

# “The Price We Pay”

## *Women, Disability and Emotion*

Margaret Charlesworth

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# **Abstract**

The emotion work of women with disabilities is seldom considered. Yet when it all boils down to it, if women with disabilities are to gain equality, they are required to suppress, pretend and to produce emotions that they do not really feel. At times women with disabilities are coerced into managing not only their own emotions, but also the emotions of others, for the benefit of those others. This is what we do to gain acceptance, to be treated as equals... This is the price we pay.

## Statement of Originality

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution. To the best of my knowledge and belief, this thesis contains no material previously published or written by another person except where due acknowledgment has been made in the thesis.

I give my consent for this copy of my thesis, when deposited in the University of Adelaide Library, to be available for loan or photocopying.

Signed: ..... Date:.....

Margaret Anne Charlesworth

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## *Introduction*

# **“The Price We Pay”**

## *Women, Disabilities & Emotions*

**“How do women with disabilities manage their emotions in their quest to be accepted and valued as credible, contributing members of Australian society?”**

“The Price We Pay” refers to the many ways that women with disabilities are required to perform emotion work so that they can be treated as equal members of society. My thesis argues that women with disabilities perform more emotion work than others—especially if their quest to be perceived as rational, contributing, and competent equal members of Australian society is to be realised. Originally my thesis was titled “doing the lion’s share”—until I realised that this implies that as a society we share a common goal of creating a society which is equitable, just and inclusive of all. That is when reality bit...the undeniable truth for many individuals within society is that it is not always just, nor does it treat everyone as equals. The price that many women with disabilities pay for seeking equal treatment is that we forfeit our own emotional needs for the benefit of others.

Arlie Hochschild introduced the concept of emotion work in 1979, when she suggested that individuals who work in service occupations such as airline hostesses perform emotion work as a necessary part of their occupation. Emotion work is the conscious and deliberate act of individuals to manage their emotions, as well as the emotions of others, for the benefit of others. Throughout my thesis I explore the

concepts that have been applied to emotion work to describe the ways that women with disabilities perform their own emotion work on a daily basis.

My thesis focuses on women with disabilities for three reasons. First and foremost is simply because I have a personal experience of disability and frequently perform emotion work. As a woman with Cerebral Palsy – I have a strong speech accent and use a scooter for long distance mobility (I speak to some of my experiences of having to do emotion work a little later in this chapter). Secondly, I argue that there are many concerns that confront women with disabilities which do not concern men with disabilities. This is because disability is perceived as being negative. Meekosha and Dowse contend that it is women with disabilities in particular who are perceived as being the “true” burden on society (Meekosha and Dowse, 1997:50). Instead of being able to independently care and nurture *others*—according to the traditional discourse of being a woman, women with disabilities often need assistance to care for themselves. My third reason is an extension of the second, and is the cycle of negativity that women with disability are subjected to. The cycle of negativity is integral to the understanding why it is that women with disabilities perform emotion work.

The cycle of negativity begins when a girl-child with a disability is born (Lee, 2004). This cycle is put into motion the first time the child hears that she is different, and will not reach milestones that other children do. It gains momentum the first time she is told she is a burden – not just on those around her – but also on society. By the time she is a teenager, the cycle is spinning out of control, as the young woman hears that she is unlikely to marry or have children, let alone pursue a career of her choice. Without realising it, the cycle of negativity has almost become her mantra because she

believes that she has nothing to offer society. So she begins to suppress her true desires to ensure she becomes less of a burden on those around her. She ceases to dream for all that she wants to become because she needs that little bit more support to turn her dreams into reality. After all, it is the least she can do, but it is also the price she will pay...



In life we all perform emotion work to be liked, loved, accepted, respected, and sometimes to be “one of the crowd”. However, for women with disabilities, I argue that performing emotion work can be a doubled-edge sword. The desire to assert our rights is often juxtaposed against sending the message that women with disabilities are fragile and should be “handled with care”. It is often a common experience for women with disabilities to be judged as needing someone without a disability to care for them, speak for them, and to act on their behalf. Owing to the physical nature of my disability, I am regularly treated as though I should have someone to speak for me and to generally be there to look after me. I am also frequently perceived as not being capable to make my own decisions, and when I dare to make decisions or have a different opinion to someone else, I hear “who’s been filling your head with this garbage?” It is because I am aware of how I am perceived by others that I am careful not to feed into their preconceived assumptions about who I am. This means not showing my frustrations when people treat me as they would treat a child; and that I do not always insist that people talk to me instead of the person I am with. The contention of my thesis is that women with disabilities should feel free to be, and to express themselves and to be treated equally within society.

Drawing upon personal experiences and knowledge of having to perform emotion work, I was eager to learn whether or not this was a common experience shared by other women with disabilities. This interest extended to wanting to understand the different ways that they dealt with their own emotions as well as the emotions of others. One of my main findings suggests that not only are other women with disabilities doing emotion work, the majority of the participants are also aware that there can be consequences of *not* performing emotion work. As one participant shared, the price she would pay for not performing emotion work is that society would judge her as being “bitter and twisted” because she has a disability.

It was not enough to simply draw on my experiences or those of other women; to argue that women with disabilities performed emotion work. I also needed to explore the literature on the subject. Chapter One of my thesis is a literature review. Here I explore and summarise the literature that exists in relation to emotion work, disability and women with disabilities. This chapter highlights that, while there is literature about emotions and disability, there is very little literature discussing emotion work for people with disabilities, and no specific literature discussing the emotion work of *women* with disabilities. I begin this chapter by defining what emotion work is, and the techniques that are frequently used when performing emotion work. I then draw attention to the fact that not only have the issues of women with disabilities been forgotten by feminism, they have just as equally been ignored, even denied, by men with disabilities. In searching for literature on emotion work and disability, I only found one article which focused on the emotion work of people with disabilities. This is a crucial article to my research, as the authors argue that it is people who use

wheelchairs who are managing not just their own emotions and feelings, but also the emotions of others, for the benefit of others (Cahill and Eggleston, 1994:303).

Chapter Two explains the methodological approach I took in undertaking the research. In this chapter I illustrate the criteria for participation in the research, as well as the questions asked of the participants, and how I gathered the data. I also highlight a few of the limitations that I encountered during the research process.

Chapter Three is the results chapter—it is here that my hypothesis that women with disabilities *do* perform emotion work is confirmed. After introducing the women who participated in my research, I discuss the major themes that the data presented. These major themes include managing physical appearance; monitoring, suppressing, and pretending emotions; and resistance. Most of the women participating in my research said that they performed emotion work. It is interesting to note that many participants indicated that having a disability was not the main reason for doing emotion work; rather, they performed emotion work in response to having to face discriminatory attitudes *about* their disability. Others suggested that they performed emotion work so that they can “fit in” and gain acceptance from their peers, and members of society more broadly. There were two participants who declared that they did not perform any more emotion work than women who do not have disabilities.

Chapter Four advances the conversations that began in Chapter Three. I do this by relating and comparing comments made by the women to the literature as presented in Chapter One. The major themes that are discussed within this chapter include body image and self-esteem; loneliness and disability; independence and dependence; the cycle of negativity; and power and relationships. I conclude my thesis by highlighting

the major findings that my research has produced. By pulling out the major themes that are discussed throughout my thesis, I demonstrate that not only are women with disabilities performing emotion work, for the benefit of others at their own expense.

## *Chapter One*

### **Literature Review**

*I am surprised that women with disabilities would feel constrained with their emotions because of their physical limitations (Francine, age 43).*

This first chapter is devoted to exploring the literature about emotions, disability as well as women and disability. As separate subjects all three have vast bodies of literature attached to them. While the above quote comes from one of the women who participated in my research, it does reflect the fact that as yet these subject terms still need to be combined and considered as relating to one another. This chapter begins by discussing the literature that exists on emotion work and goes on to describe some of the more relevant literature that comes from the discourse of disability. It then explores the small amount of literature that does combine the subjects of emotion work and disability. I then examine the existing literature on women with disabilities. I wish to note here, that the literature that appears within the section of disability and women with disabilities are by no means exhaustive, but have been selected because of their relevance to my argument.

### **Emotion Work**

In her paper “Emotion Work, Feeling Rules and Social Structure” Hochschild (1979), defines emotion work as the “act of trying to change in degree or quality an emotion or feeling”, declaring that to “work on” emotions and feelings is akin to managing emotions. Hochschild further notes the importance of remembering that

“emotion work refers to the effort—the act of trying—and not the outcome”, which are particularly important in circumstances where the intended outcome may not have been successful. Failed acts of emotion work are just as important as successful ones because they give the individual the opportunity to learn from, and improve on future acts; so that a desired outcome may eventually be achieved (Hochschild, 1979:561).

To bring this back to the subject of women with disabilities, the “act” of emotion work may involve a woman not showing her frustrations of constantly being spoken to as though she does not understand what is going on. In “The Lived Body: Experiences from Adults with Cerebral Palsy” Karin Sandström (2007) points out this is a common experience for people who have Cerebral Palsy. She says that this is because the disability of Cerebral Palsy is seriously misunderstood owing to the physical characteristics of the disability that often imply that individuals with Cerebral Palsy also have an intellectual disability (Sandström, 2007:435). This is just one example of the ways that certain disabilities have been misunderstood by society. For many having to remain poised in situations where women experience unequal treatment (because they are perceived as having an intellectual disability) on a continual basis can lead women with disabilities to experience a momentary need to break their composure and express their anger. To relate this back to Hochschild, the “act” of emotion work is motivated by the desire that women with disabilities be treated as an equal. However, for various reasons, the outcome may not have been successful owing to a build up of negative emotion. This is what Hochschild (1979) refers to when she says that “failed acts of management” are important, and not just those that succeed (Hochschild, 1979:561). This is because these “failed acts” serve to remind women that by not

keeping their emotions in check, their actions often reinforce the negative perceptions that exist about women with disabilities.

### **The Three Techniques of Emotion Work**

Hochschild (1979) also speaks about the three techniques that women can use when performing emotion work. The three techniques of performing emotion work that Hochschild talks about are cognitive, bodily, and expressive. The first refers to the *cognitive* ways a person performs emotion work as a way of attempting “to change “images, ideas and thoughts” which ultimately changes “feelings associated with them” (Hochschild, 1979:562). In describing this Hochschild presents examples from her own research where her participants used active verbs when describing their emotion work. Some of these included thoughts like “I psyched myself up” and “I tried hard not to be disappointed” and “I tried to feel grateful” (Hochschild, 1979:462). The second technique of performing emotion work is *bodily*. This refers to controlling “physical symptoms of emotion”, such as slowing down of breathing to calm one’s body or “trying not to shake” (Hochschild, 1979). The third technique is *expressive* and relates to the ways people alter their gestures in an effort to change their inner feelings, such as by smiling or crying (Hochschild, 1979). For women with severe and profound disabilities both of these present difficulties—especially where fine motor control is an issue or when the ability to control the physical symptoms of their disabilities is limited.

### **Surface Acting and Deep Acting**

Ashforth and Humphrey (1993) discuss Hochschild’s concepts of “surface acting” and “deep acting”. Surface acting refers to “simulating emotions that are not actually

felt”, which is facilitated by the “careful presentation of verbal and nonverbal cues” (Ashforth and Humphrey, 1993:93). Deep acting refers to the summoning up of strong feeling—“whereby one can actively attempt to evoke or suppress an emotion”. Put simply, “[s]urface acting focuses directly on one’s outward behavior; whereas, deep acting focuses directly on one’s inner feelings” (Ashforth and Humphrey, 1993:93). Chapter Three will continue discussing these concepts and the ways that they apply to women with disabilities who perform emotion work.

