DOCTORAL DISSERTATION

MEANING MAKING AT THE INTERFACE OF GENDER, DISABILITY, AND POLICY:

PHYSICALLY DISABLED WOMEN

IN LONDON AND COVENTRY, ENGLAND,

EXPLORE THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

by

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Abstract

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Heidi Bjorgan

Advisor: Professor Anna Stetsenko

Historically, persons with disabilities are socially, culturally, and economically underprivileged and neglected worldwide (WHO, 2006, 2011) and this is especially true of women with disabilities. The intersection between women's gender and their disabilities, although overlooked for many decades, has been described as the phenomenon of a dual handicap. The Convention on the Rights of Persons with Disabilities (CRPD, 2006) was created to protect the rights of all people with disabilities and, for the first time in history, identified women with disabilities as a population that has unique rights and needs that warrant special legislation and protection.

This qualitative study explores the lived experiences of physically disabled women living in England, while contextualizing them within the discourse on disability rights within the sociocultural and historical-political context (England). The lived experiences of physically disabled women are posited to be mediated by human rights documents as well as by political

discourses and practices that surround and accompany these documents. Framed in socio-historical cultural theory (Vygotsky, 1978) and Bakhtin's (1986) dialogical works, this study investigates how policy documents are meaning-making systems (Daiute, 2008, 2010) that shape and serve as the tools to organize and frame disabled women's experiences. Narratives collected through group meetings with 18 physically disabled women in London and Coventry, England, were first analyzed using a values analysis (Daiute, Stern, & Lelutiu-Weinberger, 2003) to understand the interactions between the CRPD and women's lives. Then a discourse analysis of group narratives and policy documents (Daiute, 2008) was conducted across the CRPD (2006) and the United Nations Convention on the Elimination of Discrimination Against Women (CEDAW, 1979) as activity- meaning making systems. Finally, a historical analysis of disability and gender within the UK and the UN was conducted.

The major findings indicate that the intersection of gender and disability is historically absent within UK and UN activity-meaning systems (Daiute, 2008, 2010) as enacted in the CRPD and CEDAW treaty. The values analysis revealed disability and diversity education at local levels (schools, councils, hospitals) and their own participation in local politics, specifically for Lambeth, with a high level of value expressions. Surprisingly, both groups given their right to have a family and a home took an opposing view to the CRPD values. Interestingly, both groups described social practices such as staring, being ignored by others as being issues within their daily lived experiences, but still provided a subjective view to Article 6: Women and Disabilities. The study suggests that there is a need for further research on disabled women's perspectives and experiences within the discourse of human rights in order to develop socio-political practices that support rather than isolate disabled women.

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Introduction

This study explores the critical perspectives and experiences of physically disabled women in England. Drawing from the central tenets of socio-historical cultural theory (Vygotsky, 1978) and Bakhtin's (1986) theoretical works, my aim is to investigate how physically disabled women's experiences in England are created through cultural practices and situated within their social, cultural, political, and historical contexts rather than, as it were, under the skin of each individual woman. This work suggests that gendered experiences of disability are mediated by cultural tools (e.g., policy documents). In this dissertation I explore how rights based activity, such as a policy document, mediates the women's local discourse practices and how the women influence the activity of policy making. I argue that both women's and disability rights are a powerful lens through which to address the multiple forms of discrimination that disabled women face. This work hopes to advance an intersectional analysis of the human rights treaties affecting women and persons with disabilities that will lead to their being implemented together. This notion explores the dynamics of dialogical practices situated in broader social, cultural, historical, and political contexts where meaning making (dual handicap) is formed through women's lived experiences.

This research will utilize the theory and method of narrative inquiry (Daiute, 2004; 2008) to present a dialogical account of how physically disabled women may make meaning through the context of their human rights. Political discourse concerning women with disabilities rarely includes the voices of women themselves. Therefore, I am motivated to examine how physically disabled women locate themselves in their political narratives. Understanding that "political identities are 'always, everywhere relational and collective'; even

when they are articulated by individuals, they are always socially embedded" (Tilly, 2002, p. 61 cited in Andrews, 2007).

This study posits that it is crucial to understand the impact of both policy documents as cultural tools and the way they mediate local social and cultural practices regarding women and disability. My argument is based on an examination with scholars and rights workers belief that women's lived experiences are influenced by policy and therefore the practical application of these policies must be fully participatory and inclusive of people with disabilities (Ingstad, 2007; Kitchen, 2000; Lord, 2002; Marshall, Kendall, Catalano, & Barnett, 2008), specifically and purposively including the affected women as the most marginalized group. This research reaches significance by including, supporting, and engaging physically disabled women's understanding of the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD, 2006) and their own political positions within the creation and implementation of United Kingdom (UK) policy. This research intends to guide and foster self-advocacy skills for the women participants, promote an understanding of their political rights, and form a stronger community of resources. This research takes the position that members of the London and Coventry communities have much to gain from the active participation of women with physical impairments, and their historically marginalized perspectives can be a powerful tool towards further understanding of the United Kingdom's disability rights dialogue (Lord, 2002) and in a comparative light worldwide.

Methodologically, this research will follow a qualitative approach using discussion groups in which the researcher and physically disabled women are simultaneously the subjects and objects of the study (Chappell, 2000; Kitchin, 2000). First, through discussion group meetings, narratives were created exploring the intersection between the participants' lived

experiences as both women and disabled within their socio-historical political experiences. Second, I analyzed the intersection of disabled women's rights in the context of two human rights documents; The United Nations *Convention on the Elimination of Discrimination Against Women* (CEDAW, 1979) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD,) using a discourse analysis approach. This approach highlights the specific words within both human rights documents, illustrating the discourse and tensions within and between documents, conceptualizing women and disability rights. This analysis provides an understanding of how the CEDAW as an activity-meaning making system has historically influenced the current CRPD activity-meaning systems (Daiute, 2008) for physically disabled women in England. The third level of analysis follows Daiute's (2003) work on values based on the socio-cultural approach to human development. This work examined the participant's group discourse and the guiding values that are contextualized with the CRPD articles. The narratives of women were analyzed for experiences against the landscape of broader, social, cultural and institutional contexts.

Finally, I compare layers of socio-cultural historical political movements and policy within the United Kingdom, the British disability Social Model movement, the British women's rights movements and the United Nations work. All inquiries will be framed in a socio-cultural historical perspective (Vygotsky, 1978) and Bakhtin's theoretical works of language, which shift the unit of analysis to the dialogical relationships with physically disabled women interacting with their situated and contextualized figured worlds (Holland, D., Lachicotte, W. & Caine, C., 1998). Drawing on concepts developed within the cultural-historical activity theory, (Andrews, 2007; Bamberg, 2004; Daiute, 2004, 2008, 2010; Solis, 2004), the dynamics of interactive positioning theory (Brockmeier & Harre, 1997; Davis & Harre, 1999; Harre & van

Langenhove, 1991; Harre & Mohaggadam, 2003), and addressivity (Bakhtin, 1986) towards explicit audiences such as the participants and their peers. This work also examines the hidden audiences such as international, national, and local governments' historical and contemporary policies, medical bureaucracies, and socio-cultural beliefs regarding women with disabilities. In line with positioning theory, the dynamics of power relationships within the processes through which persons' experiences are created and constructed through social interactions are highlighted.

Rationale

This study engages physically disabled women's in interpreting and interacting with the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD, 2006) so as to explore their understandings of their own values and political positions in regards to that document and the world which they inhabit. This approach is important because it positions the disabled women as major actors within the contexts and practices in which their ritht6s are at stake. The broader rationale is to guide and foster self-advocacy skills for the women with disabilities, help promote an understanding of their political rights, and improve and strengthen the resources available to them.

Following a number of difficulties and arduous negotiations, gender was included in the 2006 Convention on the Rights of Persons with Disabilities. Up until this point, there was a disconnect between legal policies concerning gender-based discrimination and disability-based discrimination, despite significant developments in both fields. Therefore, I contextualized this research within the CRPD (2006) to further explore and connect the gender perspective with disability human rights work and to acknowledge that gender complicates the experiences of disability. Through exploration of disabled women's narrative, this information will provide a

greater understanding of disabled women's human rights discourse and practices. This could be one step in the process of an opportunity triggering major shifts in mindsets, social structures, public intervention and legislation including through drawing attention to the need for a broader use of the CRPD as an invaluable political, social and legal instrument for promoting the rights of disabled women.

This research was conducted in England for two specific reasons. First, the United Kingdom (UK), was one of the first countries to sign the United Nations CRPD in 2007. Thus, England was chosen because it represents the context in which social, discursive and dialogical practices at the intersection of disability, gender and human rights have been already established and carried out. In addition, since the discourse surrounding the CRPD was still fairly recent, this opened up the possibility to explore how disabled women made sense of their experiences contextualized through innovative human rights work.

In contrast, since the creation of this document, President Obama had committed the U.S. as a signatory of the CRPD in July of 2009, but Congress has not yet ratified the convention. Therefore, the CRPD is not a legally binding document within the U.S. even though the CRPD closely connected with the frameworks of the U.S. federal disability civil rights laws, such as the American with Disabilities Act (ADA, 1990, 2008) and the Civil Rights Act (1964).

The second reason I conducted my research in England, is that since the 1970s, England specifically has had a strong disability rights movement, which has led to what is termed the Social Model of Disability, also referred to as "the Big Idea" of the British disability movement. The British social model of disability is the ideology that governs and organizes the academic and political disability discourse within England, socially re-constructing the

meaning of disability over the last 30 years. In addition, since the late 1700s, England has had a robust women rights movement. This history is important because it situates the disabled women in established cultural practices and discourses that affect their daily experiences and meaning making processes.

This dissertation bridges these gaps and expands on the existing disability studies work by focusing on women with physical disabilities and their experiences within the context of human rights in England. The study will reveal (a) how social-cultural historical beliefs, values, and silences in policies and practices are related to physically disabled women's experiences; (b) how physically disabled women make meaning around the discourse on their rights and co-create social-political perspectives; and (c) how women position themselves and others when co-narrating their lived experiences. To achieve these goals, I review literature from the British social model literature; earlier narrative work conducted by disabled women; British policy specific to gender and/or disability; and the British feminist rights movements. I develop and draw together ideas from sociocultural-historical theory and Bakhtin's theoretical works on language, narrative analysis, and positioning theory to present a broader dialogical approach between the social categories of gender, disability and policy work.

Research Questions

These following research questions address the lived experiences of physically disabled women and the intersection among gender, disability, and policy.

1. How do women with physical disabilities understand and make meaning of their lived experiences through the lens of human's rights document of the CRPD? What is the nature of physically disabled women's discourse across the CRPD activity-meaning system (Daiute, 2008)?

2. How is the concept of dual handicap socially, culturally, and historically constructed? How do participants position themselves and others within their personal and political narratives? To whom do they address their narratives?
3. How does a history of United Kingdom's policy documents and disability social and cultural practices, the British disability and women's rights movement and the United Nations documents influence physically disabled women's political discourse and local social, cultural practices?

Chapter 1 discusses the need for an interdisciplinary approach to this research, the literature review, and the theoretical perspectives used within this research. Chapter 2 includes the design, methods and rationale for using multiple analyses.

The four subsequent results chapters contain data that address how meaning making is made for disabled women within the context of their human rights; they are divided according to broader social, cultural, historical interactions within and among groups and individual relative to a broader political system, as suggested in cultural-historical activity theory. Chapter 3 provides a historical-to-contemporary overview of the broader activity- meaning making systems which may have influenced local socio-political discursive practices within Britain and the United Nations for disabled women. As theoretically and methodologically elaborated by Daiute (2008), these activity systems include, but are not limited to, larger socio-political movements such as, the Industrial Revolution, World War I and II, with local socio-political movements such the First and Second Wave Feminist movement and the Disability Rights movements within Britain. The purpose of this chapter is not to provide an exhaustive historical explanation. Instead, the purpose is to highlight the broader interactions and tensions within activities which encapsulate historical and continuing relations of political, material, and

social inequality and stigma (Cole, 2009; Daiute, 2008, 2010) as contextualized through human rights for disabled women. Towards these ends, this chapter presents an analysis of the broader CRPD activity systems, especially in relationship to disabled women's rights based understanding situated within England. Findings suggest that within the broader sociopolitical systems, activities (e.g. feminist social movements) remained bounded to specific social categories (gender) and did not intersect with the social category of disability, within and across history. Ultimately, women's rights-based understanding across activities did not intersect with disabled person's rights based understanding. As a result, this analysis offers insights about the complex nature of defining disabled women's rights.

Chapter 4 extends from the historical overview and looks specifically at the activity-meaning making systems of policy documents. Through a discourse analysis approach, following Daiute's (2008) methodological and analytical insights, I reviewed the broader interactions and activities leading up to the CRPD activity-meaning making system. Then I provided a discourse analysis within and between two relevant United Nations policy documents, the CEDAW (for women) and the CRPD (for disability). The purpose of this analysis is to gain further understanding on how the two documents address one another by analyzing language within context of both documents. Findings suggest that the values and principles within each document do not link together and neither document expresses characteristics of a sociopolitical discourse that makes meaning for disabled women regarding their human rights.

Chapter 5 examines how the women participants valued the CRPD articles during their co-constructed narratives during discussion groups. Following Daiute et.al., (2003) work, I used the socio-cultural theory of values defined as, "culturally specific ways of knowing,

feeling and acting in response to environmental, economic and social circumstances" (p. 85). Using the relational positions analysis approach, this chapter describes how the women participants interacted with their rights through their lived experiences and local discourse practices. This chapter highlights the analytical move from a larger international and national context, or rights-based activity, to the local level, situated in London and Coventry, and how these two frames of reference interact. Finding suggest, that there are important differences across Lambeth and Coventry's social, cultural and political lives- differences that influence their meaning making of the participants' human rights. In addition, there were surprising similar tensions across both groups regarding the interaction with issues of being a mother as a physically disabled women.

The concluding Chapter 6 provides the discussion, findings, significance, and considerations of this work and suggestions for future research. Here I examine the long term implications of meaning making for disabled women with the context of their human rights understanding in Coventry and Lambeth, England, as well as the relevance of such implications towards the intersection of human rights documents for disabled women's protection. Also, I consider the future research that further integrates sociohistorical activity theory with discussion groups to create collaborative discourse at a local level to connect disabled women's rights based discourse with broader policy documents activity-meaning systems.

For the remainder of this chapter, I present literature describing the intersection of disability and gender work– primarily in the United Kingdom but also to some degree in the United States– that conceptualizes the term *dual handicap*. The first two sections, Feminism and Disability and the Social Model and Feminism, purposefully highlight only one specific social category (either disability or gender) at a time, creating a deeper conceptual

understanding of how categories of rights and categorical social movements overlap, intersect, and can mutually reinforce and depend on each other. I highlight the importance of how different social movements must come together at these points of intersection (gender and disability) in order to create a more inclusive form of human rights practice that is necessary and sensitive to disabled women's lived experiences. These sections highlight how each social category depends on the other for meaning, despite the obvious fact that every individual necessarily occupies multiple categories (e.g., gender, disability, race, and class) all at the same time (Cole, 2009). For example, King (1988) showed that major U.S. social movements organized on the basis of race, class, and gender failed to consider the intersection of these categories in their political analysis. Consequently as an overall outcome, the "interests of those who experienced multiple forms of subordination (e.g., Black women, working-class Blacks) were often poorly served" (Cole, 2009, p. 170).

Therefore, this work does not make the same mistake and explores how both gender and disability interact with another for meaning within the context of human rights. The concluding section follows de Silva de Alwis (2009) work, which argues for a "shift in the human rights paradigm that enables the different human rights treaties affecting woman and disabilities to be implemented together, creating an intersection of human rights framework" (p.293). The overall goal is to advance an intersectional analysis of the rights of women with disabilities and provide a more inclusive use of human rights work to insure the necessary safeguards for disabled women. Here, I provide a brief overview of two UN human rights work (CEDAW and CRPD) and the activity-meaning making systems that lead up to them. Then I provide an introduction and examples on how articles from both documents intersect and provide a rights discourse for disabled women. Within the theoretical sections, I develop and draw together

ideas from socio-historical theory, narrative analysis, and positioning theory to present a greater understanding of the interaction of gender and disability within a human rights context.

CHAPTER 1

LITERATURE REVIEW AND THEORETICAL PERSPECTIVE

Intersecting Women and Disability: Dual Handicap?

I am a disabled woman now. Two strikes. I'm almost out?

You have to find the able parts of the disabled woman. (Rogovsky, 1991, p. 49)

International research has shown that women with disabilities have chronically and historically been perennial outsiders and positioned by society as doubly disadvantaged- both by being a female and with a disability (Asch & Fine, 1988; Emmet & Alant, 2006; Garland-Thomson, 1997; Linton, 1998; Meekosha, 2006; Morris, 1991; Thomas, 1999; WHO, 2006, 2011). Often disabled women face what has been termed *dual discrimination* in work, education, and politics, and a variety of economic and social measures have worked against them (Asch, 1984). Seemingly, societies' understanding and negative reactions to both disability and gender create societal beliefs that are profoundly discriminatory and result in less favorable experiences. It is clear that Elliens 1984 assessment still largely holds true, "the needs of disabled women have been largely unidentified and unexplored" (p. 10).

This research examines how the intersection of gender and disability operates, structures and reproduces inequalities, through multiple oppressions, as termed 'dual handicap'. Vernon (1999) offered the term 'multiple oppression' to describe an individual being stigmatized with more than one imposed identity (e.g. gender and disability). She stated that "Multiple oppression refers to the fact that the effects of being attributed several stigmatized

identities are often multiplied or exacerbated and they are usually experienced simultaneously and singularly depending on the context" (p. 395). These intersecting identities can weave a web of complexities when negotiating lived experiences while enacting both roles and the nature of oppression on a daily occurrence.

The term intersectionality was first introduced in the 1990's by critical race feminists, whose seminal works introduced the "intersectionality" model. Crenshaw's (1991) work illustrated the inadequacies and countered essentialist beliefs, illuminating the fact that everyone will stand at multiple intersections, with various disadvantages or discriminations that result from these identities at any given point. These counter beliefs to essentialism argued that women cannot be defined by one single identifier but rather their identity is shaped by multiple characteristics and experiences (Crenshaw, 1991). This work uses intersectionality as an analytical tool for "studying and responding to the ways in which gender intersects with other identities and how these intersections contribute to unique experiences of oppression and privilege" (Symington, 2004, p. 2).

Using this intersectional perspective encourages moving away from binary thinking to an understanding that the conception of disability interacts with other conceptions of gender and one cannot be reduced from the other category. Given these intersections of identities, the disadvantages women with disabilities face are often amplified by multiple factors such as race, poverty, minority status, and social status (Banks, 2007, 2010; de Silva de Alwis, 2009). Although research in the United States has been conducted and examined on how the intersections of race and social class (Anderson, 1990; Liebow, 2002), disability and race (Stuart, 1992, 1994; Hill, 1994), and how gender and race (Collins, 2000a,b; hooks, 2000) operate to structure and reproduce inequalities, very little has been articulated about the

experiences between gender, disability and race (Peterson, 2006). This research will not explicitly address this perspective due to the dearth of research and analysis needed to provide a possible understanding of this multidimensional nature of oppression. However, it is noted and agreed that more research needs to be conducted in the way of theorizing on how gender and disability intersects with race (Thomas, 1999; Petersen, 2006).

In the industrialized countries, data shows that disabled women are, in general, "more disadvantaged than men with disabilities, with indicators for income, education, employment and social assistance showing consistent, although not always large gender differences" (Emmet & Alant, 2006, p. 447) and a small difference in income for disabled women will have profound implications for households in general. As Pokempner and Roberts (2001) argue that disabled women are especially vulnerable not only because of their weak positions within labor markets, but also because within the highly skewed distribution of domestic labor most of the responsibility for parenting and caregiving falls on them as well. According to Emmett and Alant (2006), beginning in the late 1990's, most of the major international development agencies have placed disability on their development agendas (e.g. USAID, 1997; European Commission, 2003). These developments prompted the United Kingdom's Department for International Development to declare that "eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account" (DFID, 2000, p. 1). Although, there are relationships between disability and gender development, it needs to be noted that the human rights discourse surrounding the intersection for disabled women did not occur until roughly 2006. Later in this chapter, this will be further discussed when reviewing the intersections gender and disability representation within the context of human rights.

The overview of the qualitative writings intersecting both gender and disability began in the early 1980's and is primarily conducted by women from the United Kingdom and the United States. These noted works illustrate for the first time how feminist writers critically engaged with the disability discourse in the areas relating to gender-specific violence, traditional social and cultural practices and economic structures which shapes all women's daily lived experiences. This section will provide an overview of key writings by disabled British and American women demonstrating the engagement between feminist and disabled feminist. As noted, these works illuminated and helped to inform disabled feminist writers today but is still a work in progress.

Literature regarding women with disabilities demonstrates diversity, crosses disciplines and policies, and is often interdisciplinary by the nature of intersecting both gender and disability. Beginning in 1981, an influential book titled *Images of Ourselves*; a British anthology was written by Jo Campling. This work was based on 23 women with disabilities describing their lived experiences of being both female and disabled. This new genre of writing connected public discourse with the private lives and stories of British women with disabilities. In the same year, one U.S. feminist journal, *Off Our Backs* (1981), devoted a whole issue to women with disabilities and later the same year the *Journal of Sociology and Social Welfare* published an issue devoted to the theme *Women and disability: The Double Handicap.* This particular issue included a cornerstone article by Fine and Asch (1981), titled *Disabled Women: Sexism Without the Pedestal.* Fine and Asch's work is particularly noted for their conceptualization of women and disabilities as "roleless" in society. This term was created from their qualitative and anecdotal findings that disabled women had limited social roles available for them within their local communities. In addition, there is also an absence of

institutional means to achieve valued adult roles compared with women without disabilities. This work exposed the social cultural beliefs that women with disabilities were unfit to fill the traditional gendered roles of mother, wife, homemaker, nurturer or lover (Fine & Asch, 1981). This work provided valuable insights into the restricted social, cultural and economic options during the 1980's for disabled women.

In 1983, the *Journal of Visual Impairment and Blindness* produced a special issue dedicated to the situation of disabled women as described by Asch and Fine (1981). Two years later, *Our Bodies, Ourselves* (Boston Women's Health Book Collective, 1985) was published in the U.S. This body of work was an attempt to reach as many readers as possible and was written in a style that was accessible to all women. The authors emphasized respect for every human body as well as individual women's experiences, however diverse their experiences and social location (Davis, 2002). This socially and culturally progressive book drew in different groups of women readers and incorporated a disability perspective into sensitive issues in detail to the concerns of girls and women with disabilities (Asch & Fine, 1998) such as reproductive technologies. Chapters written by disabled women included topics regarding the moral dilemma between disability rights and reproductive rights. Specifically, how women with disabilities were believed to be asexual and as a consequence, education and access to birth control, understanding of consensual sexual experiences and the possibility of having children were limited. Unfortunately, there are only scattered accounts of motherhood as experienced by women with disabilities. The few available resources at the time found that 25 percent of women with disabilities had their children removed from their care (Whitman & Accardo, 1990).

In 1991, Jenny Morris wrote a book titled *Pride Against Prejudice: Transforming Attitudes to Disability*. This work was the first of its kind within the United Kingdom to reflect on disability from a feminist perspective. Within the United Kingdom in the late 1990's, a body of qualitative work intersecting women and disability experiences, were authored by disabled women themselves. Jenny Morris pioneered the exploration into the intersection of gender and disability within the UK literature. Morris (1998) presented a paper in Sidney, Australia, titled *Feminism, Gender and Disability;* she discussed her own social, cultural, and political experiences. She wrote and spoke about her experience first as a feminist and then later in her 30s, after an accident, as a disabled feminist.

Morris described:

> *..she was plummeted into a new experience of social exclusion, I soon realized that there had been no room within either feminist ideas or the women's movement for disabled women and that some of the views I had taken for granted were, in fact, highly questionable from my new standpoint—or at least from where I was sitting. (p. 17)*

Morris (1998) asserts that there has been little analysis with women and disability and she feels uncomfortable supporting the term of 'dual handicap' or double discrimination. She believes that supporting these conceptions further victimizes disabled women stating:

> *I always feel uncomfortable reading about our lives and concerns when presented in these terms. I feel burdened by disadvantage and I feel a victim-such writings do not empower me. As disabled women, we have to find a way of making our experiences visible, sharing them with each other and with non-disabled people, in a way which-while*

drawing attention to the difficulties in our lives-yet does not undermine our wish to assert our self-worth. (p. 5)

Shortly thereafter, Carol Thomas a non-disabled woman from the Centre for Disability Research from Lancaster University, wrote *Female Form: Experiencing and Understanding Disability* (1999), in which she collected personal accounts of disabled women. Through letters, self-recorded tapes, and interviews, these women shared with her their personal experiences in an attempt to demonstrate some of the wide range of gendered experiences faced by women of varying ages, impairments, and social circumstances. Thomas highlights that the disabled women's narratives ultimately "inform us very powerfully about the intersection of disability and gender, as well as about the significance of impairment effects, in the fabric of individual lives" (p. 85).

As reviewed above, research regarding physically disabled women remains largely descriptive and anecdotal and comes almost completely from the writings of physically disabled women themselves. Carol Thomas (2006) explains that disabled feminist researchers writing about disability experiences in the United Kingdom are concerned about theoretical underpinnings. In contrast, women write to explain the notable lived experiences of women intersecting with the multiple dimensions of disability. Some women speak of anger and bitterness of the isolation, despair, poverty, and powerlessness, while others celebrate achievements, strength, happiness, and fulfillment despite their struggles.

Although research in this area is relatively new, the UK writings over the last 20 years have provided research-based information about the social, economic, and psychological circumstances of women with disabilities. Their work is extremely relevant and pertinent to understanding a specific standpoint, but the reality remains that qualitative or quantitative work

relevant to the intersection of disability and gender with physically disabled women is limited in scope and often presents a victim or deficit representation of disabled women. As previously discussed, more information is required regarding the perceptions and experiences of the women themselves. The next section examines the literature that takes a deductive approach and will examine the cumulative impact on disabled women being ignored by both the British mainstream feminist movement and British social model.

Intersecting Feminist work and Disability

> *For the disabled feminist, neither the disability movement nor the women's movement fully addresses her concerns… we must educate both movements in the issues specifically affecting disabled women, especially since the women's movement has shown a willingness to learn about the issues affecting women and dual identities.. (Blackwell-Stratton et al., 1988, p. 307)*

The relationship between feminist disability studies and mainstream feminism in general is an uneasy one. Women with disabilities have historically been ignored by the second and third wave feminist movement. The 1970's United States and United Kingdom women's movement tended either to ignore disability completely or actively distance themselves from disabled women (Thomas, 2006). Later in the 1980's and early 1990's, disabled feminists found themselves "shut out" of the wider feminist movement (Thomas, 1999). Generally, feminist with disabilities have criticized feminist scholarship for excluding the experiences of women with disabilities from feminist analysis (Fine & Ash, 1988; Hammaford, 1985) and larger socio-political movements.

In response, disabled feminists such as Jenny Morris (1991, 1993, 1996) advanced strong criticisms of these exclusions from the feminist's movement. For disabled women, this was significant and discussion began about issues such as care, abuse and the right to reproduce and parent (Meekosha & Shuttleworth, 2009). Currently, feminist researchers are writing about the gendered realities of daily living with disability and impairment. Nevertheless, the research agenda remains a long and complex one (Thomas, 2006), with feminist disabled writers and research having minimal impact.

Despite the women's rights movement's over the last 50 years within western cultures, advocacy towards positive changes for women with disabilities has been ignored by the feminist movement. Even feminist scholarship that has attempted to incorporate other diversities of women experiences based on race, class, sexual orientation, body image and other social dimensions has excluded disabled women. Martha Banks (2010) extends these points into the field of Psychology and states that "traditional feminist psychology has seldom considered the influence and impact of disability on women's lives. Ableism continues to be a covert, but still detectable and powerful, force in feminist psychology" (p. 432) and considerations based on biases related to disability add to the possible complex needs of clients. Interestingly, Banks (2010) notes that sometimes women do not "identify with a particular cultural group, nor do they perceive the issues they face as specific to being women" (p. 431). Feldman and Tegart (2003) found similar results with the impact of multiple marginalization's that sometimes result in lack of development of disability identification. These findings resonate with the results of this work conducted in England with physically disabled women.

Feminists with disabilities have criticized feminist work for excluding these experiences and perspectives from feminist analysis (Fine & Asch, 1988; Hannaford, 1985; Morris, 1996; &

Meekosha, 2002). One example in the UK during the 1980's and 1990's was feminist research on the "community care" developments in health and social care systems (Thomas, 2006). This feminist work strongly objected to the British Government's extension of community care, arguing that these unpaid services are women caring for family members. Unfortunately, many UK feminists identified entirely with the interest of women only and completely ignored the interest of the disabled or older women that need to be 'cared for' by others. Ultimately this oversight reinforced prejudicial ideas about disabled people being dependent burdens (Thomas, 2006) and separated feminist from disabled feminists.

Narratives of disability and gender have been one way in which disabled women have sought to fashion spaces in which they can be heard. This need for further information comes through in Thomas' (1999, 2001) narrative based work with disabled women. These women spoke about gender norms that make up their social worlds, demonstrating full, conventional pathways. Thomas (2006) identifies how the disabled women constructed their narratives using explicit or implicit reference to public discourse about "what it means to be a woman" (p. 178). Here the women describe through their narratives around the themes of partnerships, motherhood, family, household responsibilities and caring, demonstrating prominent gendered positions and practices.

Furthermore, feminist work quite legitimately decries the sexual objectification of women throughout multiple contexts such as work, universities, and home; women with disabilities are often viewed as asexual. As an American women psychologist, Banks (2003b) notes that "Women with Disabilities are often discouraged about being able to enter meaningful and satisfying romantic relationships with others" (p. xxxi), which supports earlier conceptualization of "rolelessness" by Fine and Asch (1998). The body is then reduced as

being perceived as being helpless, childlike, dependent, needy, victimized, and passive. They further suggest that "…non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent, and appealing female icons" (p. 4). Unfortunately these beliefs can create a social invisibility and cancellation of roles, making it difficult for disabled women to claim the female identity that the culture denies them (Garland- Thomas, 1997).

Banks (2010) notes that within the Psychology of Women Quarterly journal there are "few articles here that directly address disability" (p. 437) and more work needs to be conducted and published. Much can be gained from understanding disability through feminist research and theorizing on the social position of women. Feminist within England have been engaged about the nature of 'oppression' or intersectionality and social disadvantages of marginalized and excluded people for much longer than disability theorists and writers. The history of the Women's Movement into Second Wave Feminism has been written and invariably discussed (Thomas, 2001), whereas the younger disabled people's movement has only recently begun to be documented (Campbell & Oliver, 1996). It is feminist writers and activists within the disability arena that have called attention to the intersectionality work that still needs to occur. I will now further describe the development of the UK Social Model of Disability intersecting with disabled feminist work and the interaction with disabled women.

Intersecting the Social Model of Disability and Feminist Work

Over two decades ago, Marian Blackwell-Stratton and her colleagues argued that "For the disabled feminist, neither the disability movement nor the women's movement fully addresses her concerns… we must educate both movements in the issues specifically affecting disabled women, especially since the women's movement has shown a willingness to learn

about the issues affecting women of dual identities… "(1988, p. 307). This statement is still relevant and critically important today as Meekosha (2002) suggests that neither the feminist scholars nor disability movements have seriously ever drawn the two social movements together.

Even though the Social Model of Disability analyzes the interaction between bodies and their social and material environments, traditionally this work has not examined the intersection of gender and disabilities. The central idea of the Social Model is that the word disability is socially constructed related to stereotypes, values and practices of communities of oppression. The word impairment is separate from the social cultural values and specific to the body only (Oliver, 1996, Barton & Oliver, 1997; Thomas, 1999). These distinctions help identify the discriminatory social barriers and socio-cultural practices of disability and the personal experiences of an impaired body.

Feminists with disabilities have complained about its male domination and male orientation (Blackwell-Stratton et al., 1988; Deegan & Brooks, 1985) and feel that the disability movement has often directed its energies toward primarily male experiences. Jenny Morris (1993) agrees that there are environmental barriers and social attitudes that disabled the person, but to also identify the personal experiences of the women's body. That a feminist perspective can provide an understanding of both the disabled men and disabled women's experiences. The leadership of the disabled people's movement in Britain has been male dominated as both theorists and holders of important organizational positions (Morris, 1991); failing to understand the some experiences of disability as specific to gender, relating to the female body.

The narratives of disability and gender described have movingly detailed body/mind, spiritual and political struggles, but while they have constituted a background of disabled

women's lives and have helped create a community, still these works show a limited engagement with broader disability or feminist theorizing, especially with a gendered, disabled body. This research aims at providing and giving authority to the disabled women regarding the social, cultural and historical beliefs between the impaired body and gender.

Women with Physical Disabilities: The Body.

"Women have long been defined by our biology" (Birke, 1999, p. 1).

This section describes the multiple parallels and differences that exist between the social, cultural and historical meanings and discourse attributed to female bodies as those assigned to impaired bodies (Garland-Thomas, 1997). Feminist concerns with the body have encompassed heterogeneity of discourses and issues and since the Second Wave feminist movement; the debates have emphasized the body as the major site for ideological contestations. Disabled, gendered bodies within this discourse still remain relatively unexplored as a broad sociopolitical critique of systemic, inequitable power relations based on social categories grounded and centered in the body (Garland-Thomas, 1997). This research follows the belief that the female body cannot be understood as simply biological or bounded, but instead represents oppressive social relations (Hughes & Paterson, 1997; Corker & Shakespeare, 2002; Wendell, 1996; Meekosha, 1998). Understanding that all bodies are socially, culturally and historically constructed has been extremely useful for this work. Given these beliefs, this work highlights a group that has traditionally been overlooked, physically disabled women. For these reasons described, the participants within this research are specifically women with physical disabilities; while centering the body, national ideologues intersecting gender and disability can then become explicit discourse further understanding the

conception of the disabled gendered body. Gendered and disabled bodies are fundamental to contemporary social analysis for they offer a site for examining the major social, cultural and political tensions and contradictions.

Feminists have made important claims about the processes of cultural inscription and representation on the surface of the body (Birke, 1999). Feminist discourses demand that the body should be seen as a sexed body, that the subjective experiences of sexuality, of child bearing and rearing are legitimate and affirmed. Acknowledging personal experiences and taking bodily control within a political context became central to the revived Second Wave Feminist movement. Bodily control, reproduction and sexuality are all part of the disability experience, even if ignored, violated or denied (Shakespeare et al., 1996; Meekosha, 1998).

Although there are similarities between feminist and disabled feminist work, there are still significant differences. Susan Wendell (1996) extends this argument to the biological reality of the impaired body and the social construction of the disabled body as being different than the privileged women's abled body. This difference in experience is difficult to identify because the biological women's body is in a complex interaction with their social, cultural and historical environment. Therefore, a theory which "posits biology as a fixed, passive and not transformative entity will inevitably support a constructed deterministic submissive political body, thus creating socio-cultural medical practices that fail women, specifically women with disabilities" (Birke, 1999, p. 157).

Interestingly, autobiographies have been used as a qualitative approach to express disabled women's bodily experiences. For example, Shilling (1993) and Linton (1998) described in their autobiographies the forms of representation used to narrate how their bodies work and in turn how they as disabled women "live our bodies". Both women express the point

of view that language, when related to impaired body, is inherently based on biomedical terms. This language fundamentally reduces the disabled body to fractioned parts. Ultimately, the body is "affected by discourse, but there is little sense of the body reacting back and changing this discourse" (Shilling, 1993, p. 5). As a result, disabled women must then defend the assessment of their bodies as unfit for common gendered roles, such as motherhood (Garland-Thomas, 1997).

Although feminist work is abundant with reproductive care rights, the discourse between the disabled body and their doctors ultimately creates a medical, fragmented body in isolation. A place where women need to prove they are fit to have children. A conceptualization of the body that becomes dismembered as "bits, a set of building blocks, and then society and medical community can coerce people to just remove some of those parts" (p. 171), this ultimately creates a disconnected self and body. Likewise, Hawkesworth (2001) refers to people with facial scarring who feel too ashamed to enter public places without first covering their face with makeup. These instances describe how individual bodies intermingle with broader social-cultural relations to produce daily values, practices and experiences. Research and an understanding of the interrelationships between the gendered disabled body, environment and their lived experiences are underdeveloped in disability studies (Edwards & Imrie, 2003).

Intersecting Women, Disability and Human Rights

Feminist Disability Studies, the Social Model of Disability and the disability rights movement within the UK are all manifestations to the fact that the conception of women and disability has been somewhat transformed for the better. The dominant feminist discourse or male disability activists have been challenged and decentered by a feminist disabled political

discourse. However, research fails to recognize political practices or perspectives of disabled women within the UK. This is partly due to the lack of disaggregated data from research conducted with disabled people taking the gender perspective. Additionally, disabled women often remain invisible in mainstream legislation and policy (Soorenian, 2012). This section will describe how two United Nations conventions can create meaning making experiences within the context of human rights work; further conceptualizing the interface between women, disabilities and human rights work.

As previously discussed, women with disabilities are more often than men to become socially, culturally, politically and economically disadvantaged which leads to vulnerability and abuses of their rights. This can include discriminatory enforcement of laws (Ortoleva, 2011), denial of equal opportunity in education and employment (Office for National Statistics, 2011), exclusion from political representation, deprivation of reproductive rights, imposition of negative stereotypes (Lonsdale, 1990; Peters, 2000), and subjection to physical violence (de Silva de Alwis, 2009). The financial dependency of disabled women, particularly on their families may result in living arrangements that subject them to different forms of abuse, including mental, physical and sexual violence (de Silva de Alwis, 2009; Soorenian, 2012). In addition, women tend to be the caregivers of family members with disabilities. While men with disabilities, such as schizophrenia, are "commonly cared for by their wives, women with similar disabilities are often abused or deserted by their husbands" (Soorenian, 2012, p. 296). According to the World Health Organization (WHO, 2008, 2011) findings, because of the high vulnerability to sexual violence, women are the group most affected by post-traumatic stress disorder.

According to Sturke (2010), within the UK disabled people are less likely than their non-disabled peers to think the Criminal Justice System (CJS) is fair (54 per cent as opposed to 61 percent of non-disabled peers). Disabled people's access to justice system is also reported to be restricted due to access and attitudinal barriers (Ortoleva, 2011). Additionally, this research has shown that a women's status as a witness, or her evidence, is less respected or weighted less than others. When a disabled women's legal capacity and rights are ignored, limited or denied, it makes it very difficult for her to address disability or gender-based violence (Ortoleva, 2011; Soorenian, 2012).

