LEISURE AND WOMEN WITH DISABILITIES

LEISURE AND WOMEN WITH DISABILITIES:
NEW DIRECTIONS IN SUBJECTIVE EXPERIENCE

By

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ABSTRACT

Disablement has been defined according to three criteria; impairment, which addresses the biological aspects of disablement, disability which addresses functional loss, and handicap which addresses the social and environmental aspects related to disability. One or more of these components influence social policy development. Unlike previous models of disability, this research uses a multidimensional approach to explore the subjective experiences of women with disabilities in relationship to leisure. Further, it addresses all the components of disablement to explore the biological and cultural aspects that impact on the female, disabled body during leisure pursuits. Leisure is one aspect of the human experience that provides the opportunity to experience the integration of the mind, body and social components of one's life.

The findings suggested that the women define leisure similarly to other women and to persons without disabilities but their definition was broad enough to incorporate differing functional abilities. Their leisure became more passive, isolated and segregated with adulthood. Reasons for this included constraints due to the body, transportation, time, environments, equipment, relationships, economics and policies which place them in a separate and distinct position in society. They must adapt their bodies, activities, time schedules, environments, and equipment to meet their desires and functional needs for leisure.

Solutions need to accommodate issues of differing needs while ensuring the treatment of persons with disabilities as persons first. Increasing awareness, incorporating persons with disabilities into decision making processes that affect their lives and universalizing policies and perceptions would encourage inclusion.

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to my parents, Gordon and Meretta Hoyle
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and for teaching me to value difference
while acknowledging my human connectedness.

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CHAPTER 1

INTRODUCTION

The term disablement incorporates three components; impairment, disability and handicap. Impairment is associated with any disturbance in the body which may be physiologically, anatomically or psychologically abnormal (Bickenbach, 1993; Jones, 1994). Disability is any loss or reduction in functional ability as a result of this biological disturbance that leads to activity restrictions (Bickenbach, 1993; Jones, 1994). Handicap refers to the social or environmental influences that exist outside of the body and place a person at a disadvantage due to their impairment or disability (Bickenbach, 1993; Jones, 1994; World Health Organization, 1980).

Although some researchers on disability issues suggest that these definitions are problematic because they assume some standard for normality (Oliver, 1990), others feel these definitions are important because they provide a standard upon which policies can be implemented (Bickenbach, 1993), and they ensure the importance of considering the implications of the biological body in policy decisions (Jones, 1994). It is important to show the distinction between the three components because it provides the opportunity to consider how much people are affected by the physical conditions that affect their daily lives. It also emphasizes the fact that people may not be able to carry out activities due to environmental barriers (e.g. physical barriers such rough ground) and cultural barriers sometimes formalized in policies and established practices. Therefore, all three aspects must be considered in order to understand the experience of disablement.

The definition of leisure used is broad and incorporates any activity that is defined as leisure by an individual and that has meaning for that individual. It may or may not be structured, organized, group oriented or physically active.

This study examines the leisure experiences of women with mobility disabilities. Particular focus is placed on subjective experiences of the body; the manner in which disability is experienced both sensually and culturally. The theoretical position taken will argue that both biological and cultural experiences of the body are necessary for the development of a subjectivity. Subjectivity involves how one thinks (human consciousness) and the manner in which this is affected by "power relationships and conflicting interests of class, race, gender, age and sexual orientation" (Roman and Apple, 1990, p.39). For this study, subjectivity also involves the manner in which the body itself informs human consciousness.

This approach is a departure from much of the previous research on the body which has often conceptualized the body as an object that is predominantly shaped by the social environment (Shilling, 1993). For example, in medical practice the body is routinely viewed without subjectivity, to be examined and manipulated. In socio-political practices, living in a particular social group within a particular social context is important in the development of one's experience (Bickenbach, 1993). Subjective experiences are explainable in terms of the social environment in which the experience occurs. The physical differences in body types which help form self-identity are often overlooked. The omission of this dimension is limiting because, for example, persons with disabilities often become conceptualized as both genderless and homogeneous in terms of abilities.

Not all theory has ignored the subjectivity of the body. Some variants of feminist theory recognize biological differences between the genders, arguing that biological determinism of the female body has contributed to the oppression of women (Wendell, 1989). In this view, women can reclaim their own bodies by redefining the female body as other than an object with specific sexual functions that place them in a subordinate position relative to men.

But, feminist theory can be paradoxical in advocating for "female specificity" based on gender while lobbying that women should not be determined by biology alone (Bigwood, 1991, p.56). In this sense, feminism introduces the importance of the body for how women develop ways of undertaking their daily lives appropriate to their "unique bodily being" (Bigwood, 1991, p.56). In the current study, it is argued that this is also true of the experiences of persons with disabilities. That is, while the body is culturally constructed, the body must also be understood within a framework of embodied giveness. This means that the physical experience associated with living in a particular biological body is as important to the understanding of disability as is the manner in which that body is perceived by others in a particular social environment.

In this sense, feminist theory provides a flexible framework from which to study disability, even though it has been largely silent on disability issues. This silence has emanated from definitions of disability that have been based on the perceptions of people living in non-disabled bodies. The subjectivity of the body within disability has been largely obscured.

The present study explores how body experiences are important for the development of consciousness. I will interrogate the proposition that our bodies are shaped both by culture and by personal experience. The focus will be on how the body is "lived by each of us" within a particular time and space or historical context (Bigwood, 1991, p.61).

Much of the theoretical discussion will take as its point of departure the literature on the gendered body. In this literature women's bodies have been predominantly conceptualized only as objects in the sense that there are standards for female beauty, behaviour and health. The manner in which the body is perceived by others often helps determine how it is cared for. But care for the body is not only explained by cultural standards. It is also influenced by the individual's sensual experience of the body. This becomes apparent in leisure activities which promote the healthy, beautiful body. For example, in traditional sport and fitness programs, the body is often objectified and treated mechanistically. It is given a prescribed, disciplined way of moving. Rationalized movements of the body suggest that the body is considered an instrument and object to be mastered and used toward a specific end; either to accomplish some movement or to become healthy and/or fit. The view that the rational, logical, mind and the physical, sensual body are separate entities is the theoretical foundation for much of westernized physical education (Bandy, 1986). This is problematic for individuals who cannot live up to these standards or those who experience their bodies as less than ideal.

Inability, through disability, to carry out physical movement necessitates either modification of the techniques needed for the activity or the modification of personal movements in order to take part in the activity. I will argue that the experience of disability gives a unique perspective on leisure and movement which is more inclusive than that constrained by non-disabled practices. People with disabilities are aware of both the limitations but also the uniqueness of their bodies while living within a culture that idealizes specific body types and actions.

Chapter Two will be a review of the literature regarding disability and women. The importance of incorporating the physical experiences of the body into disablement research will be considered. Also discussed will be the models of disability used to inform social policy. A multidimensional model which includes biological and cultural aspects of gender and disability will be proposed as a framework for this research.