### **Emotion Work and Disability**

Before going on to discuss the literature relating to disability and women with disability, I introduce the article that has the most relevance to my subject of women, disability and emotion. “Managing Emotions in Public: The Case of Wheelchair Users” by Spencer Cahill and Robin Eggleston (1994) suggests that it is wheelchair users who take the responsibility of not only managing their own emotions but also the emotions of others. They explain that wheelchair users manage their emotions so that non-wheelchair users can begin to feel at ease when they meet and interact with a person in a wheelchair (Cahill and Eggleston, 1994:303). This occurs because there are times when people in wheelchairs need assistance from the non-disabled population. This means that the wheelchair user must “remain poised and good-humored in frustrating and potentially embarrassing circumstances (Cahill and Eggleston, 1994:303). Cahill and Eggleston also mention that it is not uncommon for people with disabilities to receive “non-person” treatment in public spaces. Essentially non-person treatment is where the person with a disability is not perceived or acknowledged as being a person in their own right (Cahill and Eggleston, 1994:303). Despite the fact

that this article is not gender specific and only discusses the emotion work that is performed by those who use wheelchairs, Cahill and Eggleston explore many similar reasons that can to be applied women with disabilities who perform emotion work

### **The Emotion Work for those Associated with Disability**

As just mentioned the article by Cahill and Eggleston is the most relevant for my thesis, this is because the other articles that I found are mostly interested in the emotion work done by people who are associated with disability. I use the term “associated with”, to mean anyone who assumes responsibility for people with disabilities—such as parents, carers, and work supervisors (see for example, (Spackman et al., 2005 and Sze and Valentin, 2007). When the focus is on people with disabilities, it is on those who had acquired their disabilities later in life. This literature focuses on the way that people with newly acquired disabilities come to terms with their new lives (see for example, Mukherjee et al., 2003).

The article entitled “When Emotion Work is Doomed to Fail”, by Martha Copp (1998) is one such example where the focus is placed on the emotion work of people who work with people with disabilities. This article focuses on individuals, who are referred to as “floor instructors”, who supervise people with developmental disabilities working in sheltered employment. The key objective for these floor instructors, was to “infuse” their “clients” with “positive feelings about work” with the aim of “transforming them into committed workers” (Copp, 1998:299). One of the key findings of this study was that many of the floor instructors found that controlling their employees was emotionally draining which often left them feeling emotionally burnt out (Copp, 1998:299). This article fails to consider the emotion work that the person

with a disability who is being “infused” with the appropriate work ethic is doing. Shula Wilson’s article entitled “To be or not to be Disabled: The perception of Disability as Eternal Translation”, (2006), is similar, in the way that it focuses mainly on the anguish that many Israeli parents experience when a child with a disability is born into the family (Wilson, 2006:178). Wilson says that in the Israeli culture, the child or person with a disability, is treated differently and not afforded the same respect as other family members—and as such are kept isolated from the main family group. Moreover, Wilson makes it clear that in instances where disability cannot be totally accepted, family members may experience feelings of guilt, persecution and blame, which are often projected onto the family member with the disability (Wilson, 2006:178). These articles portray disability in a negative light, giving the impression that people with disabilities are a burden not only on those who are closely associated with them but also on society as a whole. I argue that this portrayal contributes to the need for women with disabilities to perform emotion work to counteract the negative stereotypes that are associated with having a disability.

On the other hand, chapters such as “Turning Points: Emotionally Compelling Life Experiences”, by Gillian King, Tamzin Cathers, Elizabeth Brown, Elizabeth MacKinnon, and Linda Smith (2003), pay attention to people with disabilities. This article was based on a qualitative study and explored how people with disabilities, learned, changed and grew during the major turning points in their lives, as well as exploring the emotional ramifications that were felt during the major turning points in people’s lives (King et al., 2003:46). This article is different to those by Copp (1998) and Wilson (1996), because the focus is on the emotion work that is performed by

people with disabilities, rather than on the emotion work of those surrounding people with disabilities perform.

## **Disability**

The existing literature on disability is as vast as it is varied. This is because there have been as many discourses as there are commentators on the subject. In “Disability as a Phenomenon: a Discourse of Social and Biological Understanding”, Marianne Hedlund (2000) suggests that the way people understand the social world is dependent on the way it is communicated to them (Hedlund, 2000:766). Hedlund goes on to argue that it is through the process of communication, that agents such as bureaucrats, politicians, the medical profession, mass media and social movements, can make their contributions to the phenomenon. Therefore, the way we understand the ideologies and discourses of disability is very much dependent on the ways that they have been communicated to us (Hedlund, 2000:766).

Literature on disability can be traced back to the early nineteenth century, where commentators took a cold and sterile medical approach. This approach was accepted up until the late twentieth century, owing to the fact that many people with disabilities required ongoing medical care, to the point where most were living in institutions (see for example of cold and sterile approach, Earnshaw, 1995, Gleeson, 1998, Holt, 1979, and McMahan, 2005). Some commentators writing about the lived experience of disability argue that placing too much emphasis on the medical discourse of disability can, and does, have detrimental effects on individuals who have disabilities (see for example Wolbring, 2003).

More recent commentaries on the disability discourse have come from social movements. Bill Hughes and Kevin Paterson are the authors of “The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment” (1997) and “Disability Studies and Phenomenology: the Carnal Politics of Everyday Life” (1999). In both articles they argue that during the latter part of last century the disability movement came together to combat issues of ‘social oppression and exclusion’ (Hughes and Paterson, 1997:235). Paterson and Hughes explain that owing to the successful politicisation of the “social and spatial environment”, the disability movement has exposed the ways that ablist norms serve to confine people with disabilities, and has focused on removing these “socio-spatial barriers which serve to deny people with disabilities their full rights of citizenship” (Paterson and Hughes, 1999:597-98).

Many Current contributions to the discourse of disability are made by people who live with the personal experience of disability. As well as speaking about living with a disability this literature also speaks about experiences of people with disabilities in relation to education, employment, access to the built environment, and issues of discrimination (See for example, Berry et al., 2006, Deal, 2007, Kayess and Fogarty, 2007 and Kittay, 2002).

### **Forgotten by Feminism**

In “Enabling Citizenship: Gender, Disability and Citizenship in Australia”, Helen Meekosha and Leanne Dowse (2002) state that despite being a gendered discourse *and* a feminist issue, disability is often ignored in debates of feminism as well as citizenship (Meekosha and Dowse, 1997:50). Susannah Mintz, the author of *Unruly Bodies: Life*

*Writing by Women with Disabilities* (2007), concurs with this and offers an explanation as to why this is so. Mintz suggests that women with disabilities are often neglected by mainstream feminism, because, while non-disabled women seek liberation from institutions such as marriage and motherhood, women with disabilities have been afforded stereotypes which prevent them from entering such relationships (Mintz, 2007:5). This is likely to be because, as Mintz suggests, women with disabilities are declared as being “incomplete, asexual and unfit for motherhood” (Mintz, 2007:5).

In the same book, Jenny Morris argues that feminism rarely incorporates “the interests” of women with disabilities such as violence, health care, economic equality and reproductive rights (Morris, 1996:5). Whilst my thesis is not concerned with these issues *per se*, I am interested in the emotional impact that experiences such as these have on the lives of women with disabilities. In *Gender and Disability*, Jenny Morris explains that the experience of having a disability has not been defined by those who have them, but rather by the people who do not (Morris et al., 1993:87). She recalls an exercise whereby some college students were requested to write down words that sprang to mind when hearing the words “disabled woman”. The words that were derived from this exercise depicted disabled women as sorrowful burdens on society, who were not conceived as women at all (Morris et al., 1993:87).

### **Denied by Men**

Not only have women with disabilities been forgotten by feminism, our issues have also been denied by men with disabilities. In “Sanctioned War: Women, Violence, and Disabilities”, author Debora Beck-Massey (1999) argues that the disability movement continues to be “male dominated and oriented”. This argument is

reinforced by Sue Salthouse and Carolyn Frohmader (2004), in “Double the Odds’—Domestic Violence and Women with Disabilities”, when they suggest that the “disability was acknowledged, named, and objectified by men” (Beck-Massey, 1999:272 and Salthouse and Frohmader, 2004). As a consequence, Beck-Massey states that women with disabilities are entwined in the “warp of male language, ideal and definition” that fails to acknowledge the undeniable differences between men with disabilities and women with disabilities (Beck-Massey, 1999:272).

This argument is continued by Frohmader (2002), in “The Status of Women with Disabilities in Australia—A Snapshot”, when she states that even according to government records, women with disabilities are “one of the most marginalized and disadvantaged groups in Australia” (Frohmader, 2002). Frohmader goes on to suggest that women with disabilities are not only disadvantaged in relation to their able-bodied counterparts but also in comparison to men with disabilities (Frohmader, 2002). This is because, in comparison to men with disabilities, women have fewer opportunities to enter into the work force; are less likely to take on higher education opportunities; and, despite earning less than men with disabilities, spend a higher amount on health care (Frohmader, 2002). Ultimately, and as both Frohmader and Salthouse assert the denial of the experiences of women promotes the perception that women with disabilities are second class citizens and it does not matter whether they are listened to (Salthouse and Frohmader, 2004). So then, if women with disabilities are not being heard by those who are supposed to listen to them (such as the feminism and disability movements), is it any wonder that the emotion work of women with disabilities has never been considered.

## **Women with Disabilities**

The final section of this chapter pays attention to the literature that exists in relation to women with disabilities. It is important to note that the literature relating to the subject of women with disabilities is extensive; and as such is not exhausted in my literature review. This said the literature presented in this section speaks to issues that contribute to the reasons that women with disabilities perform emotion work. The literature reviewed in this section comes from authors who write about the cycle of negativity and relationships; independence and dependence; self-esteem; relationships; and abuse of women with disabilities.

### **The Cycle of Negativity and Relationships**

The first two articles I mention in this section explore power relationships and the lasting effects of the cycle of negativity that many women with disabilities experience. “The Cycle of Negativity” a conference paper presented by Glenda Lee in 2004, explores what happens when a child with a disability constantly hears negative messages about themselves. In “A Relational-Cultural Theory of Human Development: The Power of Connection” (2006) Judith Jordan examines inter-personal relationships that exist with obvious power imbalances. According to Jordan (2006) power imbalances are likely to occur when one person has a clear dominance over the other (Jordan, 2006:5). This argument relates to women with disabilities because in general women with disabilities are perceived as being powerless. Therefore, when women with disabilities form relationships with people without disabilities, they are likely to find themselves in relationships where the other person has and maintains the power

Lee (2004) and Jordon (2006) both explore the ways that power dynamics are present in relationships between people who have disabilities and people who do not. While Lee (2004) argues that when girls with disabilities constantly hear that they are a burden on society their self-esteem and self-worth diminishes (Lee, 2004), Jordon adds that, “these kinds of relational images take people out of connection” (Jordon, 2006:5). Jordon continues to say that, such repeated behavior, especially during formative years, serves to “keep people locked into certain patterns of disconnection” (Jordan, 2006:5). Furthermore, by suppressing their “true” feelings of anger or sadness, in favour of cheerfulness, children learn that such a display of emotions is favoured by parents or others in positions of power (Jordan, 2006:5). To bring this back to my topic of women with disabilities and emotion work, it is easy to see that if girls with disabilities are “conditioned” to seek favourable attention, then they would continue to do so in adulthood. Therefore, as adults, women with disabilities would be performing emotion work by suppressing and pretending emotions at their own expense, for the benefit of those around them.