There is minimal aggragated data demonstrating discrepancies with gender to support the above claims. Research conducted on disabled women's political participation generally tends to predict little to no political involvement. Findings suggest that women with disabilities "have fewer resources; experience greater isolation, which decreased recruitment opportunities; feel relatively powerless- all of which have been found to discourage political participation in general populations" (Verba, Schlozman & Brady, 1995). According to a 1998/2000 US political participation survey, "women with disabilities are significantly less likely than nondisabled women and men to participate in a variety of political activities, such as voting, writing or speaking to public officials, and working with others on a community problem" (Schur, 2003, p. 263). A notable finding with this research showed that "being a women and having a disability do not in themselves predict lower levels of political involvement" (p. 263). Instead, social and economic disparities factors with employment, income, and group attendance primarily account for the participation gap between disabled women and others. Overall, disabled women remain less likely to engage in campaign activities, and possibly as a result demonstrate a lower understanding of internal political efficacy, civil skills and political

interest (Conway, 2000) than others. This research further examines these practices specifically for physically disabled women.

Meekosha and Frohmader (2010) assert that disabled women have been hidden from history and need to emerge as political actors to create and maintain human rights within their own localities. Joanna Weinberg (1989) examined law through a historical lens as applied to disabled women. She found political (e.g. legal systems) and institutional (e.g. hospitals) practices have historically made decisions for women about their own bodies; such as removal of reproductive organs without given medical permission. Weinberg found that since the 1970's women's rights movements, disabled women's political discourse is still limited when it comes to autonomy or choice with their bodies. Other researchers believe that the feminist disability rights work has only recently entered the broader international agenda of human rights (Ingstad, 2007; Asch & Fine, 1988; Linton, 1998), approximately 30 to 40 years later.

Over the last 20 years, the rise of feminist disability movements within the UK has prompted socio-political shifts and struggles for justice. As previously described the public face of disability politics, or the Social Model of Disability, has primarily been disabled men scholars and activists, resulting in limited sustained analysis of the gendered nature of the socio-political movements within the UK (Meekosha, 2002).

The concepts of multiple forms of discrimination or the intersection of multiple identities (gender and disability) have been acknowledged through the United Nations *Convention on the Rights of Persons with Disabilities* (UN CRPD, 2007). The next section will first briefly note the international human rights movement leading to the creation of the CRPD and the transformative potential for disabled women within the UK. Second, this section will discuss an older convention *the Convention on the Elimination of the Discrimination Against*

Women (UN CEDAW, 1979) and lastly provide a discussion and examples of articles between both conventions demonstrating the intersection of gender and disability. Even though the majority of this work has been centered on the CRPD, the purpose of discussing both conventions within this work is to argue that an intersectionality discourse can enrich the human rights landscape further for disabled women beyond the compartmentalization of each human rights convention. Currently, the rights of disabled women are best protected when the CRPD is read together with the rights of the CEDAW, supporting both gender and disability rights (Silva de Alwis, 2009) that is explored further below.

The *Convention on the Rights of Persons with Disabilities* (CRPD) has transformative potential for the rights of disabled women. This convention provides a shift in the human rights paradigm intersecting, overlapping and mutually reinforcing both gender rights and disability rights. The disability community strongly influenced the writing of the United Nations Disability Convention, which was adopted on December 13, 2006, by the General Assembly. Advocacy by women's groups succeeded in getting a separate clause in the text of the Convention, which then provided an entry point for intersectional analysis. For example, Article 6: *Women with Disabilities* is a stand alone article that direct addresses gender and disability within the human right discourse for the first time.

Convention on the Rights of Persons with Disabilities (CRPD, 2006)

In December 2006, history was made with the United Nations adoption of the Convention on the Rights of Persons with Disabilities. The Convention and its Optional Protocol opened for signatures at the United Nations headquarters in New York on 30 March, 2007 and is the first legally binding treaty that holds governments accountable to the rights of persons with disabilities. Over time, the CRPD (2006) has been guided and shaped by two

landmark historical events marking the trail leading to this Convention. These initiatives include The World Programme of Action Concerning Disabled Persons, 1982 and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993. A major hallmark of the International year of Disabled Persons was the formulation of the World Programme of Action concerning Disabled Persons (WPA), adopted by the General Assembly on December 3, 1982.

Specifically the WPA speaks about the status of women:

> *The consequences of deficiencies and disablement are particularly serious for women. There are a great many countries where women are subjected to social, cultural and economic disadvantages which impede their access to, for example, health care, education, vocational training and employment. If, in addition, they are physically or mentally disabled, their changes of overcoming their disablement are diminished, which makes it all the more difficult for them to take part in community life. In families, the responsibility for caring for a disabled parent often lies with women, which considerably limits their freedom and their possibilities of taking part in other activities.*

The grand theme of the WPA is "Equalization of opportunities" and it remains the overarching theme for the achievement of full participation of persons with disabilities in all aspects of social and economic life. Unfortunately, the WPA speaks about women "overcoming their disablement", which ultimately does not observe oppressive social, cultural or historical barriers and the intersection of disability and gender (Ribet, 2010).

The second influential event came through outcomes of the Decade of Disabled Persons was the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities by the General Assembly on December 20, 1993. This work is not a legally binding

instrument, but does represent a movement for governments to take action towards the equalization of opportunities for persons with disabilities. The Standard Rules is known to be a powerful tool to guide the creation of the CRPD. The above movements, activities and documents represent a "symbolically linked interactions of individuals in meaningful contexts and institutions" (Engestrom & Miettinene, 1999, cited in Daiute, 2008, p. 706) constructing and shifting discourse, values, beliefs and practices leading up to the creation of the Convention on the Rights of Persons with Disabilities (CRPD).

This Convention has been described as the "paradigm shift" for people with disabilities. According to the United Nations Department of Economic and Social Affairs (DESA, 2009), the CRPD is a human rights instrument with an "explicit social development dimension", that will move social and cultural beliefs and practices away from culturally and historically embedded paternalistic attitudes of protection, welfare and charity work. Instead, this convention features persons with disabilities as "rights bearers who are capable of claiming those rights" (de Silva de Alwis, 2008, p. 1). One of the purposes of the convention is to reaffirm to the international community that people with *various* types of disabilities must enjoy all basic human rights and fundamental freedoms on an equal basis.

The CRPD contains an innovative component that intersects both gender and disability rights. This intersection provides a number of entry points for the analysis of women's, and disability rights within a holistic human rights framework (de Silva de Alwis, 2008). During the Third CRPD Ad Hoc Committee meeting in 2004, South Korean representatives unexpectedly proposed adding language combining both 'gender' and 'disability'. This proposal suggested extending the mission of the CRPD by adding an insertion of a new article with a gender based approach. During the sixth Ad Hoc meeting, Kenya and South Korea

followed closely followed with a similar proposal as South Korea. According to the Ad Hoc notes (2006), these proposals were fiercely debated and discussions concentrated on whether and how to introduce gendered articles into the disability convention (Ad Hoc minutes, 2006). These discussions ranged from including only one article representing the "intersected discrimination" to incorporating gender throughout the entire convention (Reina, 2007). Ultimately, the European Women's Lobby and other developing countries organization advocated for one stand along article and the intersection of gender throughout the whole disability convention (AHC, 2006). The International Disability Caucus introduced what is now termed the "twin pack approach" and for the first time a human rights instrument intersected both gender and disability into the human rights discourse.

The following section will provide the CRPD articles that represent the intersections of both gender and disability. First, the eight guiding principles for the CRPD are listed below, noting the gender entry in Principle 7. Second is Article 6, the only stand alone article noting both gender and disability for the first time and then Articles 8, and 16 address issues of stereotypes and violence specific to disabled women.

From Eight (8) Guiding Principles:

1. *Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; 2) Non-discrimination; 3) Full and effective participation and inclusion in society; 4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; 5)Equality of opportunity 6) Accessibility; 7) Equality between men and women; and 8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

From Article 6- Women with Disabilities

1. *States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.*
2. *States Parties shall take all appropriate measure to ensure the full development, advancement and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.*

From Article 8-Awareness Raising

1. States Parties undertake to adopt immediate, effective and appropriate measures:
   a) *To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*
   b) *To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*
   c) *To promote awareness of the capabilities and contributions of persons with disabilities.*

From Article 16- Freedom from exploitation, violence and abuse

1. *States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside, from all forms of exploitation, violence and abuse, including their gender-based aspects.*
2. *States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender-*

and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.

As a critique, Ribet (2010) points out that gender is briefly acknowledged in a few places in the text of the Convention, and mostly compartmentalized to a very minimal discussion in Article 6, titled Women with Disabilities. The phrase "multiple discrimination" she argues is the totality of the Convention's engagement with the specific disability experiences of women and girls" (p. 41), and ultimately is only an acknowledgement to the bigger disability and gender issues. In addition, Ribet (2010) acknowledges that these mentions are an affirmation of women's human rights reminiscent of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). Below the second United Nations convention, CEDAW will be described and reviewed, exploring the possibility of the two documents acknowledging the intersection of gender and disability together.

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) was adopted in 1979 by the UN General Assembly. The United Nations Commission on the Status of Women worked diligently for five years creating a document often described as the "international bill of rights for women" consisting of a preamble and 30 articles. The Convention entered into force in 1981 following its ratification in 20 Nation States. By February 2002, the number of State parties had risen to 168.

The CEDAW's primary purpose is to focus and enforce human rights and the non-discrimination practices against women specific to men. These non-discrimination rights cover

the whole spectrum of human rights, including civil, political, economic, social or cultural activities for women. The CEDAW was unique for its time; being the first human rights convention to address both public and private acts, taking a whole life approach. Prior women's rights documents only covered state actions and action in the public sphere. With the new convention both public (e.g. work) and private (e.g. home) could be monitored by the CEDAW. Below are three examples of articles conceptualizing women and their human rights specifically intersecting with men as defined by the CEDAW:

From Article 1

Specifically defines discrimination against women as,

...any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

The following five articles of the Convention are overarching in the sense that they create general obligations to States parties to end discrimination against women.

From Article 2-

States Parties condemn discrimination against women in all its forms, agree to pursue by all appropriate means and without delay a policy of eliminating discrimination against women and, to this end, undertake:

a) To embody the principle of the equality of men and women in their national constitutions or other appropriate legislation if not yet incorporated therein and to ensure, through law and other appropriate means, the practical realization of this principle;

b) To adopt appropriate legislative and other measures, including sanctions where appropriate, prohibiting all discrimination against women;

c) To establish legal protection of the rights of women on an equal basis with men and to ensure through competent national tribunals and other public institutions the effective protection of women against any act of discrimination;

From Article 4

1. Adoption by States Parties of temporary special measures aimed at accelerating de facto equality between men and women shall not be considered discrimination as defined in the present Convention, but shall in no way entail as a consequence the maintenance of unequal or separate standards; these measures shall be discontinued when the objectives of equality of opportunity and treatment have been achieved.

Many of the remaining articles deal with general human rights but tailor them to the circumstances of discrimination against women in everyday life practices. Article 10 identifies respect to women's education; Article 11 identifies reverence to women's employment options; Article 12 identifies regard to women's health care options.

The UK signed the CEDAW in July of 1981 and was not ratified until April 1986. According to Friedman (2010) an attorney of Law at Oxford University, there is a lack of interest and little is known about the CEDAW from the United Kingdom government. She states that although the Government "goes through the motions of preparing reports and responding to questions, it does not regard CEDAW as normative, in the sense of shaping policy or providing direction" (p. 1).

The Optional Protocol is even less visible than the Convention itself. The UK signed the Protocol in December 2004, and it entered into force on March 2005. In its most recent Fifth

and Sixth reports, the UK did acknowledged that the general public does not know about the Optional Protocol or even the rights within the CEDAW, the views of the Committee were not widely known, nor sufficiently practiced or utilized by women. In 2008, a Shadow Report was conducted by the Women's Resource Center (WRC), a non-government organization (NGO) based in London in response the United Nations Committee on the Elimination of Discrimination against Women (CEDAW) 6th Periodic Report. This Shadow Report particularly described the lack of representation of women's organizations in local decision making bodies, possible closure to women's black, Asian and minority ethnic women's organizations, Rape Crisis centers, health organizations and domestic violence centers. In addition, the report noted an increase in and impact of 'gender neutral' decisions made by public sectors.

This convention was chosen for discussion and analysis within this research because the Convention on the Elimination of the Discrimination against Women (CEDAW) has tremendous potential for the human rights of women with disabilities. Read with the CRPD, this convention has greater resonance to address abuse, exploitation and discrimination against disabled women in both private and public context and in turn, will enhance their participation at all social, civil and political levels. Below further described this overlap of rights between both conventions previously described.

Intersecting the CEDAW and CRPD

As described, the CRPD recognizes that the intersection of gender and disability increases the rate of recognized human rights violations. When the CRPD and other international legal instruments, such as the CEDAW are read together there is a greater level of support against both gender-based violations and disability discrimination (de Silva de Alwis,

2009). This section will review and provide examples across two United Nations conventions, demonstrating the intersections of gendered articles from the CEDAW and disability rights articles from the CRPD.

From Article 7 (CEDAW)- Participation of women in Political and Public life

... to eliminate discrimination against women in the political and public life of the country and, in particular, shall ensure to women, on equal terms with men, the right:

a) *To vote in all elections and public referenda and to be eligible for election to all publicly elected bodies;*

From Article 29 (CRPD)- Participation in political and public life

a) *…to ensure that person with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons to vote and be elected..*

From Article 10-(CEDAW)- Education

States Parties shall take all appropriate measures to eliminate discrimination against women in order to ensure for them equal rights with men in the field of education

b) *The same conditions for career and vocational guidance, for access to studies and for the achievement of diplomas in educational establishments of all categories in rural as well as in urban areas; this equality shall be ensured in pre-school, general, technical, professional and higher technical education, as well as in all types of vocational training;*

c) *Access to the same curricula, the same examinations, teaching staff with qualifications of the same standard and school premises and equipment of the same quality;*

d) *The elimination of any stereotyped concept of the roles of men and women at all levels and in all forms of education by encouraging coeducation and other types of education which will help to achieve this aim and, in particular, by the revision of textbooks and school programmes and the adaptation of teaching methods;*

e) *The same opportunities to benefit from scholarships and other study grants;*

f) *The same opportunities for access to programmes of continuing education, including adult and functional literacy programmes, particularly those aimed at reducing, at the earliest possible time, any gap in education existing between men and women;*

g) *The reduction of female student drop-out rates and the organization of programmes for girls and women who have left school prematurely;*

h) *The same opportunities to participate actively in sports and physical education;*

i) *Access to specific educational information to help to ensure the health and well being of families, including information and advice on family planning.*

From Article 24 –(CRPD)- Education

States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:

a) *The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;*

b) *The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;*

c) *Enabling persons with disabilities to participate effectively in a free society.*

From Article 12 (CEDAW)- Health care

States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

From Article 25 (CRPD)- Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

a) *Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the*

area of sexual and reproductive health and population-based public health programmes;

b) *Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*

c) *Provide these health services as close as possible to people's own communities, including in rural areas;*

d) *Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*

e) *Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*

f) *Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

Given the way the rights guaranteed by the CRPD and the CEDAW intersect, both women's groups and feminist disability advocates need to come together and form alliances on law, policy and practices. A gender based approach (CEDAW) and a disability based approach (CRPD) link together groups and individuals already working on the rights of women and individuals working on disability rights. This hopes to insure that each convention does not

have a stand-alone approach, when really everyone has multiply identities. The discussion highlights that the experiences of women with disabilities are always situated and contextualized across cultures and environments. In the end, different social movements (disability and women's) must come together at these points of intersection in order to create an inclusive form of human rights practices that is sensitive to the multiple identities of women with disabilities and all the historical, social, political and cultural challenges that complicate these identities (de Silva de Alwis, 2009).

Theoretical Framework

Recent years have witnessed the emergence of sociocultural perspectives in British Disability Studies literature. This is the result of researchers and activists and their identification with the Disability Rights Movement and the Social Model approach. This work acknowledges the sociocultural dimension of disability and gender as part of human experience. These emerging perspectives on the experience at the intersection of disability and gender have led to the understanding of what has been referred to as a *dual handicap* or *double discrimination.* These terms recognize that women with disabilities have been subjected to discrimination and segregation because of their situation as both disabled and female, belonging to two separate groups that have historically been oppressed. In this study I examined the experience of living where gender intersects with disability and provide a broad perspective on the ways in which social, historical, and environmental factors come to define the lived experiences of physically disabled women. In addition, these gendered experiences of disability are mediated by historically developed cultural tools such as language and policy documents.

This work will make use of a number of theoretical frameworks. The overarching theoretical perspective for this study stems from the work of Lev Vygotsky and Mickhail M. Bakhtin. In conceptualizing both disability and gender as culturally embedded and socially defined, this work first applies Vygotsky's (1978) socio-historical theory. His work is important, because it provides an understanding of how women with physical disabilities create knowledge in their social relational worlds and make meaning through their lived experiences from a developmental approach, while using cultural tools. Mikhail M. Bakhtin's work (1981, 1984, 1986) complements upon Lev Vygotsky's (1978, 1981). Bakhtin's dialogical approach reveals how language and policy as cultural tools inform meaning-making through a wider social process. These theoretical works guide this research towards the understanding that the intersection of disability and gender is a cultural, social, and historical phenomenon and that knowledge or meaning making is made only within the dialogue in which every person is an ideologue.

In the following section I will review theoretical approaches to understand the notion of dual handicap as being formative for individual women and the collective meaning towards the intersection of both gender and disability. The sociocultural historical lens which will guide this work takes as a given the understanding that disabled women, like everyone else, live in a dynamic sociocultural world. Indeed, their bases of meaning are informative of collective actions and by these actions women are considered to be collective actors. Grounding this research with the experiences of physically disabled women, makes it possible to argue that the experiences and outcomes related to the notion of dual handicap cannot be attributed or reduced solely to the biological characteristics of impairment or a of a gendered individual. As with the essentialist theoretical beliefs which frame the individual as a "solitary, lonely

cognizer"; contained, unbounded by social life, and "thing like" (Stetsenko & Arievitch, 2001), this cannot be the case. Rather, the sociohistorical perspective differs from the biological or medical models approaches to disabled women, which fail to recognize the embededness of human beings in socio-cultural contexts. These perspectives guide my theoretical approach and methodological choices in the present research, which emphasizes the centrality of wider social processes of a reciprocal, mutually influential interaction among the women, their cultural tools, and their environment or activities. This section explains this theoretical perspective further, using a socio-cultural, historical standpoint merged with Bakhtin's dialogical work. Ultimately, this work takes the perspective that all language is alive and is historically, socially, and culturally situated. This interaction using language is where shared meaning is made, influencing gender and disability experiences.

This dissertation will first argue that the experiences of women with disabilities are created through the interactions and activities embedded in cultural practices and situated within the social, cultural, political, and historical contexts rather than located "under the skin" of an individual woman with a disability. Socio-historical theory, rooted in the work of Vygotsky, views individuals as social and relational; ultimately, social interactions are profoundly central and inherent to human development (Vygotsky, 1978; Rogoff, 1998; Wertsch, 1991). The mind is inherently social. Vygotsky (1978) believed that "each function of the child's cultural development appears twice, or on two planes: first on the social level, and later on the individual level; first between people (interpsychological) and then inside the child (intrapsychological)" (p. 57). This theory proposes, then, that disabled women's' psychological functions originate through external social activities and, subsequently, they gradually become individual functions (Vygotsky, 1978; Wertsch & Stone, 1985).

This is equally true in regard to higher psychological functions such as voluntary attention, logical memory, and to the formation of concepts such as gender or disability (Vygotsky, 1981), which maintains that "each mental function was at one point external or social at some point before becoming an internal, truly mental function" (Vygotsky, 1981, p. 162). Mental processes can only be understood by examining the social and cultural processes from which they derive (Wertsch & Tulviste, 1994). Taking this perspective, Cole and Wertsch (1996) describe psychological functions as being "culturally, historically, and institutionally situated and context specific" (p. 4). Therefore, Vygostky's theories highlight that development cannot be understood from a purely biological or genetic angle, given the understanding that human consciousness emerges out of social life. This work will thus explore how disabled women may, from their larger social worlds, come to understand their disabled and gendered human rights.

With the understanding that all experiences are situated and contextualized, it is necessary to extend the socio-historical view and emphasize that individuals are social and best understood in relation to the contexts in which their experiences are embedded. Any human development is inherently contextualized, culturally and historically defined (Stetsenko & Arievitch, 1997). This viewpoint does not separate individuals from their social contexts (Stetsenko & Arievitch, 1997); instead, it describes a relationship in which individuals are shaped by their environments, while they simultaneously act upon and transform these environments (Stetsenko & Arievitch, 2004). This pushes forward the socio-historical theories that the self is "profoundly social and relational" (Stetsenko & Arievitch, 2004, p. 475) but still not "dissolved in collective dynamics of social processes" (p. 479). Therefore, the self and the environment are not separate but instead in constant interaction. This concept is described by

Stetsenko and Arievitch (2004) as, "each living organism exists only as part of a dynamic system that connects it with the environment and with other organisms" (p. 482). Within this research, context will refer to both the larger culture that the women with physical disabilities may live in and to their cultural discourses within their immediate environment (e.g., house, work place, doctor's office) and activities (e.g., riding a bus, shopping, working, social functions).

Holland and her colleagues (1998) have conceptualized the notion that experiences are always situated and contextualized as what they termed *figured worlds*. These worlds contain shared social activities within social, cultural, political, and historical contexts which extend beyond the concrete physical environment. Figured worlds rest upon the social-relational world and people are formed collectively realized as "realms", ultimately shaping the "coproduction of activities, discourses, performances, and artifacts". Each world "is peopled by the figures, characters, and types who carry out its task and who have styles of interacting within, distinguishable perspectives on, and orientations toward it" (p. 51). Therefore, through social activities, people position themselves to others according to the location, time, and place of the activity per world. There is always a possibility that certain interactions and figured worlds are valued over others. A person or group of people may never enter a particular figured world due to a person's social position or rank within a particular contextualized, culturally embedded, and historically influenced activity.

Each figured world is considered to be a historical phenomenon, collectively and socio-historically constructed. A person's ability to know each figured world comes from past experiences with these worlds and through the continual participation within the context of them. Holland and her colleagues (1998) note that these worlds are "formed and re-formed in

relation to the everyday activities and events that ordain happenings within it" (p. 53). Therefore, the interactions and identities formed within figured worlds are "historical developments, grown through continued participation in the positions defined by the social organization of those worlds' activity" (p.41).

Holland and her colleagues' 1990 work, *Educated in Romance*, highlights the point that figured worlds are socially, culturally, and historically formed through their work with racially diverse women on two university campuses in the American South during the 1980s, they found figured worlds of romance. Their study was designed to explore how women developed their sense of place as gendered actors contextualized through the cultural and historical practices of romance. The researchers found that romantic-figured worlds did, indeed, exist for the women participants. Through shared social activities contextualized in local bars or social events, the women encouraged romantic encounters or practices within a culturally defined figured world. In addition, the researchers found that each woman had to negotiate other forms of figured and positional aspects of identity at the same time. These positions were negotiated from larger historical ideologies amongst race, class, and sexual orientation contextualized in the southern United States.

Moreover, Holland and her colleagues' theory of figured worlds lends itself to the belief that the experiences of women with disabilities are created and maintained through these socially-collective, historically-constructed figured worlds rather than solely within the individual. In the current research the historical ideologies of gender and disability automatically will situate and contextualize the participants. With this understanding, this research takes the position that women also have agency in their lives and are not merely fated to exist only within their social, cultural, and historical deterministic worlds. This work

considers figured worlds by drawing upon Leontiev's notion of activity and self, where figured worlds are not objects or places to approach but are instead interactions between self and activity, situating identity in collectively formed activities. The following discussion will explore this point further.

According to Leont'ev (1978), self is embedded in and originates from human activity. Stetsenko and Arievitch (1997, 2004) take his concept a step further and highlight the self *as* activity not as self emerging *from* activity, i.e., the activities that individuals engage in *are* the self. Therefore, the activity within the figured world is not something that happens to women (e.g., riding on a local London bus); instead their context situates them as being fashioned within and by historically specific times and places (Skinner, Holland, & Pach, 1998). It is important to note that physically disabled women are also in constant interaction with their environment and their own "cultural and socio-political contexts may invite opportunities or may provoke struggle within individuals to overcome imposed constraints" (Skinner, Holland, & Pach, 1998, p.8). Therefore, the women in this research have experiences within their own social, cultural, political, and historical contexts, while they simultaneously act upon and transform social values encoded in such contexts (Vygotsky, 1978; Daiute et.al., 2003), creating a self-understanding in and across their own figured worlds.

Holland and her colleagues' (1990) provides an example of figured worlds being cultural realms created by people with collective imaginings. Academia, for example, and romance are figured worlds and are all created and "take shape within and grant shape to the coproduction of activities, discourses, performances, and artifacts" (Holland et al., 1998, p. 51) and are in constant interaction with the environment and the world, creating knowledge and meaning. Therefore, the self as gendered (and disabled) can be viewed not as a static entity

held in the mind but instead as a continuous negotiation through practices and interactions within and across figured worlds. The next section will further explain how figured worlds provide a way to conceptualize how historical structures influences disabled women's interactions within their socially-produced and culturally-constructed activities, or figured worlds.

History in the World and In Person?

One central objective of this work lies in the inquiry into the influence of historical structures of privilege rooted in gender and disability becoming embodied over time. This section will argue that past experiences within larger social, political, and historical contexts are told and retold over time. This re-telling and re-experiencing eventually will inform a disabled woman's outlook, behaviors, and her everyday local discourse and situated practices. Vygotsky emphasized that the sociopolitical history of a culture powerfully shapes all levels of contexts. This will also affect the practices and knowledge production within a culture, ultimately influencing the development of higher mental processes (Scribner, 1985). Vygotsky's socio-historical work contradicts "history as being a succession of value-culture, and politics-free individual pursuits carried out in a sociocultural and sociopolitical vacuum" (Stetsenko & Arievitch, 2004, p. 61) and ultimately rejects the notion of individuals being biologically determined. Instead, Vygotsky perceives that "higher mental functions have a social-historical, rather than biological origin, setting his theory apart from others and certainly distinguish[ing] it from the thinking of the genetic psychology movement" (Scribner, 1985, p. 128). It is important to understand that the interaction between history in institutional structures will influence women with disabilities and that women will influence history.

Vygotsky (1978) believed that two lines of cultural historical development occur, one on general world history and the other on the level of individual history, both co-occurring. Examples of the larger sociopolitical historical contexts include prior nation-state revolutions, wars, natural disasters, and civil rights work. Here movements can reverberate on all contextual levels, directly interacting with and influencing self and society. This work argues that history is not an "abstract story from the past but a meaning making process in which individuals and groups contend with perceptions and interpretations of events as they participate in public and private life" (Daiute, 2010, p. 41). Therefore, history can be considered to be alive in present time, and disabled women can be identified as actors within their own histories, influenced by and influencing a local, national, and global history. Holland and Lave (2001) termed this *history in person*. Therefore, the women within this study are social, cultural, and historical beings, linking their social history of culturally and politically distinctive groups or social categories to their local practices and experiences, creating a history in practice.

Understanding that societies are influenced from the past and larger historical structures influence and possibly restrain or expand local practices, Holland and Lave (2001) explain that "history in institutional structures and history in person are never simple equivalents" (p.5). Instead, the two come together again and again in conflicted practice, changing the terms of culturally produced forms which 1990s British national policy demonstrates this point. It dictated to local governments that they needed to make buildings accessible through physical modifications (e.g., ramps, elevators). This alteration of culturally-embedded and historically-influenced buildings changed the discourse and local practices for disabled women. From that point on, based on a politically-influenced decision, disabled women had access to buildings or figured worlds which they could not previously enter. The newly accessible buildings shifted

disabled women's connection with their environment and with others. The historically-influenced, culturally-embedded buildings created different activities for disabled women, forming and re-forming discourse and local practices in relationship to gender and disability.

This work directly applies the above theoretical points by examining the impact of both international and British national policies, creating local cultural discourses and shared social activities. These multiple levels of social, historical, and culturally-embedded discourse inform the everyday local practices of disabled women's lives. The following section will expand the theoretical understanding that the self is relational and situated within the social cultural, political, and historical contexts by describing how cultural tools are collectively developed and create meaning "as tools that people use to affect their own and others' thinking, feeling and behavior" (Holland et al., 1998, p. 50). The habitual use of these cultural tools creates socio-cultural resources available for use within activities which shape thought, emotion, and behavior. Cultural tools such as international and national political movements, documents, and social language will be discussed, and the argument will be made that these cultural tools have shaped the figured worlds in which disabled women of England live in today.

Cultural Tools Mediating Activity

The views offered by scholars who emphasize the agentic role of self are consistent with the grounding assumptions offered in Cultural-Historical Activity Theory (CHAT). This theory rejects the role of self solely as a mental construct that resides within individual cognitions; instead, it emphasizes the idea of the self as originating in the everyday processes of human interaction and activity. In fact, the individual and the world cease to be separate realities. Instead they appear simultaneously within activity development. The same "self always returns to and acts back on the world through activity, transforming the world according

to human goals and, thus creates a humanized world that can then shape new activity cycles in a constantly unfolding, never ending, open ended process of life" (Stetsenko & Arievitch, 2004, p. 492). The next section will expand on the understanding that women's interactions are embedded in context and history and will further explain how women's knowledge related to the notion of their dual handicap is not created in isolation but is in constant interaction with the environment. Through cultural tools such as language and speech genres, women link the actions of individuals or groups to their cultural, historical contexts and make meaning of their lived experiences.

An initial premise of CHAT is the notion of mediation through artifacts (Cole & Wertsch, 1996) or cultural tools. Vygotsky (1981) believed that "humans master themselves from the outside through psychological tools" (p. 141). These psychological tools or signs can include language systems, "various systems for counting; mnemonic techniques; algebraic symbol systems; works of art; writing; schemes, diagrams, maps, and mechanical drawings; all sorts of conventional signs" (p. 137). Physical tools, such as computers and calculators are directed toward the external world. Both of these examples of cultural tools cannot be invented by the individual in isolation but instead are social, cultural, and historical products emanating from communities and generations.

Cultural tools shape environments and interactions, allowing humans to "transform the world rather than passively [to] adapt to the world's conditions" (Stetsenko, 2004, p. 9). Individuals act on their social world through meditational means or cultural tools (Vygotsky, 1978; Wertsch, 1998). Tools as human creations are naturally social for two reasons. First, cultural tools are collective experiences embodying a collective social knowledge and experience (Stetsenko, 2004), essentially linking the interpsychological processes to the

intrapsychological functions. Second, psychological tools are part of a collectively formed meaning and are "products of sociocultural evolution and, hence are inherently situated in sociocultural context" (Wertsch, 1991, p. 91). Understanding that a person's "mind(s) rarely works alone… and the intelligences revealed through these practices are distributed—across minds, persons and the symbolic and physical environments, both natural and artificial" (Pea, 1993, p. 47). Thus, "knowledge is commonly socially constructed, through collaborative efforts toward shared objectives or by dialogues and challenges brought about by differences in persons' perspectives" (Pea, 1993, p. 48).

Figured worlds rely upon cultural tools as mediators in human action (Holland et al., 1998). Humans use cultural tools (e.g., language) and form activities, shaping and transforming mental processes (Cole & Wertsch, 1996). Cultural tools then "act as the mediators of action" (Wertsch, 1998). Wertsch (1994) elaborates on Vygotsky's work and describes mediation as:

> *…an understanding [of] how human mental functioning is tied to cultural, institutional, and historical settings since these setting shape and provides the cultural tools that are mastered by individuals to form this functioning. In this approach, the meditational means are what might be termed the "carriers" of sociocultural patterns and knowledge* (p. 204).

Therefore, cultural tools are the means by which "figured worlds are evoked, collectively developed, individually learned, and made socially and personally powerful" (Holland et al., 1998, p. 61) through the use and re-use of cultural tools which are in relation to intentional human actions. Scribner (1985) provides an example using writing as a cultural means.

Scribner (1985) explains that particular societies may "adopt the 'same' cultural means "(writing system)" but because of the individual histories, its cognitive implications may differ widely from one society to the other" (p. 139). Scribner's example emphasizes the levels of variation in the social formation and cultural production of a writing system. Holland and Lave (2001) build upon Scribner's example, describing that the range of cultural tool used within societies can be dependent upon their political-economic, social, and cultural structuring. As a result, these factors will shape the local daily practices and lived activities, ultimately changing the way people culturally mediate the writing systems (Holland & Lave, 2001). At a local level of practice, "material and symbolic resources are distributed disproportionally across socially identified groups" (Holland & Lave, 2001, p. 5); this generates different social relations and perspectives among groups.

Therefore, disabled women may form their knowledge or meaning making of dual handicap from their historical, cultural, and social worlds mediated by language related to *women* or *disability* or even through parallel words, *man* or *normal*. The language or mediating device is constructed by the meaning or social history collectively assigned to each word. This symbol or language is then placed in the environment so as to affect mental events or to control psychological processes (Holland, Lachicotte, Skinner, & Cain, 1998). When there is repeated experience with this mediating device or word, then the meaning becomes internalized or *fossilized*, as Vygotsky termed the state of the meaning (Vygotsky, 1978; Wertsch,1985b). Therefore, it is important to understand that women's meaning making is never a detached process and that in fact, we "exist in the world as living bodies in a society with a culture and a history, rather than as isolated inanimate mechanisms" (Shotter & Billig, 1998, p. 16).

This dissertation will later extend from the above discussion and will describe social language as a cultural tool mediating behavior. First, this work will identify political documents as another type of cultural tool revealing intelligences across minds and history. These policy documents carry socio-cultural historical patterns and knowledge from past activities. This work will argue that policy documents are another cultural tool creating meaning making activities that construct the figured worlds within which women's experiences are framed. The next section provides further explanation on policy as a cultural tool mediating socio-cultural patterns of thought, behaviors, and knowledge.

Policy Documents: Activity-meaning making systems

This section draws attention to women as sociopolitical beings simply by the fact that they live in a world joined and socially mediated by policy. They are social beings who interact with the "material and symbolic circumstances in their environments, including the political processes like rights, which are essential to their lives" (Daiute, 2008, p. 703). This section seeks to demonstrate the importance of understanding the influence that policy may have as a mediating artifact, supporting or contradicting the notion of dual handicap within the sociocultural, historical, and political figured worlds of disabled women. I argue that the disabled women in this study are located within and directly influenced by British policy (e.g., DDA, 1995) and influential international policy; such as the *United Nations Convention on the Elimination of Discrimination Against Women* (1978) and the *Convention on the Rights of Persons with Disabilities* (2006). .

Policy, "like any other meaningful creation of the human mind, must be considered to be alive" (Stetsenko, 2004, p. 1), born from a "collective, not solitary, efforts of many people, who are involved in the process of knowledge" (Stetsenko, 2004, p. 1). Policies as a cultural

tool "carry intelligence in them" (Pea, 1993, p. 52) and represent an activity full of others' knowledge, words, and utterances. Therefore, knowledge is transferred over time through political text, carrying patterns of collective efforts, and "previous reasoning and may contribute to patterns of distributed intelligence configured in activity" (Pea, 1993, p. 53). This pattern of knowledge through policy then embodies activities or practices for disabled women within the context of their human rights understanding.

Following the cultural-historical theoretical underpinnings that "Every function in the child's cultural development appears twice: first, on the social level, and later, on the individual level; first between people (interpsychological) and then inside the child (intrapsychological) " (Vygotsky, 1978, p. 57). Daiute's (2008) work demonstrates this point well using sociocultural activity theory to describe the broader institutions and systems (interpsychological) and the sociopolitical actor's interactions and representations within these systems (intrapsychological). Daiute's (2008) work creates the concept of "activity-meaning making systems" as "symbolically linked interactions of individuals in meaningful contexts and institutions" (p. 706) and explains that rights policy is embedded within a system of institutions and activities, and relationships. Therefore, policy documents are created within the midst of activity-meaning making systems and are created from prior meetings and interactions, which are all part of the symbolically linked interactions. Political documents express prior dialogical relationships and future desires for interactions. Ultimately, these documents enact values, principles, concepts and tensions involved in society and the disabled women's rights process within their everyday lives.

The social-political context in which disabled women interact from birth to present not only affects them but also defines them. In order to determine whether and how disabled

women are treated as members of sociopolitical life, it is critical to consider how disabled women interact in society, not only in terms of abstract cognitive processes but also in terms of their experiences in their local contexts or environments. One example of a policy document as an activity-meaning making system is the 1979 *United Nations Convention on the Elimination of Discrimination Against Women* (CEDAW), which focuses on the concept of women as political beings with concurrent political rights. For the first time, this Convention gave women an international cultural tool that could shift historically-gendered figured worlds and could conceive new meaning making activities, knowledge, thought, and behaviors. Within the broader CEDAW activity-meaning making systems, prior dialogical activities occurred such as, human rights policy, feminist rights movements and meetings leading to the creation of the CEDAW as a policy document within the activity-meaning systems for allowing disabled women to express and develop their rights based understandings.

Throughout this research, participants have shared their knowledge about their contextual experiences, which have been mediated through a particular sociopolitical cultural tool, the 2006 United Nations *Convention on the Rights of Persons with Disabilities* (CRPD). This human rights tool introduced for the first time the notion of dual handicap by including both language and rights reflective of disability and women, known as the twin-pack approach, possibly creating a "new form of mediated action" (Wertsch, 1998). The analysis of this dynamic process provides concrete, in-depth details that illuminate disabled women's experiences and meaning making within dialogue and illustrate how women experience themselves and their figured world. Through dialogical practices situated in broader social, cultural, historical, and political contexts meaning making (dual handicap) is formed through lived experiences. I argue that, through Bakhtin's (1986) theoretical work, policy documents

express dialogical relations within an activity-meaning making system. Through documents as an activity, shared meaning is made between societal values, principles and tensions and the disabled women's rights based understanding through their lived experiences.