In keeping with the suggested means of conceptualizing issues of gender and disability, Chapter Three outlines the qualitative methods used in this research. Problems associated with the research process will be considered and the manner in which these issues were addressed will be discussed.

Chapter Four presents the findings of this thesis and compares them, when possible, with previous research.

Chapter Five asks what can be concluded from the findings and the analysis. Also, solutions as suggested by the women themselves, other researchers and myself, will be discussed. Recommendations for social policies affecting leisure activity will be addressed.

The research is concluded with an epilogue where I reflect on my research experiences and try to make some theoretical connections regarding the body and social interaction.

CHAPTER 2

LEISURE, DISABILITY AND WOMEN
A REVIEW OF THE LITERATURE

Brief Review of Theoretical Approaches to Disability

Historically, research on disability has been approached either from biological or from cultural perspectives which, respectively, recognize the physiological aspects or the social consequences of disability. Bickenbach (1993) identifies three theoretical models that have been used to inform social policy on disability; the biomedical model, the economic model and the social-political model. Associated with the latter model is a fourth model that is described by Gadacz (1994) as the equality rights model.

In the biomedical model, disabilities are conceptualized as inherent bodily impairments caused by "disease, accident or a defective gene" (Nixon, 1984, p.163) rendering the victim as sick, misfortunate, to be pitied, to need help, and dependent upon specialized care (Bickenbach, 1993; Morris, 1989). Since disability is seen as being located within the body, it is categorized as needing control and treatment by medical workers. In this process, bodily conditions and experiences are defined and controlled by medical experts, rather than by individuals with disabilities. The disabled person becomes defined according to her/his differentness, becoming an "object of curiosity" (Malec, 1993, p.22).

When the body is medicalized, intervention is focused on short-term care and rehabilitation (Wendell, 1989). Within dominant medical discourses, people whose conditions are difficult to control or cure by medical intervention are problematic.

Bickenbach (1993) argues that some biomedical responses to disability are based on models for chronic care that focus on self-empowerment emphasizing coping rather than curing. As a result, they seek to establish long term environments. The focus, however, remains on the medical model.

Much of the contemporary legitimacy of dominant medical discourses is based in their affiliation with the ascendant value-free model of science, a connection which has eroded the legitimacy and expansion into other health alternatives (e.g., acupuncture, therapeutic touch, massage, naturopathy among others). By claiming to have access to objective truths about illness and healing, the chronically impaired may be discouraged by mainstream medical practitioners from pursuing alternative modalities (Bolaria & Dickinson, 1994). As Johnson (1992) suggests, though, people with chronic impairments cannot always cure their bodies through modern medicines and they do not always accept traditional diagnoses. Sometimes, they discover new treatments outside of the medical model and discover alternative physical therapies.

In sum, medicalization of the body has located disability issues within the auspices of the medical model such that disability becomes defined and managed largely by dominant medical discourses. The implications of this appropriation of responsibility are that alternative perspectives on disability issues and the subjective experiences of people living within a chronically impaired body are often inadequately articulated or broadly appreciated.

In the second model, the economic model, disability is conceptualized predominantly as a financial issue needing policy intervention. In this view, treatment of disability is a social obligation more than an individual or medical obligation. People with disabilities are viewed as economically problematic because of their frequent difficulty with employment; a human role considered central in the model. Consequently, social policies are needed to help disabled people enter the labour market (Bickenbach, 1993).

This model, of course, is based on the particular notion of "value" in market economics. Value, in this sense of the word, is defined according to a person's ability to be productive in the labour market. By definition, those who are not productive in the labour force are a financial burden to society at large. Ideally, in this view, social policies are necessary to assist persons with disabilities become more employable.

In a critique of the economic model, Bickenbach (1993) argues that it is overly simplistic because it ignores the heterogeneity of disability. Differences in abilities are great, enabling some people, but not others, to enter the labour force. Implicitly then, the economic model does not address the needs of those who need the most support in becoming employable. Often, in conventional economic terms, meeting the needs of persons with disabilities is too costly relative to their potential productivity (Bickenbach, 1993). The notion of "value" then, is based purely on economic productivity and largely excludes other types of value (e.g. cultural, social, interpersonal). That is, this model focuses predominantly on the economic costs of disability to other members of society. This reduces the economic question to whether persons with disabilities are capable of being productive members of the paid labour force or whether they are simply an economic burden to society because of their impairments.

In the third model, the social-political model, it is argued that people with disabilities are disadvantaged by negative stereotypes which label and stigmatize them (Bickenbach, 1993). The implications of a stigma as a "discrediting attribute" is that it becomes the focus of social attention turning other people away from the one who is stigmatized (Goffman, 1963). This process, caused by a negative reading of a person's impairment, may lead to a devalued label; one that is internalized by the disabled person (Becker, 1987;

Nixon, 1984; Nixon, 1991). As with the economic model, accommodation for disabilities is considered a social obligation (Bickenbach, 1993). Social policies do not change the impairment or the process of stigmatization, but they attempt to change the experience of disability with the social context.

Oliver (1990), a supporter of this socially constructed model of disability, argues that changes to social policy do not necessarily address issues associated with the underlying ideology of normality. Since disablement is socially constructed it is perceived as an individual disadvantage. Such a construction assumes a standard of normality and those who live outside these standards are considered to be disadvantaged. For Oliver (1990), the social construction of disability is not totally dependent upon an individual's internalized perceptions or on those of powerful groups with vested interests in defining disablement. Disablement is also the result of an ideology of normality that is embedded in the social consciousness and is legitimized in social policies (Oliver, 1990).

Bickenbach (1993) argues that the proponents of this model (i.e. Oliver) underestimate the importance of biomedical and economic approaches to disablement. As a result, the causes of disablement become located solely within society and social organization.

The legitimacy claims of the socio-political perspective are based on its civil rights focus on issues in areas such as accessibility (to buildings, employment, recreation), independent living, equality, protection of the law and improved quality of life (Bickenbach, 1993; Morris, 1989). This brings us to the fourth model of disablement which addresses equality rights. These rights are the same as human rights, minority rights and civil rights. Their emphasis is upon commitment to political equality (Bickenbach, 1993). Since they are legally enforced rights they have more political weight than moral rights. These are rights that are presumed to be available to all citizens, giving people with disabilities avenues to organize themselves politically (Bickenbach, 1993).

Gadacz (1994) argues that independent living/disabled consumer movements feel equality rights within legislative practices need to incorporate both formal and substantive equality. Formal equality, as stipulated within section 15(1) of the Canadian Charter of Rights and Freedoms, ensures equality of treatment of all citizens so that everyone is assumed to have access the same rights before the law. For persons with disabilities this is important as it ensures that the law must include and treat every citizen fairly. However, it does not address the differences among individuals (i.e. socioeconomic status, gender, ability, and political inequalities). Individuals who share these differences are considered members of a disadvantaged group. Here, substantive equality becomes important for persons with disabilities. A claim can be made against any law that perpetuates discrimination toward any social group and can make demands such as reasonable accommodations, special tax reduction, and accessibility (Gadacz, 1994). Therefore, this type of equality in the law ensures that persons with disabilities can be treated differently according to their differing needs.