### **Independence and Dependence**

I begin with the subjects of independence and dependence. In Mark Priestley’s chapter “Disability and Adulthood” found in his book *Disability a Life Course Approach* (2003), Priestley emphasises that Western societies place great emphasis on independence, competence and autonomy. This is because these are meant to be the primary definers of adulthood (Priestley, 2003:116). Priestley maintains that concepts of both disability and adulthood are socially constructed and adds that “thinking about disability helps to problematize our understanding of what it means to be an adult in

society” (Priestley, 2003:116). He suggests that people with disabilities are considered as “non-adults”, because they are not seen as being independent and autonomous (Priestley, 2003:116-17). According to this understanding then, to be an adult is to be independent with a fully functioning body and an “autonomous sense of adult self identity, with cultural constructions of adult individualism” (Priestley, 2003:116). In expanding this point, Priestley draws upon Hockey and James who argue that in Western societies it is often the case that “dependency and impairment are regarded as “childlike” states” (Hockey and James, 1993:118). This “symbolic approach”, serves to exclude people who are dependent (such as people with disabilities and older people) from being defined as adults (Priestley, 2003:118).

Authors such as Sandström (2007), Susan Lonsdale (1990) and Maria Saviola (1981, address issues concerning the subjects of autonomy, independence and dependence. While the Sandström article focuses solely on the lived experiences of people with Cerebral Palsy, Lonsdale’s book entitled *Women and Disability: The Experience of Physical Disability Among Women* (1990), discusses the lived experience of women with physical disabilities in general. Saviola’s article “Personal Reflections on Physically Disabled Women and Dependency” is different again because it focuses on women who have acquired their disability in later life. Despite their different definitions of disability, all three articles place great emphasis and respect on the importance of independence to the people they write about—they do so without compromising or playing down the lived experiences of their participants.

Saviola begins her article by suggesting that the phenomenon of dependency is not unique to being disabled because at some stage in life we are all dependent

(Saviola, 1981:112). Her article explores the “double burden of dependency” that women with disabilities are automatically perceived to constitute. The double burden of dependency is when women with disabilities cannot fulfill the same traditional caring and nurturing roles like other women do. Instead the reality for many women with disabilities is that they need to be cared for (Saviola, 1981:114). Despite writing separately Lonsdale and Saviola agree that because less is expected from girls with disabilities they are not afforded the same responsibilities and opportunities as girls without disabilities, thus relegating them to a life of dependency (Lonsdale, 1990:82, and Saviola, 1981:112). Sandström contributes to the argument by explaining that dependency is a learned behaviour from childhood that creates a false sense of security which carries on into adulthood (Sandström, 2007:437).

In discussing the issue of *independence* Saviola argues that women with disabilities can be handicapped by family and friends—albeit unintentionally. This can be most prominent when the women with disabilities assert their desire to become independent (Saviola, 1981:114). Saviola makes the point that women with disabilities can become suffocated by the discourse of *dependence*, so much so that often family and friends hinder women with disabilities from developing and advancing their “true” independent abilities. This is because family and friends often find it difficult to believe that women with disabilities have the same potential to become “independent and self-directing” as non-disabled women do. As such one might argue the leap of independence for a woman with a disability is emotionally harder for her family and friends than for her (Saviola, 1981:114). Many women with disabilities would perceive this as a denial of their rights and ability to become independent and self-directing—as

such women in these positions would be performing emotion work by suppressing anger and frustrations at not being afforded the opportunities that adults without disabilities take for granted.

The next few sections talk about a variety of issues such as self-esteem; assumptions; loneliness and isolation and violence. While I discuss them separately, I conclude the chapter by linking them together to illustrate the ways that these issues contribute to women with disabilities needing to perform emotion work.

### **Self-Esteem**

Issues of self-esteem are not unique to women and girls with disabilities; many girls can be seduced by the pressures of trying to obtain the *perfect* body. In “Enhancing Self-Esteem in Women with Physical Disabilities”, Margaret Nosek, Rosemary Hughes, Nancy Swedlund, Heather Taylor, and Susan Robinson-Whelen, (2003) argue that “self-esteem plays an important role in the well-being of women with physical limitations” (Nosek et al., 2003:295). They argue that for women with disabilities, self-esteem has been compromised. This is because of the “internalization of the social stigma, exclusion, and devaluation that society often imposes on persons with physical impairment” (Nosek et al., 2003:295). In a similarly named article “Self-Esteem and Women with Disabilities”, Hughes and Nosek, Swedlund, Taylor, along with Paul Swank (2004) discuss how women with disabilities construct their “sense of self” (Hughes et al., 2004:1738). This article is primarily about the “sense of self” that women with disabilities hold about themselves (Hughes et al., 2004:1738). One of their central arguments is that self perception can often be linked with the environment

that women with disabilities grew up in, and whether they were encouraged to live an “ordinary” life (Hughes et al., 2004:1738).

### **Assumptions**

Saviola also makes the point that many within society view disability as being “a regrettable condition” that expects the “unfortunate” to “mourn, grieve and express suffering” (Saviola, 1981:113). In fact, when people with disabilities do not express these emotions they may be perceived as “deviant” or “being saintly” (Saviola, 1981:113). So when women with disabilities appear to be happy with the person they have become, there will always be questions and assumptions about whether or not they are *truly* happy living with their disabilities. Lonsdale picks up on the ways that having a disability in most instances means prolonged and, at times, arduous dealings with medical professionals. Lonsdale’s study revealed that many doctors and other medical professionals were condescending, dismissive, and unhelpful towards women with disabilities (Lonsdale, 1990:52). The women in her study suggested that more often than not medical professionals displayed a greater interest in attempting to find a way to “cure” the women of their disability rather than assisting them to live with their disability (Lonsdale, 1990:52-53).

The question to be pondered here appears to be, are the doctors seeking to “fix” the disabled body because that is what the woman wants? Or, are they just following what “society” desires most—a “blemish” free world? The emotional consequences of such an attitude can only be described as negative. Not only is it the ultimate denial of who women with disabilities are, it also forces women to strive for abilities that are

unachievable rather than focusing on improving on the abilities that they already have (Lonsdale, 1990:52)

### **Loneliness and Isolation**

In “Loneliness of People with Disabilities”, Ami Rokach, Rachel Lehcier-Kimel and Artem Safarov (2006), contend that, having a “physical disability has a profound effect on one’s quality of life, social intercourse and emotional well being” (Rokach et al., 2006:681). Where once people lived as families and tribes, we have forfeited this connectedness in favor of technology which serves to further isolate people from one another (Rokach et al., 2006:682). While social isolation is a real issue for many people, I argue that for women with disabilities who are isolated and lonely, any little bit of attention can sometimes be better than none at all. This belief often leads women to enter into relationships that are harmful to their physical, spiritual and emotional wellbeing (Rokach et al., 2006:682). This brings us to discussing issues of violence and abuse of women with disabilities.

### **Violence**

There is a misguided assumption by many people that because women with disabilities are perceived as being “*cared for*” that this would decrease instances of abuse. Perhaps it is because of this misguided assumption, that Beck-Massy (1999) identifies violence against women with disabilities to be a “sanctioned war” (Beck-Massy, 1999:275). The authors of “Vulnerabilities for Abuse Among Women with Disabilities”, remind us that women with disabilities are exposed to greater rates of abuse than their able-bodied counterparts because “certain disability-related settings increase vulnerability for abuse” (Nosek et al., 2001:177).

One such setting for violence can be in the homes of women with disabilities. Because many women use personal assistance services to help them with everyday living activities – which are mostly conducted in privacy – there is a high probability that abuse can occur. The article entitled “Barriers and Strategies in Addressing Abuse: A Survey of Disabled Women’s Experience” explores this very subject. The authors suggest that within this context abuse has a “unique meaning for women with disabilities” owing to the relationship between the individual women and their personal support worker (Powers et al., 2002:4). Whilst abuse and violence towards women can occur anywhere and be perpetrated by anyone, the violence and abuse that women with disabilities encounter can be much more pervasive (Powers et al., 2002:4). These pervasive forms of violence that can be perpetrated against women with disabilities can be at the hand of support workers or carers and include withholding devices such as mobility and communication devices; leaving a woman’s electric wheelchair out of reach or unlocked (so that she can not move); and denying the woman of medical care and medication. Violence may also occur in the form of intimidation which can include the support worker or carer yelling, punching walls, and using verbal threats. Verbal threats are a somewhat more sinister form of abuse for women with disabilities because the perpetrator may use the system against the women. Beck-Massey states that the threats of being placed in a home or institution, or the threat to remove a woman’s children from her, are forms of abuse (Beck-Massey, 1999:276) (see also Salthouse and Frohmader, 2004 and Saxton, 2001).

I began these sections with the issue of self-esteem and led into discussing that there are assumptions made about women with disabilities that suggest that living life

with a disability should be considered as being a regrettable condition. This contributes too the loneliness and isolation of women with disabilities because their self-esteem continues to be eroded by these negative messages. And as mention above, when this cycle of negativity is continued, women with disabilities are likely to find themselves in relationships where they have no power.

This literature review has explored three central themes relevant to my thesis. These central themes are emotion work, disability and women with disabilities. After exploring the literature that exists in relation to emotion work, I declared that I had only found one article that had explore the notion that people with disabilities do indeed perform emotion work. I then explored the literature that exists in relation to disability. Here I argued that despite disability being a gendered discourse, the issues for women with disability have essentially been ignored by feminism and also denied by men with disabilities. The largest section was a review of the literature relating to women with disabilities. Although this literature was by no means exhaustive it was a reflection of the many reasons why women with disabilities perform emotion work.

When considered separately, issues such as the cycle of negativity; self-esteem; loneliness and isolation; and violence may *not* cause women with disabilities to perform emotion work. The need to perform emotion work is something that everyone does throughout life. However, I argue that it is the combination of two or more of these issues that contribute to the need for women with disabilities to perform an unfair share of emotion work.

## *Chapter Two*

# **Methodology**

The purpose of this chapter is to explain the methodologies that have been employed in undertaking this research. In this Chapter I explain the theory I have based my methodology on, the criteria for participation, the questions asked of the participants, as well as the limitations I found during the research phase.

## **Theory**

While my thesis is based in feminist theory the methodology I have used is standpoint research. Tong et al., suggests that,

Feminist theory encompasses a range of diverse ideas, all of which originate with the following beliefs: (a) society is patriarchal, structured by and favoring men; (b) traditional ways of thinking support the subordination of women and the neglect or trivialization of issues particularly affecting women; and (c) this patriarchal order should be overthrown and replaced with a system that stresses equality for both sexes (Tong et al., 2001:5485).

Tong et al., also state

Yet for all the diversity within feminist theory, there remains the belief that despite women's many differences, women everywhere share some basic 'sameness' (Tong et al., 2001:5485)

While I agree that there are many similarities between women with and without disabilities, there are just as many differences. This is because, as I highlighted in Chapter One, while feminism is trying "to dismantle" many institutions such as marriage

and motherhood, women with disabilities are trying to find a way to enter into them (Morris, 1996:5).

[k]nowledge claims are socially located and that some social locations, especially those at the bottom of the social and economic hierarchies, are better than others as starting points for seeking knowledge not only about those particular women but others as well (Olsen, 2005:243).

Standpoint research challenges the way that feminist theory has failed to consider women who sit on the margins of society. According to Virginia Olesen (2005) standpoint research criticises the way that feminist theory has neglected to include women from the margins (such as women with disabilities) that have previously been left out of mainstream feminism. She argues that because standpoint research does include women from the margins it is somewhat more inclusive than some other versions of feminist theory (Olesen, 2005:243).

As I mentioned in Chapter Two, the voices of women with disabilities are still not being heard by those who claim to represent them (such as feminism and the disability movement). Because women with disabilities are being denied this opportunity to be heard, they are in the unique position of being able to understand the nature of power dynamics based on the experience of belonging to a minority group. And because women with disabilities are located at the “bottom of the social and economic hierarchies” they are in a better position to speak about forms of oppression which are particular to them because they are women and have disabilities.