Language: Mediating Shared Meaning and Practices

This section introduces and explores how M.M. Bakhtins work complements that of the socio-historical school of psychology. Bakhtin focused on the areas of sociolinguistics and literary criticism, while Vygotsky focused on a developmental approach; integrating cultural symbols (e.g. language) as a way to free us from our environmental limitations. Bahktin was not necessarily interested in language as a developmental process, but instead tied cultural forms to social others, creating an understanding that dialogical practices are social by nature and include the elements of "power, status, stratification, and ownership" (Holland, et al. 1998, p. 176), creating conflicts within the many historical institutions in which humans interact. The following section will explore development as a dynamic process, as an ongoing contextualized interaction mediated by language and tools in cultural-historical contexts (Stetsenko & Arievitch, 1997). First, I will identify the role of language as a cultural tool that mediates both meaning and individual-social relationships (Daiute, 2010), beginning with inner speech developing into social languages (Vygotsky, 1978). Second, Bakhtin's dialogical work will be described, using the notion that through words, utterances, social languages and speech genres we author the figured world and ourselves (Holland et al., 1998, 2001).

For Vygotsky, language is the most important cultural tool that enables individuals to mediate their social world. As Vygotsky (1981) claims, "Humans master themselves from the outside- through psychological tools" (p.141). Language provides a tool to communicate with self and others and shapes meaning by directing thinking, organizing categories of reality,

representing the past and plans for the future. Since development is a socially embedded process dependent on the interaction of others, the creation of social cultural categories within language are absolutely tied to human social interactions (Wertsch & Stone, 1985). Again, as previously discussed the intermental becomes intramental for the women participants and is a way to provide individuals with the experience of past generations.

Bakhtin (1981) describes language as being alive, because it is an interaction of speech spoken by real individuals in specific situations and addressed to audiences both immediately and distantly present. Language is a lived perspective of the world and all language conceptualizes the "world in words" by juxtaposing and contradicting one another and still interrelated dialogically. When people speak to each other, something happens; we not only shape our living relations to each other and to our surroundings, we can also reshape the already existing historical and ideological influences at work (Shotter & Billig, 1998). "Language lives", says Bakhtin (1994), "only in the dialogic interaction of those who make use of it" (p.183). Life therefore is a dialogic experience. Consequently then, *meaning emerges only within the dialogue.*

This research will highlight the dialogical practices and the influence of the broader social, cultural, historical and political contexts through Bakhtin's "pragmatic aspects of language- how it was used, how it communicated power and authority, how it was inscribed with status and influence" (Holland, et al., 1998, p. 178), dependent upon the social-relational context in which the language is being spoken. A.N. Leontiev (1978) insisted on the importance of "activity" in understanding human behavior. He believed that people respond to what "they find in the environment in the context of a historical, socially and culturally

constructed form of social (inter)action that he called an activity" (Holland, et al, 1998, p. 39), or what Holland and her colleagues (1998, 2001) have previously termed as 'figured worlds'.

Authoring the Self: Dialogical Activity

Mikhail Bakhtin (1929/1984) developed an explicit argument that the mind is not a contained center but a product of dialogic relations (Hermans, 2001a; Hermans & Kempen, 1993; Sampson, 1993). Hermans (2001) explains that the "self and culture are conceived of in terms of a multiplicity of positions among which dialogical relationships can develop" (p. 243). The dialogical self-highlights the individual as social and all of our words spoken are filled with others words, intentions and experiences of others (Graue, Kroeger & Prager, 2001). This is the crux of Bahktin's dialogism; that people coexist and are always in a "state of being addressed and in the process of answering, moving towards a state of action" (Holland, Lachiotte, Skinner & Cain, 1998, p. 169), where identities are shaped and created from dialogue, mediated through language as tools, which have left residues of meaning within the world.

These perspectives shift the understanding to the "transactions" between individuals and their social world, and in turn, are transformed themselves (Stetsenko & Arievitsch, 1997). In line with this view, dual handicap is created through the interactions between activities, embedded in cultural practices and situated within the historical contexts rather than located under the skin of the disabled women. In this section I will apply the understanding that through dialogical practices, which are situated within the social, cultural, historical and political contexts of figured worlds, meaning is made or as Holland and her colleagues note, the self is authored. I argue through Bakhtins' dialogical approach and theoretical works of

language (words, utterances, social language and speech genres) that language is socially organized and culturally reproduced within historical figure worlds.

The author of a narrative generates novelty by taking a position in which meaning is made- a position that enters a dialogue and takes a particular stance in addressing and answering others and the world (Holland et al., 1998, p. 173). There are a variety of ways in which the self as author incorporates the words and voices of others (Bakhtin, 1981, 1990). As Holland and her colleagues (1998) explain this rests within the "I" and authoring comes from the "I", but the words come from collective experience" (p. 171) using a collective language. The authors words come from a previous dialogue in situations that have formed meaning and the author will then anticipate these words in future dialogues. Basically, people are "always in the state of being "addressed and in the process of "answering" (Holland et al., 1998, p.169) within a figured world.

Bakhtin explains this process as "authoring the self", or the meaning that we make of ourselves. The site at which the authoring occurs is a "space defined by the interrelationship of differentiated "vocal" perspectives on the social world" (Holland et al., 1998, p. 173). The self is in a "position in which meaning is made, a position that is addressed by and answers others and the world, either physical or the cultural environment" (p. 173). Therefore, the speaking and authoring of self can be very creative and a novel endeavor, "an act that constructs personal and cultural meanings" (Skinner, 2001, p. 4). The self can never be finalized because it is always in dialogue with others, answering people that may be present or who are far removed in time and space.

The process of internalization is active throughout the life of the individual via a continuing internal dialogue during which the word of the other is constantly (re)evaluated. The

participants within this work co-constructed narratives by taking particular positions in addressing and answering others and the world (Holland et al., 1998) depending on their perceived social context. Considering when they spoke, their "word is oriented toward an addressee, toward who that addressee might be: a fellow member or not of the same social group, of higher or lower standing (the addressee's hierarchical status), or someone connected with a speaker by close social ties… or not" (p. 85). The task of the women answering is through the development of social speech, where "inner speech works primarily through the "sense" of words and events; social speech depends more upon meaning" (p. 186) through experience and embodiment with the words. There it is not necessarily "the experience that organizes expression, but the other way around-expression organizes experience"(p. 187).

This point highlights how women influence the social world just as the social world influences them, creating a multiplicity of positions. The women's authored selves are formed with figured worlds and each identity develops dialogically through continued participation with others in social, cultural and historical worlds. Indeed, within the making of meaning, people "author" the world and ourselves into the world (Holland & Lave, 2001). Always coexisting with others, the women's authored selves are never settled. They will always answer differently depending on the social relationships at the time and positions assumed; drawing upon the "languages, dialects, genres, and words of other to which she has been exposed" (Holland & Lave, 2001, p. 11). These emergent perspectives, along with differencing in positioning are mediated by context, will be analyzed using a conversational analysis to develop suggestions for research and practice.

The Word and Utterance: Discursive Activity

This section will highlight the figured world of dialogism, in which the self authoring comes from the "I" but the words, utterances and social languages from for collective experiences which are culturally historically embedded. First, the word is socially, culturally and historically created and maintained; second, words are collectively created and performed within figured worlds, and third all words are filled with intentions and evaluations in dialogically agitated and tension filled environments. Ultimately, Bakhtin (1981) believed that words are socially charged and learned by others that are "dialogically engaged with past, present and future audiences and populated by the intentions of the unique speaker" (p. 293).

All words used have a "taste" of the context in which it has lived its socially charged life- either of a profession, a genre, a tendency, a party, a particular work, a particular person, a generation, or an age group (Bakhtin, 1981). Within dialogue, it is impossible for anyone to use a neutral word that has never been articulated by others, in situations that have left residues of meanings in the words (Skinner et. al, 2001). Each word that is used by a person, does not forget where it has been before. It has been learned in the past, from the mouths of others. Therefore, historically each word carries the baggage, so to speak into the next conversation from its past usages. Words come from collective experiences and each word is indeed half someone else's, carrying the dialogical nature of the word. As Bakhtin (1986) explains "I live in a world of others words" (p. 143) and the word can never exist in a neutral and impersonal language, but rather exists in other people's mouths in other people's context.

All words are populated by intentions (Holland et al, 1998). The word is then dependent upon the associations and evaluations given by society as a whole and the act of responding to the word will inform one world with another. For example a single word such as

'disability' or gendered word such as 'female' may represent an entire discourse bearing its own intention and meaning. My dissertation adds in the gendered word, 'woman' and another discourse with meaning and intention is now added to the dialogue.

Bakhtin(1981) describes the word as being alive, trying to find its own orientation through the world of others' words. That the word is quite dynamic and can be understood as a "ray of light", trying to find its way through a "dialogically agitated and tension-filled environment of alien words, value judgments and accents. It recoils with some of these and merges with others" (p. 276). The process in understanding another person through words is based on the "wealth of human culture (expressed in a word or the other semiotic materials)" (Bakhtin, 1986, p. 143). When people are in dialogue, one person needs to speak the words loaded with intentions, values and meanings and then the listener has the job of understanding the word and making it their own word using through their own accents, semantic and expressive intentions. It is not only a person being addressed by others words, receiving others' words, but the act of responding to these words that informs our social, cultural, historical relational figured worlds through others.

Bakhtin's conceptualization of the word supports a level of understanding towards the formulation of meaning that is made and carried around from activity to activity via the word. This meaning or living word becomes part of a history of activities and a layer onto subsequent activities. The next section will expand from the word into the speaking of words, together as utterances. Each utterance is a living social process, further addressing how utterances are multivocal and dialogical by nature formed within figured worlds.

Utterances contain at least two voices, and "all utterances themselves are "multivocal and dialogic" (Skinner et al, 2001, p. 4). Through a conversation each utterance is always

addressed to someone and as a result, there is always a response. It is important to return to the speakers' initial utterances, which does not exist by on its own, but instead contains "the existence of preceding utterances- his own and others'– with which his given utterance builds on them, polemicizes with them or simply presumes that they are already known to the listener." Therefore, Bakhtin (1986) states that the "utterance is a link in a very complexly organized chain of other utterances" (p. 69) that has:

> *.. taken meaning and shape at a particular historical moment in a socially specific environment, cannot fail to brush up against thousands of living dialogic threads, woven by socio-ideological consciousness around the given object of an utterance; it cannot fail to become an active participant in social dialogue. After all, the utterance arises out of the dialogue of a continuation of it and as a rejoinder- it does not approach the object from the sidelines"* (Bakhtin, 1981, p. 276-277).

Applying this theoretical notion to this research, disabled women's utterances cannot exist on their own but instead contain "the existence of preceding utterances- their own and others', as "a link in a very complexly organized chain of other utterances" (Bakhtin, 1986, p. 69) created by larger cultural meanings or worlds (Skinner, 2001). For this research, it is essential to understand that each of the women's living utterance takes on "meaning and shape at a particular historical moment in a socially specific environment, and cannot fail to brush up against thousands of living dialogic threads, woven by socio-ideological consciousness" (Bakhtin, 1981, p.276). These dialogical threads within the women's lived experiences may reinforce or challenge the notion of 'dual handicap' in their lives.

Dialogical Nature of Social Languages

Bakhtin was interested in living language or speech that is spoken by "real individuals in specific situations and addressed to audiences both immediately and distantly present" (Skinner, Valsiner & Holland, 2001, p. 3). Living language is made up of social languages, each containing specific ideologies or perspectives. Bakhtins' conception of Ideology describes an approach that people may have developed to view the world, a system of ideas or what Bakhtin calls an ideological self.

For Bakhtin, ideology is a dialogized system. This concept refers, on the one hand, to the generalized belief systems which organize the political, religious, economic, and other institutions in any given historical time and place and also to the personal belief system under which the individual conducts their everyday life. When Bakhtin states "every man [and woman] is an ideologue", it possibly can be understood that every person has a viewpoint, but they are not locked into it, simply because they are always making new meaning with others. Therefore, ideological beliefs can shift and change over a time, sometimes from one situation to another, influences people's actions. As Aronowitz (1994) has explained best:

> *Ideology is not located in consciousness as a subjective reflection on reality. It consists of practices, not disembodied thoughts. Ideology is inscribed in the way we deal with the practical problems of daily life, in the things we buy and eat, the ways we "spend" time, which movies and TV shows we watch, the kinds of friends we choose to keep* (p. 164)

Holland and her colleagues (1998) expand on the above point, that there is a history in person, which also shapes social activity. Every person has a stabilized inner speech that then forms a "stabilized social audience that compromises the environment in which reasons, motives, values and so on are fashioned" (p. 189). These stabilized audiences may include

specific persons or an idealized one, creating an ideology, or a system of knowledge. Therefore, ideology can be viewed as a habituated, figured world, where views become stable and "identity becomes habituated, usually common" (p. 189) towards a significant audience. These ideological beliefs create and form social languages that are "socio-ideological; languages of social groups, "professional" and generic" languages, languages of generations, and so forth" (Bakhtin, 1981, p. 271). Here the person's ideological beliefs and values are created and contested interpersonally through the discourses that created and maintain such positions; examples of these social languages specifically related to dual handicap can include the professional jargon of psychologists, any social group, the language of political campaigns specific to gender and/or disability, and the language of doctors.

A living language is made up of multiple social languages, each attached to different ideologues and perspectives. The style of the speaker depends on how they relate to the social group containing the particular social language. In every society there is a social group that is not equal in power, prestige or authority (Skinner, et al., 2001) and in another society there are counter-hegemonic social language that "threatens to weaken and subvert more authoritative ones" (Bakhtin, 1981, p. 240). For Bakhtin then, "language is heteroglossic, composed of a combination of social languages, some of which are engaged in opposition and struggle" (p. 294).

Meaning Making through Speech Genres

In addition to social languages, heteroglossia is also realized through what Bakhtin terms as speech genres. I will address speech genres through this work as a stable type of utterance, which develops around any particular activity in which people use language "confidently and skillfully in practice and do not necessarily even suspect that they exist in

theory (Bakhtin, 1986, p.78). Speech genres are typically learned in childhood and develop out of social interactions, learned as people learn language and before grammar is acquired. I use Bakhtin's speech genre work to demonstrate how the language and the practices embodied in disability-related policy documents are translated into the realities of women's lives and their experiences. In particular, my analysis of disability and gender related policy documents (CEDAW and CRPD) in light of how they address the interface of gender and disability, aims to understand how women's narratives (i.e., as the primary genre in Bakhtin terms) are influenced by the figure world permeated by the policies and practices (i.e. secondary genre in Bakthin's terms).

In general, the ability to understand and manage "genres are not relative to language ability but rather stems from a familiarity with various spheres which is obtained in one's culture" (Bakhtin, 1986, p. 80). Skinner and her colleagues (2001) believe that the theoretical concepts of speech genres are not necessarily associated with a particular social group as is a social language, but instead associated with particular forms of utterances and particular speech situations (Wertsch, 1991). Examples of speech genres include poems, folksongs, parodies, scholarly treatises, and for the purpose of this research, I will add political text such as policy documents. Although there is room for creativity, often the particular speech genre "shapes one's words and manner of speaking in ways that are predictable and customary" (Holland et al., 1998, p. 8).

Wertsch appropriated Bakhtin's (1986/1952) notion of speech genres and coupled it to the notion of mediation (Wertsch, 1991, 1998). Speech genres as a cultural tool are used to mediate action, treated as "systems of meditational tools rooted in sociohistorical, cultural and institutional settings" (Cresswell & Teucher, 2010, p. 3). These institutional systems all have

their speech communication marked by the communities themselves. Therefore Wertsch (1991) argues that by acquiring the speech genre or generic language and learned utterances of a community, is the same as acquiring tools that mediate one's higher mental functions and action.

Bakhtin differentiates between two basic types of speech genres, the primary (simple) and secondary (complex) speech genres. The primary speech genres are concretely and immediately related to our everyday experiences. Primary genres in a given society might include greeting and farewells, congratulations, good wishes, informal inquiries about health or business as well as the more personal family and intimate genres. They may be highly ritualized, as such as greeting exchanges, or particularly creative and expressive they are unmediated. Generally, individuals do not have to think about them before speaking and become natural, occurring as part of our social day.

The secondary speech genres (complex) are described as a "more complex and comparatively highly developed and organized, cultural communication" (Bakhtin, 1986, p. 62). Examples of secondary speech genres can be found within artistic, scientific and sociopolitical realms through novels, dramas, scientific research and policy. This category includes most written communication from the novel to the business letter but other examples may include a military command, the language of the professional or of the courtroom, the speech of a news broadcast or a political speech.

The primary speech genre are performed in the everyday sphere, through "unmediated speech communion" (1986, p. 62), where the secondary genre "absorbs and digests" and alters the primary speech genres, which is why "the nature of the utterance should be revealed and defined through analysis of both types" (1986, p. 62). Therefore it is important to note that for

Bakhtin the primary and secondary genres do not represent two mutually exclusive categories and "one must analyze both types to understand the nature of the utterance" (Bakhtin, 1986, p. 62) and may act as a signifier of social, cultural change. Genre forms remain stable as long as they adequately refract the underlying social evaluations, the social reality of their surrounding environment. Once a particular genre no longer adequately represents the evaluation of a constantly changing society, it becomes destabilized and either changes to adapt to the social conditions or else fragments and disappears. For the purpose of this research, historical and contemporary British and international policies will later be defined in this section as a secondary speech genre, used as a mediating artifact, influencing the primary speech genres of physically disabled women in everyday conversations.

This research questions and reflects on the discussed dialogical framework and the words of the others when asking physically disabled women in London to co-construct their personal experiences. This work specifically explores Bakhtin's notions that the participant's words have previously been spoken by others and any social relational experiences they have will play at the core of their meaning making within their culture and context. As a result, the women participants react to others in the present situation or a perceived audience in the future. For this dissertation, Bakhtins' concepts of living language, previously discussed includes prior policy work (CEDAW, 1979), specific to women, practicing at a local policy level or other contextually situated audiences such as parents in relationship to these women as child, teachers in relation to them as students, relationships between gender roles, disabled women in relation to institutions power holders (doctors, nurses, travel insurance), disabled women in relation to British culture and so forth. Each of these relationships provides a context for each other.

This dissertation will be framed in a socio-historical perspective using Bakhtin's theoretical works of language; such as words, utterances and social languages. This approach gives primacy to the dynamic relationships between individuals and the social, cultural and historical contexts that embed their experiences, and provides a new lens for understanding physically disabled women's experiences. The dissertation will rely heavily on positioning theory and narrative theory to analyze physically disabled women discourses in England.

Narrative Analysis: An Overview and Rationale

This dissertation revolves around narrative analysis and this section's purpose is to unfold the relevant literature with the lived experiences of the participants. In this study, it is argued that socio-historical theory frame narratives as an interactive cultural activity (Bamberg, 2004). Narrating is an activity that individuals engage in specific cultural contexts (Daiute & Lightfoot, 2004) and are not simply reflections of a cultural world, but instead narratives are cultural tools and sites of social interaction. Narratives reveal personal constructions of events, as well as the relationship between the individual and society, yielding critical perspectives on the impact of policy and local practices.

I use narrative analysis to investigate how physically disabled women explore and interact with their human rights within their lived experiences as both women and women with physical impairments. I use a dialogical perspective, focusing on the transactions and complex relationships between women and their environments (Stetsenko & Arievitch, 2004). Narrative analysis provides a theoretical and methodological foundation to demonstrate the use of international policy as a mediating tool dialogically joining physically disabled women and their local contextualized practices situated in London and Coventry, England.

For the purpose of this research, I framed all narratives as "a story told by an individual or group of individuals" (Plummer, 2001, p. 42) and are "sites of development as well as sites for examining development" (Daiute & Lightfoot, 2004, p. viii). As explained by Daiute & Lightfoot (2004), "narrative discourse, like other discourses, is thus of the world not about it" (p. xi). The discursive activity acts as a site for the construction of knowledge and "come to endow experience with meaning" (Bruner, 1986, p. 12). Therefore, narratives are characterized by rich descriptions of human experiences and function to locate these experiences in time and place (Bruner, 1986) and function to contextualize the person and their story (Bruner, 1990).

This research conceptualizes narratives as complex personal and interpersonal relationship. Bakhtin described narratives as "externalized, multivoiced utterances that originate from the author's internalization of past and imagined dialogues and encounters in the social world" (Skinner, Valsiner & Holland, 2001, p. 3). Where speech is a living language and all complex societies take place against a "varied and multiply accented voices which a member of a given society encounters every day" termed heteroglossia (Bakhtin, 1981, p. 262). Within a narrative, language such as social dialects, professional jargon, language of generations and age groups, and language of the authorities, can all be used differently depending on the context and purpose of the interaction (Bakhtin, 1981). Therefore, narratives are a "primary site for analysis of the mutual constitution of self and the social world, of meanings at the personal and cultural levels" (2001, p. 2) emerging from "changing socio-historical contexts" (Daiute & Lightfoot, 2004).

In recent years narrative forms of inquiry have become increasingly visible within disability studies (e.g. Marks, 1999; Thomas, 1999; Goodley, et. al, 2004; Smith and Sparkes, 2005; Todd, 2006), but are still considerably limited when addressing the intersections of the

experience of both disability and gender. Physically disabled women's narratives are still largely absent from the forefront of disability literature and qualitative research. This research will attempt to address this gap by utilizing narrative approach to understand how physically disabled women co-construct their lived experiences within the context of group semi-structured interviews.

As discussed previously, to date autobiographical work is the most common form of qualitative work by physically disabled women from Britain and the United States. Key disabled women scholars such as Morris (1991), Smith (1999) and Sparkes (2002); Linton (1998) and Neville-Jan (by Fran, 1995) have crafted such work. In contrast, this dissertation hopes to act as a manifesto for women with physical impairments tell their story together creating coherences and tensions, build communities with others who may share common experiences and 'produce change in the political process by challenging the dominant narrative" (Smith & Sparkes, 2008, p. 24). Bakhtin (1981) stressed that "struggling with another's discourse is crucial for the development of an individual's (or group's) ideological consciousness" (Skinner et. al, 2001). This research hopes to provide this within the discussion groups.

The focus of this study is to explore physically disabled women's experiences, which are not often represented within these institutions, cultures or relevant areas of political activism and academia. Within particular societies and cultures throughout history, some narratives are privileged and others silenced. In the context of the proposed study, typically marginalized disabled women narratives will be collected to analyze the relationship between disability and women within a broader social, cultural, political and historical context as mediated by gendered (CEDAW) and disability focused (CRPD) political documents.

As a methodology, narrative inquiry allows an understanding of how disabled women experience their lives in relationship within historical and contemporary policy and practices. This exploration is through narrative work, allowing a social dynamic process, as groups of women narrate together, co-constructing meaning, shedding light on relationships and reflecting the dynamics of power and positioning within their lived experiences. In the context of this dissertation, narrative inquiry is utilized to provide a window into disabled women's perspectives and experiences as they reflect and discuss the role of policy in their lives.

Dominant Discourse

Although a person is guided by their reconstructions of culturally available means like speech genres and social languages (Skinner, et. al, 2001), this work will also discuss the significance of dominant discourse within narratives. When Mikhail Bakhtin (1998) states "every man [woman] is an ideologue" or every person has a viewpoint, it is critical to understand that these perspectives are not necessarily locked. Instead, each person is making new meaning with others and individual's belief shift and change over a lifetime, sometimes from one event to another. Therefore, yes, physically disabled women are guided by their "reconstructions of culturally available means like speech genres and societal languages, and are reproduced with certain meanings and echo familiar or dominant voices but reproduction is not certain" (Skinner, et. al, 2001, p. 13) within every interaction.

Within the field of narrative analysis, several theorists have discussed the role of dominant or master narratives, which are "frames according to which courses of events can be easily plotted, simply because one's audience is taken to 'know' and accept these courses" (Bamberg, 2004, p. 361) through which people make meaning. These dominant discourses permeate cultural knowledge, creating a social group that is not equal in power, prestige or

authority. Therefore, the voice of one group may be authoritative and hegemonic, suppressing other voices (Skinner, et al., 2001). In this studies context, I frame the dominant discourse of disability and gender, as being abled bodied, "normalized" (Davis, 1987) and male as the dominant discourse (Linton, 1998). I follow Linton's' work (1998) and I analyze disability as a social, political, cultural, historical and discursive phenomenon rather than an individual or medical notion and understand that this construction is even further complicated by gender. But as Bakhtin (1981) believes, in any society there is heteroglossic language, composed of a combination of social languages, some of which are engaged in opposition and struggle"(p. 294) creating counter-hegemonic voices that threaten to weaken and subvert more authoritative ones.

Bamberg notes that while dominant discourses provide coherence and a "sense of direction" towards thoughts and meaning making, these discourses are problematic in that they potentially marginalize people (2004). Dominant discourses are reflective of cultural expectations and sometimes reduce the range of socially possible actions (Bamberg, 2004; Harre & Mohaggadam, 2003). In the context of this dissertation, I argue that historically the dominant socio-political discourses have been male focused and non-disabled, ultimately contributing to cultural expectations and experiences that have limited and constrained physically disabled women's lived experiences. Ahearn (2001) notes an "impersonal" nature which characterizes dominant discourses, which "leaves no room for tensions, contradictions, or oppositional actions on the part of the individuals and collectivities" (p. 110) can possibly be applied to physically disabled women.

Different from individual interviews, group 'communicative competence' can support cohesion between members; the group of interacting women also provides opportunities for

contestation of opinion. Adversarial sites also "arise from within different group affiliations and subgroups contesting the conclusions of other subgroups" (Adler, 1996, p. 111). As the physically disabled women construct narratives within discussion groups, they can together create experiences which may challenge dominant power relationships and social expectations. These described experiences can complicate and restructure dominant constructions, allowing "the diversity and multiplicity of language creating the possibility of resistance because non-hegemonic discourses which can be used to destabilize and subvert hegemonic discourses" (Bamberg, 2004, p. 204).

By engaging group narratives, feminist perspectives suggest that research actually becomes more objective and expansive (Harding, 2003). Harding (1993) puts forward the notion of the social construction of knowledge, questioning the traditional positivist premise of a single, fixed, objective reality. Instead, she argues that individuals construct reality in multiple ways, from various standpoints, mediated by social context, power, and position (Harding, 1993). She argues that researchers should first engage marginalized individuals to elucidate silenced perspectives; marginalized lives, she argues, often bring forth new perspectives on powerful groups and social norms overlooked by the powerful groups themselves (Harding, 1993). Therefore, by engaging and privileging multiple perspectives, and particularly, by starting with marginalized lives, the researcher actually becomes more objective and informed, compared with traditional positivist methods (Harding, 1993).

Extending from Harding's work, feminist Standpoint theory has specifically reformulated gender identity as a complex, dynamic matrix of interrelated, often contradictory, experiences, mediated by culture and individual history (Garland- Thomson, 2005). This extension of Standpoint theory recognizes the immediacy and complexity of physical existence.

Emphasizing the multiplicity of all women's identities, histories, and bodies, this theory asserts that individual situations structure the subjectivity from which particular women speak and perceive (Garland-Thomson, 2005). The multiplicities of women's bodies allows for fat, disfigured, abnormal, ugly, or deformed to enter into identifying sites where individuals and others situate meaning and discourse.

Eliciting narratives embedded in their lived experiences from physically disabled women, as a generally understood marginalized and socially silenced group, can inform the current body of research. These alternative stories challenge prominent social constructions (Bamberg, 2004). Engaging women and asking them to discuss their life experiences as mediated by policy can contribute to the further construction of counter-narratives, which can bring forth new research questions and implications for policy and local practices.

Carnivalization

The carnival is introduced and inspired by Bakhtin's book on *Rabelais and His World* (1968), which specifically addresses the inherent nature of the carnival. In carnival, "laughter and excess push aside the seriousness and the hierarchies of the "official" life. Carnival shakes up the authoritative version of language and values, making room for a multiplicity of voices and meanings" (Elliot, 1999). Here Bakhtin's theory of multiplicity and dialogic language disrupts uniformity of thought.

Two main characteristics that portray the carnival within discourse are laughter and ambivalence. "Through laughter, the world is seen anew, no less (and perhaps more) profoundly than when seen from the serious standpoint…. Certain essential aspects of the world are accessible only to laughter" (Bakhtin, 1968, p. 66). It is not the objects of laughter but instead the perspective of laughter (Elliot, 1999) which allows "movement" and "draws

attention to the forms of relationship, rather than the one-sided fixed hierarchal relationships. As Lachman (1989) describes, "In the carnival, dogma, hegemony, and authority are dispersed through ridicule and laughter" (p. 130) and carnivalesque rituals are "not actually directed against institutions, whose functions and forms are only usurped for a temporary period of time, but rather against the loss of utopian potential brought about by dogma and authority" (p. 130). Laughter "overcomes fear, for it knows no inhibitions, no limitations" (p. 131).

Therefore, Bakhtins' theory of carnival can be connected to Bakhtins' theory of dialogue. The carnival is a vehicle for the voices of the oppressed, a time and place for marginal expression is heard, or carnival can be a vehicle of control whereby the powerful and conservative forces allow the people a limited time and space of freedom. Stallybrass and White (1986) refer to a large and increasing body of writing which sees carnival not simply as a ritual feature of European culture but as a mode of understanding, an analytic category. The carnival itself is not adequate to affect a revolution or even deep social change. Instead at the site of discourse, the act of laughter challenges and creates tensions towards groups and classes "situated" by the dominant or marginal positions. This laugh act can carry the promise of politically transformative power. Elliot (1999) claims "awareness and creative manipulation of diverse modes of discourse" and even a "control of the major sites of discourse is fundamental to political change" (Stallybrass & White, 1986, p. 201). By integrating the carnival or laughter into the discourse analysis, I extend the understanding of how women with physical disabilities may create various positions from the dominant narratives.

Positioning Theory

Positioning theory is a way of conceptualizing social relationships through the manner in which individuals position themselves and others in discourse (Harre & Gillet, 1994).

Positioning theory (Brockmeier & Harre, 1997; Davis & Harre, 1990; Harre & van Langenhove, 1991; Varela & Harre, 1996, cited in Morgan 2004) suggests that "we speak ourselves into our communities, producing ourselves as subjects and communities of voices simultaneously and re-producing them in various versions through multiple relationships" (Morgan, 2004, p. 334). "Positioning" is a fluid concept that replaces the more static notion of "roles" that individuals possess in social relationships (Harre & Gillet, 1994) and recognizes the force of discursive practices, the ways in which "people are positioned through those practices and the way in which the individual's 'subjectivity is generated through the learning and use of certain discursive practices" (Davies & Harre, 1999). As discussed within the theoretical section, this research centers on the belief that a conversation unfolds through the "joint action of all the participants as they make (or attempt to make) their own and each other's actions socially determinate" (p. 34).

Each speaker within the conversation is not a fixed end product but instead is a "mulit-positioned author-in a temporal movement of positioning and re-positioning- addressing simultaneously the interlocutor and other audiences, including him/herself, and other social discourses that contrast with that specific utterance" (Cunha, 2009, p. 123). The person brings to the particular situation that from their own history that a person "has been in multiple situations and engaged in different forms of discourse" (Davies & Harre, 1999, p. 37) throughout their lives.

The act of positioning can be deployed in an interactive or reflexive context (Davies & Harre, 1999). Interactive positioning occurs when individuals position others through discourse, and reflexive positioning occurs when individuals position themselves (Davies & Harre, 1999). This process is complex and relational and the manner in which individuals

position themselves and others (Harre & Gillet, 1994) highlights perceived power differentials and relationship dynamics, as "language and power are…intertwined" (Ahearn, 2001). What often occurs through social discourse is the act of challenging the manner in which one is positioned and proceeding to reposition oneself, a process Harre and Moghaddam term "metapositioning" (2003). Parker (1997) suggests that the "notion of subject position is a valuable tool for understanding abuses of power" (p. 291). Positioning reflects the continuously changing nature of power relations within the context of social exchanges, but also in relation to "the socio-political level which unfolds and is inseparable from the personal" (p. 291) in a fluid manner.

Using a positioning theory analysis within the discussion group methodology provides a means for studying human behavior and relational dynamics in an interactive context. As Harre and Mohaggadam explain;

> *An important feature of social behavior is the collaborative construction of social reality and the mutual upholding of particular interpretations of the world. By implication then, psychology should also explore collective processes rather than only focusing on isolated individuals in static situations* (2003, p. 3).

In the proposed study, narratives will be analyzed with the understanding, that each woman is a dialogical self in a "dynamic movement of positioning and re-positioning in time" (Cunha & Goncalves, 2009) and the awareness that "we speak ourselves into our communities" (Morgan, 2004). These women's narrative includes their personal experiences within their own social realities, exploring their collective processes and their "knowledge of social structures and the roles that are recognizably allocated to people within these structures" (Davies & Harre, 1999, p. 42). For the purpose of this research, the inquiry is not filtered through the

discourse of professionals. Instead this research explores the "language of power" and how physically disabled women together make meaning of their own socio-cultural political worlds, mediated by their own personal histories. For example, when the women discuss Article 24-The Right to Education (CRPD, 2006), they might refer to their own schooling experience and define their educational rights through the learned roles of 'teacher-student' as the language of power, being positioned within the structure of a school. Language that reflects paternalistic roles such as "wrong", "help", or "support" could be used to demonstrate this position.

Bakhtin: Addressivity

A central consideration for social discourse within the framework of positioning theory is the notions of addressivity. Bakhtin (1986) recognized that individuals only exist and derive meaning in relation to one another. Each social relationship is contextualized and plays a role and they become what they are in relation to others, both in present and historically (Graue, Kroeger & Prager, 2001). This social-relational theory is the foundation for addressivity, which "focuses attention on how acts have trajectories created for presumed audiences and hoped for ends" (p. 473).

Since humans are "sentient beings always existing in a state of being 'addressed' when "the world addresses us and we are alive and human to the degree that we are answerable"(Holland et. al, 1998). Therefore, "we are compelled to respond, we cannot choose but give the world an answer" and "we must keep on forming responses as long as we are alive"(Holoquist, 1990). We are all involved in creating an addressivity and answerability dynamic. This highlights the notion that individuals are social beings, and all of our words and acts are filled with intentions and experiences of others.

Embedded in narratives are hidden and explicit "audiences" (Daiute, 2001). To fully understand a narrative is to listen to "voices that have in some way influenced the narrators, those that would want to silence them and those who might be influenced by them" (Dauite & Lightfoot, 2004, p. 1). A methodological tool for exploring the role of audience in the construction of narratives is to make such audiences explicit for the participants by asking participants to specifically orientate their narratives to certain persons or institutions (Daiute, et. al., 2003). For example, in this dissertation, I would request the group of participants to speak about a specific United Nations article relevant to their medical rights. By requesting the group to address certain institutions; such as the medical institutions, such audiences are made explicit. This strategy hopes to clearly delineate to whom the participant is speaking, and the manner in which the participant positions themselves to the audience, revealing valuable insight into social dynamics and power relationships (Daiute, 2001) and then exposing the Hidden or implicit instead. By integrating audience into a positioning analysis, I extend the inquiry, facilitating an exploration of the struggles and intentions involved with the implicit and explicit audiences.

CHAPTER 2

METHODOLOGY

Research Methods

Study Plan

In this study, I took the standpoint that in order to understand physically disabled women's lived experiences as political beings, the starting point of knowledge must be the women themselves. This is consistent with Standpoint epistemology (Harding, 1993) which stresses that the shared and situated perspectives of those who have been marginalized provide the "grounds" for knowledge or the "sites" from which critical questions emerge.

Based on this grounding assumption, I used a narrative analysis approach, which is an appropriate method for achieving the objectives identified for this study. Using qualitative methods including narrative analysis and discourse analysis, group narratives were collected from physically disabled women about their lived experiences as being social political actors, their perceptions of being a woman with impairment, and the ways in which they make sense of their experiences in the context of the society in which they exist. This method is consistent with the study's emphasis on the social, cultural and historical contexts within which meaning is derived. Women generated stories in response to open-ended questions framed by a new United Nations international convention (CRPD, 2006). I examined the positions that the women took within the context of their human rights and privilege their standpoint.

Study Setting

This research has been conducted in England; specifically participants are recruited from London and Coventry, England. This section will attempt to describe these two areas in

England utilizing indicators such as ethnicity, age, gender, marital status and disability. These points are noted in an attempt to contextualize the locations and address if the participants within the study are representative of the demographic indicators within these regions.

Coventry is considered to be the ninth largest city in England and is located in the West Midlands approximately 95 miles northwest of London and 19 miles east of Birmingham. This city is historically known for the severe bomb damage during World War II, known as the "Coventry Blitz" in 1940. Firebombing led to severe damage to large areas of the city center and to Coventry's historical cathedral. As a result, this city suffered more damage than any other British city with more than 4,000 houses were damaged or destroyed, along with around three-quarters of the city's factories. Due to these raids, most of the historical buildings and the city's infrastructure was rebuilt and almost completely altered by 1970.

During the 1950's and 1960's was the 'Golden Age' in Coventry where the motor industry boomed and this area had the highest disposable income in England which highlighted both the sports and the arts for the area. In 1965, the new University of Warwick campus was opened and become one of the country's leading higher-education institutions. Over this time, Coventry's large industrial base made it attractive to Asian and Caribbean immigrants from the Commonwealth colonies after 1948. In 1960, one of Britain's first mosques was opened in the city's growing Islamic community.

In the 1970's however, the British motor industry declined and Coventry economically suffered. By the 1980's, Coventry had one of the highest unemployment rates in the country and crime rates were also high. Thirty years later, Coventry is now considered to be a much safer city and is gradually recovering economically, although the motor industry continues to

decline. Large city initiatives are occurring in hopes to redevelop the city center by adding more shopping and walking paths for pedestrians.

The Office of National Statistics (UK, 2009) states that the current population for Coventry is approximately 310, 000 people total. From this population, the largest percentage is described as 'White British Persons' at 74.1% , which is representative of the women participants in this research. The largest group of people living in Coventry is between 75 to 84 years old (National Statistics, 2004), which is not representative of this study. Data for gender shows that there is almost equal numbers of males (149,000) and females (151,000) and the number of people never married is almost half of the total population at 145, 000 (National Statistics, 2004). The individuals that have been married, statistics show they have been 'married one time' at 96, 0000 which is representative of the participants in this study.

In 2005, the Coventry City council organized and adopted what is called the Disability Equality Scheme. The objective of this report and an action plan is to "make sure that we take the priorities of disabled people into account in everything we do, including our roles as service provider, leader, partner and employer" and "outlines our commitment to making life better for disabled people in the city" (p. 3). This report has noted that the population in between the ages of 16-24, there are approximately 843 adults with a physical disability, 830 adults with a learning disability, and 979 adults with a mental health disability. It has also been noted for adults aged 65 and older in Coventry there are 3536 individuals with a physical disability; 38 people with a learning disability and 860 people with a mental health disability. At this point within the Coventry City Council report, the variables of gender and disability have not been noted.