Therefore, combining equality rights and substantive rights ensures that persons with disabilities have the potential of being treated like every other Canadian citizen while having their different needs protected under the law.

To ensure the rights of persons with disabilities requires the input of consumers of persons with disabilities. For example, in Canada in 1976 the Coalition of Provincial Organizations of the Handicapped (COPOH) was formed to enable people with disabilities to articulate and defend their rights. Formerly, rehabilitation organizations and professionals had in varying degrees acted in this capacity for disabled persons (Driedger, 1993). This change in responsibility shifted the very definition of the realities of persons with disabilities. Subsequently, perceived realities became more subjectively-oriented and less objectively-oriented, more disability-oriented and less medically- or economically-oriented. This type of reorganization was an example of disability rights groups working toward change in the legislation affecting them as a group.

In general, disability rights groups argue that persons with disabilities comprise a minority group which is distinct from the larger culture (Philips, 1985). They lobby for the reasonable accommodation of physiological differences and work toward greater self-reliance among the disabled.

While this is a liberal approach to disability issues, some argue that disability rights groups tend to overlook individual experiences of disability (Morris, 1993). Thus, while people with disabilities have experiences of discrimination in common, their struggles with the body are diverse (Wendell, 1989).

This, by itself is a valid point of criticism. Further, though, all of the theoretical approaches reviewed above are inherently limited because they do not incorporate the subjective experiences of disabled people. This is not to say that these models do not help explain how the lives of disabled people are structured and experienced. For example, to dismiss the medical model is to deny the lived reality of physical experiences of disability, such as living with pain and physical limitation (Morris, 1993). The problem with ignoring economic and social-political theories is that the experience of living within a physically impaired and gendered body within a social and economic context would be overlooked.

All of the theories mentioned above, though, have some commonalities. In each model, disability tends to be defined as being homogeneous and genderless. The end result is an us/them dichotomy which suggests that persons with disabilities are separate and distinct from those without disabilities obscuring any similarities between disabled and non-disabled persons. Given these limitations the potential of feminist theory for addressing these aspects associated with disability will now be addressed.

Feminism: An Alternative Perspective on Disability

> Feminism challenges assumptions of the traditional view of authority, power and privilege and strives to create space for collaboration, a revision of history, an alternative view of the world, a fresh and different approach. (DePauw, 1994, p.473)

In recent years, progress in social theory in general can be attributed, at least in part, to the expansion of the boundaries of feminism beyond the study of women alone to becoming an alternative way of understanding the world in general (Morris, 1993). Although feminism has often been associated with the study of women only, some feminists have incorporated the study of both genders in their research (see, for example, Smith, 1987). The difference between their approach to the study of genders and those of non-feminist researchers is that they begin with a woman-centered viewpoint (Eichler, 1988; Smith, 1987). Ground-breaking work in this area suggests that a more subjectively-based perspective on the social world needs to be incorporated into traditional social scientific approaches. This integration of objective and subjective material allows for a more non-sexist, balanced approach to studying social phenomena. As argued below, this type of research has enormous potential for the study of disability and women.

In her work on feminist methodology, Eichler (1987) argued that women's concerns are relatively ignored in social science research, and that it is important to integrate their concerns into the social sciences in order to eventually achieve a non-sexist approach to research. Smith (1987) adds that traditional malestream research has tended to ignore subjective experiences of the body through the senses. Hartsock (1987) continues this line of thought suggesting that women have a deeper understanding of social reality because they unite the actions of their mind and their body to carry out their daily labour. For

Hartsock, women have the deepest understanding of reality because they are always combining the abstract and the actual through their work which often vacillates between home and the public realm. This suggests that the balancing of work and home responsibilities, of physical labour and mental labour, creates a different knowledge in women than in men.

These feminists, then, advocate a woman-centered approach where the subjective experiences of women are a cornerstone of the body of knowledge hitherto relatively unexplored. In the current study, feminist perspectives are also adopted because they are flexible enough to consider disability from a disabled-centered point of view, where the person with the disability defines and describes her/his reality.

Recent developments in feminist theory recognize and probe differences among women and other social groups, although these have been rarely explored from a non-disabled point of view. For example, Collins (1990) suggests an alternative Afrocentric feminist epistemology. For her, what is important to the black women's consciousness is the idea of being a member of a group (e.g. woman) yet standing apart from it, making her unique (e.g. as a woman who is Afro-American). This approach recognizes the differences and similarities between men and women of the minority group of race and it addresses differences that exist among the minority group of women.

At first, this theoretical approach may seem to be unproblematically appropriate for the study of disability because it recognizes that women with disabilities experience their life not only as women, but also as persons with disabilities. These two experiences are intertwined. The direct application of this model to the study of disability becomes problematic to some extent, though, because differences are not defined only within a cultural context. Physical ability and subjectivity must also be taken into consideration. In the study of disability, regard must be given to the effects of physical experiences. For example, while disability, as with race, constrains activity due to social barriers, most persons with disabilities are also limited by physical impairments. Women with disabilities are forced to approach physical activity within social and physical constraints. In sum, as Cassidy et al. (1995, see also Morris, 1993; and Wendell, 1989) suggest, in some ways feminist theory differs little from traditional theories because it sometimes excludes the subjective experiences of women with disabilities and defines disability in non-disabled terms.

The potential of feminist thought for disability issues, though, lies in its potential to probe individual subjectivity. This includes examining perceptions of negative and positive lived experiences and ways of viewing the social world. Hillyer (1993) suggests that the experience of disability can help in the development of feminist theory because that which may be seen as positive or negative is not necessarily understood that way by persons with disabilities. Persons with disabilities are well aware of limitations and negative attributes associated with "losses that cannot be repaired" (p.15) so their strengths and weaknesses must be consolidated as part of their reality.

When feminists attempt to understand disability through the experience of a non-disabled body, physical impairments are often overlooked. For example, disabled individuals become labelled as "other" such that attributes associated with "us" (non-disabled) are considered positive and universal while those associated with "other" (disabled) are negative and particular (Morris, 1993, p.67). Similarly, attributes associated with disability such as dependence, illness, and weakness, are valued only negatively when defined from a non-disabled perspective.

Consequently, non-disabled feminists have tended to exclude the subjective reality of women with disabilities from their agendas. Much feminist thought has implicitly assumed white, middle-class, feminist explanations as the norm and that other differences are particular and separate (Morris, 1989;1993). This separates women with and without disabilities from each other. They are presented as two separate groups with different interests resulting in a lack of recognition that both groups include women with common concerns. Israel and Odette (1993) have suggested that disabled women have experiences different from their non-disabled counterparts, but that there are also "common threads" that all women experience such as living within a female body.