## **Participation Criteria**

The participation criteria for my research included women who were either born with a disability or had acquired their disability before they were three years of age. The criterion central to my hypothesis is that when women present as having an obvious disability, interact with anyone without a disability, they are automatically “othered” and as such are treated differently. This knowledge is based on the personal experience of being treated differently because I have Cerebral Palsy. My experience has taught me that women with disabilities are required to perform emotion work if we wish to be accepted and treated equally within society.

Where once, disability could be classified by four main groups; physical, intellectual, sensory and psychological, the definition of disability is expanding to include impairments, handicaps and long term health conditions. According to the Australian Bureau of Statistics website, The World Health Organisation defines disability to be

[a]ny restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (Australian Bureau of Statistics, 2006).

The sample group for my thesis included women who had a wide range of disabilities including Polio, Sensory impairments, Spina Bifida, Muscular Dystrophy, Osteogenesis Imperfecta or Brittle Bones Disease, Scoliosis, Autism Spectrum Disorder, Congenital Muscular Myopathy, Spinal Muscular Atrophy, Epilepsy, Intellectual disability, Achondroplasia (a form of dwarfism), and Cerebral Palsy. These women were aged between 19 and 62, and came from all over Australia. All of the participants are referred to by pseudonyms—some of the participants even suggested their own pseudonym.

Because my research called for women who identified as having obvious disabilities, there were some women with disabilities who were excluded from my research. These included women with learning or developmental disabilities (as they are also referred to), such as Dyslexia Attention Deficit Disorder (*ADD*), as well as other long-term health conditions such as Arthritis and Diabetes. The decision to exclude these women from my research was based on the premise that although developmental disabilities and some long-term health conditions can become obvious in time, they are not apparent when the woman first comes into contact with other members of society. This exclusion is not intended to imply that these women do not perform emotion work; but that it would likely differ from that of women who were born with obvious disabilities. It is also for this reason that women who acquired their disabilities later in life were excluded. The other exclusion was of a woman who identified as being a “carer” of people with disabilities. Although the woman said she had Arthritis, she did not fit the criteria in spite of her declaration that she *understood the* issues because of her occupation. As such her inclusion in this research would have been inappropriate.

## **The Method**

All of these women participating in the research were found by using the internet. I used this method for three main reasons. Firstly because I have a disability myself, I needed to find a way to record the participant’s responses accurately. Secondly, because many of the participants had physical disabilities, it was considered that this method would permit participants to answer the questionnaire at their leisure. The third advantage was that the questionnaire could be accessed and responded to. This enriched my research because it included a diverse range of disabilities and experiences.

The initial call for participants occurred in March 2008, and was sent to personal contacts, as well as 14 disability organisations, 58 Disability Liaison Offices of Australian Universities and 32 TAFE colleges. My initial e-mail contained three attachments including the information sheet; a letter to the participants explaining about the research, and the questionnaire (see Appendices Two, Three and Four). These were distributed as widely as possible to attract as much attention to the study as possible. This attracted slow response. However, once the e-mail was distributed to students with disabilities from one particular university, there were a flood of responses within a matter of hours. Unfortunately many of these responses were from women who had either acquired their disability after the age of three, or had other conditions that by nature excluded them from my research (i.e., learning disabilities or long term health conditions). As such these responses could not be included.

By the end of June, the response rate had ceased, and consequently a second call for participants went out in July. Unlike the first call, an e-mail was sent to two organisations who I had hoped would be able to tap into otherwise unavailable resources. This time it was suggested that I write a brief description of the project, which would be sent out to networks, and then it would be left to the women to contact me directly if they were interested in participating. I discovered that many of the women who responded to this second call were automatically describing their disability and asking whether or not they fitted the criteria. This method proved somewhat more successful because it allowed me to keep track of how many women were interested as well as whether they could be included because of the types of disabilities they had.

The information sheet that was sent with the questionnaire provided participants with background information about my research. In defining my project, I was mindful that while I needed to provide some information about what emotion work was, I also needed to frame the information so that I would not influence the responses from the participants.

### **The Questions**

The questionnaire was designed to encourage the participants to share their own stories about whether, and if so, how and why, they performed emotion work. (See Appendix Three for a copy of the questionnaire.)

The first question encouraged participants to think about whether or not they paid particular attention to their overall appearance. They were encouraged to consider this question in relation to facial gestures and expressions, and in showing strong emotions. There were three sub questions associated with this, which encouraged the women to consider whether they believed that there were constraints on the way they presented themselves; whether they were careful about how they came across to others and if there were aspects of their disability that caused them to constrain their expressions. I asked this question to learn more about whether women with disabilities were conscious about the way they appeared in public. I also wanted to know about the types of situations that cause them to modify their emotions.

The second question asked the participants whether or not they “pretended” emotions in order to “fit in”. The third question asked whether or not they found it to be emotionally draining because they had to monitor their emotions on a continual basis. This question also had a sub-question, for those who said they did not feel that it would

be emotionally draining. This asked them to explain how they negotiated around this. These questions were designed to encourage participants to consider why they performed emotion work. It also invited the participants to think about how performing emotion work made them feel.

The fourth question asked whether or not participants thought that men with disabilities needed to perform emotion work as much as themselves. This question was to gauge whether the women believed that emotion work only applied to being a woman with a disability. (See Appendix Four for discussion on men with disabilities.)

The final question asked participants about themselves. They were asked to describe their disability and at what age it was diagnosed, their current age, where they spent the first twelve years of their lives, as well as their current living situations. The purpose of this question was to gain an overall sense of who the participants were. In many instances participants said more in this section than the rest of the questionnaire. From this information I was able to construct a sense of who the participants were and gain a little more insight into why they perform emotion work.

## **The Limitations**

While the preferred method of data collection for my research was using the internet, there were four obvious limitations to only relying on this method. The first limitation was that despite having an information sheet, which clearly defined the aim of my research, some of the participants found it difficult to answer the questions. This was reflected by participants writing “I do not understand this question”, or simply leaving it blank. In a larger project with a longer research period I would have been able to spend time explaining the concepts to my participants, which may have assist them in

answering the questions. This may have not been a problem if I had performed one-on-one interviews, I may have been able to assist the participants to understand the meaning of the questions, which may have assisted them to feel comfortable and able to answer the question.

The second limitation was that despite having one respondent who identified as having an intellectual disability, it was upon e-mail conversations with the advocate of this woman that I discovered that there were other women with intellectual disabilities who showed an interest in my research. Owing to the fact that they had intellectual disability, the advocate thought that I would either need to devise an easy to read and understand format of the questionnaire and information sheet, or conduct either face-to-face interviews or focus groups. Again, in a larger study I would have been able to devote some more time to develop an easy-to-read and understand survey which may have enticed more women with intellectual disabilities to participate in the research.

The third limitation to only using a single method of data collection was when a few potential participants requested a hard copy of the questionnaire be posted to them. Unfortunately, meeting both of these requests was not feasible for two reasons. Firstly it was my understanding that these requests came from other states within Australia, and it was not physically practical for me to meet these requests. Secondly, and again due to the location of the participants, and also the time needed for me to manually type in the data once the survey had been returned, it was not feasible to accommodate this request.

The final limitation was due to my limited understanding of what emotion work was when I initially constructed and sent out the questionnaire. It was during the literature review process that I discovered that there were many ways to perform emotion work. In

hindsight a deeper understanding of the concepts associated with emotion work would have led me to ask different questions which may have enriched the responses I received.

## *Chapter Three*

### **Women, Disability and Emotion Work**

This is the results chapter of my thesis, and is broken into two distinct sections. The first section introduces the participants, their age, their disabilities and discusses their current living situations. By including the descriptions of the women at the start of this chapter, it provides an insight into why it is that they perform emotion work. I also discuss the fact that some of the participants use in-home support. Here I argue that despite living independently, the use of in-home support can also create situations that mean women with disabilities perform emotion work.

The second half of this chapter demonstrates the ways that women with disabilities perform emotion work and suggests that the performance of emotion work involves many conscious and deliberate acts. These acts include maintaining a good physical appearance to monitoring their emotions in public to, pretending, producing and suppressing their emotions. Some of the participants were however resistant to the idea that they performed emotion work on the premise that they had a disability.

#### **The Women**

This first section introduces the women who participated in my research. As I have just stated this background information provides an insight into who these women are, their age, as well as type of disability they live with. I also provide a snapshot of their present living environments. It is interesting to note that many of the participants relished the opportunity to provide personal information about their lives—in many instances this section attracted more comment than the rest of the survey. From the 26

women who responded, the youngest two participants are 19 and the oldest is 62. The majority of participants were in their 20s or 30s. Again, all of the women are referred to with pseudonyms.

The disability most represented in my research was women who were born with Cerebral Palsy. Cerebral Palsy is caused by a lack of oxygen to the brain, either during or shortly after birth. Even if it is present at birth Cerebral Palsy is not always diagnosed until the early childhood developmental stages. Cerebral Palsy affects no two people in the same way (Scope, 2007).

The women who were diagnosed as having Cerebral Palsy at birth include, Mary, 54, Yasmine, who is over 50, Paula, 38, and Vanessa, 40. Aleica who is 37, was four days old when she was diagnosed with the disability. “Sticks”, 31, was two, while Elizabeth, 36 and Eileen, 56, were three when their parents were informed their daughters had Cerebral Palsy.

Three participants identify as having sensory disabilities. Jelena, 21, was born with severe to profound hearing loss in both ears, while Jodie, 19, has moderate hearing loss. Despite having different degrees of deafness, both say they are proficient lip-readers, and comment on how there are times when people around them forget that they have a disability. Gerri who is in her 20s also identifies as having sensory disabilities that affect her vision and hearing. All three women have lived with these disabilities since birth.

Chantelle, 24, has Osteogenesis Imperfecta, or Brittle Bones disease. This is a genetic disorder which is characterised by bones which break easily. Thirty-eight year old Alexis, has multiple disabilities, as a result of an operation she had to mend a hole in

her heart when she was 10 weeks old. At the age of five, Alexis was also diagnosed as having Scoliosis, which meant she needed to use a Milwaukee Brace to walk. Despite having very different types of disabilities, both Chantelle and Alexis feel betrayed by their disabilities because of the way their disabilities cause both women to look and sound like children.

Roxanne was born with dislocated hips, which were not picked up until she began to walk. At the age of two, Roxanne was taken to hospital, where they tried to correct the problem, however it was too late, as her bones had already set into place. At the insistence of doctors, Roxanne has undergone many operations which have done little but cause pain—and at 54, she expects there are more operations to come.

Amy is 34, and has the dual disabilities of Autism Spectrum Disorder and Myoclonic Dystonia. Autism Spectrum Disorder is a life long disability which affects how the person relates and communicates with the world around them (Autism Spectrum Australia, 2007). Myoclonic Dystonia is characterised by rapid jerky movements (Dystonia Research Foundation, 2006). Amy is mindful that there are times when her disability is highly visible, especially because she feels unable to control the movement disorder such as repetitious voice tics, excited arm flapping and screeching.

Jen, Georgii and Hannah all contracted Polio as young children. Polio is a neuromuscular disease. Fifty-four year old Hannah was diagnosed at 15 months and considers her disability to be very apparent and feels constrained by her bodily appearance. Jen is a proud 60 year-old, and was diagnosed with Polio at 20 months of age and walked aided by a single caliper and crutches. In 1981, Jen had a fall resulting in severe fractures, rendering her unable to walk again. Georgii, who is 62, was diagnosed

when she was 14 months old. For Georgii her Polio causes weakness in her right leg and hip and she walks with a limp.

Sixty year old Violet has Spina Bifida Meningocele. A disability since birth, Spina Bifida often leaves many people with a variety of health issues. For Violet her disability means that her right leg is two inches shorter than her left, so she has a few mobility issues including poor balance. Violet has had Neurosurgery, and has early signs of Parkinson's disease.