The second setting for this study was in Lambeth, a borough of south London, considered to be a historically urban multi-ethnic area. According to Census data (2001), the total population for this borough is approximately 266,000 people with an almost equal distribution between men and women. The majority's age ranges between 25 and 35 years. With a noted 118,000 households the majority of people live either alone (45,000) or as a 'one family household only' (52,000), with married families at 21,000. Marital status shows that a majority of the residents (266,000) have never been married (177,000) and 54,000 are on their first marriage. The majority of the individuals were born in England: United Kingdom (177,000) and secondly from Africa (24,000) primarily from Central and Western Africa (14,000).

When comparing the women participants within this study to the above demographics, the age range, housing status and marital status are representative of this London borough but the birth of origin is not representative of the participants within this research. According to United Kingdom Census Data (2001) the majority of this London suburbs' population is considered to be White British (132,000) with the next largest ethnicity being Black or Black British, which may include women from (prior) colonized countries such as the Caribbean and African countries, which represents the majority of the participants.

For this borough, specific data regarding impairments could not be found. Although data that could be of similar findings titled, 'Incapacity Benefit/Severe Disablement Allowance' described over 11,000 people within this area are entitled to this allowance. The majority of the people were between the ages of 25-49 years old and the majority were male (6,900) versus female (4,900). The medical reasons described, claiming for 5 years or more were "mental disorders" (5,800) and then "other disorders" (2,000). These statistics from May,

2010 through the Office of National Statistics do not represent the participants within this research.

In 2006, the local council created a document called the Disability Equality Policy created from legislation, the Disability Discrimination Acts (2004, 2005). This document includes identifying all the possible ways discrimination can occur including the point that "some disabled people face discrimination not on the grounds of being disabled but also on the grounds of their gender, race, sexual orientation, age, religion, etc." The local authority council uses the Disability Discrimination Acts'(1995) definition of disability as a "physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities". Under the Disability Discrimination Act (2005), this definition has been extended to cover Multiple Sclerosis, HIV and cancer from the point of diagnosis. In addition, the local authorities have taken the liberty within this document to extend this definition using the social model of disability as well.

Participants

Eighteen women with physical disabilities participated in this research over the summer of 2009. These participants met the following criteria: (a) women medically and self-identified with a physical impairment which may include, but not limited to, partial or whole body paralysis; partial or whole loss of limbs, or deaf and hard of hearing; (b) women are 18 years or older; (c) able to provide consent for themselves and; (e) women living in Greater London area. It was assumed that participants would include variance in age, race, ethnicity, income, policy experience and education.

The fourteen participants in Lambeth included women with physical disabilities between the ages of 23 and 54, with various physical disabilities such as, Cerebral Palsy,

Arthritis, Brain Injury, Stroke paralysis, hard of hearing, and blind. The information was obtained by an informal questionnaire provided by the researcher at the beginning of the study. A majority of the participants are originally from other countries such as Jamaica, Kenya, Nairobi, Ireland and two women out of the fourteen were originally from the London area. Twelve out of the fourteen women were not married or in a romantic relationship. Only one woman during the research was married with children and explained that her marriage and birth of her children occurred before the onset of her impairment; and one woman was in a relationship with two children prior and during the onset of her impairment. All women had minimal educational experience and were members of the local Rehabilitative Centre, where the research took place and all lived locally and had previously attended the women's group meeting.

The 4 participants from Coventry ranged between the ages of 45 and 52, with various identified physical disabilities such as Cerebral Palsy and Multiple Sclerosis. Three of the four participants are originally from the London area and one participant is originally from China but had lived in England for years and spoke English fluently. All women lived locally and all had high school equivalent or above. They had previously met at training on disability benefits provided by their local city council. Three of the four women were currently married and one was divorced, three women had two or more children and one did not have children.

Procedures for Recruitment

The participants of interest for this study are women (18yrs or older) with identified physical disabilities living in London or Coventry, England. After researching over the internet for organizations that work with both women and women with disabilities, a London based non-profit women's organization was contacted via email with an attached explanation of the

study. Through further phone contact, this women's organization provided a contact list of women with disabilities that were interested in participating in research. I was able to travel to London in the spring of 2009 and discussed the research in small information sessions with fourteen physically disabled women in London and four in Coventry, England who all met the criteria and agreed to participate in the research. Fortunately, three weeks prior to my initial contact, one Rehabilitation Center in a borough of London affiliated with the women's non-profit organization had recently established what was described as a 'physically disabled women's support group'. These women were currently meeting once a week for 1.5 hours at a Rehabilitation Center for an open informal round table discussion. It is the researchers' understanding that the intended purpose of the meetings was for peers and staff to provide social and emotional support specific to the women's needs or wants. The group included approximately 20 women identified with physical disabilities, such as but not limited to Cerebral Palsy, significant physical limitations due to arthritis, and stroke paralysis. Fourteen of these women agreed to participate in the research, understanding after each meeting they would be reimbursed a 5 pound gift card to the local Body Shop store.

The second group of women in Coventry was formed by one woman working with the women's organization in London. Three other women agreed to learn more about the study. At this point research information was sent via email attachment and all four women with physical disabilities agreed to participate. This group met over two consecutive days and each person was reimbursed for transportation and lunch; in addition snacks were provided both days.

Procedure for Data Collection

Prior to making contact with participants or beginning date collection, an Institutional Review Board application was submitted and approved by the CUNY Graduate Center.

Data was collected in three parts. First, through semi-structured interviews conducted with physically disabled women. Next, data was collected using two United Nations policy documents, the *Convention on the Elimination of the Discrimination Against Women* (CEDAW, 1979) and the *Convention on the Rights of Persons with Disabilities* (CRPD, 2006). The documents were downloaded and analyzed from the United Nations website. Last, data was collected through a literature review obtaining information for a historical analysis. These data collection points are discussed further below.

Discussion Groups

The methods central premise is to recognize that the experiences of physically disabled women are valid and have authority with their own lived and political experiences. I elicited co-constructed narratives from physically disabled women through a semi-structured process. For the purpose of this research, the term 'discussion group' will be used to describe this format.

This methodology aimed at shifting power and knowledge production to the women with disabilities from the "other" authorities or audiences. This study was consistent with "inclusive, action based research strategies, where disabled people are involved as consultants, not as research subjects" (Kitchen, 2000, p. 26). By seeking and presenting the views of the participants, this research responds to the call of the international disability movement and feminist disability studies by only undertaking research towards the removal of disabling barriers (Kitchen, 2000, Chappell, 2000).

Data was collected through the discussion group sessions. Group narratives have important advantages both in the dynamics present and the outcomes that can be achieved for individuals due to physical limitations, (e.g. individual interviews, questionnaire) would be

more difficult. These groups include a place for women to interact and be influenced by each other. As a result, women can make decisions after listening to the advice and counsel of other women around them. Here they can tap into the natural processes of communication such as joking, boasting, teasing, persuasion, challenge, and even disagreements (Wilkinson, 1999). Therefore each participant is not an individual acting in isolation but instead, a member of a social group, interacting with each other, providing a social cultural context and generating meaning making together. The group work is a social experience, and conversational questions help create and maintain and informal environment. Participants are encouraged to build on one another's comments, rather than directing each comment to the researcher (Krueger & Casey, 2009). This methodology is not often used within feminist work or even in feminist psychology (Wilkinson, 1999). Other work using group discussions has been completed within the United Kingdom, but primarily with groups of adolescents or adults with learning difficulties (Goodley, 1998, 2000).

While group narratives have positive attributes, it is beneficial to note and consider a number of obstacles as well. Common criticisms related to this methodology are often specifically related to individuals with limited or non-verbal communication. This did occur within this research and often the group discussion was slowed down when the participant raised their hand to discuss their experiences. This needed to be established within the group ahead of time to decrease the possibility of limiting participants their opportunities to discuss their opinions. Furthermore, during the discussion groups either staff members or family members were present, which was not the original structure agreed upon by the women participants. Having these family members or staff members present and active in discussion could shift the power dynamics within each group. In addition, Krueger & Casey (2009)

describe the possibility of participants to intellectualize their experiences and not "tap into their emotions" (p. 13) or may make up their answers if they are unclear of the topic discussed. While it is acknowledged by the researcher that these concerns did exist, discussion groups were still considered to provide a "potentially powerful tool for communicating experiences which would otherwise remain hidden or invisible" (Cambridge & McCarthy, 2001, p. 477; Stalker, 1998).

I arranged to meet with women at a time and location that was convenient to them. The locations of the groups, which are discussed later in this paper, include two locations, a room within a Rehabilitation Center in a borough of London and a café located in an art museum in Coventry.

Between 07/01/09 and 09/01/09 each person who met the study inclusion criteria, first attended a research information session. During this session, the purpose and goals of the research were explained; they were assured confidentiality and provided time to answer any questions and decline to participate in the study. Only 6 people (out of 20) refused in London and all four participants in Coventry agreed to participate. Another meeting was organized, IRB consent forms (see Appendix C, Consent Form) were distributed and explained, each women was encouraged to think about the research further and bring the participation form back the following week.

Additionally, I asked the women to provide non-identifying demographic information, on age, ethnicity, sexuality, education and country of origin. This non-identifiable demographic information was shared with the Women's Resource Center providing information for future work and support through them. Each group discussion was recorded and then transcribed by the researcher. A sample introduction to the first group meeting is provided (see Appendix A).

The following meeting, fourteen women in London and four women in Coventry returned their consent forms and asked any further clarifying questions regarding the research objectives and their involvement within the research. The remainder of the meeting sessions, this time consisted of introducing and reviewing human rights articles from the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD, 2006), asking women to discuss their personal experiences in regards to explicit articles. Articles from the convention were chosen by the researcher that specifically identified both women and disabilities. For example, Article 6 titled *Women and Disabilities*, specifically states, ***States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedom.*** This specific article and others were pre-determined by the researcher, and were intended to focus the narratives on the particular concept of 'dual discrimination' or 'dual handicap' previously discussed in this dissertation. These articles were identified solely to begin points of discussion and reflection for the groups (See Appendix B). These articles were discussed through questions such as; Why do you believe there human rights articles were created specifically for women with disabilities? How would you apply this to your life experiences? Following questions of this nature, women were asked to discuss their beliefs and perceptions about their political rights at their local and national level, as well as, what to do about any changes they may want to see within their identified experiences. It should be noted that while the questions specific to gendered articles within the international conventions provided a framework for the generating of the narratives, the narratives were not strictly directed by these questions or articles within the CRPD (2006).

Once the group narratives began, the issues raised by the women themselves served as points of inquiry. To a great extent, the women naturally determined through spontaneous discussion what they wanted to focus on together. Here they generated their own narratives based on their own personal experiences that were meaningful and significant to them. The researcher would then support the discussion by asking guiding questions for clarity in relationship to specific articles within the CRPD.

At the fifth and last meeting, the researcher introduced identified key themes from the previous four meetings. At this time, participants were asked questions that were self-advocacy based, such as "What if anything is next? Who is responsible to make these changes the group has identified? These questions were asked and a group action plan was created, directed by the researcher, to identify the women's understanding as political beings within their daily lives. Further, the stories generated in response to these questions were intended to highlight ways in which these women are positioned and position themselves through social discourse and to further understand the "language of power" embedded within their contexts.

Each group meeting with Lambeth lasted 1.5 hours (once/week for 5 weeks) and the Coventry group meetings lasted over two consecutive days for 3 hours each. All interviews were audio recorded. Each article that was chosen by the researcher or spontaneously discussed by the women was written and recorded on large chart paper in the front of the room and reviewed briefly each meeting. The objective of this exercise was to build on the knowledge of rights each week and hopefully extend and make connections or identify contradiction between articles. In addition, the women's group action plan was created and recorded on large chart paper at the front of the room.

Two United Nations Conventions

This research examines two United Nations treaties, the *Convention on the Rights of Persons with Disabilities* (CRPD, 2006) and the *Convention on the Elimination of Discrimination against Women* (CEDAW, 1979). Following Daiute's (2008) work, this research does not only focus on the treaty document itself, but reflects on the broader CEDAW and CRPD systems and that "documents are reference points for a broader range of activities by institutional actors" and are "created in the midst of activity-meaning making systems" (p. 706).

The CEDAW (1979) was purposively chosen because it represents women equality and anti-discrimination for over 30 years. The CRPD (2006) was chosen because it is a human rights instrument that represents equality for all individuals with disabilities and for the first time includes women with disabilities. I went to the United Nations website (www.un.org) and downloaded each convention as a word document. An identified list of words was created representing concepts specific to gender (e.g., girl(s), women), inclusive language (e.g., all, everyone), or impairment (e.g. disability). Both United Nations human rights documents content will be reviewed for specific language in context and the implications for disabled women as socio-political actors.

Data Analysis

As discussed, I recruited participants for this study by contacting women's organizations and rehabilitation centers. I conducted semi-structured group narratives with physically disabled women at a location of their choice and convenience. "Discerning distinct voices and their dialogic relationship in narrative is not a simple task" (Skinner, et. al, 2001, p. 13) emphasizing that "human development is a social process involving individuals,

institutions, and cultures and, therefore, requiring multiple level of analysis" (Daiute & Lightfoot, 2004, p. xii). This need for pluralism is supported by Coffey and Atkinson (1996), who suggested that qualitative researchers should consider a variety of analyses in order to understand their data in different ways. It is argued that analytical diversity is useful, because we researchers "can use different analytics strategies in order to explore different facets of our data, explore different kinds of order in them, and construct different versions of the social world" (p. 14).

Below I will describe the analytical tools I used to make sense of the data collected from the women's narratives contextualized within their human rights in England. All data was transcribed and analyzed. First, I constructed a historical overview intersecting disability and women's rights within the United Kingdom, England and the United Nations. The purpose of this section is to contextualize the social, political, cultural and historical production of the intersection of disability and gender and the set of values or meaning created over time. Second, I conducted a discourse analysis within and between two United Nations human rights documents (CEDAW and CRPD) as activity-meaning making systems. The purpose of this section is to demonstrate how each document separately and together provide a values system for disabled women within the human rights context. The third level of analysis demonstrates the interactions between the disabled women participants' narratives and the CRPD using a Relational Positions approach. The fourth and last level uses a discourse analysis approach to pull themes from the women's narratives when describing their lived experiences within the context of human rights (CRPD).

Historical Analysis: Context of British and UN Rights

Ann Borsay (2002) highlights that the understanding of disability history has been a missing piece of the jigsaw for Disability Studies across cultures. She argues that Disability Studies as a whole has expanded into areas such as, politics, culture and media; still "historical perspectives across the entire range of a disabled person experiences are virtually non-existent" (p. 11). 207). In examining the social, cultural, historical, and political developments within the United Kingdom over time, I relied on a number of Ann Borsay's (2002, 2005, 2006) writings about disability history. For the United Kingdom women's rights work, I conducted a review of the historical literature and news sources, such as British Broadcasting Corporation (BBC) *(*www.**bbc**.co.uk/). When I examined the British Disability Rights movements, I reviewed work by British disability rights activists, primarily through academic writings along with political and legal documents. For the United Nations disability and gendered political documents and movements, I mainly reviewed the United Nations website (www.un.org). This review of multiple sources helped to examine the dominant national ideologies as well as the most salient issues, discussions, and perceptions surrounding disability and gender within Britain and the United Kingdom. For example, this analysis may undermine the passive, tragic assumptions of the medicalized, biological model of disability and might suggest a shift in the burden of responsibility to the economic, social, and political organizations of society. Second, this review may demonstrate that attitudes and policies can construct societal beliefs about gender and disability making it clear that "policies from multinational agencies, central governments, local governments and institutions have shaped the lives of disabled people throughout the world" (French & Swain, 2006, p. 147). Third, the review seeks to identify whether disabled women specifically are mentioned within disability history. The question of how and if

disability and gender policy has developed within the United Kingdom "then reaches into global politics, power structures, ideologies and humanity" (French & Swain, 2006, p. 147).

CEDAW and CRPD: Activity-Meaning Making Systems

This analysis is based on Bakhtin's work (1986) and the assumption that secondary genres (policy documents) influence primary genres (women's narratives) where genres are defined as "culturally developed, that is meaningful, shared, and repeated discursive routines" (Daiute, 2010, p. 50). To conduct this analysis, I adapted Daiute's (2008) analytical design and data analysis procedure derived from a sociocultural activity theory of development and the discourse analysis methodology derived from this theory. In this view, this analytical design conceptualizes policy documents as dialogical "reference points for a broader range of activities by institutional actors…that are created in the midst of activity-meaning making systems within a series of meetings, as a response to previous interactions and directed toward future ones" (Bakhtin, 1986, as cited in Daiute, 2008, p. 707). This chosen analytical approach provides a way of considering the system of activities and interactions leading up to and within the broader CRPD activity-meaning making systems relevant to disabled women's sociopolitical understandings.

I first examined the broader CRPD systems and interactions, which included other policy work and key meetings examining international treaty documents as activity-meaning making systems. These systems of interactions, involved identifying activities such as policy documents, international initiatives; key Ad Hoc meetings that address dialogical relations from previous interactions and the characteristics of these discursive activities. Following Daiute's (2008) use of discourse analysis approach, I examine how dialogic relations across the CRPD activity-meaning making system offers insights about the tensions and dilemmas between the

broader CRPD systems and the women themselves developing their own rights based understandings.

Thus, in addition to further understanding the interactions within the broader CRPD activity-meaning system, I analyzed the language within and between two policy documents. Through a qualitative analysis of women's and disability rights, I reviewed both a gendered policy (CEDAW, 1979) and a disability policy (CRPD, 2006). Using a discourse analysis approach, I analyzed specific words (e.g., "girl", "women", and "disability", and "equal") in a context that examined the notions of women, human rights discourse and disability. For example, words such as *women* or *female* identified gendered language; words such as, *equal* or *some* identified human rights discourse and words such as, *disability* or *impairment* identified disability language within the context of the human rights. These words are further reviewed in Table 2 of chapter 4. Then, I counted the number of occurrences and documented each targeted word within both documents. These results are in Table 3 of chapter 4. Ultimately, I explored how these documents address one another through their representation, values and principles of disabled women as psychosocial actors within their own socio-political systems.

Paying attention to these small words within a larger document, I use Bakhtin's (1981) theory that all words are "tastes of the context in which it has lived its socially charged life; all words and forms are populated by intentions" (p. 293). Therefore, by linking the words and values in one document to another, I understand and further capture the nature and relationships among these documents. The discourse analysis approach focuses on identifying the explicit words within the two policy documents to then highlight the possible implicit values and discursive activities in which are embedded in a cultural-political system for disabled women.

Finally, I review the implications of the systems of interactions and the language in context across the CEDAW and CRPD as activity-meaning making systems. This analytical design was inspired by sociocultural theory understanding that disabled women interact within the broader institutional structures and systems within their everyday lives (interpsychological) to then make their own rights based meaning (intrapsychological). This research explores the major actors in the CRPD activity-meaning systems to reveal the tensions and power relations that may limit disabled women's rights.

In line with Bakhtin's (1981, 1986) theory that words are never neutral and come from collective experiences, I have chosen to interview physically disabled women and analyze their narratives against the background of the secondary genres or activity-meaning making systems. The purpose is to further explore through my analytical design, how competing discourses are interactive rather than predetermined for disabled women as psychosocial actors within the human rights context.

Relational Position Values Analysis: Interaction with Rights

This analysis is informed and inspired by Daiute, Stern, and Lelutiu-Weinberger (2003, 2004), where documents are used as analytical tools to understand the social values within institutional practices and the ways in which children express these values across different contexts. Within this work, 'values' is defined as "culturally-specific ways of knowing, feeling and acting in response to environmental, economic and social circumstances" (p. 85). This level of analysis will focus on the tensions and transformations of these values described by the women participants when discussing the interactions between the CRPD within the context of their lived experiences.

I used three value systems, “performing self,” “contesting self,” and “centering self”. Performing, contesting, and centering self are all social interactions, yet differ in their dialogic emphasis. As Daiute described (2003, 2004, 2010):

Performing self activities, “the social context is the predominant influence- with narrators reproducing context values” (Daiute, 2004, p. 119) and in the case of this research, the context values are contained within the CRPD policy document. If the women agree with the values of the CRPD, then they are performing the values of the document, or the cultural norm.

Contesting self activities, in contrast takes an opposing view of the context values. Here the women participants would disagree or contradict the values within the context of the CRPD document.

Centering self activities incorporates both Centering and Contesting values and can be viewed as transformative. The women participants did not agree or disagree with the cultural norms and therefore, must still be reflecting on how they feel or think about the values.

The values analysis was conducted in several steps. After collecting and recording the semi-structured interviews from two different discussion groups (Coventry and Lambeth, England), I transcribed all the interviews. The Values Analysis was conducted separately from the categorical analysis described later in this chapter. Then I created a Relational Position Data Collection Template (see Appendix E), which identified all the CRPD articles in the left column and then the type of values (Performing, Centering, or Contesting) noted for each article located within the participants dialogue. The unit of analysis is the ‘meaning unit’ (Daiute, 2004) which were several utterances that created a meaning, within the women participants dialogue.

Next, I read every transcription and noted on the Relational Values template which CRPD article was discussed and how they valued that article by either performing values of the United Nations *Convention on the Rights of Persons with Disabilities* (UN CRPD) policy, Centering values of the policy and/or Contesting values of the policy. Each meaning unit has several utterances and therefore could have multiple values.

Below is an excerpt of a spontaneous discussion initiated by the women participants implicitly discussing the CRPD Article 23: *Respect for Family and Home* demonstrating how each utterance within the dialogue can have a different value.

PART1: So if the doctor asks who is going to look after the child, you can't say nanny because that is not fair on the child. That child will not have a bond. (*Contesting value of the article)*

STAFF: You can be able bodied and then tomorrow be struck down by a disability. And be abled bodied and tomorrow die. (*Performing value of the article*)

PART2: The difference is if you didn't know and it happens suddenly, (*Centering value*) but if you know you are having a disability and it is continuously going, then there is no hope of you getting any better, and having that child it is not fair on that child. (*Contesting value)*

PART3: If you are sick, then you are not supposed to have a child. (*Contesting value*)

Procedure of Data Analysis

Data Collection

Discussion group meetings were recorded and later transcribed. Field notes were completed after each group session, or within the next day of meeting. During one meeting, the recorder would not work and field notes were used instead. All women sat together and their answers and broader discussions were recorded, having the feel of a discussion group versus a research group.

In the first stage, the women's' discussions were coded using the date of meeting and an "L" for London or a "C" for Coventry meeting (e.g., C, 08/17/09 and L, 08/18/09). Each meeting was downloaded into a digital voice file onto a personal computer into a research file. Each file was organized by a "C" for Coventry or "L" for London. Each of these files has been transcribed into a Microsoft Word document.

After each group discussion, the researcher completed written field notes for the purpose of capturing any relevant aspects of the group session that could not be audiorecorded. These notes included both logistical and reflective points. The logistical notes may include, but are not limited to, the number of people that attended, start and end times and if staff members or carers entered the group discussion. In addition these notes included any CRPD articles there were spontaneously discussed and needed to be identified to the group for the following meeting. The personal reflective notes included any conversations continuing after the group meeting had closed, how the researcher was feeling during the discussion group and other more personal, emotional thoughts and ideas.

Data Analysis

UN Documents: Discourse analysis

Using the United Nations *Convention on the Elimination of Discrimination against Women* (CEDAW) and the *Convention on the Rights of Persons with Disabilities* (CRPD), I reviewed and analyzed two United Nations Conventions using a Discourse Analysis approach. The purpose of this section is to compare and contrast two political documents' text to see what themes emerge specific to the conceptualization of gender and disability experiences. I selected these documents because the CEDAW supports women's human rights and the CRPD supports disability rights primarily and has added gender throughout the convention, what is called the

'twin pack approach'. Together these texts demonstrate and take into account specific vulnerabilities and strengths based on age, gender and disability that supports or contradicts the notion of 'dual handicap' in a disabled women's life. A discourse analysis approach has been chosen to investigate the author's intentions, positions and a further understanding of the activities that may have occurred at the time the documents were created within the context of a purposeful political activity. The main goals when examining the two political texts is to explore if the CEDAW compliments and intersects with the CRPD and to find any possible implications through words or silences towards the development of 'dual handicap' for women with disabilities.

First, I will identify the categories of value and their units of meaning. The three categories chosen are: Sex/Gender, Inclusivity/Universality, and Disability/Impairment. The synonymous words within each category including their purpose and properties will be described. Words as coding units are classified together in categories to provide semantic validity (Weber, 1990). Below is a brief description of each category, the list of words within each category and their units of meaning:

The first category-Gender and Sex**,** includes words that have gendered or sexed meaning and practices. I tried to use an exhaustive list of words that represented both gendered categories and sexed categories. Guided by Judith Butlers' work (1990), the term 'sex' is based on biological binary categories identifying male and female bodies. The 'gendered' terms are based on social, cultural and historical performances based on the biological male or female body. Butler argues that the sex (male, female) is seen to cause gender (masculine and feminine). In Gender Trouble, Butler describes gender as a performance; "it's what you *do* at particular times, rather than a universal who you *are*" (p. 25).

The second category-Inclusivity or Universality includes words that have been framed from a human rights based approach. Taking the common understanding identified through the core principles of the Universal Declaration of Human Rights which states, "All human beings are born free and equal in dignity and rights" and "all individuals are equal as human beings and by virtue of the inherent dignity of each person." All human beings are "entitled to their human rights without discrimination of any kind , such as race, colour, sex, ethnicity, age, language, religion, political or other opinion, national or social origin, disability, property, birth or other status as explained by the human rights treaties bodies" (Universal Declaration of Human Rights).

The third category Disability/Impairment**,** includes words that have historically been used to describe people with disabilities or impairments through the medical model, also termed the deficit model, the British social model or the larger United Nations World Health Organization (WHO 1989, 2001) level.

After finding words for each value category, I totaled all categories. At this point, compared and contrasted categories within and between each treaty. The questions I addressed for analysis are:

1. Why did I choose the categories and words within each category?
2. Why did I choose the treaties specifically to compare and contrast?
3. What are the difference and similarities within and between each category and then treaty?
4. How consistent are these findings with the purpose of the treaty?
5. What is surprising to find?
6. What, if any, are the implications for disabled women?

Further along within my analysis, I will compare the treaty findings with the narrative work. The questions I will address for analysis are:

1. How do the findings from the discourse analysis reflect the women's narrative work? How do they differ?
2. How do they speak to each other? How do they inform each other? What can be learned through comparing policy documents with discourse? What are the implications?
3. How has the secondary genre (policy) influenced or supported the primary genre (discourse) against the backdrop of the British context?

Historical Timeline

This next section will review how the current thought and practices specific to disability and gendered experiences have been conceptualized, developed and practiced within the United Kingdom, over the last 200 years, beginning with the Industrial Revolution in the 1700's and later within the United Nations. In this section, I will draw from cultural-historical theory, reiterating again that humans are social beings and understanding that "the psychological life of an individual is inextricably entwined in public life and public space" (Daiute, 2010, p. 40). In addition, I explore how historical national and international contexts may have shaped disabled women's lived experiences within the United Kingdom. Ultimately, I argue that social, cultural, historical and political analysis is necessary to reflect on the meaning-making processes for individuals and groups, providing perceptions and interpretation of life events (Daiute, 2010). This section will provide a historical overview of a timeline (see Appendix D) relevant to the intersection of women and disability social and political movements within the United Kingdom and the United Nations. All components of the timeline will not be discussed here but can be reference within Appendix D. The League of Nations work, beginning by World War I,

later forming the United Nations, will be in bold to distinguish between nation state history and global work. I have selected specific areas of historical analysis that highlights each historical group within time and their social, cultural, historical and political national and international developments. Although, I am not able to provide a fully comprehensive analysis across economics, cultures and race, for example, this section aims to illuminate historical activities; making broader connections in hopes to facilitate further discussion regarding the social, cultural and political landscape for women with disabilities within England and hopes to provide an explanation of the dominant national and international ideologies, as well as the most salient issues, discussion and perceptions surrounding gender and disability within and between the United Kingdom and United Nations.

CHAPTER 3

HISTORICAL ANALYSIS: CONTEXT OF BRITISH AND UN RIGHTS

This next section will review how contemporary thought and social and cultural practices specific to disability and gendered experiences have been developed over the last 200 years in the United Kingdom, Britain and the United Nations. There is little doubt that a larger understanding and conceptualization of disability and gender has been transformed over time. Although the individualistic medical model approach still remains prevalent, many societies across the world, "including politicians and policy makers, now recognize that disability is an equal opportunities/human rights issue on a par with sexism, heterosexism, racism and other forms of social exclusion" (Barnes & Mercer, 2001, p. 12). This chapter will review and highlight the different social, cultural and political and legal movements' specific to disability and gender framed within a historical timeline (see Appendix D.). Next, through this historical analysis, I plan to unpack and highlight any patterns of themes that have emerged on how the women participants within this research have come to internalize ways of making meaning within their own worlds contextualized through human rights discourse (e.g. United Nations work, the United Kingdoms' work and the Disability Rights movement) within England specifically. This historical link is created to further assist in the broader understanding between the past activities and current lived experiences from the women's narratives.

As previously discussed within the theoretical section, one central objective of this work lies in the inquiry into the influence of historical structures of privilege rooted in the intersection of gender and disability. Through social interactions, past experiences within larger social, political, and historical contexts are told and retold over time. This re-telling and re-

experiencing eventually will inform a disabled woman's social interactions, outlook, behaviors, and her everyday local discourse and situated practices. Stetsenko and Arievitch (2004) point out that Vygotsky emphasized that the sociopolitical history of a culture powerfully shapes all levels of contexts, which contradicts "history as being a succession of value-culture, and politics-free individual pursuits carried out in a sociocultural and sociopolitical vacuum (p. 61). This strongly rejects the notion of individuals being biologically determined and instead highlights the interaction between history influencing disabled women and women influencing history. Ultimately, "knowledge about the past is widely viewed as a crucial ingredient in the construction of identity" (Wertsch, 1997, p. 5) specifically with the intersection of gender and disability.

To summarize, this work argues that history is not a cause and effect but instead "a meaning making process in which individuals and groups contend with perceptions and interpretations of events as they participate in public and private life" (Daiute, 2010, p. 41). History can be considered to be alive in present time, and disabled women can be identified as social actors within their own histories, influenced by and influencing a local, national, and global history. Below describes the historical overview relevant to the intersection of gender and disability within broader political systems.

This section centers on the process of social, historical, cultural and political change over time within the United Nations, United Kingdom and the Disability Rights movement within Britain; ultimately leading to the impact of disabled women experiences in today's Britain. Since the 1980's, both the United Kingdom and the United Nations has promoted various initiatives to highlight opportunities moving towards disability rights. In addition, these achievements are due to the social and political disability movements within the United

Kingdom and their political organization throughout the world (Barnes, 1997; Campbell & Oliver, 1996; Driedger, 1989). As Ann Borsay (2002, 2005, 2006) highlights that within history Disability Studies is the missing component and history has lessons to teach contemporary societies. Then, society can contribute and reflect on the personal and collective identities woven for disabled women between the past and present. Here, historical discourse can offer a "public space for reflexive interaction with the past having proved its worth as a pedagogical political culture that helps individuals and social groups to comprehend their "place in local, national and international realities" (2006, p. 207).

For the United Kingdom and the United Nations a social and political timeline was created highlighting the disability and feminist rights movements. An overview and explanation of key literature was conducted, primarily through books written by British disability rights activists. This review of sources, first, helped to examine the dominant national ideologies as well as the most salient issues, discussions, and perceptions surrounding disability within Britain. For example, this analysis may undermine the historical understanding that the passive, tragic assumptions of the medicalized body with disabilities was created only through social cultural interactions and shift the burden of responsibility to the economic, social and political organization of society. Second, this review may demonstrate that attitudes and policies can construct societal beliefs about disability understanding that "policies from multinational agencies, central governments, local governments and institutions have shaped the lives of disabled people throughout the world" (French & Swain, 2006, p. 146). Third, this review identify if disabled women specifically are mentioned within the literature artifacts towards disability history. The question of disability and gender policy then "reaches into global

politics, power structures, ideologies and humanity" (French & Swain, 2006, p. 147) as identified within the research goals.

Disability history within Britain has been noted by many disability rights activists as being a field of inquiry still in its infancy (Barnes, 1997; French & Swain, 2006; Hirsch, 1998; Shakespeare, 2006); although there are several empirical histories of the disabled people's movement, both internationally and in Britain (Pagel, 1988; Drieger, 1989; Borsay, 2005). It has been increasingly recognized that the writings and political involvement from disabled people themselves are largely absent in disability history in general (French & Swain, 2006) and direct disability policy was not introduced until the 1970's. Below is a historical overview of disability rights policy within Britain demonstrating the birth of policies and the development of cornerstone disability rights organizations. First a brief overview, beginning in the 1970's will describe the political, social and historical context of disability within the United Kingdom into specific policy for people with impairments. The history of women within the United Kingdom and United Nations is interwoven within this work providing a parallel understanding of the social, cultural and political implications of the time for women specifically. The political movement for disabled women is not noted until the 1980's with Jenny Morris work. The timeline begins in the era of the Industrial Revolution (1750-1850) and ends with United Kingdom's ratification of the *Convention on the Rights of Persons with Disabilities* (2006). Again, it should be noted that points over 200 years are noted and the comprehensive timeline is located as Appendix E.

Disability Rights Policy and Practice Situated in Britain

Anne Borsays' (2002; 2005; 2006) work offers a historical interpretation of Britain demonstrating that disability has clearly been a neglected area of historical inquiry. Colin

Barnes (1997) notes that within western culture relatively little has been written on disability particularity with reference to the period before industrialization. Borsay believes that the British Industrial Revolution (1750-1850's) was a formative time for people with impairments. Here the swift economic shift created social policies and practices that ultimately still sustain the social, cultural, economic and political discrimination and exclusion today. The British Industrial Revolution was a time where each citizen was assessed against their economic value to society. These economic conditions then opened the necessity of charity work or the voluntary sector, providing isolated resources and support to disabled people. The Industrial Revolution created the social, cultural, and political upheavals and isolated individuals into larger homogenous communities' directly influencing individual's personal and political identities.

As a result of homogenous communities, the conceptualization of institutional living or community care within Britain was established. In Britain during the 1600s, the rise of workhouses, hospitals, asylums, and schools did create settings into which people with impairments were placed. Borsay (2002) notes that in the late 1800s, the openings of charity organizations and services within Britain accelerated rapidly. These new philanthropic organizations were frequently patronized by members of the middle class, speaking of evangelical religion. Within the institutions and the organizations' work a hierarchy of impairments was established. Borsay (2002) states that the "blind and deaf people, denied access to the word of God, appealed to Christian sympathies" (p. 105) and "provisions for physical, as opposed to sensory, impairments, on the other hand, was slower to materialize" (p. 106). In 1817 a small General Institution for the Relief of Person Laboring under Bodily Deformity was established in the city of Birmingham (Borsay, 2003; White, 1997). But despite

the "toll of factory accidents, and their exploration in the campaign for legislative reform foundations for physically impaired people burgeoned only in the late Victorian period" (Borsay, 2002, p. 106).

Mary Wollstonecraft, born in London (1759-1798), became a British writer, philosopher, moral and political theorist and advocate for women's rights. Wollstonecraft is best known for her writing *A Vindication of the Rights of Woman* (1792), in which she argues that women are not inferior to men as practiced during this time, but is simply lacking the privilege to be educated as men. Today she is noted as being one of the first feminist philosophers of her time, facilitating the 1850's First Wave Feminism movement within the United Kingdom.

The First Wave Feminism was a social and political organized movement for the reform of women's social and legal inequalities in the nineteenth century. Although individual women like Mary Wollstonecraft argued against the gendered injustices, it was not until the late 1850's that an organized feminist movement evolved in Britain. The headquarters for the First Wave movement was located in London, England specifically. Here a group of middle-class women met to discuss their own experiences of injustice they faced and eventually published the English Woman's Journal (1858-1925). The key concerns for the First Wave Feminism within Britain were education, employment, the marriage laws, and the plight of privileged middle class women. Their major achievements included reform of the girls' secondary-school system, including girls participating in national examinations and the enactment of the Married Women's Property Act of 1870. It is important to note that at this time, women were still not allowed to vote.

During this same time, from 1870 to 1914 the poor law infirmaries joined the voluntary hospitals. These public hospitals relocated within the local authorities and became responsible for what was termed special education and the mental deficiency institutions. At this time, the "cripple child" was discovered as a non-wage earner in the labor market and placed in schools instead. The movement of state schools "joined charitable and commercial schools to provide elementary education that was free and compulsory—more than forty voluntary agencies for 'crippled' children appeared" (Borsay, 2002, p. 106). Here schools became places for disabled children to go and become economic earners amongst other disabled children.

Borsay (2005) explains that schools focused on humanitarian goals and placed heavy emphasis on preparing children with impairments for economic independence. Geriatric funding was redirected to create resources for the younger, productive populations. These beliefs and practices surrounding disability and economic fruition created the social and cultural paternalistic beliefs of helping and fixing people to become economically viable. Ultimately, however, the described paternalistic beliefs of the time still did not support or protect the civil liberties of individuals living in asylums.

In 1872 a women's national movement created the National Society for Women's Suffrage and later the more influential National Union of Women's Suffrage Societies (NUWSS). Although for women, in 1884 political civil liberties in Britain shifted to include the male working class to have a parliamentary vote. Unfortunately, the new liberal democracy also expected its voting participants to be self-sufficient; as a result, women, asylum patients, and recipients of relief to the poor were still excluded from the voting process. Not until 1918 were women over 30 granted the right to vote in Britain with the Representation of People Act further described below.

Economic Commodities

Under the influence of the First World War (1914-1918), the quality of life of people with impairments was contingent on their participation in the labor market in Britain. Institutions for the blind sought to make their patients economically active through workshops as well as educational programmes. These workshops eventually matured into work centers with jobs geared to physical recovery and economic independence. Borsay (2002) notes that prior to 1939 most employment initiatives were still through charitable organizations, segregated and limited to manual craft skills that left disabled people exposed to low wages and often unemployment. Actually, it was not until the economic recession after World War I where services for people with physical and mental impairments became increasingly thrust in a community direction. Policy makers recognized the financial and the human costs of institutional care (Borsay, 2006) and shifted work practices for people with impairments.