In sum, it is argued that while the disability rights movement has largely failed to acknowledge that women with disabilities have different issues than men with disabilities, feminist theory has also not satisfactorily conceptualized the links between gender and disability. As a result, the issues of women with disabilities have received inadequate attention by both the women's and the disability rights movements (Driedger, 1993; Israel and Odette, 1993; Morris, 1993). It is the unique position of disabled women that provides them with the opportunity to bring their knowledge into feminism as well as bring a feminist perspective into the disability rights movement.

The Body as an Integrating Force in Subjective Experience

"Different kinds of bodies give us different raw materials for artfully constructing our view-points of life" (Johnson, 1992, p.61). Although Johnson (1992) warns against exaggerating sexual differences into the oppressive sexual stereotypes of biological determinism, biological differences between men and women shape their lived experiences. For example, since men do not experience the rhythmic changes that women's bodies experience during menstruation and pregnancy, their individual perspectives would not be informed by them (Bigwood, 1991). This does not mean that the environment has no effect on the gendering of life experiences or that biological characteristics are the sole determinants of her life experiences. Similarly, a body that is disabled would experience a unique relationship with its environment (both physical and social) based on the manner in which the body receives information from the environment and interacts with it.

Merleau-Ponty (1962) suggests that a person's ability to be in this world is only made possible through the body and that it is through this "living body" that the meaning of the world is revealed to a person. By "living body" he does not mean the body that is experienced as an object, but the biological body that interacts with the elements of the environment (e.g. relationships, time, space, and with itself) and changes accordingly. This is the body that experiences subjectivity.

Toombes (1992) and Van den Berg (1972) refer to the "lived body" not as the body which one possesses but, as that which one is or which one experiences through the senses. It only becomes a possession or object when one reflects on it. Reflection involves conscious thought. Subsequently, mind and body become separate because sensations are no longer just experienced; they are thought about (Bigwood, 1991). Cultural attitudes affect how we think about our bodies, but our bodies can unconsciously react to the environment and to itself (Van den Berg, 1972). This means that the body has a knowledge of its own to add to the subjective experience.

Johnson (1992) suggests that our culture ignores our body and focuses on the mind. This may not appear to be true at first glance because our culture places considerable attention on body work (e.g. regular exercise, cosmetic surgery to obtain the ideal body). This attention, though, is on the exterior surface of the body and not what the body is experiencing inside. Both Johnson (1992) and Shilling (1993) suggest that the focus on how the body looks externally and how it is cared for has to some extent replaced religious frameworks on which we formerly relied on for our identity formation.

In Western society, our identity becomes based in large part on the physical. The body is idealized in terms of strength, appearance, energy and ability to be controlled

(Wendell, 1989;1993). Value is placed on the youthful, thin, sensual body (Shilling, 1993, p.3). This idealizing of the body prevents non-disabled women from identifying with and loving their bodies. A gap develops between the biological experiences of the body and the cultural experience of the body. Wendell (1989;1993) suggests that, at first, an acquired disability can alienate a woman from her body. There is a realization that the non-disabled can postpone the task of identifying with the messages given them by their bodies. When the body is idealized, that which does not fit the ideal is seen as negative, to be avoided.

The body receives external information as our point of access to the world through the sensory experiences of touch, smell, sight, sound and taste (Toombes, 1992). Bigwood (1991) suggests that the body actively interacts with the environment and does not just passively receive sense data, reacting to outside influence. The sensations of the body are experienced as involuntary and unconscious until they are reflected upon (Bigwood, 1991). For example, the experience of listening to music may manifest itself in movements of the body that are not consciously reflected upon, but are automatic and individualistic.

Bodily sensations are experienced and not just thought about or rationalized in the mind. Bigwood (1991) argues that our human being takes place within a "natural-cultural relational field," meaning it is involved in the cultural forces as well as being interconnected with its biological components (p.60). Therefore, the body has a nonlinguistic, noncognitive, uncontrolled component which comes from the physical body alone (Bigwood, 1991).

This is very important to the understanding of disability because the physical limitations of the body affect not only how others define persons with disabilities, but, how the disability defines their day-to-day realities as well. Non-disabled people do not have to listen as intently to the needs and sensations of their body. People with disabilities have to pay more attention to them for survival and to prevent deterioration of their physical bodies (Wendell, 1993).

To date, most theories on disability (including feminist attempts) have neglected the fact that the body has a biological component and that it changes physically according to its relationship with the environment and itself. For example, women with disabilities may experience the social repercussions of not fitting into the non-disabled ideal, but their bodies may experience physical changes in its response to an inaccessible setting or pain.

The Body and Women with Disabilities

> We claim our bodies and our integrity as disabled women. We insist on our right to make informed decisions about our bodies. We do not have good parts, bad parts, or inner beauty. We come in many sizes, shapes and colours. Our bodies deserve our love, tenderness and pleasure. We are whole, beautiful and sexy women. (Browne, Connors and Stern, 1985, p.247)

Insights by women with disabilities have rarely been integrated into feminist theory of the body. This is a significant conceptual gap given the importance of the body for women in general and women with disabilities in particular (Wendell, 1989). Female bodies are largely defined by male, ostensibly objective, medical, physical fitness standards which define what is appropriate female, physical appearance and what is a healthy body (Bolaria & Dickinson, 1994; Cassidy et al., 1995). Women with disabilities are largely excluded from these discourses on health and beauty and tend to see themselves as separate from other women:

> Our beauty is reserved for the inside. Inner beauty is used by our culture as a consolation prize for those it finds ugly. (Browne, Connors and Stern, 1985, p.246)

Under the weight of these standards, women with disabilities are often viewed as "defective, unattractive, and unable to manage their own bodies" (Cassidy, 1995, p.55).

They are seen as "asexual"(Sherrill, 1993, p.144) and like non-disabled women, become objectified, but differently. Malec (1993) suggests that, as a woman with a disability, she is objectified twice. Her disability defines her as an "object of curiosity", but her femaleness also defines her as a sexual object (p.22). The combination of these two objectifications presents women with disabilities as subordinate objects twice over.

The combination of biological and cultural experiences of disability as a woman is usually different from that of men with disabilities and women in general. Women with disabilities cannot completely separate the biological and social aspects of experience because they live in bodies that carry less value than ones that are fully able.