Forty-three year old Francine identifies as being diagnosed as having Muscular Dystrophy when she was seven. Muscular Dystrophy is the name given to a group of "neuromuscular disorders", and generally refers to the wasting of muscles (State Government Victoria Australia, 2006).

Samantha 18 has Congenital Muscular Myopathy which was present from birth. Although Samantha states that this disability is similar to Muscular Dystrophy she is yet to receive an official diagnosis. She experiences weakness throughout her entire body and also experiences secondary respiratory complications due to a weak diaphragm and chest wall—resulting in her health being extremely fragile. Samantha has accepted that her life expectancy is likely to be shortened because of the nature of her disability.

Maudie is 51 and has Spinal Muscular Atrophy. Although she has had her disability since birth Maudie was diagnosed when she was three. Spinal Muscular Atrophy is also a neuromuscular disorder (State Government Victoria Australia, 2006). Although Maudie is able to take a few steps, she uses an electric wheelchair for mobility. For Maudie this disability means that her arms are weak and that she cannot perform

tasks that are above head-height. She also experiences an “all-over low amount of pain” which increases when she over-does things.

Forty-five year old Suzie was diagnosed between the ages of two and four as having Epilepsy (Complex Partial Seizures) as a result of damage in the Left Temporal Lobe of her brain. Suzie explains that one of the tell-tales signs that she has Epilepsy is that her eyes well up with tears. When this occurs, she says that people think that she is about to burst into tears when in actuality it is just a side-effect of the medication that she is on.

Glenda, 54, has Achondroplasia which is a type of dwarfism where her body is the same size as an average height person but her arms and legs are shorter. Although Glenda gives the impression that she had a happy childhood, she points out that when she was in her 20s, she was quite angry at her parents for “not helping” her. She appears to have reconciled with them now and acknowledges that her parents may not have known how to assist her.

At the age of two, 37 year old Melanie suffered from her first Cardiac arrest—her second one occurred when she was five. Both arrests caused significant brain damage. Melanie is the only participant who identifies as having an intellectual disability.

### **Living Situations**

For various reasons seven of the participants still reside with either one or both of their parents, and/or their siblings. These women are Aleica, Chantelle, Elizabeth, Jodie, Paula, Samantha, and “Sticks”. It is important to recognise that these are mostly young women who have not had a lot of life experience. Two of these women have indicated

that they have thought about moving out of the family home. Chantelle says that her parents currently meet her care needs and that she is in the process of “trying to plan an independent living arrangement”. Elizabeth says that it is fear that keeps her from leaving home, while, Aleica comments that because her parents are getting older, she fears that she will be placed in a “home”, this is something she does not want to happen to her because she works in one voluntarily.

Although a further three say that they live with their parent/s there are mitigating circumstances involved. Alexis says that even though she currently lives with her mother she adds that it is a mutual arrangement that meets both their needs at this point in their lives. Alexis states that prior to this she rented a house for 16 years, and shared it with different people. She also lived by herself for another six years. Suzie also lives with her parents along with her two children. And Yasmine lives with her 85 year old father, whom she cares for.

Eileen, Francine, Georgii, Glenda, Jen, Melanie, and Violet are all married, and all apart from Melanie and Glenda have children. Glenda added that she and her husband decided not to have children, owing to her husband’s experiences of having an abusive father. Suzie also has children, and as mentioned lives with them and her parents. Eileen and Violet mention that they also have grandchildren.

While Gerri lives with her carer, Amy, Hannah and Vanessa live with their partners; and Faith and Maudie live alone. Maudie points out that she shares her home with three adoring cats who she says “provide me solace as they don’t discriminate against me or avoid me”.

Drawing from my own experiences of various living situations, having lived alone and with others (my family, others with disabilities and fellow university students), I can imagine the various degrees of emotion work that would be involved in many of the environments that the participants described. I found that when I lived with others my emotion work was reflective of the way I interacted with the people I lived with. Whereas, when I live alone, as I currently do, I have no need to perform emotion work at home, because I do not need to consider the emotions of others.

### **In-Home Support**

For many women with disabilities, the use of in-home support is vital for them to gain and maintain their independence. This type of support can be made available<sup>1</sup> to women living either within the family home, or independently. This support is individualised and under the direction of the woman who is using the support. For example, living alone for Maudie is assisted by her home being totally and fully accessible, and being able to have 12 hours of paid personal support a week. Women like Maudie are very much in control of what their support workers do and do not do. There are instances where women can receive this type of personal care even when living either in the family home or a relationship setting. Aleica, who as mentioned above lives with her aging parents, states that she receives home care twice a day, to attend to her personal care needs. Vanessa lives with her partner and uses her personal support not only for personal care needs, but also for basic house-hold chores such as cooking and cleaning.

Despite the concept of in-home support being intended to enhance the independence of the women who use it there are instances where women with disabilities

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<sup>1</sup> In-home support is often funded by governments and is subjected to affordability by funding bodies.

would perform emotion work, for the benefit of their support workers. One explanation is that although in most instances, women using this support would generally be in control of when and how the support is provided, it is not always understood by the person providing the support that they are required to take direction from the women that they are supporting. In these situations women may need to suppress their frustrations (especially if they know they are not being listened to), so that eventually they can get everything done that they need in the time that is allocated.

The second half of this chapter demonstrates that for these women who participated in my research, “proving” themselves as free-thinking, independent and contributing members of society, also forces them to perform emotion work. I begin this section by talking about how many of the women said that it was important that they maintain a good physical appearance. Discussions will then lead into the various ways that the women perform emotion work, and why they feel the need to do so.

## **We Are Doing Emotion Work**

### **Physical Appearance**

In opening these discussions I begin by establishing that some of the women linked their degree of comfort in performing emotion work with feeling positive about their physical appearance. There are three conclusions provided by the women as to why they feel that maintaining a good physical appearance is important to how they perform emotion work.

The first consideration that has been presented here is that when the women with disabilities feel confident about who they are, it is conceivable that they would feel

themselves as being more in control of the physical manifestations of their disabilities. Many of these women associated being well-presented with needing to be accepted as an equal. Eileen, Mary and Vanessa all have Cerebral Palsy and place great importance on the way they present themselves.

For Eileen, performing emotion work involves looking reasonably presentable and learning to be more relaxed. She alludes to the need to surround herself with “good friends” who accept and respect her for who she is. Further she asserts,

*I have learnt to be a bit more relaxed. So if I have done those things that make me look reasonable [sic] presentable, and if I [have] some good friends who respect me then I feel [I] can't do anything more. It is [a] great assurance to have good friends.*

The second consideration is that physical appearance can be associated with a person's intellect. Chantelle, Maudie and Mary all agree that their physical appearance is often judged as reflection their level of intelligence as perceived by others. Maudie emphasises that for her, having a good physical appearance is very much related to minimising this false perception of the nature of her disability. She says,

*My clothes must fit well and not be rumpled. I must drive my wheelchair smoothly and with “style” to show that I am competent. I look out for other pedestrians and avoid them to an enormous degree so they do not hurt themselves on my wheelchair. I must sound intelligent all the time to “prove” that I don't have an intellectual disability.*

The third consideration is that having a good appearance is a learned behavior from childhood. Vanessa and Yasmine, talk about how having a good appearance was instilled

in them from a young age. While having a good physical appearance was an expectation, of not just Yasmine, but also her siblings, Vanessa states,

*I can remember [that] my parents dressed me in nice clothes, “so other people would know I was loved and valued”. This attitude has made me aware (perhaps, hypersensitive) [sic] to how people perceive me. I have also come to know that people do perceive people with disabilities differently and this can be negated by appearance.*

Chantelle shares that owing to her “child-like” appearance; she struggles to project herself as a competent self-aware adult.

*Approaching new people is always a struggle for me and I always try to make myself look and sound my age when indeed I don’t sound or look the part. Being accepted as an intelligent woman in my 20’s[sic] is one of the hardest things I face.*

Finally Alexis states,

*I don’t like being different, sounding different, looking and walking differently from others. As an adult I am very careful about how I dress, trying to hide my scoliosis. I’m amazed sometime when people give me the impression that they don’t see my scoliosis because to me it’s very obvious, especially when I look in a mirror or at a photo.*

These women believed that maintaining a good appearance promotes their self-confidence which in turn assists them to relax and to be themselves. This is not to suggest that by maintaining a good appearance would negate the need for the women to perform emotion work. However, it maybe assumed that if these women are feeling

more relaxed and confident in themselves their levels of performing emotion work may decrease; because they may feel equal to the person they are interacting with.

### **Monitoring Emotion**

As well as having to maintain a good physical appearance, I also wanted to know whether or not the participants felt the need to continually monitor their emotions. While Amy talks about self-monitoring, Jen is aware that she needs to be more self-aware at certain times. In relation to self monitoring Amy says,

*I think the self monitoring performed for a multitude of reasons is one of the most taxing aspects of living with disability [sic]. Hyper-vigilance and stress lead to adrenal fatigue and immune dysfunction and may cause chronic fatigue. Emotional drain [sic] has very real physical impacts.*

Jen comments that in times of depression, she needs to be more “self-aware” and says she monitors her emotions more rigorously.

*During times of depression I am not at my cheerful best, and this is obvious by the reaction of those around me, who expect differently. Therefore I am aware always of what I say, moderating gestures (when many times I simply want to thump the table or the person talking!!!)*

Many women with Cerebral Palsy are aware that there are times where the display of emotions can be louder than intended—particularly when laughing. Elizabeth notes that as she got older, she began to notice the impact that her apparent “loud and over the top”, show of emotions had on those around her. Hannah recalls that as a young woman she was encouraged not to be “over-expressive”, because it did not “suit” her. She says

*[W]hen I was a young woman with a disability, I was often told that I should not be over-expressive – that this didn't suit me, and perhaps it made me more obvious – or my disability more obvious*

As a result, Hannah felt that this need to suppress herself made her disability “more obvious”. She also states that this evoked a need for her to “disguise or constrain my attraction to people for fear of rejection”.

### **Suppressing Emotion**

Many women testified here, that the need to suppress emotions is paramount—especially in public spaces and dealing with people who do not always know how to relate to disabilities—let alone the women that have them.

Chantelle and Maudie tell of their experiences with sales assistants. Chantelle shares that despite being the purchaser of a product, she is often ignored by sales assistants, who instantly converse with the person with her and appear not to have a disability. Chantelle says,

*[What] continually happens is when I do the grocery shopping or I'm with someone while purchasing something and when I ha[n]d over the cash to them, they hand the cash back to the friend or relative I'm with.*

Maudie also indicates that often shop assistants will ignore her, in spite of the fact that she may be “in front of them and looking expectantly” at them. Despite wanting to scream at them for ignoring her, Maudie knows that she must suppress her “righteous anger”. Maudie writes that the consequences of not suppressing her emotions are that,

*I will be judged as bitter, twisted and unreasonable and they will dismiss my claims or arguments of discrimination. [So] I continue*

*to be polite or ignore it when mostly I want to yell at people who: do not provide me with enough room to get past them (even tho they can see me), patronise me, exclude me and don't care, stare at me, ignore me.*

Jen talks about suppressing emotions while she is advocating for the rights of people with physical disabilities at a national level. This involves Jen presenting herself as being “capable, intelligent and able to communicate”. Jen concludes that failure to demonstrate these attributes could result in her being perceived and treated as a “lesser person”.

Yasmine relates her desire of not wanting to be confrontational with suppressing her “true emotions”. This attitude has afforded her with the “unwarranted reputation of being a good listener”. Going on to say that although there are times when she wants to appear to be sympathetic to the person, Yasmine’s true desire is to scream at them to “get a life”. Yasmine recognises that she needs to be “very, very careful” about what she says.