During World War I, women were also required to take on work practices that had been traditional male roles. Here, political movements for women suffrage increased, the Parliament of the United Kingdom passed an act granting the vote to women over the age of 30 who were householders, occupiers of property with an annual rent and graduates of British universities. Then in 1918, the Eligibility of Women Act was passed, allowing women to be elected into Parliament. Ten years later, the Representation of the People Act of 1928 extended the voting franchise to all women over the age of 21, granting women the same voting terms as men.

After World War II economic marginality perpetuated the exclusion of people with impairments further. Until this time, most lived with relatives and "relieved the state of the cost of caring" (Borsay, 2006, p. 201). Overall, "rudimentary health care became available through the poor law, the school medical services, the national insurance panel, and the Ministry of

Pension's Limb Service" (p. 201), but the social care services were still funded by the charitable sector until the 1970's Chronically Sick and Disabled Persons Act. This act required local authorities to provide a range of need based support services that reinforced socio-economic giving priority to patients' with "therapeutic potential". Borsay (2005) describes social policies that became contrived ways to make disabled people excluded citizens by implementing criteria based on economic rationality.

During the 1970s, organized political activism in Britain by disabled people began. This movement was inspired by the political and social upheavals of the period. Large numbers of people with impairments came together to protest against their incarceration in residential institutions, their poverty, and the discrimination they encountered. Within this time of social, cultural and political upheaval the formation of the Disablement Income Group (DIG) and the Union of the Physically Impaired Against Segregation (UPIAS) in Britain occurred (Campbell & Oliver, 1996). The British experience has been noted by Barnes and Thomas (2006) as being especially important, given that this disability rights movement generated a radical and controversial new sociopolitical approach to theory and practice generally referred to as the social model of disability. In 1976 Safilios-Rothschild suggested, "This time may be ripe for the disabled to generate a social movement patterned after the at least partially successful examples of the Black Movement and the Women's Movement" (p. 45). This disabled persons political movement did occur, but still did not overlap with the either the black or the women's movement of the time.

During this same time the Second Wave Feminist movement was occurring in American, Britain, and Europe from the late 1960's onwards. The Second Wave Feminism in Britain was derived from working class socialism, as demonstrated by the strike of women

workers at the Ford car plant for equal pay in 1968. The slogan 'The personal is political' extended the feminist social political movement to different classes of women with a focus on reproduction, sexuality and cultural representation within the media to change their public and domestic or personal lives. The first annual women conference within Britain was held in Oxford in 1970, demanding equal pay for equal work; equal opportunities in work; free contraception and abortion rights and childcare at work. The first demonstration was held in London 1971 and a substantial number of women's groups and organizations were formed during this socio-political shift. Further demonstrations were formed securing the 1970 Equal Pay Act and the 1975 Sex Discrimination Act. During the 1970's as well, the Black Feminist movement emerged within the United Kingdom, challenging race issues within the United Kingdom.

Returning to disability movements at this time, the first steps toward affecting an anti-discrimination law were taken by the Committee on Restrictions Against Disabled People (CORAD). The Committee was appointed by the Labour government in 1978 and chaired by Peter Larges, a disabled man. His work highlighted the inability to access buildings, transport systems, educational institutions, employment, and entertainment venues, and it located societal and cultural discrimination within structural and institutional contexts (Barnes & Mercer, 2001). However, in 1979 Margaret Thatcher came into office to begin almost 20 years of Conservative Party rule.

The Thatcher government was prominently described as being unsympathetic to Peter Larges findings and the disability political movement in general. Instead the Conservative Party seemed to try to move past the post-war welfare state and the "citizenship of entitlement" to a "mixed economy of welfare in which the commercial, voluntary and informal sectors played an

enhanced role" (Borsay, 2005, p. 202). During this time, Jack Ashley, a deaf Labour MP, introduced a private member's anti-discrimination bill in July 1982, but the bill was defeated. As Barnes and Mercer (2001) explain, after "14 subsequent attempts, and 13 years later…the 1995 Disability Discrimination Act (DDA) was passed" (Borsay, 2005, p. 16) challenging Thatcher's Conservative Party beliefs to move beyond the Welfare State from Britain's past.

At this time Britain's campaign for anti-discrimination legislation really gathered momentum. In 1995 the Conservative government responded, and the United Kingdom Disability Discrimination Act (DDA, 1995; amended 2005) was created. Now public attention focused on the demand for civil rights legislation for people with impairments specifically within the employment sector. This policy was the first legislation specific to disability discrimination and was the direct result of sustained campaigning by disabled people in the United Kingdom. This act was hailed as a major breakthrough by the Equal Opportunities Commission, and in 1999 the disability rights movement took the lead in securing legislation for a Disability Rights Commission (DRC) which requires that a majority of the DRC Commissioners be disabled people, supporting the common politicized slogan, "*Nothing about us without us".*

The new legislation was still described as flawed by disability rights advocates. Under this act only direct discrimination was prohibited, which left the subtle, everyday interactions untouched, allowing possible "indirect oppression brought about by 'in built or institutional patterns of inequality' (Borsay, 2005, p. 1). Therefore, disability rights organizers argued that the legislation was too "weak and toothless" to reverse "the economic and political, social and cultural exclusion that prevented disabled people from claiming the full rights of citizenship" (p. 1).

The Disability Discrimination Act (DDA, 1995) defines disability as

> *a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities. The impairment must affect one of the following day-to day activities: mobility: manual dexterity; physical coordination; continence; ability to lift, carry or otherwise move everyday objects; speech, hearing or eyesight; memory or ability to concentrate, learn or understand; perception of the risk of personal danger. Long-term means that the disability has lasted or can be expected to last at least 12 months.*

After intense lobbying from multiple sources, (Tony Blair's) Labour government established the DRC in April 2000. It is notable that the British Disability Rights Commission (DRC, 2006) has proposed that the definition should include anyone who has any level of impairment. This has been noted within the commission as being important to people with disabilities. This language intends to shift the focus from an earlier medical model of disability to an experience of societal, cultural, and environmental barriers possibly creating discrimination (DRC, 2006). The disability anti-discrimination legislation is "less extensive than that in place in relation to gender, ethnicity or religion, although the 2005 DDA extends the definition of disability and places a duty on all public bodies to promote equality of opportunity and positive attitudes towards disability" (Purdam et. al, 2008, p. 53). However, by the time the DDA reached British society, the principles, beliefs, ideas practices and values related to disability intersected with gender had become internalized ways of knowing and behaving for approximately 200 years.

In 1998 The Human Rights Act was passed by the British Parliament, which primary aimed at incorporating the rights from the European Convention on Human Rights into United

Kingdom law. For example, Article 14 within the European Convention specifically prohibits discrimination on a wide range of grounds including "'sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status." The Equality and Human Rights Commission identified the term *other status* to include disability, sexual orientation, illegitimacy, marital status, trade union membership, transsexualism, and imprisonment. This term was used to challenge discrimination on the basis of gender and impairment.

In 2000**,** all patients detained in mental hospitals became entitled to vote if they were not guilty of a criminal offense. Besides this practice being disenfranchising, Borsay (2005) explains that to exercise that "formal right is more difficult given the physical inaccessibility of polling stations, the complexities of postal or proxy voting, and the continuing omission of institutionalized disabled people from the electoral register" (p. 202). The quoted discussion continues to note that voting does not necessarily guarantee political inclusion for disabled people. Although since 1981 the British Council of Organization of Disabled People has coordinated a coalition of groups that disabled people themselves control, it is through this social movement, rather than through the formal political system, that the case for an inclusive society based on the extension of rights has become most vigorously articulated.

In December 2006, as an amendment to the DDA (1995), the Disability Equality Duty (DED) was implemented as a positive step towards widening access to higher education. The DED builds upon another DDA amendment, the Special Education Needs and Disability Act (SENDA, 2001). This act specifically makes it unlawful to discriminate against disabled students during the application, admission and enrollment process, as well as student services while at the university (Madriaga, 2007). In 2006 the SENDA amendment shifted the emphasis

to institutions to make a change, whereas the 2001 SENDA relied on people with disabilities to complain about discrimination. It states that "Institutions will be required to involve disabled people in the planning and implementation of the 'positive duty' within their organizations to prohibit discrimination" (Madriaga, 2007, p. 400), calling for the universities, among other institutions, to be more culturally diverse and to work toward social justice goals for disabled people.

This section overview has demonstrated that Britain has had a relatively young disability and women rights movement which began as an organized movement approximately 30 years ago. The next section of this paper will further review the British social model of disability defining the difference between disability and impairment briefly mentioned above in regard to Finkelstein's 1970s UPIAS as the first social relational understanding of disability. This social model was born from the disability rights movement and has been the main foundation of the current disability rights movement with the understanding that "we (disabled people) need to put back the experience of impairment into our politics" (Crow, 1996, p. 4).

British Disability Rights Movement

It took the rise of a strong disabled people's movement from the 1970s to bring about major change within the United Kingdom. That is not to say that prior to this time disabled people were passive; "groups such as the National League of the Blind (1899) had a radical agenda but they lacked sufficient power to bring about substantial change" (French & Swain, 2006). Over the past 30 years the disabled people's movement has grown nationally and internationally.

UPIAS emerged in the 1970s created by Paul Hunt, Finkelstein and others, as being one of the major influences in the disability rights movement. For its first couple of years, the

network seems to have concentrated on discussion and debate in the attempt to develop a political ideology of disability. According to their resulting policy statement (adopted December 1974), the aim of UPIAS was to" replace segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their own lives"). The policy statement defined disabled people as an oppressed group and highlighted barriers, as shown, **"**We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, righted work routines in factories and offices, and a lack of up-to-date aides and equipment" (UPIAS Aims, paragraph 1).

However, the policy statement did not specifically define disability as social barriers or as oppression. The terms *physically impaired people* and *disabled people* were used interchangeably, and in one place there is a reference to *physical disability*. The statement called for "alliances with other groups such as the 'mentally handicapped' and 'mentally ill' and with non-disabled allies. However, only people with physical impairments were eligible to become full members of UPIAS and as Shakespeare (2006) describes there was clearly a fear of being of the organization being taken over by non-disabled people.

Fundamental Principles of Disability

In November 1975 the UK organization Union of the Physically Impaired Against Segregation (UPAIS) met and created a booklet called the Fundamental Principles of Disability was born from a discussion between UPIAS and the Disability Alliance. UPIAS elaborated its position on disability and for the first time explicitly distinguished the term impairment instead of disability in a way in which the UPIAS 1974 Policy Statement does not. The Fundamental Principles defined disability as follows:

> *Disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people*. (UPIAS, 1976, p. 3)

UPIAS has been celebrated by disability rights advocates as the inspiration for the British disability movement and as the pioneer for what will be later discussed in this paper as the social model. As Shakespeare (2006) notes, these policies never initiated a "mass movement. It was dominated by wheelchair users, perhaps because many had previously been able-bodied and had been involved with other political movements" (Finkelstein, 2001, p.4). Shakespeare (2006) explains that some activists remember it as being sexist (Campbell & Oliver, 1996,) and dominated by a typically masculine form of politics which was "hard, ideological, and combative" (Campbell & Oliver, 1996, p. 67).

An important group with an alternative approach to disability politics was the Liberation Network of People with Disabilities. This network, like UPIAS, was clear that disability was a form of social oppression and in 1981 argued within their draft liberation policy "while the basis of social divisions in society was economic, these divisions were sustained by psychological beliefs in inherent superiority or inferiority" (Shakespeare, 2006, p. 198). They were significantly different for the time because they were determined to involve the comments and contributions of others outside of the male disabled politicized community. This included women as leaders and reflected a feminist style, supporting an individual transformation and mutual support, modeled on feminism and personal growth (Shakespeare,

2006). This feminist and disability political movement will be explained further within the disability and feminist section of this paper.

The UPIAS led the British disability rights movement and in 1981founded the British Council of Organizations of Disabled People (BCODP). Here a new adoption and distinction to the definition of disability and impairment was created:

> *Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. (Therefore, disability, like racism or sexism, is discrimination and societal oppression).*
>
> *Impairment is a characteristic, feature or attribute within an individual which is long term and may or may not be the result of disease or injury. This may affect the function of that individual's mind or body, either because of, or regardless of society, and/or cause pain, fatigue, affect communication and/or reduce consciousness.*

The BCODP grew to a coalition of 110 organizations controlled by people with impairments encompassing England, Wales, and Scotland. At this time, Finkelstein and other BCODP members formed and created the Disabled People's International (DPI).The DPI representatives in 1981 argued at the Singapore Congress for a social model of disability definition. The definitions of disability adopted in 1982 marked a further development of the original UPIAS social model. Impairment was defined as "the functional limitation within the individual caused by physical, mental or sensory impairment' and the community due to physical and social barriers" (Disabled People's International, 1982).

Before the 1980s academic interest in disability was characterized by conventional individualistic medical explanations and dominated by medicine and related professional interests (Barnes & Thomas, 2006). However, the UK rarely moved beyond the traditional medical or psychological approaches until the establishment in 1986 of the international journal, *Disability, Handicap and Society* (renamed *Disability and Society* in 1993) by Oliver and Len Barton. This journal focused on the sociopolitical and cultural dynamics of the complex process of disablement. It has been a cornerstone for the establishment of disability studies as a legitimate area of scholarly enquiry at both national and international levels. In addition, in 1990 the publication of Oliver's book, *The Politics of Disablement*, provided the first comprehensive theorization of the sociopolitical interpretation of disability. Barnes and Thomas (2006) note that both of these academic developments generated a host of new questions and dialogues about the relevance of disability theory, politics, and practice.

During the late 1980s into the 1990s**,** the disability rights movement went into what was termed the direct action approach. This approach has a number of different elements. It is a way of "focusing attention on the institutions and environments that create disability; the inaccessible transport, the demeaning television charity spectaculars. It is an overtly political act, showing that disability is a matter of social relations, not medical conditions" (Shakespeare, 2006, p. 56). A prime social justice example occurred in 1992 at the Researching Disability Conference. During this conference people with impairments told the attending researchers they had no right investigating the disability experience. This highlighted the fact that even the academic study of disability has felt the politicizing effects of the movement (Shakespeare, 2006) and shift in daily practices.

Crowther, a member of the Human Rights Commission (2007), states "No one can sensibly dispute the enormous achievements of the United Kingdom's (UK) disability movement over the last 15 years" (p. 791). The decade between 1995 and 2005 was highlighted by two Disability Discrimination Acts and punctuated by a series of legislative and policy developments. As a result of these achievements, the United Kingdom has seen a remarkable sociocultural shift in the approach of grudging acceptance of disability rights from British society to positive duties to promote equality. Any attempts to construct a sociopolitical theory of disability cannot ignore either history or context; however, as yet neither a history nor anthropology of disability has been written (Oliver, 2006). There is ample sociocultural, political and historical evidence that an absolutist view of disability could not be sustained through societal discourse and practices.

Since the mid-1960s, organizations from within the disabled power movement (the Union of the Physically Impaired Against Segregation, the Liberation Network of People with Disabilities, the British Council of Organizations of Disabled People, Disabled People's International) have been fighting to raise the political consciousness of their constituencies (Dartington et al., 1981; Oliver, 1984; Sutherland, 1981, as cited in Borsay, 2006). They have met with some success but still face some identified obstacles, furthering human rights for physically-disabled women specifically. Borsay (2006) explained that a barrier is the capitalist cultural beliefs, which segregates those who are not fully productive and discourages them from organizing around a generally negatively perceived condition as a disability. In addition, Borsay believes (2006) that it is the inability of recognizing "impairment as a political group", which ultimately reduces disability organizations impact.

Review of Human Rights International Policy and Disability: Historical and Contemporary

The League of Nations, an international organization, was founded during the First World War and established under the Treaty of Versailles (1919). The purpose of this organization was to maintain international cooperation and to achieve peace with security in contributing countries after World War I. The goals identified and upheld were the Rights of Man, Disarmament, Preventing War through Collective security, Settling disputes through negotiations, Diplomacy and Improving Global Quality of Life. The League of Nations ceased to exist in 1946 due to the beginning of World War II, but was the forerunner to the current United Nations (UN).

The United Nations was founded in 1945, replacing the former League of Nations (1919), for the sole purpose of creating and maintaining international cooperation for peace and security. In 1945, representatives of 50 countries met in San Francisco, California, at the United Nations Conference to write the United Nations Charter. In 1948, the General Assembly adopted the Universal Declaration of Human Rights (UDHR).

The UDHR was the first internationally organized human rights instrument created by the United Nations. Drafted by representatives with different legal and cultural backgrounds from all regions of the world, the Declaration was proclaimed by the United Nations General Assembly in Paris on 10 December 1948 "as a common standard achievement for all peoples and all nations. It sets out, for the first time, fundamental human rights to be universally protected" (OHCHR, 2010). For the purpose of this research, it is important to note that in 1948, words such as "sex" and "everyone" are not mentioned, and language related to 'disability' or 'impairment' are also not mentioned within the declarations preamble or articles. There are 30 articles total within the Charter and multiple articles use the words 'everyone', 'all

human beings' or 'no one', language that presumably is inclusive to all human beings, and not exclusive of any individual.

Below are articles specifically chosen to further demonstrate the use of language as being inclusive of every person, presuming to include women with disability:

From Article 1, the language of "All human beings.." *All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.*

From Article 2, the language of "Everyone…" , although 'disability is not mentioned specifically "or other status" may be applied to disability. *Everyone is entitled to all the rights and freedoms set forth in the Declarations, without distinction of any kind, such as race, sex, language, religion, political or other opinion, national or social origin, property birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it is independent, trust, non-self-governing or under any other limitation of sovereignty.*

From Article 5, the language of "No one" demonstrates that everyone is included and no one is left out. *No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.*

From Article 16, words specific to both male and female are mentioned for the first time within the UDHR in three sections;

1. Men and women of full age, without limitation due to race, nationality or religion have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and its dissolution.

2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

From Article 25, the only article within the UDHR that uses the word 'disability' and 'child'; *everyone has the right to a standard of living adequate to the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.*

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

The Universal Declaration of Human Rights provides an example on how language specific to 'gender' and 'disability' has shifted to include disabled women as institutional actors within the human rights work (Daiute, 2008). As Ingstad (2007) noted, this previous United Nations discourse has only recently entered the broader international agenda. Beginning in the early 1980's, the disability rights movement has demanded the use of language specifically stating that disabled people have full participation in society and securing their equal rights, comparatively to the women's rights movement during the 1970's. In 1983, the United Nations General Assembly signed its World Program of Action Concerning Disabled Persons (WPACDP), followed by the Decade for Disabled Persons (DDP) (1983-1992), and then slowly developed into the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD, 2006). For the purpose of this section, a brief description of international conventions and specific articles will be highlighted. These articles will be chosen to

demonstrate changes of language within and between international conventions purposively influencing nation state into local policy. First, the paper will begin with the *Convention on the Rights of the Child* (CRC, 1989), the rules within the United Nations Standard Rules on Equalizations of Opportunities for Person with Disabilities (1993), the Salamanca Act (1994) which formed the Education for All Act, introducing the *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW, 1979), the *Convention on the Rights of Persons with Disabilities Act* (2006) and comparing the latter two conventions.

The Convention on the Rights of the Child (CRC, 1989) United Nations General Assembly (1989) was originally constructed from the United Nations Charter, identifying the basic human rights for children everywhere. This convention sets out children's rights in 4 articles and two Optional Protocols. The four core principles of the Convention are non-discrimination; devotion to the best interests of the child; the right to life, survival and development; and respect for the views of the child. This work "is a major breakthrough in defining children as fully human and working to ensure them the attendant benefits worldwide (Daiute, 2008).

For the purpose of this section it is important to note Article 23 is the only article within the CRC that uses non-gendered language specifically locating the child and 'disability. This is the first instance within the UN policy that children with disabilities were noted amongst the human rights legally binding agreements.

Article 23 has three parts, State parties recognize that *mentally or physically disabled children should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.* (2) State parties recognize the right of the disabled child to special care and shall encourage and ensure the

extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and the circumstances of the parents or others caring of the child; (3) Recognizing the special needs of a disabled child, assistance extended…to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development and (4) promote the spiritual and international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational series, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas.

None of the remaining 53 CRC articles identify disability or combine disability and gender together. Although entered into force on January 18, 2002, *The Optional Protocol on the Rights of the Child on the sale of children, child prostitution and child pornography*, states only one specific gendered point within the preamble:

> *Recognizing that a number of particularly vulnerable groups, including girl children, are at greater risk of sexual exploitation and that girl children are disproportionately represented among the sexually exploited.*

From Article 1; For the purpose of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.

From Article 2 has two sections; (1) States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status; (2) States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.

For the purpose of this dissertation, I would argue that previous research identified would suggest that girl children with disabilities, if consistent with the previous research mentioned, may have an even higher risk, than an abled-bodied girl child. Therefore, disability and gender may possibly need to be identified to support the human rights of girl children with disabilities as well demonstrating a possible policy illustrated "dual discrimination".

To extend on this point, I will compare the CRC (1989) and the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities (1993) for language. Among the major outcomes of the Decade of Disabled Persons and following the 1982 World Programme of Action Concerning Disabled Persons, a global strategy to enhance disability prevention, rehabilitation and equalization of opportunities for people with disabilities. The World Programme of Action emphasized the need to approach disability from a human rights perspective. As a result, the adoption by the General Assembly, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993. Although not a legally binding instrument, "the Standard Rules represent a strong moral and political commitment of Governments to take action to attain equalization of opportunities for persons

with disabilities. The rules serves as an instrument for policy making" (UN, Enable 2010) The mission of the Standard Rules was to address policy makers, create a plan of action, and set international standards specific to people with disabilities.

The Standard Rules consist of 22 rules summarizing the message of the World Programme of Action. The 22 rules concerning disabled persons consist of "four chapters-preconditions for equal participation, target areas for equal participation, implementation measures and the monitoring mechanism" (UN, Enable 2010). The main components below are all specific to individuals with disabilities, but again (unfortunately) are not a legally binding document for nation states. Unfortunately, the CRC has only one article using the word 'disability' and the Standard Rules on Equalization mention both disability and gender but is not a binding document and cannot be enforced within nation states. Below identifies three rules and a section within the preamble that language within the Standard Rules specifically mentions disability and gender:

> *The purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others.*

Within Rule 4, Support Services, gender is specifically mentioned and can be compared to the CRC language of 'everyone':

> *The purpose of the Rules is to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others.*

Within Rule 6, Education, gender is specifically mentioned:

> *In States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.*

Within rule 9, Family Life and Personal Integrity, gender is specifically mentioned:

> *States should promote measures to change negative attitudes towards marriage, sexuality and parenthood of persons with disabilities, especially of girls and women with disabilities, which still prevail in society. The media should be encouraged to play an important role in removing such negative attitudes.*

In 1994, representatives of 92 governments and 25 international organizations formed the World Conference on Special Needs Education held in Salamanca, Spain. The objective was to review necessary policy shifts to "promote the approach of inclusive education, namely enabling schools to serve all children, particularly those with educational needs" (UNESCO, 1994). Organized by the government of Spain in co-operation with UNESCO, the Conference brought together senior education officials, administrators, policy makers and specialist as well as representatives of the United Nations and the Specialized Agencies, other international governmental organizations, non-governmental organization and donor agencies.

All the above mentioned organizations created a new statement, now known as the Salamanca Education Act (UNESCO, 1994). This statement begins with a commitment to policy named 'Education for All' endorsing the approach of inclusive schooling to support the development of "special needs education" as an integral part of all education programs. The guiding principle "that informs this framework is that schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions." (UNESCO, 1994).

Within the Salamanca Statement (1993), the language of 'girl' is noted one time within the document. "Girls education is specifically noted:

> *Girls with disabilities are doubly disadvantaged (previously defined as "dual discrimination"). A special effort is required to provide training and education for girls with special educational needs. In addition to gaining access to school, girls with disabilities should have access to information and guidance as well as to models which could help them to make realistic choices and preparations for their future role as adult women.*

Recently the United Nations Education for All (2009) website has updated their information specific to gender stating that "Discrimination still persists against girls and women in education. Today, more than 55% of out-of-school children are girls, and two-thirds of adults without access to literacy are women, sparking special efforts "from recruiting female teachers to supporting poor families to making schools more girl-friendly." Within the same paragraph it further states, "Other groups have also been neglected, including indigenous populations and remote rural groups, street children, migrants and nomads, the disabled and linguistic and cultural minorities" but not connecting gender and disability specifically.

Convention on the Rights of Persons with Disability (CRPD)

In December 2006, history was made with the United Nations adoption of the *Convention on the Rights of Persons with Disabilities*. The Convention and its Optional Protocol opened for signatures at the United Nations headquarters in New York on 30 March, 2007. According to the United Nations, there were 82 signatories to the Convention, 44 signatories to the Optional Protocol, and one ratification to the Convention on its opening day,

which was the highest first day signature historically within the United Nations' Conventions. As of recently, there are 118 signatories to the Convention, 67 to the Optional Protocol, and 12 ratifications, with Nicaragua, Spain and Namibia being the latest in the month of December 2007. Once a country ratifies the Convention, it needs to be reflected in its national development framework using approaches such as the Common Country Assessment (CCA), United Nations Development Assistance Framework (UNDAF), and Poverty Reduction Strategy Papers (PRSP).Theoretically, through these broad-reaching approaches to development, the Convention will become a reality within states, communities and in the daily lives of the individuals who need the support that the Convention proclaims.

According to the United Nations Department of Economic and Social Affairs (DESA, 2009), the Convention is a human rights instrument with an "explicit social development dimension". It reaffirms to the international community that people with various types of disabilities must enjoy all basic human rights and fundamental freedoms on an equal basis with others. This work is instrumental in clarifying and qualifying all categories of human rights. It applies to persons with disabilities, identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights, determines where their rights have been violated, and establishes where protection of rights must be reinforced.

The CRPD (2006) has been guided and shaped from various Conventions and policies already created, ratified and implemented by international communities and nation states. These policies include but are not limited to, the principles within the historical Charter of the United Nations, the Universal Declaration of Human Rights, and Standard Rules on Equalization of Opportunities for Persons with Disabilities, the World Program of Action Concerning Disabled Persons, and the *Convention on the Elimination of All Forms of*

Discrimination against Women. The eight guiding principles formulated by the founding Conventions, identified by the United Nations of the *Convention on the Rights of Persons with Disabilities* (2006) are:

1) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; 2) Non-discrimination; 3) Full and effective participation and inclusion in society; 4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; 5) Equality of opportunity 6) Accessibility; 7) Equality between men and women; and 8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

An innovative component of the CRPD (2006) is the combination and understanding of both gender and disability. As research undertaken by the Economic and Social Commission for Asia and the Pacific (ESCAP, 1995) indicates, gender discrimination presents additional obstacles to educational opportunities. In addition, the problem of dual discrimination, previously discussed in this dissertation can be found in every country of the world regardless of its economic or political situation. In developing nations, the problem is rooted as much in the actions of developed nations as in local conditions and attitudes. One example is provided within a small 2004 survey conducted in Orissa, India. This research found that virtually all of the women and girls with disabilities were beaten at home, 25 percent of women with intellectual disabilities had been raped and 6 percent of disabled women had been forcibly sterilized **(**Mohapatra and Mohanty 2004**)**. Women face these disparities due to lack of access to equal education, health care, economics, and employment.

Women and the Convention on the Rights of Persons with Disabilities (CRPD)

In 2004 during the Third Ad Hoc Committee creating the CRPD, South Korean representatives unexpectedly proposed for the first time adding language combining both 'gender' and 'disability' within the newly developing convention. This proposal suggested extending the mission of the CRPD and adding an insertion of a new article solely related to disabled women. This proposal would require nation states to include issues specifically affecting women with disabilities into their laws, monitoring bodies and data collection to ensure special consideration beyond disability. Kenya followed closely behind South Korea and presented a similar proposal during the sixth Ad Hoc (2006) meeting. According to the Ad Hoc notes (2006), these proposals were fiercely debated and discussions concentrated on whether and how to introduce gender perspective articles into the convention (Ad Hoc minutes, 2006). Perspectives from different countries varied immensely, beginning with establishing one specific article within the convention addressing "intersected discrimination" or previously discussed as "dual discrimination" against disabled women. This range extended to broadening from one article to incorporating gender throughout the entire convention (Reina, 2007). Reviewing the notes of the final meeting of the AHC (2006), the European Women's Lobby and many women's organizations in developing countries strongly advocated not for one proposed gendered article but instead infusing the concept of gender throughout the whole convention.

At this point, the International Disability Caucus introduced what was termed the "twin track approach", which would create not only a standalone gendered article incorporating women and disability but in addition incorporate language based on gender discrimination throughout the whole convention. Continued discussions between the two ideas of one article

solely specific to gender versus the "twin pack approach" created polarization between nation states (Ad Hoc minutes, 2006) leading to an intervention by an article facilitator. Gender mainstreaming was introduced by the Beijing Platform for Action to promote the second part of the twin pack. In addition, the European Union specifically suggested the incorporation of gender criteria in different general provisions rather than only in one article. The focus was to incorporate gendering within all policies and programs so that an analysis could be made of the effects on women and men. Both the twin pack approach and stand alone article succeeded, creating for the first time a human rights instrument incorporating both gender and disability. The following section will demonstrate how the CRPD uses both gender and disability language to support the "twin pack approach". Below are both Article 6 the stand alone article and examples of the twin pack approach, with occasional research supporting the importance of particular articles.

From Article 6- Women with Disabilities

1. *States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.*
2. *States Parties shall take all appropriate measure to ensure the full development, advancement and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention*.

The preamble describes the forms of discrimination based on "sex and nationality; risk of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, both

inside and outside of the home; and the need to incorporate a gender perspective in all efforts to promote the rights of people with disabilities"(Reina, 2007, p4).

From Article 3- General Principles. Please note within Article 3(h), language incorporated from the *Convention on the Rights of the Child* (1989) is but expanded with word 'disability'.

a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

b) Non-discrimination;

c) Full and effective participation and inclusion in society;

d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

e) Equality of opportunity;

f) Accessibility;

g) Equality between *men and women*;

h) Respect for the *evolving capacities of children with disabilities* and respect for the right of children with disabilities to preserve their identities

From Article 8, *Awareness-Raising***.** The aim of this article is to change negative perspectives and social prejudices through ability awareness. There are two main provisions within this article with various sub points. The specific mention of gender specific language is 1(b*); to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life.*

From Article 16, *Freedom from Exploitation, Violence and Abuse*. The abuse of women with disabilities is a global issue; specifically subjected to forced sterilization, abortion, and

genital mutilation. Women with disabilities are at higher risk of experiencing emotional abuse by attendants, strangers, or health care providers in both private and public settings (Reina, 2007 p. 5).

1. *State Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect person with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects*
2. *… to prevent all forms of exploitation, violence and abuse by ensuring, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families …*
3. *…measure to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse...such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age- specific needs.*
4. *… Put in place effective legislation ad policies, including women and child focused legislation ad policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriated prosecuted.*

From Article 25, *Health***.** This article requires health services, including rehabilitation services, to be gender sensitive. Unfortunately, "civil society and other stakeholders did not succeed in including the express mention of particular aspects of feminine health such as family-planning, pregnancy, childbirth, and the post-natal period"(Reina et al., 2007).

States Parties shall take all appropriate measures to ensure access for person with disabilities to health services that are gender-sensitive, including health related rehabilitation

From Article 28, *Adequate Standard of Living and Social Protection*. This article supports the concern that often individuals with disabilities are denied the full range of economic, social, and cultural rights. In particular, women with disabilities are more likely to be poor or have a lower standard of living than men with disabilities (Reina et al., 2007). This article has two sections, but will only focuses on the second section that relates specifically to gender and disability:

2(b) to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programs and poverty reduction programs.

From Article 34, *Committee on the Rights of Persons with Disabilities*. This article relates specifically to the monitoring procedure. As referenced in third to fifth Ad Hoc notes (2006), discussions on international monitoring were intense, with most countries arguing for a treaty-monitory body including people with disabilities. In this article there is one specific mention of gender in the section relevant to the eligibility of committee members which calls for, *balanced gender representation and participation of experts with disabilities.*

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)

The *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW) was adopted in 1979 by the UN General Assembly. The United Nations Commission on the Status of Women worked diligently for five years creating a document

often described as the "international bill of rights for women consisting of a preamble and 30 articles. The convention specifically defines discrimination against women as,

...any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

CEDAW's primary purpose is to focus and enforce human rights for women and girls, "greatly increasing the visibility of women in the human rights system" (Bruce, Quinlivan, Degener, 2002, p. 10). The overarching goal of CEDAW (1979) is the achievement of de facto equality for women, including identifying and eliminating the causes for such discrimination. The non-discrimination rights of CEDAW (1979) cover the whole spectrum of human rights, including civil, political, economic, social or cultural. This convention does not explicitly mention women with disabilities; and often times within monitoring of this convention, women with disabilities have not been implicitly represented. One very important aspect of this convention is it's applicable ability in the private sphere. "This is important since a great deal of discrimination against women, including women with disabilities, occurs in the private sector" (Bruce, Quinlivan, Degener, 2002 p. 104).

Overview and Findings

Any attempts to construct a United Kingdom, British or United Nations sociopolitical theory intersecting gender and disability cannot ignore either history or context; however, neither a history nor anthropology of disability has been written (Oliver, 2006) nor has a gender and disability history been completed. Since the late 1990's in Britain, the social and political dimensions of disability only have intensified, primarily at the universities and academic

institutions. I agree with Colin Barnes (1997) from Leeds University that to "eliminate oppression, in all its forms, we must confront the value system upon which western capitalism rests" (p. 4). Below will attempt to highlight key points intersecting gender and disability within the sociopolitical, cultural historical timeline previously discussed.

In Britain, as reviewed the politicization of gender as separate from disability (Campbell & Oliver, 1996) can be traced back to the 19th century. Through an expansive historical account, it is possible to argue that many of the women or disability sociopolitical movements happened at subsequent times. In addition to further this argument, it is possible to argue that the deterministic practices for gender and disability functioned through a complex system of commodity production and distributions; the principal means of allocating rights was for work (Barnes, 1997).

Wolfensberger (1989) extends this argument further by suggesting that the social and economic dependency for disabled people has been a result of the human service industries in the post 1945 period. Albrech (1992) extends this point and suggests that disabled people have become medicalized, which in turns creates a 'disability business' for others to make money. Notably, Albrecht suggests that issues such as poverty, race, ethnicity, gender and age are significant factors in the construction and production of disability and dependence. Using the limited anthropological and historical resources available, Albrecht asserts that disability and rehabilitation have been commodified and transformed into a commercial enterprise (Barnes, 1997) after World War II in Britain. Therefore, disabled people being seen as 'sick or unable to work', in need of services is supported by the abled body values (Hunt, 1996). The relationship between material considerations and cultural perceptions of disabled people then contribute to the 'economic good of the community'.

Vic Finkelstein (2001) a British disability rights activists, continues with this historical economic point, and highlights the nineteenth century. A time where people with impairments were excluded from employment because of factory based work systems and the belief that they could not keep up with the assembly lines. Hence, individuals were segregated from the mainstream of economic and social activity into a variety of residential institutions or hospital based medicine (Finkelstein, 1990). He extends this argument and believes that these sociopolitical and economic moments then created a construction of disability to become a social restriction over a period of time. Therefore, 'the personal tragedy theory' of disability has become an ideological hegemony and has become translated into common sense and everyday assumptions, values and beliefs (Oliver, 1990).

Only since the early 1990's has the intersection of gender and disability been explored (Morris, 1991; 1996) by a new generation of writers. These writers as discussed in the literature review work from within a mainly feminist or post-feminist framework. Following the work of the disabled feminist, Morris (1991), Shakespeare (1994) contends the historical overview is not only material discrimination but also the 'othering' of the visual limitations of the body. Adapting a similar position, Susan Griffing (1984) explains that women's oppression is based in terms to their relationship to the body, instinct and sensuality, rather than economy and exploitation.

As mentioned throughout this chapter, until the 1990's within the United Kingdom and the United States relatively little has been written about the history of the oppression of disabled people within the context of the western world. In contrast, Mary Wollstonecraft (1792) had written one of the first British women suffrage movement books, describing the experiences of middle class women and gender roles. On the contrary, disabled women's

experience and history is absent or simply lost (Hanson, 2002) or owing to perceived invalidity or lack of worth (Barton, 1996). However, it is important not to insert disability within the United Kingdom sociopolitical women's rights movement and believe that it will naturally overlap. There is a huge gap and a need for future inquiry to move beyond the historical narratives based on a male dominated disability rights movement and the feminist movement with an abled-bodied women perspective.

CHAPTER 4

ACTIVITY-MEANING MAKING SYSTEM (Daiute, 2008, 2010):

CRPD AND CEDAW

"In order to claim rights, one must first be recognized as an actor in the legal system."
-Jürgen Habermas

One specific reason for this dissertation was the absence of studies that focus on the meaning making processes of disabled women within the context of human rights. Since no comprehensive work exists on the topic, the literature review at the beginning of the dissertation presented variations of qualitative work from primarily autobiographical accounts by disabled women. As illustrated within Chapter 3, a Historical Analysis: Context of British and United Nation Rights, the history within the United Kingdom for disabled women does not shape or provide a discourse of strong, political actors within their own socio-cultural political worlds. At this point of analysis in Chapter 4, I extend from this larger historical context into a discourse analysis of policy documents that are relevant to disabled women in England. Closely following Daiute's (2008) analysis of children's rights discourse within the *Convention on the Rights of the Child* (CRC, 1989), this next chapter offers a qualitative analysis of two policy documents, the U.N. *Convention on the Elimination of all Forms of Discrimination against Women* (CEDAW, 1979) and the U.N. *Convention on the Rights of Persons with Disabilities* (CRPD, 2006), as activity-meaning making systems.

Drawing from sociocultural activity theory to design (Daiute, 2008), I apply and implement a discourse analysis of disabled women's rights policy related to the CEDAW and the CRPD. Understanding that women rights policies (CEDAW) and disability rights policies

(CRPD), are embedded within a system of institutions, activities, and relationships over a period of time. Therefore, each policy document reviewed within this analysis expresses dialogical beliefs and discursive practices, providing a snapshot of values, principles and beliefs regarding disabled women as political actors in England. First, I briefly reviewed an analysis of the disability and gender rights activity-meaning system. This involved identifying the range of interactions between meetings, social movements, activities and documents leading to the CRPD document itself. This theory based design provides a way of considering the broader CRPD processes relevant to disabled women's sociopolitical understandings. Second, I conducted a discourse analysis focusing on specific language within the context of both documents. I identified specific language within the document that represents women (e.g. girl, sexed), disability (e.g. disable(d), impairment) and rights language (e.g. equal, same) and checked how many times they occurred within and between both the CEDAW and the CRPD. Those words that appeared within each document create a conception disabled women's rights. This level of analysis illuminates how each document enacts values, principles and concepts specific to disabled women expressing and developing their own rights based understandings.