Wendell (1993) suggests that feminists have tended to provide an unrealistic picture of disabled women's relationship to their body by suggesting that social justice can be used to overcome the cultural alienation of the female body and provide a more enjoyable experience of it. This latter notion ignores experiences created by the sensations of the body which may not be enjoyable (e.g. pain). For this reason many women with disabilities disassociate their bodies from their real selves (Browne, Connors and Stern, 1985). Others accept these negatively perceived experiences of the body. This may not be enjoyable, but it allows for the transformation and re-interpretation of the bodily sensations so the experience of them will not become overwhelming:

> In a sense, I discovered that experiences of the body can teach consciousness a certain freedom from suffering and limitations of the body. (Wendell, 1993, p.119)

Incorporating the importance of the experience of bodily sensations into theory moves us beyond the limitations of the traditional mind/body dichotomy and suggests that explanations for social phenomena do not have to be defined exclusively as being on either side of the nature/nurture debate. For Wendell (1993), it is not enough to incorporate the awareness of these sensations. Theory must incorporate that awareness into a new understanding and perception. For example, by accepting the suffering body, the consciousness is informed. New thought and experiences develop that can acknowledge the sensations of the body while not being ruled by them (Wendell, 1993). This suggests that the experiences of the conscious mind and the unconscious body are connected when limitations of the body are accepted. As Wendell (1993, p.122) suggests: "...the body itself takes us into and beyond its suffering and limitations."

Wendell (1993) also suggests that disabled people cannot celebrate their bodies until they accept their limitations. This is what persons with disabilities can teach the non-disabled; how to commune with one's own body and listen to what the body is saying as opposed to what the culture is saying about the body. Focusing on the latter alienates people, women in particular, from their bodies and creates a wide gap between the body and the mind.

This awareness of the body's limitations and sensations, coupled with the reflective qualities of the mind, suggest that women with disabilities have experiential knowledge unavailable to non-disabled culture. They may be better able to go beyond the dominant cultural conceptions of the female and non-disabled body.

Feminist theory has often suggested that women consciously control the appearance of their bodies within historically and culturally defined contexts. In this view, gender is predominantly culturally determined with few characteristics determined by biological and physical factors (Bigwood, 1991). Interest has often been in factors which are external to women's bodies (e.g. how culture affects a woman's experience of her body), rather than looking at the body's unconscious, involuntary reaction to the environment at a given moment and place. A feminist theory of disability must recognize that the subjective experience of living in a particular body has a cultural and a biological component as is the case of living in a female, disabled body. Since we as humans live in bodies and are subject to the experiences of the body and because these bodies live in culturally-historical contexts, we cannot be either totally biologically determined or socially constructed (Bigwood, 1991).

Toombes (1992) states that bodily dysfunction necessarily causes a change in how the embodied person interacts with the world. The way the body is experienced is influenced by its specific biological attributes. For disabled people, there are differences in the body's relationship to others, its relationship to itself in terms of gait, gesture, posture and ability, its relationship in space (or the environment), and its relationship to time. For example, there is a change in posture, gait and the way in which persons with disabilities use gestures in their interaction with others. This physical difference in turn affects social interaction (Toombes, 1992).

Also, for persons with disabilities, physical space no longer takes on an outwardly directed dimension, rather it becomes a restriction of possibilities because the range of movement is limited (Toombes, 1992). There are also restrictions in available space outside of one's personal space. Different spatial needs are required for maneuvering the body to carry out an activity, and in negotiating stairs that are too steep or doorways that are too narrow. Disability becomes socially constructed due to physical environmental constraints.

The experience of time is also different because it is more static and confined to the present. Meeting the goals of here and now are more important than what will happen in the future (Toombes, 1992). This is at least in part explained by it taking longer for disabled people to carry out many activities.

How can this analysis be related to women in general? One connection exists in considering the natural, biological function involved in pregnancy. As the body transforms, a woman's relationship to herself in terms of posture and gait changes. Her relationship to space changes because she now must manoeuvre her body differently since it takes up more personal and interpersonal space. She may find it takes her more time to do things and she is focused on the present as meeting immediate needs are important to both her and her baby. Her relationship with others may also change. She may be seen differently by others as her physical status changes.

In sum, the experience of the physical body affects women in general and women with disabilities as they live lives impacted by culture. Klein (1992), a woman who became paralyzed after several strokes, talks about the manner in which her physical limitations help her connect with her own body and its relationship to the environment in which she lives:

> The rhythm of my life has changed dramatically. Before it was governed by the calendar and the clock. Now I follow the natural pace of my body.....I have to ration my limited energy and choose carefully what I do. I have no time to waste on bullshit, but I do have time to smell the flowers. (p.74)

Women with disabilities have much to add to the feminist understanding of the body because they not only experience cultural attitudes toward the female body and the disabled body, they also experience the sensations of these two types of bodies. They possess insights regarding the needs and sensations of the body through their experience of it. Ironically, lack of control of the body, while invariably disturbing to non-disabled people, is a daily reality for person with disabilities and the transcendence of it creates new frontiers of learning and exploring. Therefore, a feminist theory of disability needs to include not only awareness of the sensations of the physical body in relationship to itself and the physical and social environment but also the manner in which these sensations are transcended.

Body Awareness and Movement

> The body, required to be docile in its minutest operations, opposes and shows the conditions of functioning proper to an organism. Disciplinary power has as its correlative an individuality that is not only analytical and 'cellular', but also natural and 'organic'. (Foucault, 1979, p.156)

To understand what is involved in the leisure activities of women with disabilities it is important to consider both biological and cultural experiences. Bodily actions need to be understood as acts that take place within a certain situation and historical context and which have practical significances for the "embodied subject" (Toombes, 1992).

In a number of ways, our environment (e.g. work place, cultural attitudes toward aesthetics) can shape our bodies and both enable and constrain ranges of movement and perceptions of physicality. First, the emphasis placed on the shapes of female bodies in Western culture influences attitudes toward bodily action (Shilling, 1993). Second, working on an assembly line dictates the movement and shape that bodies take. Disciplinary techniques are used to make their bodies into objects by "disconnecting them from their sensual authority" where sensual authority is that which is experienced through bodily senses (Johnson, 1992, p.80).

In leisure, learning about movement involves becoming aware of the actual physical sensations of the muscles involved in movement (Ryman, 1978). Activity becomes a matter of self-education based on body awareness. The body is not, or at least is less so, an object or instrument of manipulation to be used in order to achieve a specific end (e.g. to learn the skill involved in an activity). Movement gains meaning when it is informed by the body as subject rather than the body as object (Bandy, 1986).

It is important to consider Foucauldian perspectives on the body. Since the social is "inscribed" on the body, Foucault centered his attention on the effects of power on the body (1980, p.58, see also, Rail and Harvey, 1995, p.165). He was interested in the systems of power that discipline the body to behave in certain ways and the knowledge that is produced by this kind of power over the body (Foucault, 1980). For him, power is conceptualized as being internalized in everyone and is transmitted through a network of individuals rather than being located in institutions alone (Foucault, 1980). Change must be instigated at the state level as well as through the changing the mechanisms of power that exert disciplinary action over the body on a daily basis (Foucault, 1980).

For Foucault, power on the body is developed around two poles. The first is the body as a machine, where the body is disciplined for optimal performance and usefulness that can be integrated into organized, effective, efficient, hierarchical and interrelated systems (Foucault, 1980;1990; Rail and Harvey, 1995). The body becomes dominated by correct training, manipulation and reconstruction (Foucault, 1979; Rail and Harvey, 1995; Vigarello, 1995). For example schools, families, factories, armies, sport are all organized, structured institutions that exert control over the body.

