s support service immediately.
3. The participant will be supported to make an immediate referral to emergency mental health services.
Women’s Mental Health Project: “How I think and feel.”

Rationale for the management of disclosure of abuse

Given the focus of this study the research team is very aware that abuse is an issue likely to be raised by some participants. People with learning disabilities have been found to be at greater risk for abuse than other members of the general population.

For this reason we cannot ignore the possibility that the researchers may become aware of historical or current abuse through their discussions with study participants. There are a number of different possible scenarios relating to the manner in which abuse may be present in a participant’s life. The possible scenarios are outlined below, along with the specific procedure to be implemented in each case. In the case of disclosure of abuse, the participant will be made aware of the procedures outlined below before any action is taken. It should also be noted that each participant will be informed of the researcher’s obligations relating to disclosure of abuse during the informed consent process, before the first interview occurs.

A participant may disclose that they have been abused in the past.

Procedure: In the situation of historical abuse the researcher would check with the participant as to whether they received any assistance
with their abuse in the past. If the participant wanted to receive support or counseling at this time the researcher would provide advice on the appropriate place to seek help.

A participant may disclose they are currently being abused.

Procedure: Integral to any action relating to the disclosure of abuse is that the person who is being abused must agree they want to take the matter further. The only exception to this would be in a situation where the abuse was being perpetrated by a person in a position where they could abuse other adults or children. The research team would address this situation by alerting the participant’s support service management, or child protection services immediately. The researcher would always inform the participant that this action was going to occur.

A participant may disclose that they are currently abusing a child or adult.

Procedure: The researcher would encourage the participant to report the neglect or abuse immediately to their support service or to child protection services on their own behalf. If the participant refused to report the neglect or abuse the researcher would report the matter to the manager of the participant’s support service, or to child protection services immediately.
Illustration of initial codes and themes, demonstrating relationships between codes

Note: the colours as simply used to assist the reader to follow the connections where lines cross over one another.