Closely following Daiute's (2008) theoretical integration of CHAT concepts into activity-meaning making systems designs, which reviewed the qualifying interactions within the CRC meaning-making activity, I begin by listing the systems of interactions leading to the CRPD treaty itself in a chart form in Table 1. The unit of analysis is the qualifying interactions (e.g. prior policy documents, international initiatives, other) with the CRPD activity-meaning making system.

Table 1

Interactions in the CRPD Activity-Meaning Making System for Discourse Analysis

Actor/Meeting/Document	Activity-Meaning
1. United Nations CEDAW (1979)	Policy-Making Treaty
2. TheWorld Programme of Action Concerning Disabled Persons (1982)	Qualifying Activity
3. Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)	Qualifying Activity
4. UN Decade of Disabled Persons	Qualifying Activity
5. Third Ad Hoc Committee (2004)	Meeting
6. Sixth Ad Hoc Committee (2006)	Meeting
7. United Nations CRPD (2006)	Policy-Making Treaty

The chart above shows that the CRPD involves a system of interactions, like international disability focused initiatives, Ad Hoc meetings by key participants and prior United Nations policy specific to women, creating a broader CRPD process relevant to disabled women's sociopolitical understanding. Below describes the interactions noted in Table 1, leading up the CRPD as an Activity Making system. In this section, I discuss how a brief analysis of dialogic relations across the CRPD activity-meaning making system offers insights regarding the tensions and silences when defining disabled women's rights.

Qualifying Rights for Women

Women's rights are qualified not only within the CEDAW document, but in the broader CEDAW system. The *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW) was adopted in 1979 by the UN General Assembly. The United Nations Commission on the Status of Women worked diligently for five years creating a document often described as the "international bill of rights for women" consisting of a preamble and 30 articles. The Convention entered into force in 1981 following its ratification in 20 States. By February 2002, the number of States parties had risen to 168.

The CEDAW's purpose is to focus and enforce human rights exclusively for women, "greatly increasing the visibility of women in the human rights system" (Bruce, Quinlivan, Degener, 2002, p. 204). The overarching goal of CEDAW is the achievement of equality for women with men, identifying and eliminating discriminatory practices. The non-discrimination rights of CEDAW (1979) cover the whole spectrum of human rights, including civil, political, economic, social or cultural.

Several articles emerge as particularly focused on emphasizing women's rights as compared to men's rights. For example, Article 1 specifically defines discrimination against women as,

...any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

The following four articles of the Convention are explicitly related to the lived experiences of women in relationship to the equality to men. From Article 2**,** requires State

parties to guarantee full enjoyment of all human rights for women on the basis of equality with men. From Article 3**,** political, social, economic opportunities on a basis of equality with men, from Article 8, women have an opportunity to represent their Governments at the international level on equal terms with men, from Article 9, women have equal rights as men in establishing the nationality of their children.

Many of the remaining articles focus on women's rights within specific contexts and the circumstances of discrimination against women in everyday life practices. From Article 10, equal women's rights to the field of education, from Article 11 states equal employment options as men and Article 12 is created in respect to women's health care options. The CEDAW articles are based on the principle that women are equal to men and are valued the same as compared to men within their daily lived experiences. Because no articles discuss women's rights without the qualifier of men, it is important to note that qualifications focus disproportionately from a privileged male standpoint. This analysis suggests that within the CEDAW, women's rights are not independent of men but the qualifier of women's rights is based on the current principles and value of the male. In addition, this begins to highlight the tension between women's rights and their sociopolitical development and rights-based understandings, beliefs and actions as political actors.

This policy was chosen for analysis because, although the CEDAW protects all women, this convention does not explicitly mention the intersection of women with disabilities. Unfortunately, when monitoring bodies review the CEDAW, "when a woman with a disability is exposed to discrimination, it is not always clear whether the discriminatory practice is attributable to her gender or her disability" (Bruce, Quinlivan & Degener, 2002, p. 107) or both. Therefore, when States parties monitor this convention, due to the intersection of

identities, women with disabilities have not been implicitly represented. As a result, this discursive gap may potentially allow cultural and political powers to override disabled women's rights.

Qualifying Activity and Disability

The next section reviews interactions across a sequence of key international initiatives and meetings inherent in the CRPD activity-meaning making system. Beginning in 1976, the UN General Assembly declared 1981 as the International Year of Disabled Persons (IYDP) and aimed at focusing attention to full participation and integration into society. During this time, two initiatives expanded the CRPD activity-meaning making system, the World Programme of Action Concerning Disabled Persons (WPA, 1982) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993).

The WPA was adopted by the General Assembly on December 3, 1982, with the focus on the "Equalization of opportunities" for persons with disabilities. It remains the overarching theme for the achievement of full participation of persons with disabilities in all aspects of social and economic life.

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities was adopted by the General Assembly on December 20, 1993. This work was not a legally binding instrument, but represented a movement for governments to take action towards the equalization of opportunities for persons with disabilities. The Standard Rules is known to be a powerful tool to guide the creation of the CRPD. The above movements, activities and documents represent a "symbolically linked interactions of individuals in meaningful contexts and institutions" (Engestrom & Miettinene, 1999, cited in Daiute, 2008, p. 706) constructing

and shifting discourse, values, beliefs and practices within the context of disability rights, leading up to the creation of the *Convention on the Rights of Persons with Disabilities*.

Qualifying meetings

In this section, I will briefly discuss the discursive interactions that occurred within two CRPD Ad-Hoc activity-meaning making meetings. The purpose of this analysis is to identify how tensions within dialogic relations across the CRPD activity-meaning system offer insights about the transformation and shift of defining disabled women's rights. For the first time, the explicit advocacy for disabled women having human rights was mentioned by disabled women themselves. Thus creating a further understanding of the development of higher order processes, like those required for rights based understanding and self-determination, as they occur in the symbolic activity of discourse (Harre & van Langenhove, 1999; Wertsch, 1999, cited in Daiute, 2008). Here I used the theoretical understanding and step by step analysis from Daiute's (2008) work that the CRPD like other international treaty practices involves a system of interactions, like Ad Hoc meetings by key participants. These qualifying meetings demonstrate the interactions of those representations with the politics of international treaty making. This theory-based design provides a way of considering the broader CRPD process relevant to the disabled women's sociopolitical understandings.

I specifically selected two Ad Hoc meetings (third and sixth) as part of the CRPD activity-meaning system as enacted in the CRPD treaty. I selected these meetings because they represent the major actors involved in stating and ensuring disabled women's rights, as later created in Article 6: *Women and Disabilities*. This section begins with the Third CRPD Ad Hoc Committee meeting in 2004, where South Korean representatives unexpectedly proposed adding language combining both 'gender' and 'disability' to the then forming CRPD. This

proposal suggested extending the mission of the CRPD by adding an insertion of a new article solely related to disabled women. This would require nation states to include issues specifically affecting women with disabilities into their laws, monitoring bodies and data collection to ensure special consideration beyond the social category of disability. This proposal was closely negotiated for multiple meetings.

Not until the sixth Ad Hoc meeting, where disabled women from Kenya closely followed behind South Korea and presented a similar proposal. According to the Ad Hoc notes (2006), these proposals were fiercely debated and discussions concentrated on whether and how to introduce gendered articles into the disability convention (Ad Hoc minutes, 2006). These discussions ranged from including only one article representing *the intersected discrimination* to incorporating gender throughout the entire convention (Reina, 2007). Reviewing the notes of the final meeting of the AHC (2006), the European Women's Lobby and other developing countries organization strongly advocated not only for one proposed disability and gendered article but additionally to infuse the concept of gender throughout the whole disability convention.

At this point, the International Disability Caucus introduced the intersectional approach as what is now termed the "twin pack approach" created polarization between nation states (Ad Hoc minutes, 2006). These tensions between the organizations attending the Ad Hoc committee meetings, lead to an intervention by an article facilitator. The Beijing Platform for Action, an international women's advocacy group, strongly supported the intersection of gender within the formation of the disability treaty document. In addition, the European Union specifically suggested the incorporation of gender criteria in different general provisions rather than only in one article. The focus was to incorporate gendering within all policies and programs so that an

analysis could be made of the effects on women and men. Both the twin pack approach and stand alone article succeeded in creating for the first time a human rights instrument intersecting both gender and disability into the human rights discourse. An analysis of the nature of the qualifying meetings offered insights about the tensions and transformations for disabled women's rights within the broader CRPD system.

Qualifying Rights for Disabled Women

In this section I identify the qualifying CRPD articles, as discursive practices representing disabled women as socio-political actors within their own political rights understanding. As previously reviewed, disabled women's rights are qualified not only within the CRPD document, but also in the broader CRPD system. In December 2006, history was made with the United Nations adoption of the *Convention on the Rights of Persons with Disabilities*. The Convention and its Optional Protocol opened for signatures at the United Nations headquarters in New York on 30 March, 2007 and is the first legally binding treaty that holds governments accountable to the rights of persons with disabilities. The Convention has been noted to be the "paradigm shift" for people with disabilities. According to the United Nations Department of Economic and Social Affairs (DESA, 2009), the CRPD is a human rights instrument with an "explicit social development dimension", that will move social and cultural beliefs and practices away from culturally and historically embedded paternalistic attitudes of protection, welfare and charity work. Instead, this convention features persons with disabilities as "rights bearers who are capable of claiming those rights" (de Alwis, 2008, p. 1). One of the purposes of the convention is to reaffirm to the international community that people with various types of disabilities must enjoy all basic human rights and fundamental freedoms on an equal basis.

As discussed, the Ad Hoc meetings negotiated women's rights across the CRPD system. The CRPD contains an innovative component that combines both gender and disability rights. This intersection provides a number of entry points for the analysis of women's, and disability rights within a holistic human rights framework (de Alwis, 2008). Specifically for this reason the CRPD has been chosen as a unit of analysis.

Several articles emerge as particularly focusing on the intersection of women and disability human rights as compared to a more gender neutral disability rights article. Three examples provided note the explicit use of the word women or girl when intersecting disability within the human rights discourse. For example, the eight guiding principles (listed below) note the gender entry within Principle 7.

From Eight (8) Guiding Principles:

1) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; 2) Non-discrimination; 3) Full and effective participation and inclusion in society; 4) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; 5) Equality of opportunity 6) Accessibility; 7) Equality between men and women; and 8) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The following, Article 6: *Women and Disabilities*, is the only stand alone article explicitly noting both women and disability with the CRPD treaty document:

....States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

States Parties shall take all appropriate measure to ensure the full development, advancement and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

The third example of the explicit use of women intersecting with disability rights is From Article 28- *Adequate Standard of living and social protection:*

"… to ensure access by persons with disabilities, in particular women and girls with disabilities and older person with disabilities, to social protection programmes and poverty reduction programmes.."

Many of the remaining articles' discourse focuses only implicitly to women through the use of words such as 'sex' or 'gender' and explicitly uses words related to disability. The following two articles demonstrate this point:

From Article 8-Awareness Raising

…requires States to "combat stereotypes, prejudices and harmful practices relating to person with disabilities, including those based on sex and age, in all areas of life"

From Article 16- Freedom from Exploitation and Violence and Abuse

… requires States Parties to "protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, *including their gender-based aspects".*

This discourse analysis highlights the dialogic relations within the CRPD activity-meaning making system when defining and conceptualizing disabled women's rights. As similar to Daiute's (2008) findings within the CRC activity-meaning system, this analysis suggests that within the CRPD, by limiting the explicit use of women(an) and girl(s) within the

articles, it therefore illustrates how State Parties qualify their compliance for disabled women within the treaty, thereby explicitly limiting disabled women's role in expressing and developing their own rights-based understanding. Because only one a few articles explicitly intersect women and disability rights, it is important to note that qualifications focus disproportionately from a privileged disabled male position. This analysis suggests that within the CRPD, disabled women's rights are not independent of men. As a result, the implication is that disabled women will not have different protections based on gendered cultural practices within the context of their human rights. This highlights the tension between disabled women's rights and their sociopolitical development and rights based understandings, beliefs and actions as political actors.

Next I reviewed and analyzed two United Nations Conventions using a discourse analysis approach. The purpose of this analysis is to highlight the dialogical relations across the CEDAW and CRPD activity-meaning systems offering insights about representation and conceptualization of disabled women's rights. This analysis involves identifying the frequency of words used within both the CEDAW and the CRPD. Together these documents express the intersection of dialogical relations (Bakhtin, 1986) through discursive practices (Harre & Van Langenhove, 1999) that reflect specific societal, cultural and historical values, beliefs and principles specific to the context of disabled women's human rights.

Qualifying Words: Treaty Making Activities

This analysis focused on explicit words within and between each document to further understand the interactions between each activity-meaning making system for disabled women. The implications for this level of discourse analysis are to illustrate the discursive characteristics in reference to disabled women's rights, their sociopolitical development and

their own rights-based understandings. I first begin by presenting the qualifying language identified within the discourse analysis in Table 2. The first column identifies the social (gender/disability) or human rights (equal, same) category; the second column and the specific words used within each category, and the third is a brief explanation of the value for each word.

Table 2

Qualifying language-Value Salient Words

Category	Words/Language	Construction
Gender/Sexed*	Woman(en); Girl(s); Female; Man(en); Boy(s); Sexes	Words with either the sexed (biological) or the gendered sociocultural, historical or political practices
Inclusivity/Universality**	Equal(ity); Same; Full Comprehensive; All	*Equal:* same value as others; *All:* the whole amount or extent *Same*: identical with/ similar to another *Full*: complete amount
Disability/Impairment***	Disability; Disable(d)(ies); Handicap; Impairment	*Disability*/*Handicap*: sociocultural practices *Impairment:* biology

*Note** J. Butler's (1990) work ** Principles from the United Nations *Universal Declaration of Human Rights* (1948) and the Merriam Dictionary (www.Merriamdictionary.com) *** World Health Organization (WHO, 2001); Social Model of Disability (1975).

Language within each document identities words within context that represents both social categories of gender and disability. The first section in the list reflects an exhaustive list of words that socially construct the social categories of 'Sex and Gender' using both the singular and plural form such as; Woman(en), Female(s), Girl(s) and Man(en), Male(s), Boy(s) and Sex(es). Guided by Judith Butlers' work (1990), the term 'sex' is based on biological binary categories identifying male and female bodies. The 'gendered' terms are based on social, cultural and historical performances based on the biological male or female body. Butler argues that the sex (male, female) or the anatomical body is seen to cause gender (masculine and feminine). In her book *Gender Trouble* (1990), Butler describes gender as a performance; "it's what you *do* at particular times, rather than a universal who you *are*" (p. 25) or sex as biological and gender as cultural.

The second section-Inclusivity or Universality includes words that have been identified from the United Nations *Universal Declaration of Human Rights* (1948) activity-meaning systems. The language identified through the core principles which states, "All human beings are born free and equal in dignity and rights" and "all individuals are equal as human beings and by virtue of the inherent dignity of each person." All human beings are "entitled to their human rights without discrimination of any kind , such as race, colour, sex, ethnicity, age, language, religion, political or other opinion, national or social origin, disability, property, birth or other status as explained by the human rights treaties bodies" (Universal Declaration of Human Rights). I further described the words using the Merriam Dictionary (www.Merriamdictionary.com). Here the word *All* is defined the whole amount, quantity, or extent of and every member or individual component. The word *Equal* is defined as the same

value, measure, quantity, amount, or number as another person. The word *Same* is defined as something identical with or similar to another.

The third section, Disability/Impairment**,** includes words that have historically been used to describe people with disabilities, handicaps or impairments. Within this work, the language is qualified using the British social model of disability as described within chapter 1 of the literature review.

The social model of disability approach was created in 1975 by the United Kingdom organization Union of the Physically Impaired Against Segregation (UPIAS). The social model of disability specifically differentiates and defines the words ‘disability’ and ‘impairment’. Impairment is used to refer to bodily contexts; such as being blind or deaf- that is part of or within the body. The word ‘disability’ is used to refer to the social, cultural, historical and environmental barriers creating larger social and cultural negative beliefs and practices for people with impairments.

Next I present results of the language identified within both the CEDAW and CRPD documents in a chart form within Table 3.

Table 3

Discourse Analysis of the CEDAW and CRPD

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW,1979)		Convention on the Rights of Persons with Disabilities (CRPD,2006)	
Category-Gender/Sexed	Value Count	Category-Gender/Sexed	Value Count
Woman(en)	45	Woman(en)	3
Girl(s)	0	Girl(s)	1
Female(s)	1	Female(s)	0
Men(s)/Boy(s)/Male(s)	20/0/0	Men(s)/Boy(s)/Male(s)	1/0/0
Sex(es)	1	Sex(es)	0
Total	67	Total	5
Category-Inclusivity/Universality	Value Count	Category-Inclusivity/Universality	Value Count
Equal(ity)	18	Equal(ity)	22
Same	16	Same	1
Full(Comprehensive)	5	Full(Comprehensive)	11
Total-Inclusive	69	Total -Inclusive	52
Category-Disability/Impairment	Value Count	Category-Disability/Impairment	Value Count
Disability, Disable(d)(ies)/Handicap	0/0	Disability, Disable(d)(ies)/Handicap	68/0
Non-Disabled	0	Non-Disabled	0
Total	0	Total	69
Total-Value Count	136	Total-Value Count	126
Total-Document	4,434	Total-Document	9,802
Total-Articles	16	Total-Articles* (31-50; monitoring and reporting articles)	50

Discourse Analysis: CEDAW

Within the *Convention on the Elimination of Discrimination Against Women* (CEDAW), the chart shows that the word *Women(an)* had the highest number of word occurrences overall. This finding is not surprising since the documents' primarily purpose is to support women's rights. Although, what is surprising is the second highest number of words was *Men(an)* at 20, almost half the amount as *Women(an)*. This finding suggests that the status of women's rights is then created and valued from the status of men's rights. This document seems to speak to men specifically, shifting the values, concepts, practices and even discourse for and towards women to be included in the same cultural, political and social systems as men.

The words that represent Gendered/Sexed children, such as *Girl(s)* and *Boy(s)* were not identified within this document, which suggests that children are not major actors within the CEDAW activity-meaning system. Interestingly, the Gendered/Sexed category has the second highest amount of words (67), which is half of the total words (136) collected within the CEDAW document. Again, this finding of such a large amount of words is interesting but not surprising, since the document itself is gendered focused, as previously discussed.

Within the second category, Inclusivity and Universality, the word *All* had the highest number (30) of occurrences. This word suggests a general holistic or comprehensive approach to women's rights. Interestingly, this category of human rights discourse within the CEDAW had the highest level of occurrences (69) across all three categories, which is half of the total words (136) collected from the whole document.

Within the category, Disability and Impairment, there were zero (0) number of word occurrences for any language that represents a social category of disability, impairment, or handicap. In addition, I analyzed for the word *non-disabled*, in case there may be an implicit

representation of disability within the document, I found none. Clearly, this discourse analysis revels that the CEDAW document does not explicitly represent the social category of disability within the human rights discourse.

Table 3: Analysis of CEDAW and CRPD presents the number of word occurrences within the CEDAW only. The general findings indicate that the first two categorical findings have the largest number of word occurrences is *Women(an)* at 45 words and *All* at 30 words, since the CEDAW's purpose is to provide all human rights to women specifically and to end discrimination of the withholding of particular rights based on gender. As stated, it is surprising that the second largest word occurrences are *Men* (20) and *Equal*(18) and *Same* (16), identifying the dialogical activity when this human rights instrument was created that men had more rights than women. It is clear that this policies intention was to stop discrimination against women and created an all-inclusive, similar, equal society to or with men. Therefore, it was not just to gain rights for women, but to have the same and equal rights as men specifically.

The same qualitative process using a discourse analysis approach is conducted with the second document, *Convention on the Rights of Persons with Disabilities* (CRPD). Information is provided within the second column in Table 3: Analysis of CEDAW and CRPD.

Discourse Analysis: CRPD

Surprisingly, within the *Convention on the Rights of Persons with Disabilities* (CRPD), the first category noted that *woman(en)* within the convention only occurred three times and the words *man(en)* only occurred once within the entire document. Words that represent a gendered child such as *Girl(s)* occurred only once and *Boy(s*) did not occur at all within this document. These finding suggest that suggests that children are not major actors within the CRPD activity-

meaning system. Overall, the Gender(ed)/Sex(ed) category provided minimal (5) word occurrence within the CRPD. Therefore, it may be assumed as well, that gender as a social category is not a high priority within the CRPD activity meaning systems.

Within the second category, Inclusivity/Universality, the highest number of word occurrences was *Equal* (22), *All* (18) and then the word *Full* with 11 word occurrences. This category, representing the human rights discourse had half (52) of the amount of total words (126) collected within the CRPD. This finding suggests that one of the main objectives of this convention is to provide inclusive and universal rights.

Interestingly, within the third category, Disability/Impairment/Handicap, the word *Disability* had the highest number (68) of word occurrences. *Impairment* occurred only once and the word *Handicap* did not occur anywhere within the document. Surprisingly the word *disability* has such a dominant occurrence. *Disability* has the highest numbers across all categories and makes up half of the total number of occurrences (126) within the entire document. Therefore, the social category of *disability* is highly valued within this document.

In addition, returning to category two for a moment, the word equal is explicit within this document. It can be assumed from previous activity-meaning making systems (e.g. WPA) that the word Equal implicitly applies to people without disabilities. It seems that any words specific to non-disabled has purposively been left out with the assumption that equality will be found generally.

Overall, it is not surprising to find the highest number of words representing human rights discourse and disabilities. Ultimately, this is the main purpose of the CRPD as a human rights instrument is to protect the rights of people with disabilities. The word occurrences within these two categories represent this purpose. Although, surprisingly the first category of

gender has the lowest number of word occurrences. These finding suggest that the documents' intention is to provide an inclusive, similar, equal society for people with disabilities as non-disabled persons. Specifically for women (and girls) with disabilities, it is implicit that the CRPD activity-meaning making system does not expand the political discourse dialogue for women. The next section compares the word occurrences between both documents. The purpose is to further explore the words and values within one document interacting with the second document to capture the notion of discourse activity systems and the values, principles and practices enacted onto disabled women.

Discourse Analysis: Between CEDAW and CRPD

In this section, I discuss the discursive similarities and differences found between the CEDAW and the CRPD activity-meaning making systems. As shown in Table 3, within the first category of Gender/Sex, the CEDAW has the highest (67) number of word occurrences and the CRPD has the lowest (5) number of word occurrences. As the opposite suggests, within the third category of Disability, the CRPD has the highest (69) number of word occurrences and the CEDAW has the lowest (0) number of word occurrences.

Interestingly, within the second category of human rights discourse, there were similarities between the CEDAW total (69) words with the CRPD total (52) word occurrences. This is not surprising in itself, since both documents are human rights treaties. What I find interesting is that the word *Equal* had similar occurrences but the word *Same* (CEDAW, 16; CRPD, 1) and *Full* (CEDAW, 5; CRPD, 11) had inverse emphasis between each document.

Within the third category, Disability/Impairment, CEDAW did not have any occurrence of words compared to the CRPD with the highest (69) occurrence and the strongest emphasis within the document. Overall, this particular discourse analysis demonstrates a social political

silence, within and between documents for disabled women's rights discourse. Clearly, the CEDAW's purpose as an activity-meaning making system is to protect and create women's rights solely; while inversely the CRPD primary focus is to protect people with disabilities, but not women with disabilities specifically. With this analysis extended beyond the language within each treaty document, I believe the finding suggest that disabled women are not key sociopolitical actors within either document. This analysis then reveals that ensuring disabled women's self-determination, having their own rights-based understanding and having protection through State Parties is problematic. Therefore as previously stated when comparing the documents, there is a clear political discursive silence for women with disabilities between the two documents.

Summary

The activity-meaning making system designed analysis, allowed me to identify the values towards the conceptions of disabled women across two different human rights treaties, understanding these documents capture the discourse activity system for them. When I cross analyzed documents, a few points stood out. The CEDAW language demonstrated the main actors as men and then women. Here the documents' discourse focused on women having equal rights as men. In opposition, the CRPD language demonstrated the main actors as disabled people, without a gender focus. Here the documents' discourse focused on the explicit word "disability" as having equal rights as the implicitly understood non-disabled person. This also emerged from the highest level of emphasis within the CEDAW (67) was gendered language and within the CRPD (69) was language describing the social category of disability. Both documents have similar number of occurrences, but with inverse representation of the political actors. This qualitative analysis demonstrated that disabled women are *not* key political actors,

nor have explicit rights or participation within either broader CEDAW or CRPD activity-meaning systems.

While indeed the British disabled women participants are social beings that interact with the "material and symbolic circumstances in their environments, including the political processes like rights, which are essential to their lives" (Dauite, 2008, p. 705), the silences or interactions within and between both documents may create practices and discourse within their everyday experiences that reflect the opposite. As previously discussed the CEDAW and CRPD documents are activity-meaning making systems that occur from a series of meetings and previous interactions, expressing the dialogical relations towards disabled women. Therefore this analysis highlights the principles, concepts, and tensions involved in society focusing on the disabled women's rights process. It is possible that the silence for disabled women between both policies is detrimental and continues the patterns of previous reasoning and discourses within larger activity systems (schools, hospitals, and home) and further defining them as dual handicap within their local dialogues and practices.

Following the cultural-historical theoretical underpinnings that "Every function in the child's cultural development appears twice: first, on the social level, and later, on the individual level; first between people (interpsychological) and then inside the child (intrapsychological) " (Vygotsky, 1978, p. 57). Therefore the social-political context in which the disabled women interact from birth not only affects them but defines them (Daiute, 2008) but the emphasis is placed on the interaction of individual and society. On a more positive note and less deterministic approach, it is important to emphasize that sometimes conflicting discourses interact in differing persuasive ways and can shift the psychosocial positions within local practices. This approach is much more interactive and dynamic then a predetermined meaning

making approach for disabled women. One example of this level of tension between people and within people was described within the third and six Ad Hoc meetings. These meetings or interactions within the broader CRPD activity-meaning making system were transformative for disabled women's socio-political discourse and context, and is an example of the actors shifting meaningful discourse as embedded within a cultural political system.

CHAPTER 5

RELATIONAL POSITIONAL ANALYSIS:

INTERACTION WITH RIGHTS

The previous chapter presents the results from a discourse analysis of disabled women's rights within the context of the CEDAW and CRPD documents. This analysis points to the understanding that each policy document is embedded within a system of institutions, activities, interactions and relationships leading up to the CRPD meaning-making activity (Daiute, 2008). The previous discourse analysis historically contextualized, highlights the dialogical beliefs and discursive practices, which provide a snapshot of values, principles and sociocultural beliefs regarding disabled women as political actors in England. The findings demonstrate that the conception of 'women' or 'disability' rights and the development of their rights based understanding can be found within activity-meaning making systems. But disabled women are still not major actors with their own socio-political systems. Emerging from this analysis is a tension between disabled women's rights and the broader CRPD systems, suggesting that disabled women themselves do not have the means to develop their own rights based understandings. This finding begins to show that the values embedded within disabled women's rights activity-meaning making systems are minimal at best.

In this chapter, I focus more closely on the different patterns of disabled women's positioning strategies within the CRPD context, noting how the emergence of *performing, centering* and *contesting* positions taken up by the studies group narrative work. This results section will answer the following research questions:

How do women with physical disabilities understand and make meaning of their lived experiences through the CRPD articles? What is the nature of physically disabled women's discourse across the CRPD activity-meaning making system (Daiute, 2008)?

Relational Position Values Analysis

As detailed within the Methods section, during each discussion group, specific articles from the CRPD were explicitly mentioned to initiate and maintain focus within each group meeting. Together, as women described their own experiences, the women participants implicitly mentioned rights based values located within the CRPD without needing to be explicitly prompted. After collecting and recording the semi-structured interviews from two different discussion groups (Coventry and Lambeth, England), I transcribed the interviews. Following Daiute (2003, 2004), sociocultural approach to human development, I have used the values analysis in a similar manner. First, I read each of the discussion groups' transcriptions and noted how the women's lived experiences are contexts for understanding tensions in the guiding values of the United Nations *Convention on the Rights of Persons with Disabilities* (UN CRPD).

In this present study, the guiding 'values' from Daiute's (2003, 2004) theoretical conceptualization as being "culturally-specific ways of knowing, feeling and acting in response to environmental, economic, and social circumstances" (Rogoff, 1990; Wertsch, 1991). The analysis across all participant narratives uses three different values or relational positions used to organize how disabled women perspectives are in relationship to the values embedded in human rights discourse within the CRPD articles. The activities "Performing self," "Contesting self," and "Centering self" are the units of analysis. Performing, Contesting, and Centering self are all social interactions, yet differ in their dialogic emphasis. As (Colette) Daiute (2004)

describes, in Performing self-activities, "the social context is the predominant influence- with narrators reproducing context values" (p. 119). In contrast, the Contesting self-activities, takes an opposing view of the context values, or the values of the relevant CRPD articles. The third and final value, Centering self-activities, expresses a more subjective point of view. Here the participants may not agree or disagree with the value of the relevant CRPD article but incorporates and negotiates both Centering and Contesting values.

While the values analysis emerged from the participant's narratives, I acknowledge that my explicit questions regarding specific CRPD articles (e.g. Article 6- *Women and Disabilities*) may have contributed to a co-construction of how the women position themselves and valued articles within the policy. Although, each discussion group meeting did begin with an explicit article, the women participants ultimately steered the conversation towards their own interests and experiences. For this reason, I believe that my questions were somewhat influential toward the relational positions analysis outcomes, but certainly did not dominate the topic of conversation for the women.

The four tables were created and organized from the participants' discourse. These tables were designed to help the reader understand the systematic process in identifying the participant's social values within a large United Nations convention. Table 1: *Overall Number and Percentage of Mentions,* presents the total number of turns by the women participants and the percentage of turns in which the 17 women participants expressed each value (Performing, Centering or Contesting). Table 2: *Ranking the Total Number of Values*, presents the number of mentions per article and then ranks and compares the mentions between each discussion group. Table 3(a) and (b): *Patterns in Relational Positioning,* presents the patterns between performing, centering and contesting within both groups, using qualifiers of 'Most', 'Some'

and ‘Least’. Table 4: *Non-identified articles*, lists the CRPD articles that were not explicitly mentioned or the value of the article was not implicitly implied through the discussion group narratives. Analysis revealed interesting patterns across contexts within and between each discussion group. In the following section I will further describe all four tables and the findings.

Table 1

Overall Number and Percentage of Mentions

		Total	Performance		Centering		Contesting	
Group	*n*	#	#	%	#	%	#	%
Lambeth	12	328	232	71.0	64	20.0	32	10.0
Coventry	5	245	177	72.0	53	22.0	15	6.0

As previously discussed, there were two discussion group narratives, one group was from Coventry, and the second group was from Lambeth, England. It is important to note, that the number of participants varied, Lambeth included 12 women participants and Coventry included five (5) women total participants. Interestingly, when making direct comparisons between both groups, even though the number of Coventry women participants are half the number of Lambeth, still the number of hours spent together co-constructing narratives were equal. I believe that the equal amount of 5 hours in active discussion is demonstrated by the similar total number of self- representation mentioned, where Lambeth had 329 mentions of values and Coventry had 245 mentions of values, even with half the number of participants. This point is important because these similarities between each group later allows for direct comparisons between both groups.

The second column in Table 1 presents the total number and percentage of Performing policy document values within each group. The percentage rate was found by dividing the total number of mentions and the number of Performing values to find the percentage of performing values out of the total number of values mentioned. For example, Lambeth had 232 Performing value mentions, out of 328 total mentions. As a result, 71 percent of the total number of mentions for Lambeth is performing the values and expectations of the CRPD document. Using the same process, Coventry had 72 percent of the total number of mentions are performing the values of and expectations of the CRPD documents. This column demonstrates that both discussion groups have similar percentages of performing the values within the CRPD. The fourth column presents the number and percentage of Centering the values of the CRPD articles. Interestingly, even with different number of participants, the percentages when Centering the values of the articles are comparable at 20 percent (Lambeth) and 22 percent (Coventry). The fifth and last column within this table compares the numbers and percentages when participants Contested the values of the articles as demonstrated from the discussion group narratives. When compared across all three Categories of values, the Contesting category reveals that both groups had the lowest percentages of mentions, but had the highest percentage of difference between each group. Lambeth contested the values of the document ten percent of the mentions and Coventry contests six percent of the mentions, a four percent difference between each group. These finding suggests that both group of women participants highly performed the values or reproduced the context values of the CRPD within their group discussions. In addition, within these discussions women also demonstrated having values that were subjective or possibly transformative within the context of specific articles and in addition, contested or had perspectives that are at odds with the values of articles within the

CRPD. Table 2: Ranking the Total Number of Values will further examine specific articles that were mentioned the most to least within the women participant's narratives.

Table 2

Ranking the Total Number of Values Mentioned in the Rights Discourse (CRPD)

	Coventry	Mentions	Lambeth	Mentions
Rank	Article	#	Article	#
1	3: Respect for Differences	37	8: Awareness Raising	61
2	8: Awareness Raising	30	29: Participation in political and public life	35
3	17: Protecting the integrity of the person	28	21: Freedom of expression and opinion, and access to information	32
4	23: Respect for home and family	21	30: Participation in cultural life, recreation, leisure and sport	35
5	6: Women with disabilities	17	6: Women with disabilities	30
6	16: Freedom from exploitation, violence and abuse	17	23: Respect for home and family	30
7	29: Participation in political and public life	17	3: Respect for differences	25
8	20: Personal mobility	15	24: Education	21
9	27: Work and Employment	13	17: Protecting the integrity of the person	17

(continued)

10	21: Freedom of expression and opinion, and access to information	12	19: Living independently and being included in the community	16
11	24: Education	10	28: Adequate standard of living and social protection	10
12	22: Respect for Privacy	8	16: Freedom from exploitation, violence and abuse	9
13	25: Health	7	20: Personal mobility	4
14	19: Living independently	5	27: Work and Employment	4
15	30: Participation in cultural life, recreation, leisure and sport	5	22: Respect for Privacy	2
16	28: Adequate standard of living and social protection	3	25: Health	1

Note: Number of article proceeds title.

Table 2 presents numbers of women participants turns mentioning a value within a specific *Convention on the Rights of Persons with Disabilities* (CRPD) article during the group discussions. The function of this table is to rank the number of mentions that each article elicited by both discussion groups narratives. This table does not explicitly describe the values discussed per article but instead introduces that overall how often specific articles related to the women participants lived experiences. This table does not describe if the women performed, centered or contested the articles, but instead ranks how often the women explicitly identified

an article or through describing their experiences an article could be implied. Within each of the discussion groups, I explicitly asked the women to discuss the same CRPD articles (e.g. Article 6: *Women with Disabilities*), but the majority of the discussions were guided by the women themselves.

The first column ranks the 16 articles (out of 50 articles total) the women valued in order from most mentioned to least mentioned. The second column identifies the article number and title mentioned for Coventry, and the third column provides the number of all mentions by Coventry related to the article to the left. The following column provides the same pattern of information but for Lambeth only. Below are discussion points comparing and describing how often each discussion group placed values within each of the articles.

Interestingly, both discussion groups ranked high when discussing values relevant within Article 8: Awareness Raising which refers *to raising awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities; (b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life; and (c) To promote awareness of the capabilities and contributions of persons with disabilities.* Although, both groups had high rankings, Lambeth had almost doubled the amount of value mentions, 61, than Coventry did, 37. This finding suggests that Lambeth significantly Performs, Centers or Contests the value indicated with the article Awareness Raising within their own lives, compared to any other article within the CRPD.

Below is an example of one participant being ignored by family in a private space. Interestingly, other participants became silent at this point and did not respond:

P5: No one ever talks to me about my disability. And I just get frustrated and I walk the streets. I just go out of the door and I leave and I don't come back. I just can't take it.

The majority of the dialogue provided examples of the interactions between the participants and strangers in a public context. Interestingly, the women participants did not generally speak about their personal homes or families as experiences, besides the excerpt above by one of the Lambeth participants. It is difficult to describe the heaviness that came into the discussion group, where a silence swept through the room when being ignored by family was questioned or explicitly discussed.

What is important to note is the second ranked article by Coventry was Article 29: *Participation in political and public expression*, while Article 3: *Respect for Differences* as the first article with the most number of mentions. What this may indicate is Lambeth and Coventry are similar characterizing Awareness raising regarding disability, but the nature of the values proves to be different. Coventry can be described as expressing values in patterns consistent with individualistic to family values, given the ranking of Article 3: *Respect for Differences*, Article 17: *Protecting the Integrity of the Person* and Article 23*: Respect for Home and family*. Again, this table is not to describe whether the women performed, centered or contested these values but instead just to note how often the articles values were mentioned within the discussion groups. In comparison, Lambeth can be described as expressing values in patterns consistent with larger group values, given the ranking of Article 29: *Participation in political and public life*, Article 21: *Freedom of Expression* and opinion, access to information and Article 30: *Participation in Cultural Life, Recreation, Leisure and Sport*.

Both discussion groups expressed similar ranking for Article 6: *Women with Disabilities* recognize that *women and girls with disabilities are subject to multiple*

discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

As discussed in previous chapters, this article combines women's and disability rights for the first time in United Nations convention documents and also adopted human rights work within Britain. I believe one of the main reasons the article had as many mentions as it did was because I explicitly asked about this article within the discussion. This is a reflection of certain values being mentioned over other values by the researcher.

Another pattern that was surprising was Article 25: *Health* that ranked low in the number of mentions for both discussion groups. This article states, that *persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.* Since all women participants self-identified as having a physical impairment, it was surprising the article related to Health was not strongly valued within their lives. Possibly, this value is commonsensical and the women felt it did not need to be mention or it is a central part of their lives and does not need to be mentioned or valued as other rights.

Table 3(a) (b)

Relational Positions-Within both Coventry and Lambeth

The following section consists of two tables. Table 3(a) is specific to Coventry and Table 3(b) is specific to Lambeth women discussion group meetings. As described within the Methods section, each table summarizes the patterning of the values for each article explicitly mentioned or spontaneously mentioned by the women across all discussion groups. The articles mentioned within their transcribed dialogues were noted either to value by Performing the article, Centering the article or Contesting the article. Each mention of an article and the value were tallied determining the 'Most', 'Some' or 'Least' categories, within each value. Most is described as the predominant strategy used across the text when discussing a value related to an article. Some is described as a strategy used some of the time and Least is described as a strategy used with no or minimal occurrences. As noted below each table the measure for Most, Some and Least are provided depending on the frequency of mentions.