The second power exerted on the body is the species body which is the basis of biological processes such as birth, death, health, life expectancy and everything that affects the variability of them (Foucault, 1990). This power is enforced through intervention and regulation such as the medicalization of body functions. This biopower is directed toward performances of the body and processes of life and has led to an "administration of bodies and the calculated management of life" (Foucault, 1990, p.139).

For Foucault (1979) individuals become the bearers of power in that they do not need to have power placed on them from the outside in order to regulate their actions. They perceive themselves to be under the constant surveillance of any number of disciplinary cultural mechanisms like the church, the legal system, and the medical and psychiatric professions. As a result people regulate their own behaviours to conform to accepted social norms. In this way, power is not seen as having a central source like the state. Rather there are multiple sites of power. Eventually the individual becomes a site of disciplinary power and through their concern for what others think of their behaviour, they regulate each other as well. This suggests that people are guided constantly not by their own desires, but by the watchful eyes of others.

In their related Foucauldian analysis, Rail and Harvey (1995) argue that there are new ways of bodily domination that are subtle and are engaged with an individual's daily reality. Bodily subordination results from a process of normalization where internalized norms become a form of power that are used by individuals themselves to correct the body (Rail and Harvey, 1995). There are forces (e.g. time and space) that are not imposed directly on the body but they have the ability to shape its movement (Vigarello, 1995).

It has been further suggested that discipline shapes the body into passivity by prohibiting new initiatives (Foucault, 1979; Vigarello, 1995). Foucault cautions that discipline and power are not imposed on the body as something repressive or negative because it is this discipline that creates life, movement and power from the body itself (Vigarello, 1995). This suggests that the body has a power and knowledge of its own and that even the smallest activities can affect its individuality.

Foucault (1980) argues that one can only consciously master her/his own body by constructing power in that body through muscular activity, exercise and/or, "nudity, glorification of the body beautiful" leading one to desire her/his own body (p.56). Once the powerful forces on the body create this desire for one's own body then there emerges a new awareness for one's own body that counteract these powers. Subsequently, the body claims what it desires such as "health against the values of the economic system, pleasure against the moral norms or sexuality, marriage and decency" (Foucault, 1980, p.56). Once the forces (disciplines) on the body are freed, the body marks its own space and independence and the individual finds autonomy. Foucault (see also Merleau-Ponty, 1962;

Van den Berg, 1972; Bigwood, 1991) suggests that the body once had a knowledge of its own, but that it would only be realized and become part of consciousness when it escaped the disciplinary limits imposed upon it. The body "traverses sanctions" (Vigarello, 1995, p.162).

This means that the motives that initially activated the body are changed by the individuals conscious awareness and discipline of their own biological bodies. McDermott (1996) uses the example of women who are initially motivated to participate in exercise classes because they are concerned about their body weight but through experiencing structured activity they become motivated by health concerns and the experience of activity. In this sense the body counter-attacks the power that was imposed on it by the individual her/himself (Rail and Harvey, 1995). At this point the natural body replaces the mechanical body so that it moves from a passive, objectified position to a more active, subjective, position that creates new meaning for the individual.

This underscores the operation of agency. Individuals exercise resistance to the constraints and disciplines placed on them by the social structures and practices. McDermott (1996) suggests that the physical expression of agency is physicality, meaning that people explore embodied experiences to understand how the body is physically engaged in life, and to gain access to the social world (McDermott, 1996).

Johnson's (1992) notion of learning through trial and error may explicate the development of agency. He suggests the need for a "technology of authenticity" which encourages people to develop their own sense of authority and their own way of carrying out a task (Johnson, 1992, p.80). This technique would encourage people to become more aware of muscles used in the movement associated with an activity and to explore the personal range of motions that they need in order to carry out a specific activity. This would increase body awareness. In this way, the manner in which an individual moves within an activity is not dictated by standardized steps that constrain the body into a controlled object of the mind. Rather it reconnects the body and mind so that the learning of movement is physically rather than socially based.

Movements that are carried out mechanically are informed by authoritarian modes of conformity and disconnect people from their bodies. For example, in dominant physical or sport culture, repetitions needed to learn a physical skill are carried out by directing our attention outside of ourselves within the context of authority. This limits "native capacities" to learn alternative ways of carrying out activities in accordance with stimuli encountered in the world of sensual experience (Johnson, 1992). This represents a loss because knowledge is gained through the "physically active, lived body experience" (McDermott, 1996, p.21). This knowledge is gained when people use any movement in their lived bodily experiences that takes them beyond the regulated, organized, structured movements required in any activity.

The way in which we carry out an activity can either connect us with ourselves or, if we choose to mechanically conform to specific standards, can draw us away from ourselves. Bandy (1986) suggests that the inter-relationship of the body and mind is the self and that the movements involved in an activity provide the opportunity to experience a unified self.

Foucault's suggestion that one must desire one's own body to create new meaning might be problematic here. Perhaps it is not a desire of one's own body that creates new meaning. This has implications for persons with disabilities who take part in structured activities. Since their bodily experiences may involve restrictions in certain kinds of movements, structured activities may lead to a new consciousness of their physical body and a desire to go beyond limitations of the body. This may in turn create new ways of carrying out activities.

Perhaps this is a reason why leisure activities have an important role in the lives of persons with disabilities. It is an area of flexibility where activities can be structured or unstructured, passive or active, carried out alone or in groups leaving more room for empowerment and the development of agency through exploration and choice.

Leisure Activities and Mind/Body Connections

Leisure activity is one of the most fundamental aspects of our lives because it is a place where individuals can meet their individual needs and desires while connecting with other human beings. Kelly (1990) suggests that leisure is a phenomenon of life where one can integrate the mind and body so as to provide an environment for self-expression. It is "action more than feeling" but the feeling is important to the action (Kelly, 1987, p.57). The way one feels before and during the leisure activity is integral to the experience of it and transcends the activity itself (Hutchinson and McGill, 1992; Kelly, 1987). Leisure provides a sense of well-being by promoting physical health, rest and relaxation and a chance to test one's abilities through risk-taking (Kelly, 1990). It is through leisure activity that people discover their gifts and talents, and gain a sense of accomplishment by mastering these abilities (Hutchinson and McGill, 1992; Kelly, 1990).

Leisure, however, is more than a subjective experience because it is experienced in social contexts. In one sense it provides people with a sense of belonging to the larger community through the sharing of their gifts, interests and talents. Access to resources in the community gives people a sense of belonging to the larger community (Hutchinson and McGill, 1992). Leisure provides the opportunity for relationship-building around shared personal interests with other members of the community rather than artificially constructed or obligatory relationships like work relationships or paid care-giver relationships (Hutchinson and McGill, 1992; Kelly, 1987; Kelly, 1990).