Drawing on personal experience, the act of suppressing emotions is extremely difficult to do. For Maudie the consequences of not suppressing emotions and expressing frustrations can have far more pervasive and detrimental consequences for women with disabilities. So it follows that if women with disabilities are suppressing their emotions, they would also need to pretend emotions to substitute their “true” emotions.

### **Pretending Emotions**

The first example of pretending emotions is Alexis, when she shares that she has been in situations with her friends, and has pretended that she was having a good time,

when in reality she would have preferred to be anywhere else. Another is of women with hearing impairments such as Jelena and Jodie, who both say that they pretend emotions on a regular basis, by copying and mimicking the display of emotions of those around them. Jodie says,

*Perhaps when in conversation when someone says a joke and you don't hear it yet everyone laughs and so you join in. This is just one trivial example of how missing important information leads you to react in accordance with the group around you in order to fit in.*

Other women including Jen, Chantelle and Amy spoke about the company they kept and the range of emotions that they felt that they needed to produce. Jen distinguishes between her public and private emotions. When in public Jen considers it important that she is well presented and that she “speak well, and restrict comments” that she would otherwise be free to express in her private life, where she feels free to laugh hysterically and make loud exclamations if she wants to.

Chantelle openly admits to always wanting to fit in. Despite her size and disability she has always felt the need to show herself “to be something”. She states

*If I can't fit in the crowd on my looks then I can certainly fit in on my opinion, intelligence, emotionally etc.*

Amy admits that there are many instances where she manufactures the appropriate responses that others expect from her. Amy states that she is not sure whether her true emotional responses, or lack of them, are related to her having Autism. Amy provides an example from when her grandmother passed away by stating,

*[W]hen my Grandmother died I was perfectly fine with her passing and thought it reasonable that she died at 89 after a long life and a short illness. I was expected to cry and fuss etc – this is not my way of doing things – perhaps as a result of my autism or perhaps just my personality. I had to act far more distressed than I actually was and also endure a degree of attention that was not welcome.*

These responses illustrate the ways that women with disabilities frequently pretend their emotions for various reasons. Common reasons described by the participants for these include to be accepted by others, “to fit in”, and to appear as being “less disabled” than they are.

## **Resistance**

A few women said that they resisted the idea that they would perform emotion work on the basis that they had a disability. Rather, many of the women shared that the need to perform emotion work had more to do with gaining acceptance within society. There were two respondents who said that they did not see the need to constrain themselves or perform any more emotion work than any other member of society. Francine, and Violet, both said that they prefer to remain “true” to their feelings at any given time.

Violet states that her disability has never “fazed” her, and that she “was never inhibited emotionally by her disability”. Violet does not feel that she constrains herself in her presentation. In her words “what you see is what you get”. However, Violet does say that she upsets herself at times when she expresses herself in the wrong context. She goes on to say that there are times when she has realised that she has said the wrong

thing, and at other times someone else has pointed out her mistake. Nevertheless, she says she feels no need to “pretend in any situation”.

Alexis, Aleica and Suzie all comment that they were raised in the same way as their siblings. Aleica commented that as a child she was like any other child, lived at home with her parents and went to a “normal school”. As children both Alexis and Suzie said that they liked to play and do things as other children did. Alexis refers to playing games with her brother, and not minding whether or not she could keep up with other children. Suzie makes a similar statement when she says,

*When I was younger I did not stop doing things because of my condition. I enjoyed various types of dancing.*

Such responses indicate that while there are instances where women perform emotion work, there are times when the women can remain “true” to themselves and resist the urge to conform to the ways that society dictates.

The objective of this chapter has been to explore the ways that women with disabilities perform emotion work. Evident throughout these discussions is that many women believed that they did perform emotion work. Despite admitting that it was draining to have to continually perform it, a number of the women were aware that there were consequences of *not* doing emotion work.

In the following chapter, I develop these conversations further by establishing links to the literature as presented in Chapter One with the responses from the participants. The objective of Chapter Four will be to explore some of the reasons that women with disabilities need to perform emotion work.

## *Chapter Four*

### **And this is Why**

I entitled this chapter “and this is why” to reflect that this is a continuation of the discussions which began in Chapter Three. In achieving this goal, this chapter will be divided into three sections. The first section will demonstrate that the participants perform emotion work by employing Hochschild’s (1979) three techniques of emotion work. Following on from this I establish that there is a connection between Lee’s (2004) cycle of negativity, Jordon’s (2006) concepts of power and relationship and the self-esteem of women with disabilities and the need to perform emotion work. The second half of this chapter will explore the reasons that women with disabilities perform emotion work. It is surprising to observe that many of the participants in my study were aware that performing emotion work meant more than “faking a smile”. Equally surprising was that despite not “naming” the emotion work they performed, some of the women gave good examples of using Hochschild’s three techniques of emotion work.

As mentioned in the literature review the concepts of emotion work, emotional labour and emotion management were introduced by Hochschild in 1979. To recap, according to Hochschild emotion work is the process of managing one’s feelings, purely for the benefit of others, whereas emotional labour relates directly to people who are employed in service industries – such as airline hostesses (Hochschild, 1979:561). And finally, emotional management refers to the way an individual is conscious of the ways that they induce or inhibit certain feelings they perceive appropriate for any given situation (Hochschild, 1979:560-61). Unlike in Hochschild’s study of individuals who were at times paid for their emotion work, this discussion will argue that women with

disabilities are expected to perform emotion work by conforming and behaving according to society's expectations of women with disabilities, without recompense for their efforts.

### **The Three Techniques of Emotion Work**

In the literature review I mentioned that Hochschild suggested that there were three techniques in doing emotion work. These techniques include cognitive, bodily and expressive (Hochschild, 1979:562). While Hochschild associated these techniques to people working in service industries, I argue that the same techniques are in fact used by anyone who performs emotion work. I now explore the ways in which women with disabilities employ these techniques when performing emotion work.

The first technique refers to the cognitive method a person uses in attempting to change or alter “images, ideas, and thoughts” ultimately changing “feelings associated with them” (Hochschild, 1979:562). Suzie says,

*I am aware of how easy tears may come to my eyes. I only need think of something that has upset me and my eyes flow. People think I am upset. I know it is [a] side effect of medicines because it has only begun since taking a higher dose. If I feel my eyes building up, I will leave the people I am talking to (if possible) and go to a bathroom (if one is nearby).*

Although Suzie's symptoms of her disability are caused by her medications, she is aware of how their physical manifestations make others feel. Where possible she tried to remove herself from the situation—one might argue to relieve the other person's discomfort. The second technique is bodily, and relates to controlling “physical symptoms of emotion”, such as slowing down of breathing to calm one's body or “trying not to shake” (Hochschild, 1979:562). Maudie writes.

*So that I don't get completely drained I count to 10 or distract myself or try to ignore things that make me angry. I self talk (when out of hearing of others) out loud occasionally to calm myself. Or I scream loudly when alone to release the pressure.*

The third technique is *expressive* which relates to the ways people alter their expressive gestures in the effort of changing their inner feelings, such as smiling and crying (Hochschild, 1979:562). While Maudie has just provide a good example of both the second and third techniques, Eileen and Georgii also talked about this technique. Eileen places the utmost importance on expressing her gratitude to people who have rendered assistance to her. Similarly Georgii was brought up with the constant reminder of expressing gratitude to anyone who has assisted or shown concern toward either her, or her family. Georgii recalls that,

*It seemed when I was younger I was always thanking people for helping me or my family. Or when embarrassing situations such as being approached by a drunk man who was overwhelmed by the image of a child in leg irons [sic].*

It is not uncommon for women with disabilities to be taught from a young age to express gratitude to anyone who assists them. In some instances this constant need to be grateful can have negative consequences for women with disabilities because it can sometimes lead women to feel inferior to people without disabilities.

### **Surface Acting and Deep Acting**

As mentioned in Chapter One, the concepts of surface acting and deep acting are also important to consider when discussing emotion work. While the findings supported the notion that women with disabilities used surface acting in a variety of situations, there

was nothing to support the claim that they used deep acting when they performed emotion work. This suggests that women with disabilities do not perform deep acting. However, this could also mean that they are not aware of what deep acting entails. Perhaps a definition of what deep acting means would have evoked memories of when they did perform deep acting in their performance of emotion work.

### **The Cycle of Negativity**

*[I]t is utterly soul destroying to try to be someone your [sic] not or apologising for having a disability. This is completely unhealthy. We should be encouraged to embrace our disabilities not feel ashamed or a sense of guilt (Paula).*

This leads us on to discuss Lee's (2004) cycle of negativity and the types of relationships that often contribute to it. Throughout this section I illustrate that women with disabilities need to pretend emotions in order to protect themselves from those who are in their lives.

It was discussed in the literature review that the cycle of negativity begins when a child with a disability is born. Lee (2004) asserts that from a young age, a young girl with a disability may often receive negative messages about herself because she has a disability (Lee, 2004). These messages often come from doctors and other medical professionals, teachers, family, and friends (Lee, 2004) While doctors and other medical professionals will focus on what the child with the disability will never do, friends of the family are likely to suggest to the parent how sorry they are that the child was born at all. Such conversations are often within earshot of the child (Lee, 2004). But perhaps the most soul destroying comment that the young girl will hear, will sometimes, exit the mouth of her parents. Comments such as "she'll never amount to anything", or that "she

is hopeless and nothing but a nuisance” further contribute to the cycle of negativity (Lee, 2004).

### **Power and Relationships**

*It was the jokes that got me. I was expected to laugh at people making fun of me. I used to be married to a man of Jamaican descent and a common racist joke was, “She used to be married to a black man, that’s why she walks funny”. Or on bad days, when I walked worse than ever, friends would imply that I had had a mad night of sex that had left me temporarily disabled (Roxanne).*

Jordon (2006) explores the differences and the implications of power imbalances in relationships. Jordon suggests that often in relationships where one person has a disability and the other does not, the person without the disability gains power by default (Jordan, 2006:4). It is therefore easy to suggest that in relationships when the person *with* power has been some cause of the hurt but does not recognise or acknowledge this, the person who is powerless is left feeling vulnerable, hurt, scared and alone (Jordan, 2006:4). The powerless or injured person is likely to retreat and isolate herself; or at the very least opt to keep parts of herself hidden to protect herself within that particular relationship (Jordan, 2006:4). According to Jordon (2006) it is in childhood where many people learn the art of self preservation. This is because where children are often subjected to injury – sexual/physical/emotional abuse—repeatedly and “not responded to in a caring way”, children can take on a spirit of disconnectedness in order to protect themselves (Jordan, 2006:4). The authors of “Self-Esteem in women with Physical Disability” argue that, “women with disabilities must continually cope with assaults on their self-esteem generated by negative societal attitudes” (Nosek et al., 2003:1738).

Moreover, they further contend that “a woman’s self worth may be compromised by internalizing personal and social devaluation that society tends to equate with physical impairment” (Nosek et al., 2003:1738).

While it is not uncommon to find that many women with disabilities find themselves in relationships which reinforce and keep the cycle of negativity in motion, there are some women with disabilities who have broken the cycle. Roxanne is one such example. She explains that as a young girl, she was always conscious of how others treated her. Roxanne married a Jamaican man, who would frequently refer to her as a “useless old cripple”. If this was not enough, her friends would also joke that the reason for her limp was that she married a black man. On days when her disability was more visible, her friends joked that it was because they had “mad sex” which rendered her temporarily disabled.

Fortunately, Roxanne managed to find her way out of that marriage, and is now married to someone who she describes as being “the antithesis” of her first husband. She also indicates that she has surrounded herself with friends who no longer make inappropriate comments about her disability.