Analyses revealed interesting patterns across values and the CRPD articles. Illustrated by the dialogical nature of women, the values of each article may change depending on the context and time discussed; therefore, articles may be in multiple categories with different patterning of mentions. As illustrated by the Coventry group in Table 3(a), Article 6: *Women and Disabilities* is located within the Performing value as Some of the time, Centering value as Most of the time and in the Contesting value Least of the time.

Table 3(a)

Relational Positions of Discussion Groups and the Values in the Rights Document (CRPD)-Coventry Only

Performing			**Centering**			**Contesting**		
Most	Some	Least	Most	Some	Least	Most	Some	Least
Coventry								
Art.3			Art.6*			Art. 8		
Art. 17			Art.8			Art. 23		
	Art.6*		Art.23				Art.16	
	Art.8		Art.27				Art. 20	
	Art. 16		Art.29				Art. 24	
	Art.20			Art.3			Art. 27	
	Art. 21			Art.16			Art. 29	
	Art.23			Art.17				Art. 3
		Art.19		Art. 24				Art.6*
		Art.22			Art.19			Art.17
		Art.24			Art. 20			Art.19
		Art.25			Art.21			Art. 21
		Art.27			Art.22			Art. 22
		Art.28			Art.25			Art. 25
		Art.29			Art.28			Art. 28
		Art.30			Art.30			Art. 30

Note: Performing: Most (34-23); Some (18-10); Least (8-3); Centering: Most (8-6); Some (5-3); Few (2-0); Contesting: Most (4-3); Some (2-1); Least (0, or no mentions)
(*) highlights Article 6: Women with Disabilities

Within Categories-Coventry

As shown in Table 3(a), only two articles were identified by the women within the Most Performing and only two articles were identified in the Most Contesting categories. This is interesting to note because there were 16 articles in total discussed within the Coventry discussion groups, but the focus of values are clustered within four total articles with opposite values. This illustrates the women are sensitive to particular values within the document articles.

Beginning with the Most Performing, Article 3: *Respect for Differences* and Article 17: *Protecting the Integrity of the Person* highlights that the women participants in Coventry express the values of the official discourse from the document within their local practices. This analysis suggests that when the women are Performing these values within the articles, they agreed with the article's main premises, intentions or meaning. These articles tend to emphasize the values of moral, ethical and honest principles contextualized within the respect of *individual* differences. This relational positioning does not necessarily mean that these article values are being performed within their communities, but instead what this Most Performing category highlights is the women highly relating to the value of the article within their own lives.

Within the Centering category, Article 29: *Participation in Political and Public Life* and Article 27: *Work and Employment* were in the Most Centering. Here Centering values expressed a subjective or transformative point of view. The Coventry participant's relational position to the value of the two identified articles is still in a state of flux with a high level of negotiation across contexts. It is unclear why the women from Coventry, Centered these two articles specifically. One of the four women worked full time at a non-profit women's rights organization and is prominent within the disabled women's rights movement in Coventry and throughout London.

In contrast, the Most Contesting article values included Article 8: *Awareness Raising* and Article 23: *Respect for Home and Family*. Here the women of Coventry diverge from the CRPD discourse and the values within and implicitly critiqued the cultural norms and practices in relationship to their own lives. Below are specific examples highlighting where the women

participants have engaged in active disagreement taken from the group discussion highlighting disagreement regarding the disability rights discourse.

The CRPD Article 23: *Respect for Home and Family* focuses on the removal of any sociocultural barriers in all matters relating to the act of marriage with or between individuals with a disability, the right to conception and carrying the child full term, being a disabled parent and maintaining relationships for people with disabilities. Interestingly as Table 3(a) shows, the women participants contest the values of this specific article as illustrated in the example below:

> P1: When it comes to the child, they (government/local agencies) always think what is the best thing of the child, human rights is all wrapped in with that.. (*Centering*)
>
> I disagree with you (other participant) see.... it is not your right to have children. For me, the child's rights come first**.** *(Contesting)*

Indeed, as one example, this participant shows quite a bit of conviction regarding the 'child's rights'. Although, what is consistently unclear or absent from this and other participants similar accounts are where the rights of the child would be violated, the values specific to home and family that would be missing from a disabled home or family. Basically, a discussion seems to be non-negotiable and instead broad, sweeping rights discourse is used almost as a barrier to the possibility of disabled women having a home with family- because it somehow would be against the rights of others if this occurred. Acknowledging the power of prior historical practices, activities and interactions as described in Chapter 3: Historical Analysis section, it may be presumed that this particular participant is reiterating sociohistorical values. The discussion regarding the value and conception of Home and Family for disabled women will remain a consistent pattern of discussion throughout this chapter.

The second article Mostly Contesting by Coventry participants is, Article 8: *Awareness Raising.* Here the article values focus on educating abled-body society and the institutions within, regarding the social category of disability, nurture receptiveness and positive 'disability' perceptions by abled-body people. As table 3(a) shows, the participants of Coventry articulated perspectives that appear to be in tension with the CRPD article, as illustrated below:

> P1: I had a security man in 'Boots', in the chemist, walked up to me and said, 'what's wrong with you then love? And I said... I was a police women on me motorbike, chasing someone and skidded and broke my legs and the bastard got away..
>
> I do make stories up.. (laughing)

In the example provided, the Coventry participant described her experience of being asked a private question about her body in a public space. She described the security guard specifically 'walking up to her' (she uses a wheelchair), and specifically points out the word 'wrong' he used to describe her impairment/body. The word 'love' within the described interaction is a word used to position gender. The participant responds and makes up a story about being a police woman (not a security woman) having an accident on her motorbike. Their interaction ends, but the security man is left feeling unsure whether to believe the story and the participant leaves as the authority from the interaction. Clearly, the values within Article 8 relating to *Awareness Raising* have been actively contested by this participant within the described interaction.

To further explain this level of Contesting, I will use Bakhtin's (1986) theoretical concept of 'Carnivalization'. The function of the Carnival is to challenge another with presumed power within a conversation. Through laughter, tension is created and 'authority' is

then described to be decrowned, using a profound and collective engagement with alternative 'truths'. Through this analysis, I believe through the women participants Contesting this article's values, it allows the women participants a way of actively re-positioning themselves as the authority and the security guard, in this instance, as the 'the fool'. I take the stance that by Contesting the values of the article and re-positioning themselves within the interaction, the women participants are taking a profound argentic role within their own interactions. These points and other examples will be discussed further within this chapter.

Across Categories-Coventry

The relatively broad range of particular articles that appear within each value may suggest context sensitivity and these particular articles are still very dialogical within the lived experiences of the women.

The first example is Article 8: *Awareness Raising*, which is discussed across all categories; in the Some Performing, Most Centering and then Most Contesting. This article identifies that cultural norms are not performed or not agreed upon. With the Most number of mentions within Centering and Contesting may indicate that Article 8: *Awareness Raising* is a value that the women perform within their social activities but mainly either contest the value of the article or are still negotiating or transforming the value of the article. As discussed within the previous section, Awareness Raising within Coventry reveals the possible foundational values within a community and can raise questions about the specific practices when conducting these values at a local level.

Article 17: *Protecting the Integrity of the Person* illustrates a similar pattern to Article 3: *Respect for Differences*. Specifically, the women from Coventry are predominantly Performing the values from the article or official rights discourse, Centering the value Some of

the time and have minimal occurrence of Contesting the values of the article within their local practices. It is important to note that both of these articles take an individualistic approach with the value within human rights. It is in this point that we perhaps see most clearly the push and pull of the processes, where individual values are being the most negotiated by the women participants at a local level.

The third article within this category, Article 6: *Women with Disabilities* Some Performing and Some Centering with Few mentions within Contesting the value of the article. This article value is particularly interesting because it is the only article within policy that directly intersects rights to women with impairments, but yet, the women in this research, do not fully Perform the value of the article. The example below demonstrates their own negotiation, even though all participants are themselves women and disabled:

> P3: And I find that (women and disability) very interesting.. but I (participant) have never really thought about it until now..(*Centering)*
>
> P2: I don't think it (women and disability) is widely known..I think if it was more available to us, we *might* do a bit more (*Centering)*
>
> But, I (participant) have not even thought about it to be honest. I am thinking more about it now, because we are talking about it. And last night I was thinking about it. But before that I would not even know where to start a dialogue or whatever..(*Centering*)

Although this article was created and designed with the women participants in mind, within the narrative transcripts each time a women mentioned this article it was in direct relationship to an explicit question that I had asked the group. Therefore, it could be understood that the women Performing or Centering their values is primarily based on the context in which

they were speaking. Furthermore, the women position themselves as constructing the concept of 'dual handicap' within their own sociocultural worlds.

Surprisingly, there were five CRPD articles that were in the 'least' mentioned category across all values. The CRPD Article 19: *Living Independently and Being Included in the Community*, Article 22: *Respect for Privacy*, Article 28: *Standard of Living and Social Protection* and Article 30: *Participation in Cultural life, Recreation, Leisure and Sport* are relative to the concepts of family and home. This may have occurred because all four women from the Coventry discussion group live with their families and own their own home. Therefore, these values are already enacted within their own lives and do not need to be mentioned or discussed.

The following Table 3(b) has the same format as the previous table describing the Values within the Rights Discourse for Coventry. Instead the emphasis is with the second discussion group located in Lambeth, a borough in south London. Similarly, a note is provided below the table describing the amount of mentions per Most, Some and Least categories within each of the values of Performing, Centering and Contesting. In addition, Article 6: *Women and Disabilities* is also noted demonstrating how to read the table, but also highlighting the intersection of gender and disability as valued through the women's daily lived experiences expressed through their dialogues.

Table 3(b)

Relational Positions of Discussion Groups and the Values in the Rights Document (CRPD)-Lambeth Only

Performing			**Centering**			**Contesting**		
Most	Some	Least	Most	Some	Least	Most	Some	Least
Lambeth								
Art.8			Art.6*			Art. 23		
	Art. 3		Art.21			Art. 29		
	Art.6*		Art.29				Art. 3	
	Art.17		Art.30				Art. 21	
	Art. 19			Art.3			Art. 24	
	Art.21			Art.8			Art. 30	
	Art. 23			Art.17				Art. 6*
	Art.24			Art.19				Art. 8
	Art.29			Art.23				Art.16
	Art.30				Art.16			Art.17
		Art.16			Art. 20			Art.19
		Art.20			Art.22			Art.20
		Art.22			Art.24			Art.22
		Art.25			Art. 25			Art. 25
		Art.27			Art. 27			Art. 27
		Art.28			Art. 28			Art. 28

Note: Performing: Most (56); Some (21-13): Least (11-1);
Centering: Most (10-8); Some (5-4); Least (2-0)
Contesting: Most (23-12); some (3-1); Least (0, or no mentions)
(*) Article 6: Women and Disabilities noted across

Within Categories-Lambeth

A significant finding from the Lambeth women's discourse was the relatively frequent number of mentions for Article 8: *Awareness Raising.* This article was the only article within the Most Performing category for this group of women, with double the amount of Performed values mentioned than any other CRPD article. This is a significant finding possibly revealing the relativity of these particular foundational values within this community, which focus on educating abled-body society and the institutions within, regarding the social category of

disability, nurture receptiveness and positive 'disability' perceptions by abled-body people. As described, the women of Lambeth seemed to really embrace these values within Article 8: *Awareness Raising*. Here they provided multiple examples on educating children specifically, see excerpt below:

> P1**:** Not necessarily teachers, it could be (P2**:** parents) a disabled person that go into school and like entertain the children (*Performing*).
>
> Teachers cannot understand, you have to be a person with a disability that goes in, so the children can see what you are talking about (*Performing*).
>
> P3: Unless that teacher has a disability (*Performing)*
>
> *Me: do you think someone without a disability can educate children?*
>
> P2: yes..
>
> P1: no! The thing is you know, it would be nice to have a disabled person to teach the children because you can feel it from your bottom and you know what it looks like. If the normal person explains that it is not like us, it would be better by disabled people, I think (*Performing*).

The participants continued at length, how adults within their communities are 'already set in their ways' and the children being 'the hope for the future' to change the "prejudices against disabled people'. Therefore the women's expressions echoed the values within this article and created a persuasive argument to implement this article further within their own lives and specifically the lives of children. The article itself does not specifically identify the audience grasping the knowledge about 'disability' and in addition, the rights discourse does not identify who will provide these teachings. As described in Chapter 4: Activity-Meaning

Making Systems, the CRPD document was created with NGO's that included disables women but with great strife. The Lambeth women's rationale to provide training themselves, seem to echo these previous struggles as well.

As Table 3(b) shows another significant finding came within the Most Contesting category for the Lambeth women in Article 23: *Respect for Home and Family.* The CRPD values within Article 23 focuses on the removal of any sociocultural barriers in all matters relating to the act of marriage with or between individuals with a disability, the right to conception and carrying the child full term, being a disabled parent and maintaining relationships for people with disabilities. Interestingly as Table 3(b) shows, the women participants contest the values of this specific article as illustrated in the example below:

> P1: The difference is if you didn't know and it happens suddenly, (*Centering value*) but if you know you are having a disability and it is continuously going, then there is no hope of you getting any better, and having that child it is not fair on that child. (*Contesting value)*
>
> P2: If you are sick, then you are not supposed to have a child. (*Contesting value*)

As the above example demonstrates, the participants negotiate by Centering the values, 'if you did not know' you were disabled and you had a baby, then that is somehow acceptable to have children-more of a rationale in being a disabled mother. Clearly, the participants identify conditions and if disabled women actively decided to have a child, somehow the rights of the child are violated. Clearly and without any hesitation conditions are provided and the values of the CRPD article are Contested amongst the group of women. Additional examples and further discussion regarding these values amongst both groups of women are discussed later in the chapter.

There were multiple articles in the Most Centering category, Article 6: *Women and Disability*, Article 21: *Freedom of Expression and Opinion* and Article 30: *Participation in Cultural Life, Recreation. Leisure and Sport* which was the highest number of Most articles. This possibly could indicate that the women participants of Lambeth expressed a higher subjective point of view, negotiation across multiple perspectives and were highly reflective and expressive when discussing their lived experiences.

Across Categories- Lambeth

Article 6: *Women and Disabilities* across categories is somewhat interesting with the higher number of mentions within the Most Centering category and then Some Performing and Least Contesting. This illustrates the Lambeth women's values expression regarding the notion of 'dual handicap' is still being negotiated or transformed for *and* by the women with disabilities.

Article 29: *Participation in Political and Public life* values within this article describes the right to vote and stand for election, and legal capacity to make their own life decisions. As Table 3(b) shows, the participants mainly diverged from the values of the articles Most Contesting and Most Centering but Some Performing. In Lambeth, the women discussed their own frustration of not having clear representation within Parliament or at the local council level:

> P1: For now, I mean, those days when people fought for human rights. But to say for, disability and women we need to see this type of women in Parliament. Not just women alone, we need to see disabled women (*Performing*).

P2: I have never seen disabled women in Parliament, apart from David Blancket.. I have not really seen a disabled person to stand up in Parliament, but we need disabled women, to see disabled women in Parliament standing up for us (*Performing*)

,the smaller people that do not have a say (*Contesting).*

P2: Sorry, do you think they (abled bodied society) want to put a disabled person in Parliament? (*Centering*)

P3: Why not? (*Performing*)

P1: It is not a matter of what we think (*Contesting).*

This women's value expression lies primarily within their disenfranchisement of government involvement in their lives. Indeed, it is correct that there has never been a disabled women active within Parliament for the women to feel represented or heard as stated by 'the smaller people that do not have a say' and 'it does not matter what we think'.

As worth noting, Lambeth women participants had many articles that remained within the Least through all three categories. Article 16: *Freedom from Exploitation, Violence and Abuse*, Article 20: *Personal Mobility,* Article 22*: Respect for Privacy*; Article 25: *Right to have Adequate Health Care*; Article 27: *Work and Employment;* Article 28: *Adequate Standard of Living and Social Protection* were barely mentioned by the women participants throughout the four discussion group meetings. None of the women within the group worked at the time, and all of their housing, health care and mobility were being provided by the State.

Indeed, the participant's basic needs were being met by the social welfare system, but the cultural practices situated at the local level were where the women put their motivation and energy. This point is highlighted by the women discursively positioned themselves with the

values of Article 8: *Awareness Raising;* Article 23: *Respect for Home and Family* and Article 29*: Participation in Political and Public Life.*

Common Patterns Between Coventry and Lambeth

For both groups of women, two common patterns of values emerged from their group narratives. As shown in Table 3(a) and 3(b) participants similarly discursively positioned themselves to Most Contesting Article 23: *Respect for Home and Family,* the Most Centering and Some Performing from their lived experiences. Below are two examples illustrating the women's struggles and negotiations when discussing whether to have children or not:

Example 1, Coventry:

> P1: My mom said I was, what is the word.. like reckless.. for having children, because I have been diagnosed with MS. I have been diagnosed at 21 and got pregnant at 26 (*Centering*).
>
> P3: It is because people here (England) think you have to be perfect to have children (*Centering*).
>
> P2: I think the social services would take over, wouldn't they?... put some kind of carer in… (*Centering*).
>
> P2: I disagree! (*Performing*)
>
> P1: I think it is the women's rights to have a child (*Performing*).
>
> P4: For me, again, it is not fair for the child. I always believe the rights of the child comes first (*Contesting*).

Below is a similar excerpt from the Lambeth group:

> STAFF: Another big issue for me is around people with disabilities having children. If you have a disability you shouldn't have a child (*Contesting*).

And what happens when you already have children but then get a disability? (*Centering*)

P2: Certain disability should not be having children, because it is not fair on the child. And it is not fair, what if you were a parent. Because you cannot look after that child, which means someone else will have to look after the child (*Contesting*).

STAFF: So if the doctor asks who is going to look after the child, you can't say nanny because that is not fair on the child. That child will not have a bond with you (*Contesting*)

P1: I will have babies until I have a girl. I don't care what you're both saying. I am a disabled and I am proud of it, and I'm going to have babies until I have a girl. I do not care. Okay? (group laughs)(*Performing*).

It is in these excerpts that we see most clearly the patterning of the values, beliefs and principles surrounding the conception of 'motherhood' for the disabled women- as not being an option for the majority of the participants. These context values are marked by the consistent usage by both groups connecting words such as 'not', 'fair' and 'child'. Additionally, these women's positions were characterized by high use of social welfare jargon, such as 'social services', 'carer', and 'nanny' as the ultimate option to maintain a relationship with their child.

Interestingly, within both groups there is one participant that strongly Performs the value within Article 23 and clearly keeps her stance throughout the dialogue, never wavering from her original position. From each group, this one participant stresses an agentic view and challenges or steps out from the local discourse, aligning herself with the values of the human rights discourse instead.

From this analysis, there is a minimal level of negotiation or attempt of transformation from any of the participants. The women express strong essentialist, emotionally laden views

that fall within 3 primarily categories: 1) I am disabled and therefore cannot become a mother- unfair and violates the 'child's rights'; 2) I am disabled and will become a mother- do not care what others think; and 3) I did not know prior that I had a disability, or I have (this) disability and therefore, I will become a mother-with a carer (of course). This level of conviction and patterns across both groups of women probably demonstrates a long standing sociohistorical discourse that the women themselves continue to replicate from past activities and interactions.

Second, the pattern of mentions for Article 6: *Women and Disabilities* were similar values between both groups across all categories; Some Performing, Most Centering, Least Contesting. The excerpts below illustrate how the women participants describe the practices specific to the intersection of gender and disability within their own lived experiences. Example 1 describes how one participant's abled-bodied female work supervisor acknowledges the disability identifier within their work, but refuses to acknowledge the gender component. The social categories seemed to be very clear-either women *or* disability as demonstrated by five different examples from both Lambeth and Coventry.

Example 1 below describes the act of positioning through the historical social reality of common discursive practices related to gendered narratives around abuse.

> P1: It is the history of disability in this country it just has been a focus on man. And also, it is not easily spoken about. I mean when is the last time you hear about.. um...sexual and domestic violence with a disabled women?? (*Performing*)
>
> P2: I don't think I have!
>
> P1: You have about the sexual abuse of a women- full stop. But *not* the disability. (*Performing*)

P3: Because it is not reported and it is probably their worry that it is their carer that is perpetrated the violence. And the husband is perpetrated the violence.. It happens everywhere and people just do not report it (*Centering*). Or it just has not been picked up in the news. But there is that report that says this is happening. It is just like hate crimes, before it was not reported. Disability was not considered a hate crime, but now the emphasis on hate crime now includes disabled people. And now you get statistics. It is only when the police are aware.... you know?? (*Centering*)

The participants claim through British history these narratives are socioculturally related between genders. Here, disability is missing and through the participants' discourse, challenges the mutual upholding's between themselves, media, police officers of the particular interpretations of the world. They describe that only through institutions will larger societal awareness occur.

Within this dialogue, the women change context from the home to an institution for disabled people. Again, the women describe values in the wider socio-historical context within socio-political institutions. In addition, they further describe the silencing of information specific to disabled women by the police and media through possible ignorance of how to enact the intersection of gender and disability and the nature of the relationships.

P1: But think about the women that are raped in institutions? Do they get flagged up? No.. it happens! I think society as a whole, does not talk about it.

P3: Well, I think we don't talk about a lot of things! I think like...the police. If you contact the police and say, I am a disabled women and my husband is raping me- they will not know what to do!?? (P2: No!) And if it goes to the news, then they will ask

should they report that or not? Probably not.. shit.. and it will go under the table. I don't think we know. Obviously it is happening, but we never heard..

Example 3 describes Performing the value within Article 6, as well as supporting arguments that Jenny Morris (1996) and others have pointed out, 20th century feminism within Britain has failed to address the question of disability.

P1: One million women rights. She never mentions, "what about disabled women?" She does not talk about it. I think because we have not been in it, that is the thing you see. That is why I get it.. because women have not been in disability,... disabled people don't want to consider the gender question and the women do not want to consider the disability question. So...

P2: To be quite honest, I went on one disability rights march and they were all men! (laughing)

Example 3 demonstrates how the value of Article 6 is Performed, Centered and Contested by two staff workers and participants during a discussion group in Lambeth:

STAFF1: One of the things I have noticed. I wonder if others have noticed it. It is very easy for a disabled man to find able body women and to go out with able body women than it is for women with a disability to go out with an able body man... I have experienced have done caring now for 23 years and right across the board, this is something I have noticed. You would see a man with a disability and would notice an able body partner, but the women are discriminated (*Performing*), it is thought because they have a disability they may not be attracted (*Centering*).

STAFF2: Sometimes when a woman has a disability they give up (*Centering)*. It is how you present yourself (*Contesting*).

P1: You have to get them to motivate themselves (*Performing*) and say listen so if you give yourself up then no one would want to look after you if you are a dirty women going around the streets (*Contesting*).

This last example was led by a staff member as being an 'authority'. Her account seems to suggest that she believed in the principle values within Article 6: Women and Disabilities but possibly did not believe in the value of the women themselves. Her experiences do not convey a hopeful outcome for the women present during the discussion group. Rather, her '23 years of experience' paints a rather a glum, lonely outcome for disabled women and a palpable outcome for disabled men. Ultimately, this lesson Contests the values of Article 6.

Differences Between Coventry and Lambeth

When comparing Table 3(a) and 3(b), there were some stark differences with patterns of values between both groups of women. The first example is demonstrated from Article 8: *Awareness Raising*, which was valued significantly different between each group. Lambeth's number of mentions when Performing the value within the article significantly exceeded Coventry's Performing values. Inversely, Coventry Most Contested the value of the same Article. Therefore, the Lambeth participants intensely orientated themselves to the values and principles and the Coventry participants, in contrast expressed contention towards the values within Article 8.

Frequently, both groups of women discussed the hypervisibility of their bodies as indicated through others staring while in public places, particularly on public transportation. Some participants described this interaction with others as being 'highly intrusive', 'rude',

'unwelcomed', and 'embarrassing'. Both groups of women described confusion about the starers intentions and how the women should answer the others in return. The two examples below illustrate these points highlighted and demonstrate how each group took a different approach when positioning themselves within the starer/stare interaction. As mentioned Lambeth Performed the values and Coventry Contested the values within Article 8: *Awareness Raising*.

Example 1 below describes Lambeth's approach when primarily expressing the Awareness Raising values:

P1: Well, sometimes you do not know why the person are staring- you don't know..

P2: The eyes tell you everything, the eye looks at you and you think why are you staring and then you think, you think I am weird don't you?

P1: No, I must bury it. (group laughs in surprise). I just very gently ask, why are you staring at me like that? And the person says nothing, and I say oh come on man, it must be something. Maybe they will! (*Performing)*

P4: I get that a lot sometimes, people staring. Sometimes I can't (*Centering*)

STAFF: It is good to say something darling, because sometimes.. (*Performing)*

P2: It depends on who you are with at the time (*Centering*).

P3: No, but some of the time you cannot be cross, because it never will get us anywhere. (Some participants agree) you can't be too cross. Maybe that person has different things on their mind (*Performing).*

P1: That is what I said, when someone is staring, you can't be too graspy, just say hi, why are you staring? Maybe the person wants to say something to you? (*Performing)*

P2: I know, but sometimes you can't say because people are so ignorant (*Contesting).*

P1: I know! But, it is worth saying, because if you shout at that person, then you are ignorant too (*Performing)*.

P3: You can ask the person why you staring, or what are you looking at? (*Performing).*

In this case, performance-dominated narrating expresses Awareness Raising values, in particular those emphasizing conflict negotiation strategies primarily through empathy for the staring stranger. In addition, the women describe taking full responsibility and 'burying' their own frustration and anger, not to appear too 'ignorant' but instead to try and understand the reasoning behind the stare. Understanding the 'why' behind the stare seems to be central for the women, to then find the best way to negotiate the interaction. If the stranger would answer, the women allude to then having an opportunity to have a peaceful resolution from the uncomfortable stare. Together the women negotiated and somewhat agreed that by "gently" verbally shifting the threat of the stare, than the implicit message is of compassion ultimately shifting the social, cultural perceived values. This resolution would occur through awareness raising and education through the disabled women themselves, an opportunity to re-negotiate the active silence. Ultimately, Performing is the predominant activity within the Lambeth women's narrative.

Example 2 illustrates how Coventry participants describe the same sociocultural practice of being stared at, while Contesting as the predominant activity within the women's narrative:

P2: I get people looking at my legs, my feet because my feet are very swollen. And if I'm not wearing boots and I've got my feet on display in public, I get children or even the

parents looking at my feet and I have stopped my wheelchair and said, "hey they are only feet" and they have gone off and they are really embarrassed (*Contesting)*.

How I confront people who stop and stare, or even children.... I mean I am forty three but if a child looks at me I will stick my tongue out and they'll go running off to their mum (*Contesting*)

P3: because it stops them (*Contesting*).

P2: It stops them doing it (laughter) and I just think, they look at me and go hmmm (sticks out her tongue to demonstrate) and I will confront it... I will not be humiliated

P3…yeah people do stare, doesn't bother me… I just stick my tongue out, (laughter). If you make the first move they don't know what to do. But I think for some people it is an issue (*Contesting*).

Participants describe being addressed and feeling humiliated by the stare. Coventry participants describe answering the stare through resistance and directly confronting others with non-verbal communication as well; as described, sticking her tongue out or through explicit verbal interactions. One participant explains that this act of positioning shifts her from being humiliated into the strangers being embarrassed.

Below is another example of a woman participant describing how her and her husband (abled body) seem to position the crowd at the shopping center and make fun of themselves The understanding motivation was to 'get to them before they stare at us' strategy:

P3: I do tell people as well, there is nothing wrong with me, I am just lazy (group laughter). At Christmas, when I have got loads of things on my lap and my husband is pushing me (*Contesting*).

> My husband will say, "she's just a trailer really..." there is nothing wrong with me really. And when he puts lots of things on my legs (while sitting in a wheelchair), I say that's why I'm disabled because he puts things on my leg (laughter from group)(*Contesting*).

Both groups of women explain staring as being an active, non-verbal form of positioning by the starer, where meaning is taking place. In addition, women participants try to shift the positions, either by confronting or re-negotiating with the starer about the function of their stare. In stark contrast, the Lambeth group described attempts to put others at ease so the silence will stop and shift the discourse to relieve the tension for the women participants. Here there seemed to be hope within the women's dialogue as an opportunity to educate an adult not to stare- through directness, kindness and empathy for the starer. The Coventry participants described educating the starer in a different way-through active engagement and embarrassment. Overall, both groups of women intention are to communicate with the starer and that the hypervisibility of their body, to a stranger, makes them highly uncomfortable.

The second example where the pattern of values between groups greatly differed was demonstrated in Article 21: *Freedom of Expression and Opinion.* This article value includes the *freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others'.* The Coventry participants through their narratives Most Performed the context values within this Article. In contrast surprisingly, the Lambeth narratives Most Centered the values to impart information and ideas on an equal basis with others. Here the women predominantly described accounts of being ignored, dismissed or avoided by strangers in public settings and seemed to be negotiating, transforming or struggling with these practices in their lives. I believe that ignoring is an imposed silence by strangers

positioning the women as being actively 'seen' but then re-positioned to become invisible within the interaction. Below is one example of these experiences in public spaces between strangers and the participants:

> P1: But because some people just do not want to listen. I have something to express, and that person does not want to hear (*Performing*).
>
> P2: There are some people do not listen to you (*Centering*).
>
> P4: They don't see you equal. Equal means if you are disabled you are down from anybody. They do not see you like equally (*Centering*).
>
> P3: And in my eyes, they do not want to give you justice anyway (*Centering*)
>
> P2: A couple of weeks ago, my brother in law took me out for my birthday and I was trying to get through a small gap-in my wheelchair and they (abled body strangers) would not move at all. Without my brother in law saying something, they would not move anyways when I am in public (*Centering*).

One participant describes her experience in public for her birthday, being ignored by strangers until her brother in law interjected the interaction. I believe that the women are Most Centering this article value because of the level of experiences they have had in their lives being disabled. Their bodies seem to be highly noticed by others, but the interactions described suggest, a body that is actively 'less valued' or 'unequal' is not allowed 'justice' by other strangers. This negotiation or transformation for the Lambeth women is possibly their own struggle with the sociohistorical practices and finding and negotiating their own human rights understanding.

Summary and Discussion

The relational values analysis conducted in this chapter, reveal patterns of similarities and differences in turns as expressed through each value (Performing, Centering, or Contesting), contextualized through the CRPD articles and as they are interpreted by two different discussion groups (Lambeth and Coventry). The research design of this study was to elicit co-constructed narratives within the context of the CRPD human rights articles and further understand how the women's lived experiences interact with the values of this human rights discourse. As discussed in Dauite, Stern & Leilutie-Weinberger's (2003) work, this level of analysis also showed the tensions in values across the various situated contexts (e.g. home, media, transportation) in which the women live. In addition, the values analysis allowed me to identify a particular set of foundational values and raise questions about the conception of the 'disabled women' and how they interact with their human rights discourse.

As the results have shown, there were common patterns across both discussion groups. The women participants in both groups had the same pattern of variation when discussing Article 6: *Women and Disabilities.* It appears that the notion of 'dual handicap' is being negotiated and transformed. Both groups of women could discuss specific instances within their lives when the intersection of gender was missing from disability sociocultural practices; such as the disability rights march and reporting of abuse by individuals, media and the police. In both instances, the social category of 'disability' was privileged. In addition, both groups of women described 'thinking about this (disability and gender) for the first time', which makes the important point that common accepted practices and values are dynamic and can shift through discursive practices. Therefore, through dialogue the women could move from *Centering* the values of Article 6 to then *Performing* them within their daily lives. It is also

important to note that this article was explicitly addressed multiple times within both groups of participants. It was perceived that neither group wanted to address how they positioned themselves within this article and possibly can be understood as an act of resistance.

Surprisingly, this analysis showed a common pattern between groups regarding the values in Article 23: *Family and Home*. Both groups of women critiqued the values located with the conception of 'family', 'home', and 'motherhood' through a lens of children's rights. Here both groups of women seemed to position themselves without the right to create a family or be a mother and the children's rights were privileged. The women's account seemed to take the position that disabled women would be morally irresponsible to have children. What is astonishing is the Coventry participants were already mothers, but the social category of disability was emphasized over gender through an ideological discourse of 'care'. These patterns of *Contesting* the values of the human rights discourse could indicate their sociohistorical aspects of knowing and conceptualizing of 'family', 'home' and 'motherhood' as disabled women.

The Values analysis also demonstrated that both groups of women 'least' mentioned, across all Performing, Centering and Contesting values, Article 19: *Living Independently*, Article 22: *Respect for Privacy*, Article 25: *Health* and Article 28: *Standard of Living and Social Protection*. One of the ways to interpret this finding is that the women live in communities where their basic needs (e.g. housing, health care) are primarily being met through the local council and other government institutions.

Beyond these common patterns, the research also highlighted striking differences across discussion groups and the patterns of turns expressing each value within the CRPD articles. Through the Lambeth group narratives, the participants described instances of being ignored or

stared at in public settings (trains, buses and restaurants) by strangers. Although, interestingly, the women primarily Centered the values and emphasized a clear discomfort with the experiences, but did express a level of agency around the silences imposed on them by others. Where women participants from Coventry clearly was Performing the values within Article 21: *Freedom of Expression and Opinion.*

In addition, The Lambeth group vehemently agreed with the human rights context values in Article 8: *Awareness Raising,* while the Coventry group positioned themselves to openly Contest the same article, using the example of being stared at in public by strangers. Here both groups of women took an agentic stance and described instances where the women had directly addressed the starer. The Lambeth group positioned themselves as the educator/teacher and the Coventry group positioned the starer as a fool through humor and humiliation (Bakhtin, 1986). It is unclear why each group of participants took such opposing positions.

While the values analysis has revealed important and new findings, and can offer a set of theoretical considerations regarding how disabled women make meaning contextualized within human rights work, it is also important to understand that the values analysis is dynamic. It appears, specifically through the findings with Article 6: *Women and Disability* that the women in each group were responding specifically to my questions as the researcher. Therefore, it can be understood that finding can also be situated rather than absolute.

Table 4 lists the CRPD articles that were never mentioned during discussion groups. As previously stated, the CRPD has a total of 50 articles.

Table 4

CRPD articles not mentioned by either group

Article 1: Purpose
Article 2: Definitions
Article 4: General obligations
Article 5: Equality and non-discrimination
Article 7: Children with disabilities
Article 9: Accessibility
Article 10: Right to life
Article 11: Situations of risk and humanitarian emergencies
Article 12: Equal recognition before the law
Article 13: Access to justice
Article 14: Liberty and security of the person
Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 18: Liberty of movement and nationality
Article 26: Habilitation and rehabilitation

The first 30 CRPD articles directly apply to the disabled women's lived experiences and the remaining 20 articles provide information on data collection and monitory procedures. Therefore, from the first 30 articles that could be applied to the women's lives during their discussion groups, not all of them were mentioned within their group discussions. The above 14 articles within the CRPD document were not mentioned during either Coventry or Lambeth discussion groups. It is important to note that while these articles are instrumental to their human rights, the women did not discursively position themselves within the articles official discourse while discussing their own lived experiences.

In addition, some articles value expressions may appear to overlap one another; for example Article 9: *Accessibility* (not mentioned) and Article 20: *Mobility* (mentioned). When I

further examined how the women described their experiences within their lives, I made a judgment to identify if they were expressing societal and environmental barriers and the accessibility to the artifact (e.g. ramps, kneeling buses, other) and their own impairment? Or were the women expressing a value within their human rights to have the options or dignity to independently travel (e.g. car, bus, train, other)?

CHAPTER 6

DISCUSSION AND CONCLUSIONS

In this dissertation, I have highlighted the profound social nature of human experience and the situated and contextualized meaning making that occurs within life. I have explored how the experiences of disabled women in London and Coventry England are created through the interactions and activities embedded in cultural practices and situated within the social, cultural, political and historical contexts rather than located solely within the disabled women body (Stetsenko, 2004). I have explored how these gendered experiences of disability are mediated by cultural tools historically developed within the broader human rights activity-meaning making systems (Daiute, 2008; 2010). In particular, this dissertation reviews prior human rights documents as cultural tools, but highlights gender and disability-related policy documents (CEDAW and CRPD) in light of how they address the interface of gender and disability, or the notion of 'dual handicap'.

This research utilized the theory and method of narrative inquiry (Daiute, 2004, 2008) of physically disabled woman narratives contextualized through the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) was instrumental in unfolding the complexities of how women make meaning and come to understand their own human rights based discourse. These complexities of women's interactions with policy as a cultural tool can be productively studied by using values analysis (Daiute, et. al., 2003) and positioning analysis (Daiute, 2004) . These analyses allowed me to layout different kinds of engagements/positions that women participants took up in relation to specific CRPD policy articles (e.g. Article 6: *Women and Disabilities*) and how they Performed, Centered or Contested the policy values.

The findings inform the research questions identified and indicate that a shift is needed to further question the experiences of woman with physical impairments contextualized within their human rights. Below I discuss the research findings and summary as located in the previous three chapters.

Discussion and Summary of Findings

I have demonstrated that the meaning of their experience ultimately lends support for the notion of 'dual handicap', but only barely captures the full extent of the current and past social, cultural and ideological discourses within which it exists.

The results of the study reflect the wider goals of the British social model and disability rights movement which makes a distinction between impairment and disability. Here the construction of the impairment is the biological and disability is the social, cultural, historical and environmental restrictions on a daily basis. This then calls into question the social and cultural responsibilities when conceptualizing an impaired women's body. The narratives highlight the ways in which the women participants guiding values within their lived experiences interact with the policy document, the UN *Convention on the Rights of Persons with Disabilities* (CRPD, 2006). Ultimately, the co-constructed discourses of the women demonstrated the ways which they engaged in meaning-making within their lives. I also discuss the specific implications in order to identify future research as well as support for women and agentic practices as well as policy implications.

The findings of this study lend support to sociocultural historical perspectives and to the works of the scholars (Banks, 2007, 2010; Fine & Asch, 1981; Meekosha, 2010; Morris, 2001) who have emphasized the social, cultural and contextualized notion on the intersection of gender and impairment, termed 'dual-handicap'. This research took a broader historical

perspective, given the understanding that the women's narratives developed in specific historical contexts within the United Kingdom over the last 200 years and the United Nations over the last 60 years. As Vygotsky (1978) emphasized, the sociopolitical history of a culture powerfully shapes all levels of contexts, and the women therefore, adopted histories they inherited to account for their experiences (Daiute, 2010).