There are often social structural constraints which may or may not affect an individual's participation in leisure. Shaw, Bonen and McCabe's (1991) secondary analysis of a Canada Fitness Survey focused on constraints on participation in physically active leisure. They concluded that identifiable constraints like lack of time, facilities, skills, available leaders, and self-discipline did not necessarily predict less participation in leisure. Rather, constraints to participation result more from "social location" within society (Shaw et al., 1991, p.299). "Social location" factors included age, gender, lifestyle, occupational status, income, class, race and an individuals location within these structures significantly predicted physical activity involvement (Shaw et al., 1991). Thus, social background factors related to gender or disability may also influence leisure behaviour.

The present study goes beyond leisure physical activities that are conventionally institutionalized. Indeed structured activity may be less conducive than unstructured activity to the integration of the mind and body. A brief explanation of the scope of leisure activities considered in this research will help to develop this position. According to Hutchinson and McGill (1992, see also Kelly, 1990) recreation is a component of leisure. It is an activity that takes place during leisure time. Kelly (1990) makes the further distinction that recreation is usually part of a social institution, organized and used to attain personal and social benefits. In other words, there is a particular goal in mind. Therefore, leisure incorporates a whole range of activities on a continuum from physically active activities (e.g. sport activities) to more passive activities (e.g. crafts, hobbies, watching T.V.). For example, in the 1991 Health and Activity Limitations Survey on Leisure and lifestyles of Persons with Disabilities in Canada, leisure activity was investigated by looking at recreation and lifestyle activities of persons with disabilities. These included cultural activities like: watching T.V.; listening to the radio; reading; telephone talking; hobbies and social activities with friends and family; physical activities like walking , swimming, jogging, and cycling; smoking; and alcohol consumption. Therefore leisure goes beyond structured recreational activities to include activities that give pleasurable meaning to an individuals daily life.

A leisure activity might be freely chosen and brings satisfaction, balance and meaning to the person involved (Hutchinson and McGill, 1992; Kelly, 1990). However, this means that although there may be activities structured to accommodate peoples' perceived need for leisure activity, leisure is very individual and can only be defined as meaningful by the person experiencing and reflecting upon it.

Mowl and Towner (1995) argue that the study of leisure should be placed contextually according to time, place, social setting and perception of the individual experiencing it. Places where leisure activities occur are not just physical locations. They are created by individuals. Places are significant to leisure if they have meaning for the individual. These leisure creations by individuals are a product of social, cultural, economical and political processes (Mowl and Towner, 1995; Smears, 1996). Thus the subjective experiences of created leisure activities are not just the result of living in a particular social context. Leisure experiences are also the result of bodily sensations.

This definition of leisure, which incorporates the subjective and objective experience of the body in leisure, suggests that women with disabilities may enhance their already integrated selves through the pursuit of leisure activities. They are forced by their impairment to make connections between their bodily sensations and the consciousness associated with culturally defined expectations in daily living. But they may also be able to transcend the physical and mental limitations of the body and develop a new way of looking at the world. Since the movement needed to carry out activities can help to unify the mind/body relationship, it becomes clear that women with disabilities may find leisure activity to be a forum where they can continue to connect with themselves and with others. They may also be able to enhance the quality of leisure activities that have been structured within a particular social context due to their ability to incorporate the feeling states of the body into those activities.

I am arguing that a feminist approach to leisure activity for women with disabilities has the potential to enhance alternative modes of movement based on the subjective experience of the sensations of the disabled, female body. Leisure activities that involve specifically defined physical techniques can potentially alienate us from the body. This differs from approaches that are informed by the sensual experience of the body. Such approaches would take us to a more basic level of studying movement of the body in leisure activity as opposed to those associated within the prescriptive techniques for bodily activities.

Persons with Disabilities and Leisure Activity

Nixon (1984) suggests that in order for persons with disabilities to overcome negative stereotypes they need to interact with non-disabled people in "informal interpersonal" ways and within social institutions. People with disabilities are often disconnected from their communities and leisure provides an opportunity for them to build relationships with other people in the community based on shared interests rather than obligation (Hutchinson and McGill, 1992). However, fundamental problems lie in the non-disabled perception of persons with disabilities and the infiltration of these perceptions into daily experiences. As a result, people with disabilities are often restricted to structured, alternative and/or competitive activities such as arranged and scheduled outings and segregated sport activities (Hutchinson and McGill, 1992).

This has implications for the opportunities afforded disabled individuals for leisure activity. Crawford (1989) suggests that persons with disabilities have less access to recreational programs because they are economically disadvantaged both individually and in their recreational programs. Although segregated programs receive more financial backing than integrated programs, funding dollars are usually given to those programs that will help disabled individuals become more self-reliant (e.g. rehabilitative programs) and decrease their dependency on the social system (Crawford, 1989). Therefore leisure activities for persons with disabilities are often developed around ideas that view the body as an object to be fixed and manipulated in order to ensure 'productive' individuals. The meaning of the activity to the individual is not the focus.

Persons with disabilities are often without two of the major component associated with leisure; spontaneity and choice. To what degree these aspects are available depends on one's cultural and bodily context. Quantitative data on leisure and persons with disabilities provides some background information regarding the extent to which persons with disabilities take part in leisure and the types of leisure they pursue. The national Health and Activity Limitations Survey divided the leisure activity of persons with disabilities into cultural activities, physical activities, alcohol consumption and smoking. Looking into these areas revealed some differences that exist between the genders and between disabilities. Regarding physically active leisure activities, slightly more than half (52 percent) of adults with disabilities participate in these types of activities (HALS, 1991). Participation is affected by a number of social background factors like age, severity of disability and physical ability, geographic location and education. Education level is positively related to participation but, age, severity of disability and physical ability are negatively correlated with participation (HALS, 1991).

Leisure activities associated with physical sporting activities will provide an example of this. Disabled sport activities tend to be separate from non-disabled sporting activities although they are often organized around the values of non-disabled sport (e.g. competition, meritocracy, winning). People who overcome their disabilities in sporting activities are idealized because they have adjusted the movements of their bodies to fit the appropriate bodily image needed to take part in physical activity; that of being healthy, strong, mentally alert, physically and emotionally fit (Hillyer, 1984;1993). Developing sport activities for marginal groups based on "achievement orientation" and "competitive individualism" does not allow these groups to experience alternatives to the "meaning and value system" that has become taken for granted as appropriate and normal (Hall et al., 1991).

Individuals with disabilities who do not take part in physically active leisure activities, take part in other leisure activities such as cultural activities, smoking and alcohol consumption. The most popular cultural activities for persons with disabilities is watching television, reading, and listening to the radio or music. These activities are done more than eight hours a week by almost seventy percent of persons with disability. The second most popular activity outside the home is visiting friends and family members followed by other cultural activities such as arts, crafts, gardening and other hobbies. Persons who are dissatisfied with their frequency of cultural activities say that physical inability is their biggest obstacle. Again, the degree of disability affects cultural activities at home.