### **Loneliness, Communication and Emotion Work**

*I feel I have learnt to use my communication device effectively however there are still situations where I am ignored. In these situations I prefer to have a support worker with me for example, with doctor’s [sic] [or] dentists appointments etc (Mary).*

There were a number of women in my study who experience various forms of communication barriers. For many individuals who have speech impediments, there is an

undeniable link between loneliness, communication and emotion work. I further argue that the ability to communicate independently is one of the indicators that anyone with or without a disability can be considered to be a “competent” person. Many respondents have already suggested that having a disability also means having their intellect being brought into question; I argue that having a speech impediment, as a result of a disability, silently invites automatic judgments about a person’s intellect.

Mary uses a “Lightwriter”<sup>2</sup> for communication. While this method of communication can be liberating, for Mary, she also talks about the isolation it creates; this is because many people become impatient when communicating with her because it takes longer for Mary to convey her thoughts. She writes,

*In these situations I try to be as patient and as pleasant as possible – not showing frustration or annoyance but it is frustrating.*

Eileen presents another scenario where having a speech difficulty can create barriers. Going into depth about her speech difficulties, she is aware that she cannot always pronounce the sounds to adequately form the words or sentences. Eileen expresses her frustrations at having everything she wants to say, distinctly mapped out in her mind, but not being able to pronounce the words as clearly as she would like. Because this can be tiring, Eileen says that there are times when she would be content to sit and listen to the conversation. She also says that when she is on the phone, and is not getting anywhere with the person she is talking to, she will sometimes “just hang up”.

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<sup>2</sup> A Lightwriter is a communication device that allows people with severe speech impediments to communicate independently. The person types what they are saying and the device says it for them.

I have already discussed the way Jelena and Jodie manage their communication dilemmas—by mimicking the display of emotions of those around them. Gerri says that because of her vision loss and hearing impairment “sometimes I feel isolated”. Consequently she is not always comfortable or sure about how to interact with people who do not have disabilities.

The connection between loneliness and emotion work is that if a woman with a disability has experienced being lonely and isolated for long enough, she may be inclined to perform emotion work to break her cycle of loneliness. Alexis spoke about going on dates and to nightclubs, despite not really wanting to be there. Other women simply appear to get used to being on their own and find other things to fill their time. Gerri comments that because she has become so frustrated by people forgetting about her sensory disabilities, she has become somewhat of “a loner”, and has attracted pen pals as her preferred method of interacting with people.

For many women with disabilities this sense of isolation often carries over into public life. The issues with communication experienced by Mary and Eileen relate to both their private and public lives. The next section of this discussion explores the way that women with disabilities manage their emotions in public.

The authors of “Enhancing Self-Esteem in Women with Physical Disabilities” (2004) and “Loneliness of People with Physical Disabilities” (2006), agree that many health issues arise as a result of low self-esteem (Hughes et al., 2004:295, Rokach et al., 2006:682: and (Nosek et al., 2003:1738). These articles establish the link between the self-esteem and loneliness in women with disabilities and major health problems (Rokach et al., 2006:682 and Hughes et al., 2004:296). In short this suggests that when women

with disabilities suffer from loneliness because they do not have the confidence or are not encouraged to establish new friendships. The experience of loneliness is a painful experience and can have detrimental repercussions on their physical, emotional and spiritual wellbeing (Rokach et al., 2006:682).

## **Independence and Dependence**

Western societies highly value independence, competence, and autonomy. Many people with disabilities are dependent on others and are rarely seen as autonomous individuals. They are therefore considered and treated as “non-adults” (Priestley, 2003:119). Saviola adds to the argument with the statement that the “ability to deal with our dependency has ramifications for all our interpersonal relations, present and future” (Saviola, 1981:112). I suggested in the literature review that, as humans, we are all dependent on others at some stage throughout our lives—and it was clear when introducing the women who took part in this research that they all varied in levels of dependence and independence. While some of my participants live with family—whether it is parents and siblings or husbands and children—others stated that they lived alone. Despite their living situation, many participants indicated that they were dependent on others for day-to-day support. While the need for support varied amongst participants, all agreed that the support that they received contributed to their independence.

Although referring to people who acquire their disabilities later in life, Saviola makes the statement that because some people with disabilities,

have no direct control over their lives [they] can become apathetic and uninvolved and can develop attitudes of inferiority and incompetence,

which, in turn, complements the view of the able bodied that the disabled person is someone to be helped and cared for (Saviola, 1981:113).

This statement certainly applies to women who were born with disabilities. As Meekosha and Dowse (1997) contend, because women with disabilities are perceived as not having any domestic, familial or public responsibilities, they are trapped in a “unique space that hovers stateless, somewhere between the public and private sphere” which ultimately renders them a “burden in both” (Meekosha and Dowse, 1997:56 and Saviola, 1981:114).

In many ways this argument is a continuation of the cycle of negativity (Lee':2004). This is because when women receive messages about them being a burden on society, they are likely to assume that everyone else perceives them to be a liability and therefore, may show more concern to others by masking their “true” emotions.

Another point to be made here is that when women with disabilities learn to become independent they are required to learn certain “behavioural traits” that will assist them to achieve this independence. These traits teach women with disabilities to become assertive, aggressive and self-directing. However, and as argued by Saviola, these behaviors are difficult to accept in women with disabilities. This is because, generally, women with disabilities are not perceived as possessing power or autonomy. When they attempt to display any form of power, these “behaviour traits” are generally not accepted as being particularly good “behaviour traits” for women with disabilities to display at all (Saviola, 1981:115).

Susan Lonsdale makes a similar observation when she refers to the doctor/patient relationship—especially where the patient is a woman with a disability. Lonsdale makes

the point that when women with disabilities choose to assert their rights to independence, medical and other health care professionals view them as exhibiting “bad behaviour”, while compliance and passivity are perceived as “good behaviour” (Lonsdale, 1990:55).

The second half of this chapter focuses on the steps that women with disabilities take in performing emotions in public. I begin by sharing some of the participant’s thoughts on body image and self-esteem.

### **Body Image and Self-Esteem**

As already stated, issues of body image and self-esteem are not particular to women with disabilities. However, Saviola (1981) reminds us that it is the able-bodied world that determines what is or is not aesthetically appropriate and pleasing to society, (Saviola, 1981:113). Relating to this, Alexis, Roxanne and Hannah say that because they all have very prominent and visible disabilities, at some stage in their lives they have suffered body-image issues. Hannah says,

*My disability is physical and very visible, I walk with a leg brace, have skinny legs and arms but a plump middle. I do not fit with any idealised body image and could never hope to. My body is lop-sided – being stronger on the left, so I am kind of asymmetrical...I have always been scared to reveal my body, and particularly in swimsuits. I am aware of how my body creates discomfort in others.*

Similarly Roxanne says that when she was younger she was “obsessive” about her body image because of the way she walked. Despite becoming a little more relaxed about this, Roxanne says that she has moments where she is still conscious about her appearance.

In sum what Hannah and Roxanne are suggesting is that there are times where they are so conscious of the way they appear to others because of their disabilities that they go to great length to disguise their disabilities in the effort to “create a more acceptable image for others”.

Saviola, states that disability, or more aptly people with disabilities, are not considered pleasing, and that for the most part, an able-bodied society views disability as being “a regrettable condition”, expecting the “unfortunate” to “mourn, grieve and express suffering” (Saviola, 1981:113). Jen and Maudie both remarked that they are careful not to go on and talk too much about their disabilities or the attitudinal and structural barriers within an able-bodied society. Hannah adds to this by saying that, in general, the subject of disability is one that society rarely discusses or acknowledges in a positive way.

When people with disabilities do not behave in the way that society expects them to, they are perceived as “deviant”. Amy gives a good example of this when she identifies as being “gender-queer”. She comments that the assumption made by many around her is that being “gender-queer” is somehow symptomatic of having Autism. If Amy did not have an obvious disability, assumptions made about her sexuality would probably not be questioned or analysed in the same way. This is juxtaposed against the ideology suggesting that women with disabilities should be perceived as “being saintly” (Saviola, 1981:115).

In her study of people who have Cerebral Palsy, Sandström (2007) explains the concept of “reverse discrimination” (Sandström, 2007:435). Reverse discrimination occurs when what may be an everyday accomplishment achieved by a person without a

disability, when performed by an individual with a disability receives undue and excessive attention (Sandström, 2007:435). Such undue and unwarranted attention can at times hinder a woman from celebrating her own achievements in gaining her independence. Reverse discrimination is something that many women with disabilities experience. When women with disabilities make ordinary choices that are similar to what women without disabilities make, they are seen as “marvelous” and “brave”. Georgii relates to this when she says,

*As a child many of the adults around me would tell me what a ‘trouper’ I was, and I felt I had to live up to the standards they set for me. It never occurred to me to consider my own feelings as I felt that would be selfish, and hurt my family*

What is often misunderstood by people without disabilities is that many women with disabilities have the right to make choices about their lives. These choices include getting married and raising a family; choosing to live alone; having a career; obtaining a higher education, and even travelling overseas. These are ordinary life choices that anyone without a disability makes everyday, without the unending adulation *or* criticism that women with disabilities frequently receive.

### **Performing Emotion Work in Public**

Many women who participated in my study made the comparison between managing their emotions in the private and public spheres. The women agreed that the need to manage their emotions was very much dependent on who they were associating with at the time. Yasmine said that there are times when she would make a joke at her own expense, but again, she acknowledges that this is only with people that she knows will perceive it as a joke. Jen also says that in private she feels free to be herself, and

laugh as loudly as she wants to. This is in stark contrast to her public persona of having to demonstrate that she is “capable, intelligent and able to communicate”.

The central argument in Cahill and Eggleston’s article is that, when in public it is people in wheelchairs who assume the responsibility of not only managing their own emotions but also the emotions of others (Cahill and Eggleston, 1994:303). Cahill and Eggleston argue that people in wheelchairs do so by remaining “poised and good-humored” in situations of frustration, anger, and embarrassment, “without increasing the uneasiness of others” (Cahill and Eggleston, 1994:303). Similarly Women with disabilities are required to remain “poised and good-humored” in situations where they are being patronised, or told “how wonderful they are, and even when they hear that they “have a chip on their shoulder”. The need to remain poised also extends to being accepting of advice or assistance from someone who does not have a disability.

This is because according to Cahill and Eggleston people with disabilities can ill afford to “alienate the walkers who populate the public spaces they frequent” (Cahill and Eggleston, 1994:306). In other words, because there are times when people with disabilities need to rely on the assistance of strangers to assist them on random occasions, it is not in the best interest of the person with the disability to show their frustrations (Cahill and Eggleston, 1994:306). These random occasions may include needing a waiter to remove a chair from the table, assistance to get up on a footpath, and getting a grocery item from a high shelf (Cahill and Eggleston, 1994:306).

## **The Cost of Inclusion**

*I have had people look at me in absolute disgust when they realise they have to talk to me because I am sitting at the reception desk (Glenda).*

Glenda alludes to the point that because of her Dwarfism she is perceived as not being capable of assisting those who appear at her reception desk. This is a clear example of the different levels of respect between women with disabilities and their able-bodied counterparts. Women with disabilities who hold positions of authority frequently have to prove themselves over and above what the non-disabled person would. This would also involve higher amounts of emotion work because they bear the pressure of having to appear competent.

Maudie and Chantelle give clear examples of “non-person” treatment when they talk about being ignored by sales assistants, especially when they were with friends or family who did not appear to have a disability. However, Maudie is mindful that although she gets angry at times she is aware of the requirement to suppress her “righteous anger”. Maudie believes that anyone without a disability may be considered as being “well off”, because they are free from the day-to-day instances of discrimination that people with disabilities face. She is conscious that she does not “tell well off able bodied people how selfish and ignorant they are”. Maudie considers that her ability to suppress her emotions in public is paramount.