Within the Cultural Historical analysis, I reviewed literature and created a timeline interweaving four main areas: British disability history (Borsay, 2002, 2005, 2006) and disability social movements (Shakespeare, 1994, 2006; Oliver,1996, 2006), British feminist history (www.bbc.org/uk), and the United Nations disability and gendered work, focusing on the broader sociocultural, historical and political context in which the participants live.

The historical analysis revealed that disabled women within Britain have been a neglected area of historical inquiry. Chapter 3 analysis begins at the Industrial Revolution (1750-1850's) within Britain, which created social policies and practices that ultimately still sustains the social, cultural, cultural, economic and political discrimination and exclusion today (Borsay, 2002). Here economic conditions opened the necessity of charity work or the voluntary sector producing isolated and homogeneous communities for disabled individuals.

Findings indicated that there are multiple historical activities (e.g. schools, hospitals, world wars, work force linked to charity work, other) in which the cultural, political, historical structures were formed in which the women participants are situated. Analysis reveals that the Second Wave British Feminist Movements and Disability Rights movements both began during the 1960's in American, Britain and Europe. As this women's rights movement was necessary and significant for its time, it did not include disabled women specifically. Comparably, the disability rights movement did not include disabled women either. In addition, this chapter

reviewed the United Nations policies and determined that a similar pattern occurred within the policy documents.

The social category of 'women' has been historically privileged over 'disability' which then has become embodied over time. What I term as the historical 'silences' re-tell and re-experience the construction of 'dual handicap' through historical activities (e.g. social movements and policy documents) that inform the participants everyday experiences- through systems of institutions, activities and interactions-ultimately leading to their own rights based understanding. Here, this research takes the stance that disabled women are not key sociopolitical actors within their own cultural-historical context.

Therefore, the findings suggest that any attempt to construct a United Kingdom, British or United Nations sociopolitical theory intersecting gender and disability cannot ignore that the 'dots' between gender and disability have not been historically connected. The politicization of 'gender' and 'disability' has ultimately been separate and it can be inferred that such representations can leave gaps in disabled women's histories and provides ideologies that are not human rights centered.

In Chapter 4, this research closely followed Daiute's (2008) theoretical and methodological approach to policy documents (CEDAW and CRPD) as larger activity-meaning making systems for disabled women. The discourse analysis of women's rights policy related to the CEDAW and disability rights policy related to the CRPD, helped me to identify the author's intentions and specific language to further understand the broader CRPD activity-meaning making systems. Here the purpose was to understand how statements in one policy document (CEDAW) linked values and discursive practices to the second policy document (CRPD) to further find out about the nature and relationships between both documents. As

previously discussed the CEDAW and CRPD documents are cultural tools used within the activity-meaning making systems that evolved from a series of meetings and previous interactions, expressing the dialogical relations towards disabled women.

The findings indicate that the author's intensions regarding the CEDAW, focused on the relationship and equality of human rights practices, specifically between women to men. Therefore, the dialogical practices, which includes power and status embedded within a system of institutional activities and relationships privilege the social category of gender only. The CRPD as the second data source, primarily privileges the social category of disability, with a mention of women (e.g. Article 6: *Women and Disability*). Therefore, neither the CEDAW or the CRPD policy documents intentions or language actively position disabled women as socio-political actors within their own human rights based understanding.

While indeed the British disabled women participants are social beings that interact with the "material and symbolic circumstances in their environments, including the political processes like rights, which are essential to their lives" (Dauite, 2008, p. 705), the silences or interactions within and between both documents may create practices and discourse within their everyday experiences that reflect the opposite. Therefore this analysis highlights the principles, concepts, and tensions involved in society focusing on the disabled women's rights process. It is possible that the silence for disabled women between both policies is detrimental and continues the patterns of previous reasoning and discourses within larger activity systems (schools, hospitals, and home) and further defining them as 'dual handicap' within their local dialogues and practices. However, women can and do engage with the dominant discourse in different ways.

As findings of this present study show, from a larger historical context and the interactions and activities leading to the larger CRPD Activity-meaning making systems, there is an unclear understanding of the developmental process in which disabled women are major actors within their own human rights understanding. Here, the narratives of the women move away from the existence of the essentialist deficit model, focusing on the dominant discourses on disability that center on stigma, burden and damage. Instead, I believe the narratives illustrate the multi-dimensional dynamic nature and richness of the disabled women's lived experiences.

Through discussion groups in Coventry and Lambeth, England physically disabled women discussed their lived experiences contextualized through the United Nations *Convention on the Rights of Persons with Disabilities*. The values analysis (Daiute, et. al., 2003) and positioning analysis (Daiute, 2004) in Chapter 5 analyzed how the participants positioned themselves in relation to the values encoded in the policy document (CRPD). Here the values are described as "culturally-specific ways of knowing, feeling and acting in response to environmental, economic or social circumstances" (Daiute et. al., 2003, p. 85). Through the women's co-constructed narratives, they position themselves as either *Performing*- the women reproduce the values within the document; *Centering*- the women participants did not agree or disagree with the document values, but possibly in a state of negotiation or transformation and Contesting- the participants took an opposing view of the documents values. I will highlight a couple of key points within the findings.

Interestingly, both groups of women positioned themselves to Contest the values within Article 23: *Respect for Family*. The women participants spoke extensively about the negotiations around having children as a disabled mother priveldged the rights of the child over

the rights of the disabled women to have a family. Their co-constructed stories about their interactions and judgments from members of the medical community, their own family members- particularly maternal mothers, general society on a day to day basis and what I am interpreting as fear from themselves, all taken together makes them doubt if they could physically take care of their own child without help from an outside carer. Here the social category of 'disability' was emphasized over gender as an ideological discourse of the institution of family. It is clear that the socio historical language and practices within medical, social and family ideologues has an impact upon the ways in which being a mother is interpreted by the women in this study. The women describe expressions of anger, recklessness or contempt from medical professionals and family members when the disabled women attempted to position themselves as 'mothers'. The findings indicate that the women struggled with the presumptions that they are more responsible of a people if they forgo having children, but if they did have a child then social services would be needed to 'help' and provide 'care' for the child, underlying the general belief that the women participants are incapable and need to be taken care of, as well as their own children.

Both discussion groups Centered the values in Article 6: *Women and Disability.* The narratives reveal that discourse centering around the intersection of gender and impairment, or the notion of 'dual handicap' were surprisingly limited to explicit questions asked by myself. It is interesting and surprising to note that, even after direct questions such as, "Why do you think Article 6: *Women and Disabilities* is in the *Convention on the Rights of the Disabilities*? Do you think or feel this right to be necessary? Why have we not spoken about gender through our sessions?" the dual handicap was still not discussed and a feeling of disbelief and lack of disclosure was felt among both groups. Although, there were limitations to their own personal

discourse, women did express situated knowledge around the abuse of women with physical disabilities within medical institutions and personal homes by husbands or care givers but only one woman expressed her personal experience. They extended these points to the policing systems not having the knowledge or training to deal with these situations. The narratives reveal that when speaking about dual handicap as a lived experience, women spoke primarily about the others experiences. Expression of disbelief, uncertainty and brief insight as a concept 'that I have never thought about before' and 'will need to think about it further' was the extent. The findings that the women's ambivalence to account for or describe their own lived experience as 'dual handicap' can be viewed as an act of resistance.

A key difference between both groups of participants was located in Article 8: *Awareness Raising*. The Coventry participants actively contested the values while the Lambeth group strongly positioned themselves to Perform the values within this article. Both groups of women describe the ways in which others interact with them (e.g. staring) while in public context (e.g. bus or train). Women from Coventry described how they shifted social interactions by making up stories in response to uncomfortable questions, staring or ignoring to then somewhat poking fun at or even victimizing others without their being aware of the shift in power from ableism or otherness. They positioned others as 'the fool' (Bakhtin, 1986), by confronting the starers to ensure that the participants "will not be humiliated".

The Lambeth group also resisted similar negative interactions (inappropriate questions by strangers, staring and ignoring) but Performed the values within this article and position themselves as the teacher or educator to raise greater awareness. Their expressions of empathy, helping, or informing strangers indicated that they positioned the starer as someone ignorant and who might not understand that they are staring. The Lambeth participants expressed their

need to bury emotions such as ‘anger’ and ‘fear’ in order to interact with the persons who are staring, in order to educate them. In their descriptions within these public, social interactions, the language participants used approached directness, honesty and gentleness in a manner of coaxing the other to have an informative dialogue with them. They represented these interactions in terms such as “bury”, “gentleness”, and “understanding”.

These findings indicated that the social relational practices were similar between both groups (staring), and that they both privileged ‘disability’ rather than ‘gender’ in relation to this article. Where both groups varied greatly was how they positioned themselves in the situated experience. These women’s perceptions and interpretations of the experience of having a physical impairment reveal that they resist being positioned by others, but their resistance takes on different forms. These findings suggest that the women’s narratives are agentic and transformative of discourse, assigning new meaning to impairment. Again gender was not privileged within either group as a social category which could account for the negative interactions that participants experienced. These findings lend support to theoretical works that conceptualize the experience of disability as embedded in shifting social, cultural, political and historical contexts.

Theoretical and Methodical Implications

The findings of this dissertation address research questions pertaining to how the construction of ‘dual handicap’ informs human activity in different ways. This study reveals the ways in which gender intersects with disability as performed through everyday discourse, contextualized through policy documents. Operating within their own context, the women in this study participated in constructing meaning through engagement in purposeful activity

together. Framing their discourse through policy documents is a way to support and understand how policy documents, as cultural tools, mediate their experiences and understandings of themselves as disabled women as contextualized within human rights discourse.

This study posits that it is crucial to understand the impact of both policy documents as cultural tools and the ways in which they mediate local, social and cultural practices regarding women and disability. Finding of this study support assertions by scholars and rights workers that women's lived experiences are influenced by policy and therefore the practical application of these policies must be fully participatory and inclusive of people with disabilities (Ingstad, 2007; Kitchen, 2000; Lord, 2002; Marshall, Kendall, Catalano, & Barnett, 2008), specifically and purposively including the affected women as the most marginalized group. This research is important because it includes, supports, and engages physically disabled women's understanding of the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD, 2006) and their own political positions within the creation and implementation of policy relevant to their lives. This research design and analytical framework offer a new or different way of studying and theorizing how policy as a cultural tool, mediates disabled women's understandings of their own experiences and selves.

From a methodological perspective, joint analysis of two policies (CEDAW and CRPD) allows for a close examination of the different and varied strategies of positioning which in turn, reveal the complex mediated nature of selves in the making (Daiute, 2004; Bamberg, 2004). Humans use cultural tools (e.g., policy) and form activities, shaping and transforming mental processes (e.g., human rights based understanding). Policy as a cultural tool "act(s) as the mediators of action" (Wertsch, 1988) demonstrating how human mental functioning is tied to cultural, institutional, and historical settings, while simultaneously acting as carriers of

sociocultural patterns and knowledge (Wertsch, 1994). It is assumed that the participants formed their knowledge surrounding the notion of 'dual handicap' drawing on the tools of their historical, cultural and social worlds. This research argues that the use of the CRPD as a cultural tool, afforded women to experience a change of perspective, as demonstrated by the participants own words:

P1: *I think society as a whole, does not talk about it.*

P3: Well, I think we don't talk about a lot of things!

P2: And I find that conversation about women and disability.. very interesting.. I have never really thought about it until now. I don't think it is widely known..

I think if it was more available to us, we might do a bit more. But, I have not even thought about it to be honest. I am thinking more about it now, because we are talking about it. And last night I was thinking about it..But before that I would not even know where to start a dialogue or whatever..

As demonstrated within this excerpt, using the CRPD document as a cultural tool is one way to elicit critical and agentic engagements with the policy as the dominant discourse.

Directions for Future Research

Practice and Policy

This research clearly suggests that within policy, disability needs to be seen within the context of other forms of policy work such as gender, class and race. These issues are linked to the concept of intersectionality (Crenshaw, 1992) that has derived from gender studies, which highlights the complexity of multiple identities and various disadvantages and discriminations that result from these identities. As discussed, in terms of the quantifiable variables such as

income, employment rates and educational levels, the data suggest that disadvantages associated with disability and gender may well be cumulative (Emmett & Alant, 2006).

However, more important to the central issues in this research, the intersectional perspective encourages policy makers and monitoring bodies to move away from binary thinking to a more global human rights perspective. Therefore, from an intersectional perspective, rather than seeing one person's rights (e.g., those pertaining to gender) at the expense of another's (e.g. those pertaining to disability), intersectional practices embrace the possibility that whole persons' rights are integrally understood.

As previously described, the CEDAW addresses issues of concern for women specifically, whereas the CRPD focuses, if taken as standing alone, focuses on issues of concern for people with disabilities. For example, the CRPD does not focus on specific risk factors and causes leading to disability, including malnutrition gendered socio-historical practices and inequality in health care. Although the CEDAW does make specific reference to the rights of women, few state party reports focus on the intersections of discrimination faced by disabled women (de Silva de Alwis, 2009). As suggested through this research, the disabled women human rights falls between both of these policy documents. Therefore, these areas can be more effectively addressed through a joint analysis and monitoring bodies of the CEDAW and CRPD, ultimately creating a paradigm shift in both the theoretical and institutional frameworks of human rights practice.

In addition, what this research also indicates is that it is important to look at why women may potentially resist the notion of 'dual handicap' as a social category in their own lives. This dissertation only begins to answer this question. One of the possibilities is that if and when disabled women identify with both gender *and* disability discrimination, that is, accept

the notion of 'dual handicap', it may produce a reading of themselves as 'doubly' disabled, a notion which can ultimately be disempowering.

National policy to local practices

As pointed out in Chapter 3, many British disability rights advocates' (Crow, 1996; Finkelstein, 2001a; Morris, 1991) and scholars (Barton & Oliver, 1997; Corker, 2001; Shakespeare, 2006) have made efforts to influence parliament and local council members to pass a social justice agenda. Unfortunately, implementing these efforts has been difficult, at least in part, due to the lack of access to information and knowledge production about national and local rights for people with disabilities within parliament, monitoring bodies, council level and within the universities. This limitations in access to information leads to problems with access to assistance and possibly slows down the shift at the local discourse and practice level. The results of this research demonstrate that the women participants are very clear that they want a higher level of government engagement and representation of women with impairments within a public government setting (e.g. Article 29: *Participation in Political and Public life*). Below is an excerpt describing how the participants address their local council about their experiences within the health systems:

> P1: *We have become a group that tried to help the council about the NHS. But we should not have to do that because we are disabled we are asked (by the local council) to sort this out. Why because we are disabled, why do people not know enough about disabilities that they can think themselves, why does it take us two in a wheelchair to go and do this?*
> P2*: Frankly, I don't mind- I only wish they would pay us for it.*
> P3: *We do it because we want to sort things out, but then the council actually gets paid- we don't. We get paid expenses but why aren't they taught disability(?)*
> P1*: Because that is what you are doing for them.*

P2*: Yes, I know but why pay somebody… if you two do it for free?*

Here the women are questioning why they are not being paid by the local council for their expertise regarding larger health institutions (NHS) and their experiences within the systems. In addition, they question why they have to educate the local authorities about their own communities regarding people with disabilities. It appears that the women describe their expertise about their own lives, but not feeling empowered or dually recognized by the local political system.

In addition, women from Lambeth were very clear that they are asking for extensive work to raise awareness about impairments within the general population (Article 8: *Awareness Raising*) and women from Coventry were very clear to in stressing the need to identify and educate local communities on individual differences (e.g. Article 3: *Respect for Differences* and Article 17: *Protecting the Integrity of the Person*). Therefore, a future implication from this research is to urge the disability advocates, Shadow Report monitors, university practices and local council workings to incorporate women in local spaces to collaborate, implement or even disagree with the official discourse within the privileged figured worlds.

Considerations

- Both the Lambeth and the Coventry discussion groups had paid carers or family members (husband and daughter) attend parts of two meetings. The rationale provided by outside individuals to participate included safety reasons (for example one woman was experiencing re-occurring seizures during the day) or emotional support and protection. Within the Lambeth group, paid carers interjected and provided their opinion within the discussions on more than one occasion. In addition, carers approached me and asked to be part of the discussion group, especially when the women participants were speaking about dating and sexuality. The paid carers were women but did not have impairments. Their own rationale was that they were having trouble with their husbands at home and wanted a place to speak

about their issues. When I explained the purpose of the research group and how another support system may work better for her, one of the women still attended the meeting later in the day. Therefore, the participation of three outside participants, might have been shifting the power dynamics as previously determined (e.g. carers, supervisors or family members). In addition, Krueger and Casey (2009) describe the possibility that participants might intellectualize their experiences and not "tap into their emotions" (p. 13) or may make up their answers if they are unclear of the topic discussed.

- A second consideration may be my own personal and professional roles with regards to ideologies of cultural norms in Britain, and women with impairments. The women participants positioned me as an American woman without identified physical impairments and likely inferred the perceived cultural norms that surround this position. These cultural norms may have affected our interactions and my interpretations of the women's narratives. Conversation directed towards me during the discussion groups highlights this point:

Because we as women and women with disability. We need a say. And with you (researcher) doing that, God is out there through you (researcher) for me (participant). I am with you because what you are saying to me what I have wanted to say, but could not put it in the right words. I (participant) want what you (researcher) got, I want you to be my mouth, talk up for me

- A third consideration may include the women participants' intention to "help" me in my research. More than once within the group sessions woman directly asked me if what they were speaking about was "helping me" finish my dissertation. This sense of support and care has possibly resulted in illuminating only specific topics of conversation that the participants perceived as something that I wanted to hear in order to successfully complete my work.

Even though my research has contributed to existing theory and literature in ways indicated above, more research is needed to understand how disabled women make meaning of their human rights as discussed in the following section.

Locating the Researcher

In this dissertation I have sought to understand the lived experiences of British women with physical impairments. In this section, I locate myself in my work and frame the knowledge generated in this study in the context of my understanding of women with physical impairments.

Before the research started, I understood the concern about qualitative research and the extent to which the predispositions or biases of the researcher may affect data analysis and interpretation (Patton, 2002). Research involving human beings inevitably represents some degree of perspective rather than absolute, objective truth (Patton, 2002). Ferguson, Ferguson, and Taylor (1989) point out that, when researchers become involved in telling others' stories, they filter those stories through their own experiences.

Throughout my career as a public school teacher in the United States, I have worked with children and youth with impairments across all grade levels. Teaching middle and high school students has had the most influence on my own experiences in this regard. While working at these grade levels, I became a child rights advocate, observing the day-to-day tensions between school ideologies and school practices in regards to youth with impairments. Teenage girls with physical impairments moving into puberty and facing general adolescent challenges and woes influenced my focus when I found that their situations were continually disregarded at dances or during many social activities such as lunch time or gym period.

My intention was to highlight the experiences of women with physical impairments and apply ways in which policy can or could support the intersection of gender and disability within a human rights framework. However, I acknowledge that my own experiences, filtered through the interactions and relationships with the women participants, may have influenced the discussion group meetings. In reflection, I did find that I had continuously to make an effort to stop myself from advocating for the women, yet it was difficult for me to listen solely as a researcher.

Intersection with Policy and Britain

My work as an adjunct professor at Brooklyn College brought me to work with the United Nations *Convention on the Rights of the Child* (CRC, 1989). Again, within a policy document, children and specifically girls with impairments comprise a population that is generally dismissed. Thus, for this dissertation, knowledge originated both from the lives of girls and women with impairments and from policy documents which I felt that, even today, neither clearly advocated for nor represented the intersection of gender with impairment.

In 2006 the United Nations created the *Convention on the Rights of Persons with Disabilities* (CRPD). This was the first international human rights document that incorporated impairment, disability, and gender as part of the human rights mission. In conceptualizing this research, I knew that the United States had not ratified either the new convention or the previously existing conventions (CRC, CEDAW). In contrast, I knew that Britain did sign the CRPD and was moving towards ratification of it and had already signed and ratified the CRC and CEDAW in prior years. A review of multiple CEDAW Shadow Reports within Britain made it clear that gender and disability were just beginning to intersect within the CEDAW monitoring reports and that there was still a minimal rate of recognition of these relevant issues.

Appendices

Appendix A

Sample Introduction for Discussion Groups

"Thank you for coming today and working and learning with me about how physically disabled women connect with the new United Nations human rights international policy, called the *Convention on the Rights of Persons with Disabilities*, known as the CRPD.

We will meet and freely discuss specific points: 1) What is the *Convention on the Rights of Persons with Disabilities?* 2. How can or does this relate to mine and others life? 3. Together, please speak freely and give your opinions, experiences and suggestions.

Each week when we meet, we will review a couple of human rights articles and how you use have them in your life. Over time, I do understand we will get more comfortable with each other and I encourage everyone to share as much as they feel comfortable. Each time we meet, I will start the meeting off with a CRPD human rights article and then I will just guide the conversation if needed.

I want to remind you that each time we meet it will be recorded, so that I can remember what everyone has said. Also, the recordings do not go further than this group. Anything you say here will be held in strict confidence; I will not tell people outside this room who said what. I have a consent letter we will review first. Are there any questions or comments at this time before we start?"

Appendix B

Purposeful and Spontaneous Articles

The CRPD articles explicitly chosen to begin dialogue within each discussion group are listed below. The criteria for the articles are the explicit mention of the intersection between gender and disability within the article.

Preamble (c), (d), (p), (q), (r), (s)

Article 3: General Principles (g): Equality between men and women

Article 6: Women with Disabilities

Article 16: Freedom from Exploitation, Violence and Abuse

Article 23: Respect for Home and the Family

Article 25: Health

The CRPD articles that were spontaneously addressed by the participants during the discussion groups. See below:

Article 5: Equality and Non-Discrimination

Article 8: Awareness Raising

Article 9: Accessibility

Article 10: Right to Life

Article 18: Freedom to Choose Liberty of Movement and Nationality

Article 19: Living Independently

Article 22: Respect for Privacy

Article 24: Respect for Home and Family

Article 29: Participation in Political and Public Life

Article 30: Participation in Cultural Life, Recreation, Leisure and Sport

The below are the CRPD articles that were discussed in *total* by the women participants:

Preamble (c), (d), (p), (q), (r), (s)

Article 3: General Principles (g): Equality between men and women

Article 5: Equality and Non-Discrimination

Article 6: Women with Disabilities

Article 8: Awareness Raising

Article 9: Accessibility

Article 10: Right to Life

Article 18: Freedom to Choose Liberty of Movement and Nationality

Article 19: Living Independently

Article 22: Respect for Privacy

Article 23: Respect for Home and Family

Article 24: Education

Article 25: Health

Article 29: Participation in Political and Public Life

Article 30: Participation in Cultural Life, Recreation, Leisure and Sport

Appendix C

Specific Gender and Disability Questions

1. Do you believe it is necessary to have more policy specific to disability? Why do you believe this? What are your experiences with current disability policy?
2. Within this convention, the word "women" was specifically added. Why do you think this word was added? Do you think it is necessary?
3. We will review the some articles within this convention, but first lets discuss how would define "rights"? How would you define or create a definition for disability rights? How would you define or create a definition for women disability rights?
4. Within this article, how does it apply to your life? Can you give specific examples of how you have experienced this yourself?

Explicit Audience and Positioning guiding Questions:

1. If you were in a position to change this previously identified barrier, what, if anything would you change?
2. Do you want to make a change? If not, why not?
3. If you would like to make a change, who would you tell? How would you do it?
4. Who or what, do you think is responsible to make these changes? Why?

Appendix D

Historical Timeline: United Kingdom disability social and political movements; Great Britain Disability and Women's Rights Movement and the United Nations Policy and Practices.

The era of the Industrial Revolution, 1750-1850

1751 St. Luke's Hospital for Lunatics was established in London

1764 The first British 'special' school for deaf children opened in Edinburgh

1774 The Madhouses Act created from the Royal College of Physicians to license and visit private madhouses in London

1791 First British charity school for blind children opened in Liverpool

1792 Mary Wollstonecraft wrote, *A Vindication of the Rights of Women*.

1792 First British charity school for deaf children opened in Bermondsey, London

1808 The County Asylum Act permitted, but did not require counties in England and Wales to build asylums for pauper and criminal 'lunatics.

1817 First orthopedics hospital in Britain, The General Institution for the Relief of Persons laboring under Bodily Deformity was founded in Birmingham

1838 The Charity movement published a People's Charter which among its six demands included universal male suffrage.

The growth of collectivism, 1850-1939

1850's First Wave Feminist movement begins; headquarters in Langham Place, London.

1851 First attempt made identifying sensory impairments in the decennial Census.

1858 English Woman's Journal published (1858-64)

1866 *The Lancet*, a leading medical journal, published a series of articles highly critical of London workhouse medicine.

1867 The London Society for Women's Suffrage formed

1870 The Married Women's Property Act- Married women could own Property even if married, divorced, single or widowed.

1872 National Union of Women's Suffrage Societies (NUWSS) was formed

1888 The Women's Trade Union League secures the first successful equal pay resolution at Trades Union Congress

1889 The Report of the Royal Commission on the Blind, the Deaf and the Dumb was published

1890 The Lunacy Act introduced a complex system of legal orders and medical certificates to prevent wrongful asylum admission.

1892 First special school for intellectually impaired children opened in Leicester.

1893 The Elementary Education (Blind and Deaf Children) Act transferred responsibility for the education from the poor law authorities to local education authorities. Given to develop 'special schools in the voluntary sector'. Parents were obliged to send children who were blind or deaf.

1899 The Elementary Education (Defective and Epileptic Children) Act empowered local education authorities to provide schools for intellectually impaired children who were not in existing facilities.

1900 Agnes Hunt's Salop Convalescent Home for Women and Children opened at Baschurch near Oswestry, later becoming a pioneer of orthopedic surgery, open-air therapy and post-operative after care clinics.

1902 Women's textile workers from Northern England petition to Parliament demanding votes for women.

1903 The Women's Social and Political Union founded in Manchester

1904 *The Report of the inter-Departmental Committee on Physical Deterioration* was published.

1905 First local authority residential school for 'crippled' children opened in Manchester.

1906 The National Federation of Women Workers founded

1907 Under the Qualification of Women Act, women can be elected onto borough county councils and elected mayor

1908 Thousands in Hyde Park, London supporting women's suffrage

1914 World War I begins

1918 Representation of the People Act was passed. Allowed women over 30 years old aright to vote in Britain

1918 The Parliamentary Qualification of Women Act is passed, enabling women to stand as MP.

1918 World War I ends

1919 The Central Council for the Care of Cripples was founded, later known as the Central Council for the Disabled and the Royal Association for the Disabled and Rehabilitation (RADAR).

1919 Establishment of League of Nations

Development of the Welfare State

1920 The Sex Discrimination Removal Act passed. Allows women access to the legal profession and accountancy.

1921 Unemployment benefits are extended to include allowances for wives.

1928 All women in Britain gain equal voting rights with men.

1928 Virginia Woolf's novel 'Orlando' (written for Vita Sackville-West) released

1929 'Flapper Election' first general election where women can vote

1929 Women become 'persons' in their own right, by order of the Privy Council

1939 World War II begins

1941 The National Service Act is passed, all unmarried women (ages 20-30 years) called for war work

1944 The spinal injuries unit opened at Stoke Mandeville Hospital in Aylesbury, Buckinghamshire.

1945 End of the Second World War

1945 Establishment of United Nations

1946 The National Health Service Act promoted a system of physical and mental health care that was comprehensive, collective, universally available to the population as a whole, and free of charge at the point of receipt

1948 General Assembly adopted the Universal Declaration of Human Rights (UDHR).

1948 Introduction of the National Health Service (NHS) provides free access to health care.

1948 The National Assistance Act: (1) required local authorities to provide accommodation for all 'who by reason of age, infirmity or any other circumstances are in need of care or attention which is not otherwise available"; (2) provided a means-tested payment for claimants who either had no right to national insurance or whose benefits fell below its own minimum standard; and (3) permitted local authorities 'to promote the welfare of persons who are blind, deaf or dumb and others who are substantially and permanently handicapped by illness , injury or congenital deformity'.

1948 Leonard Cheshire Disability charity was formed

1958 Life Peerages Act, women can sit in the House of Lords for the first time.

1962 A Hospital Plan for England and Wales was published, introduced the concept of the district general hospital having between 600 and 800 beds

1963 *Health and Welfare: The Development of Community Care* was published, containing how the local authorities will expand their social services.

1964 The Married Women's Property Act woman can keep half of any savings she has made from the allowance given by her husband.

1965 Barbara Castle is appointed Minister of Transport, first female minister of state

1966 UN International Covenant on Civil and Political Rights

1960+ Second Wave Feminism formed- '*The Personal is Political*' slogan

1967 Abortion Law Reform Bill, which becomes the Abortion Act, decriminalizes abortion in Britain on certain grounds.

1967 The contraceptive pill available through Family Planning Clinics. The NHS (Family Planning) Act permits health authorities to give contraceptive advice regardless of marital status and the Family Planning Association (FPA) follows suit.

1968 The Report of the Committee on Local Authority and Allied Personal social Services (the Seebohm Report) recommended: (1) unified social services departments (in place of the

former health, welfare and children's departments); and (2) the transfer of responsibility for community health services to the reorganized NHS.

1968 Women workers strike at the Ford car plant for equal pay

1968 Equal Pay Act for women created

1970's United Kingdom Disability Rights Movement began

1970's United Kingdom Black Feminist movement begins

1970 The Local Authority Social Services Act unified social services departments in England and Wales .

1970 The Chronically sick and Disabled Persons Act required local authorities to: (1) inform themselves of the number of disabled people requiring assistance; (2) publicize the services on offer; (3) provide community support services; and (4) have regard to (3) provide community support services; and (4) have regard to the needs of disabled people when framing housing policies.

1970 Britain's first national Women's Liberation Conference is held at Ruskin College, Oxford. The Women's Liberation Movement (WLM), influential throughout the 1970s, develops from the conference.

1971 The United Nations Declaration on the Rights of Mentally Retard Person was ratified.

1971 *Handicapped and Impaired in Great Britain* was published, first of three disability reports commissioned by the Department of Health and Social Security, from the governments' Office of Population Censuses and Surveys.

1971 First Women's Liberation march in London

1973 Britain joined the European Economic Community, now the European Union.

1974 *Disability Alliance* created in United Kingdom

1974 The Union of Physically Impaired Against Segregation (UPIAS) policy

1974 Housing for disabled people were identified: (1) wheelchair housing for full-time wheelchair users and housewives who used a wheelchair indoors; and (2) users and housewives who used a wheelchair indoors; and (3) mobility housing for able-bodied as well as disabled occupants who were ambulant rather than full-time wheelchair users.

1975 UN First World Conference on Women, Mexico City

1975 UN International Year of the Women

1975 *Fundamental Principles of Disability* publication

1975 The United Nations Declaration on the Rights of Disabled Persons was ratified

1975 The Sex Discrimination Act was implemented. Illegal to discriminate against women in work, education and training.

1975 The Employment Protection Act, cannot fire a women if pregnant

1975 The National Abortion Campaign is formed, creates largest women's rights demonstration since the suffragettes.

1975 Welsh women drive to Brussels delivered the first petition to the European Parliament calling for women's rights

1976 The Chronically Sick and Disabled Persons Act amended added accessible workplaces

1976 The Union of the Physically Impaired Against Segregation published its definitions of impairment and disability

1976 The Race Relations Act illegal to discriminate by race in employment and education.

1976 Domestic Violence and Matrimonial Proceedings Act introduced protect women and children from domestic violence.

1977 UN International Women's Day becomes an annual event

1977 First Rape Crisis Centre opens in London.

1978 The Report of the Royal Commission on Civil Liberty and Compensation for Personal Injury (the Pearson Commission) was published.

1978 The United Nations Convention on the Elimination of the Discrimination Against Women

1978 The Women's Aid Federation of Northern Ireland established

1978 First Organization of Women of African and Asian Descent created in Britain at a national level

1979 The feminist journal 'Feminist Review' founded

1979 Six women are acquitted in the 'Reclaim the Night trials' in London.

1979 The Conservative government led by Margaret Thatcher was elected as Britain's first female prime minister

1979 Peter Townsend's monumental study of Poverty in the *United Kingdom* was published.

1980 UN Second World Conference on Women, Copenhagen

1980 Women can apply for a loan or credit in their own names.

1980 The World Health Organization published an expanded version of the International Classification of Impairment, Disability and Handicap (ICIDH).

1980's The Third Wave of Feminism emerged

1980 The Liberation Network of People with Disabilities was established

1981 Liberation Network Policy was created

1981 The British Council of Organization of Disabled People was established.

1981 The Disabled People's International (DPI) was established

1981 Baroness Young, House of Lords first woman leader

1981 **United Nations declared, the "International Year of the Disabled People"**

1982 The United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities, creating the Decade of Disabled Persons

1982 The Court of Appeal decides bars and pubs cannot refuse service to women

1983 Lady Mary Donaldson becomes the first woman Lord Mayor of London.

1983 UN World Program of Action Concerning Disabled Persons (WPACDP)

1983 Decade for Disabled Persons (DDP), 1983-1992.

1984 The national Black Feminist Conference held

1985 The Hampshire Centre for Independent Living was established to secure facilities and allowed disabled people choice and control.

1985 UN Third World Conference on Women, Nairobi

1985 The Equal Pay (Amendment) Act allows women to be paid the same as

men for work of equal value.

1985 The first black lesbian conference is held in Britain.

1985 Foundation for Women's Health, Research and Development leads to the Prohibition of Female Circumcision Act

1986 The Social Security Act replaced supplementary benefit with income support and set up a discretionary social fund to meet exceptional circumstances.

1986 United Kingdom of Great Britain and Northern Ireland signed and ratified CEDAW

1986 The Sex Discrimination (Amendment) Act women can retire at the same age as men

1986 National demonstration of women against violence against women

1987 Diane Abbot becomes the first black woman member of the Westminster Parliament

1988 The Education Reform Act introduced the National Curriculum, allowed modifications for disabled children at the discretion of the head teacher.

1989 The United Nations Convention on the Rights of the Child

1990 The NHSS and Community Care Act: (1) reduced the flow of state subsidies to private residential homes; (2) allowed hospitals and general practitioners to opt out of state control; and (3) applied market principles to the organization of health and social services.

1990 Mike Oliver, a disabled male writes, *The Politics of Disablement*

1990 Human Fertilization and Embryology Bill, monitor the performance of fertility treatment clinics, and any research using human embryos

1990 First independent taxation for women, now married women are taxed separately from their husbands.

1991 Jenny Morris, a disabled feminist writes, *Pride against prejudice: Transforming attitudes to disability*

1991 Opportunity 2000 launched, pushing for more women in commerce and public life

1991 Jenny Morris, a disabled feminist writes, *Pride against prejudice: Transforming attitudes to disability'*

1993 The United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities

1994 World Conference on Special Needs Education held in Salamanca, Spain

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1994 Salamanca Education Act

1994 'Take Our Daughters to Work' Day starts in UK

1994 The government introduces 'Changing Childhood', allowing maternity services focused on the individual woman

1994 Rape in marriage is made a crime

1995 The United Kingdom Disability Discrimination Act (DDA) made it illegal to discriminate against disabled people 'in connection with employment, the provision of goods, facilities and services or the disposal or management of premises".

1995 UN Fourth World Conference on Women, Beijing

1996 Community Care (Direct Payment) Act, United Kingdom

1996 Northern Ireland's Women's Coalition founded as a political party. Promoting inclusion of women in social and political life, on an equal footing to men. Helped elect two women members, to the Irish National Assembly

1996 Women's Aid successfully lobbies government for effective civil remedies for protection from violent partners

1997 General election, 101 Labour women MPs elected.

1998 The Human Rights Act was passed by the European Union and British Parliament

1999 Disability Rights Movement took the lead in securing legislation for a Disability Rights Commission (DRC),

1999 Parental leave law allows both men and women up to 13 weeks off from work to care for children under age five

1999 The Sex Discrimination (Gender Reassignment) Regulations, ends employers discriminate against transexuals

2000 Patients in mental hospitals became entitled to vote if they were not guilty of a criminal offence.

2000 UN Millennium Development Goals

2000 CEDAW Optional Protocol enforced

2000 Refugee women's groups in the UK to bring a gendered analysis to asylum claims. The UK's Immigration Appellate Authority (the immigration and asylum tribunal) launched its *Asylum Gender Guidelines* determining asylum appeals. They aim to ensure that the gender of the asylum seeker does not prejudice their application.

2001 London Partnerships Register, created by Mayor of London. Allowing lesbians, gay men and unmarried heterosexual couples to register their partnerships.

2001 The Special Education Needs and Disability Act (SENDA)

2002 Lesbian and unmarried couples can adopt children, Parliament passes

2003 The Employment Equality (Sexual Orientation) Regulations introduced

2003 The Female Genital Mutilation Act amends the Prohibition of Female Circumcision Act of 1985. Now an offence for UK nationals or permanent UK residents to carry out female genital mutilation abroad, or to aid, abet, council, or procure the carrying out of female genital mutilation, even in countries where the practice is legal.

2004 Women march on Parliament, protesting that one in four retired women live in poverty

2004 Members of the disabled people's Direct Action Network protest against the Draft Disability Bill

2005 Civil Partnerships Act, first registration of same sex couples

2005 A joint report *Improving the Life Chances of Disabled People* was published with the Department of Work and Pensions, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister. Four key areas were identified: (1) support independent living,(2) support families with young disabled children, (3) facilitate a smooth transition into adulthood and; (4) improve support and incentives for getting and staying in employment.

2005 Disability Discrimination Act was amended

2005 New Office for Disability Issues reporting to the Minister for Disabled People was established from report.

2006 Equality 2025, formed a network of disabled people that advises the Westminister Government on disability equality.

2006 The United Nations Convention on the Rights of Persons with Disabilities (CRPD)

2009 United Kingdom ratification of the CRPD

Appendix E

Relational Position Data Collection Template-EXAMPLE

Heidi Bjorgan **Relational Positions: CRPD rights and Narrative work**

CRPD Preamble/Principle/ Article	**Performing-** *conforming to policy values/ practices*	**Centering-** *Combo of both/ transformation*	**Contesting -** *differ from policy values*	**Total # of mentions**	**Total % of mentions**	**Notes:**
Art 6: Women With Disabilities Preamble s: incorporate a *gender perspective* Art. 3: Principle G: *Equality between men and women;*						
Art. 3: Principle A: Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons						
Art. 3: Principle D: *Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity*						

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