## **Simply Because We’re Women**

*[M]any men with disabilities have more opportunity than [women with disabilities] so perhaps might not feel so devalued and frustrated (Maudie).*

The final explanation that women with disabilities provide as to why they needed to perform emotion work is because they are women. Reflected in the literature review was the point that the disability movement has been largely influenced by men with disabilities (Mintz, 2007:5). As mentioned in Chapter One, this argument is reinforced when we consider Beck-Massey's (1999) argument that because disability has been named and objectified by men, women with disabilities are caught up in "the warp of male language" (Beck-Massey, 1999:272).

Despite not including men with disabilities in my research, I wanted to know whether or not the women considered that men with disabilities performed emotion work to the same extent as themselves. The responses to the question varied. While the majority of participants said that men do perform emotion work, there was no clear consensus on the *reasons* men performed emotion work. Jelena, Francis and Jodie agree that men with disabilities perform the same level of emotion work as women with disabilities.

Both Maudie and Chantelle thought that because there are obvious differences between men and women with disabilities, there would be differences in the way that they performed emotion work. However, Maudie hypothesises that because they are men, living in a male-centered society, that it is easier for men with disabilities to find acceptance. She goes on to suggest that because men with disabilities have more opportunities compared to women with disabilities, they "might not feel so devalued and frustrated".

Other women, including Glenda, Samantha and Georgii, surmise that men with disabilities may find it difficult to fit with the social construction of what it is to be a

man. Glenda suggests that it would be harder for men to express their emotions “due to the macho image” that men aspire too. Samantha suspects that

*[T]he social idea that men are physically and emotionally strong under all circumstances doesn't allow much expression in regard to their disability to take place.*

Georgii suggests that during the last century it was probably “harder” for men with disabilities than women because “they were supposed to be the tough breadwinners protecting the little woman from the real world”.

Despite having different opinions on what the differences of performing emotion work would be between men and women with disabilities they do agree that the differences are based on gender.

The objective of this chapter has been to demonstrate that women with disabilities do in fact perform emotion work, and that there are many factors that contribute to this necessity. Throughout these discussions I emphasised that many women with disabilities consider themselves as autonomous individuals who are worthy of equal treatment within society. However, and as demonstrated, there are many negative ideologies about women with disabilities that prevent this.

In discussing the cycle of negativity (Lee, 2004) it became obvious that negative ideologies are impressed upon girls with disabilities from a young age. As has been argued throughout my thesis, while some women manage to break the cycle of negativity, many cannot. Many women with disabilities grow up not knowing any different, and therefore are have not been able to challenge these negative ideologies or break free from the cycle of negative. While others who do dare to stand up and be counted are still met

with resistance. Is it any wonder then that there is a need for women with disabilities to perform emotion work?

## *Conclusion*

### **The Price We Pay**

The phrase “The Price We Pay” is intended to describe the amount of emotion work that women with disabilities must perform if they are to be perceived as competent equal members of Australian society. My hypothesis that women with disabilities perform emotion work was supported by the majority of the women who participated in my research.

Within the introduction of my thesis I discussed the concept of the cycle of negativity. While the cycle begins in the private sphere of the woman’s life, I argue that it gains momentum when the young woman with a disability begins to interact with the world around her. In chapter one, I argued that not only had the plight of women with disabilities been forgotten by feminism, but also denied by men with disabilities. The connection between this exclusion and the cycle of negativity is that, if women are being excluded by the very movements that are supposed to support them, it then sends the message that the issues of women with disabilities are not important—therefore it follows that women with disabilities may conclude that they are not important either. As discussed in chapters three and four, some of the participants acknowledged that performing emotion work was a part of their lives because of the way society perceived them, just because they were women who had a disability.

A number of the participants firmly believe that the way that society perceives them is associated with maintaining a good appearance. While some shared that by having a sound appearance they were able to feel more relaxed and confident in their interactions

with those around them; others said that maintaining a good physical appearance was also important because it is a reflection of their intelligence. Two of the participants indicated that having a good appearance was something they learned during childhood. As surmised in this section, if the women feel confident about the way they present themselves, they may not feel the need to perform as much emotion work; because they may be able see themselves as an equal to the person they are interacting with.

In the final Chapter I confirmed my hypothesis that women with disabilities do perform emotion work. This Chapter testified that for many of the women who participated in my research, performing emotion work meant more than “faking a smile”. According to the participants, performing emotion work involves monitoring, suppressing and pretending emotions. This implies that the women are conscious of how they are feeling, and of whether or not they need to (outwardly at least) change one emotion to another, depending on the kinds of interactions they are having. It was also clear that some of the women resisted the sentiment that they should be required to perform emotion work over and above what anyone else performed.

Much of my analysis has focused on the negative reasons that motivate women with disabilities to perform emotion work. Although many women with disabilities are performing emotion work for these reasons, many do so because they are living their lives to the full and as such yearn to be treated as rational, contributing, competent and equal members of Australian society. This is the price we pay.

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## **Emotions, Women and Disability**

### **Information Sheet**

#### What is this Study About?

This study on Emotion, Women and Disability is a relatively new field of research and seeks to explore the ways that as women with disabilities we are frequently required to express certain emotions or suppress others in order to 'fit in' with peoples as well as societies expectations. For many of us this is a skill we have developed and have used to prove to ourselves and other that we are credible and valued members of society.

#### Why are you being invited to take Part in the Study?

You have been invited to take part because you are a woman with a disability. The questions in this research are specifically tailored for a select group of women who were either born with a disability or acquired their disability before the age of three.

#### What Does Taking Part Involve?

The study has been developed so that you can participate online so that you can complete the questionnaire in your own time and return to my student e-mail.

#### Confidentiality and Assurances

Owing to the sensitivity of the information I am seeking for my research, this questionnaire does not ask for names – this has been done to protect your confidentiality and to preserve your anonymity. I assure you that you will have complete anonymity and security when participating in this research. Once the information is collected, the results will be reported in my Honours thesis, as a requirement for my degree. My thesis will not identify any woman taking part in the questionnaire.

This study has been approved by the University of Adelaide Human Research Ethics Committee. If you would like to speak to a person not directly involved in the

study, particularly in relation to your rights as a participant or to make a confidential complaint, please refer to the attached form.

### **Further Information**

If you have queries about the study, please feel free to contact either Margaret Charlesworth or Margie Ripper at contacts as listed below.

**Margie Charlesworth (Researcher)**

Discipline of Gender, Work and Social Inquiry

Email: [margaret.charlesworth@adelaide.edu.au](mailto:margaret.charlesworth@adelaide.edu.au)

**Associate Professor Margie Ripper, (Supervisor)**

Discipline of Gender, Work and Social Inquiry

Phone: 8303 5947

Email: [margie.ripper@adelaide.edu.au](mailto:margie.ripper@adelaide.edu.au)

### **Contact details return form**

All questionnaires responses may be returned to Margaret Charlesworth's University e-mail address (*as above*).

*Appendix Two*

Dear Participant

My name is Margaret Charlesworth; I am currently undertaking a study as a part of my Honours Degree in the Discipline of Gender, Work & Social Inquiry, at the University of Adelaide. My research project is titled “Emotions, Women and Disability. Please find enclosed a brief information sheet that describes the project.

If you are interested in participating, you can do so by using the attached questionnaire and return it directly to my student e-mail address which is [Margaret.charlesworth@student.adelaide.edu.au](mailto:Margaret.charlesworth@student.adelaide.edu.au). Please feel assured that your response will be private and confidential, as I am the only one who has access to this e-mail account. For purposes of writing my thesis the survey period will begin in March and will end by May 15, 2008.

I wish to thank you once again for participating in this research project. Regrettably I am unable to provide you with financial benefit for your participation. However I do hope that you might see my project as a positive way of understanding ways that we as women with disabilities manage our emotions.

Yours Sincerely  
Margaret Charlesworth

## Emotions, Women & Disabilities

1. Many women with disabilities feel that they need to pay special consideration to their overall appearance, such as gestures, facial expressions, and to showing strong emotions. Think about the questions below and please give some examples (stories) from your own experiences.
  - a. How do you relate to this? Do you feel that there are constraints on how you present yourself which would not be there if you did not have a disability?
  - b. Do you feel you that you are careful about how you come across to others? Can you talk about the ways that you control this?
  - c. What aspect of your disability do you think causes you the most need to constrain how you express yourself?
2. Many women with disabilities have also discussed the fact that they sometimes find themselves pretending emotions that they do not really feel in order to please others or to “fit in” with others expectations. Can you think of occasion where this has happened to you? Please describe.
3. Many women with disabilities have found that it is very emotionally draining to continually monitor the way they express themselves. How much (if at all) does this fit with your experiences? Please describe?
  - a. If not at all, can you think about and describe how you avoid this problem?
4. To what extent do you think that the experiences of men with disabilities might be similar or different from you in relation to the emotion work as you described in questions 1-3?
5. A bit about you
  - a. Please describe your disability?
  - b. Age at which you acquired your disability? Or age at which your disability was recognised?
  - c. Your age now?
  - d. Please describe your current living/home situation (who you live with and their relationship to you).
  - e. Please describe your living situation for the first twelve years of your life?

*Thank you for you candor and time.*

### Men, Disability and Emotion

While there were a few women who felt unable to answer the question, the majority of the participants did, and the responses were as diverse as they were interesting. While some simply left the question blank others commented that they did not know how to answer it. Faith made her contribution by stating,

*It's probably hard to speak from the perspective of a man, never having been one, and probably more authentic if men could be asked about these issues.*

While Chantelle says she has not “had much experience” of being around men with disabilities, she bases her answer on her high school experience of boys. She recalls,

*I do know from high school the boys seemed to be more relaxed than the girls. Though that could be just at my school I'm not saying that in general. But then boys do feel differently about these things than girls do.*

Despite having little to do with men, Chantelle's answer demonstrates that she believes that there are differences between men's and women's emotional experiences of disability. Maudie offers the suggestion that this may be because they are men, living in a male centered society, which makes it easier for men with disabilities to find acceptance. She goes on to suggest that because men with disabilities have more opportunities compared to women, they “might not feel so devalued and frustrated”.

Amy makes a similar argument when she states,

*[M]en operate in a significantly different emotional sphere and hold a far more privileged position in society. And that whether disabled or not, the emotional work that men do, would inevitably be differ [sic] to the emotion work done by women.*

However, Glenda, Samantha and Georgii argue that men who have disabilities would find it difficult to fit with the social construction of what it is to be a man. While Glenda

believes that it would be harder for men to express their emotions “due to the macho image” that men aspire to, Samantha surmises that

*[T]he social idea that men are physically and emotionally strong under all circumstances doesn't allow much expression in regard to their disability to take place.*

Whereas, Georgii sees that during the last century it was probably harder for men with disabilities because “[t]hey were supposed to be the tough breadwinners protecting the little woman from the real world”.

Hannah and Roxanne talk about there being less pressure on men to pay too much attention to their appearance but both women considered that there would be times when men needed to either suppress or pretend emotions. While Roxanne makes the suggestion that, “I imagine the teasing and bullying would be just as hurtful and emotionally draining”, Hannah writes,

*I have observed that men with disabilities seem to suppress much of how they feel when around people without disabilities. Some of them fear rejection in relationships, some of them try hard to be “jolly”.*

It is interesting to discover that three of the women spoke about protection and being “looked after”. Mary said she thought that men with disabilities had expectations that

*[T]hey will be looked after and it is expected that they will be in a relationship that should last. Whereas for women, it is “lucky” if they find a partner and even “luckier” if it lasts. This can cause women a lot of frustration.*

However, both Georgii and Glenda argue that many men perceive women with disabilities as needing to be looked after. In comparing men and women of short stature, and relationships, Glenda makes the observation that,

*Most women want a man taller than them for a partner. Women see men of short stature as mates only. On the other hand men see women of short stature as someone who needs protecting and looking after.*