The study also shows that smoking and alcohol consumption by persons with disabilities decreases with more severe disabilities (HALS, 1991). Smoking decreases when education level increases and alcohol consumption increases with higher educational attainment. There is little difference between the proportion of males and females who smoke, but more males than females consume alcohol.

Unfortunately, the HALS study did not allow for a subjective examination of leisure. The survey also did not examine cultural activities by gender.

Women and Leisure Activities

The literature suggests that in general, gender inequalities exist in leisure. Research about women and leisure during the 1980's revealed that women's leisure is constrained by factors that men experience less. Economic constraints limit leisure activities for women more than for men and women's leisure opportunities are limited in both the public and private sphere (Scraton, 1994). For example, women's leisure is not just affected by work schedules that also affect men's leisure. It is structured as well, by their domestic time which supports the "institutionalized time tables of men" (Chambers, 1986, p.322). This may explain why two leisure constraints that are associated with lower levels of physical activity for women are low energy and ill health since these affect women more than men (Shaw et al., 1991).

According to Chambers (1986) gender inequalities in leisure are due to different cultural perceptions held by men and women concerning their roles. Harrington, Dawson and Bolla (1992) suggest that leisure constraints for women are based on both objective and subjective constraints with more emphasis on subjective experiences. Objective constraints that exist outside of the woman's body are lack of time for oneself, scheduling problems, and home confinement in order to meet the needs of others. Subjective constraints are feelings of guilt that they must always be 'on duty' and feelings that they should subordinate their needs to those of others (Harrington et al., 1992).

In the public realm, the physical structures of cities support the patriarchal value of the nuclear family so that leisure resources tend to be located away from home and therefore more accessible to men (Mowl and Towner, 1995). Many leisure resources are the products of male-oriented planning and decision-making. This is apparent in those leisure activities associated with institutionalized sport which is "constituted for and by those in power" (DePauw, 1994, p.473).

Feminists have described traditional sport activities as "gendered activities" organized "out of the value and experiences of men" (Coakley, 1994, p.38). They help preserve the patriarchal social order (Coakley, 1994, p.37; Hall, 1984) and maintain inequality of gender in other social settings beyond sport (Theberge, 1985). The male preserve of sport includes "overemphasis on winning, a hierarchy of authority, elitism of skill, social exclusion", belittling of opponents and the "ethic of endangerment" (Birrell and Richter, 1987, p.395). Feminist alternatives to those activities are those which are "process-oriented, collective, supportive, inclusive" and emphasize an ethic of caring (Birrell and Richter, 1987, p.408).

For a better understanding of women's leisure, a more holistic approach is needed which gives insight into a woman's social context; her "social, economic, physical and cultural world" (Scraton, 1994, p.258). For example, while changes in these areas are believed to instigate changes in the women's experience of leisure, changes in the compositions of households, in the welfare state and in employment have not changed the "gendered images and style" or the gendered experiences of everyday reality for women (Scraton, 1994, p.258). The welfare state is disappearing and households are more fragmented meaning the leisure time of women is being replaced with the increased responsibility associated with child care and community care (Scraton, 1994).

Women continue to be objectified and placed in an inequitable position relative to men in leisure pursuits. For example, violence and pornography is now available for leisure television viewing in the home (Scraton, 1994) and women continue to be constrained from leisure activity outside of their homes for fear of violence (Mowl and Towner, 1995).

It is apparent that constraints to women's leisure are the result of living within a particular social context and women's perception of their position within that context.

Scraton (1994) suggests that more research needs to be carried out around the aspect of differences in leisure activity among women. She suggests that research on women with disabilities may add to the recognition of the importance of different experiences as well as the importance of shared leisure experiences (Scraton, 1994)

Scraton (1994) also suggests future research which views leisure as empowering and the creation of alternative types of leisure that "challenge unequal gender relations" (Scraton, 1994, p.258). Therefore, an alternative approach to leisure activity is needed that is based on the subjective experiences of subordinate groups. Subjective experience relates to how the body experiences the environment both sensually and culturally.

Women with Disabilities in Leisure Activity

> ...connections between disability, women and leisure have been largely ignored in both mainstream leisure journals and journals addressing disability. (Smears, 1996, p.79)

Sherrill (1993) proposes that the differences between men and women with disabilities are less pronounced because men are treated in much the same way as women; they are overprotected, low expectations are placed on them, and they are treated as persons to be cared for. For example, persons with disabilities are viewed as frail and relative non-participants in physically active endeavors, lacking funds for these activities due to their devalued status, and as fearing that they will be injured (Mastro et al., 1988). This viewpoint reveals the significance of attitudinal barriers to participation in physical activity. It also reveals the lack of appreciation of the differences which exist among women and among the disabled.

Quantitative studies on persons with disabilities suggest differences between disabled women and men as well as between women with and without disabilities regarding leisure. The findings of the HALS (1991) study suggest that women with disabilities participate in physical activities slightly more than men with disabilities. This does not mean that all women with disabilities are physically active or are content with this type of leisure activity alone.

A 1988 survey conducted by the Canadian Government on the physical activity of women with disabilities (GCFAS, 1988) indicated that most women with disabilities felt that they were not as physically active as they should be even though they recognized the importance of physical activity .

The women surveyed experienced a preference for non-competitive or recreational competitive/non-organized physically active activities (GCFAS, 1988). Only 4 percent were fully satisfied with available activities (GCFAS, 1988). The majority of the women surveyed did not care whether or not they participated with males or/and females. Nor did they care if they participated with disabled or non-disabled individuals (GCFAS, 1988).

The initial participation of the majority of women with disabilities who did participate (49 percent) was self-motivated (GCFAS, 1988). This is consistent with persons with disabilities in general who use self-motivation and friends to learn physical activity (Sherrill, 1993).

Physically active women with disabilities are active for the same reasons as non-disabled women; for pleasure, to feel better, to relax and reduce stress and to maintain or improve fitness (GCFAS, 1988). Although their interests are similar, their physical needs differ from non-disabled women. Medical factors were not the primary limiting factor, but they felt it was important for leaders and programmers to recognize these needs and adapt programs accordingly (GCFAS, 1988). Other factors that limited participation were time constraints, inaccessible facilities, transportation problems and lack of available information as to available opportunities (GCFAS, 1988).

In contrast, persons without disabilities found lack of leaders, lack of time, inadequate facilities and lack of skills only as minor constraints (Shaw et al., 1991).

Perhaps this is indicative of the greater availability of leisure resources for non-disabled persons.

The recommendations resulting from the survey centered on resource collaboration. As has also been suggested in a number of other studies (Bedini, Driscoll and Bullock, 1991; Block and Vogler, 1994; Blake, 1992), recommendations include making transportation facilities and information more accessible and affordable, training leaders and programmers to recognize the uniqueness of these women, focusing on their individual needs, and better promotion in the media of women in general (GCFAS, 1988).

In a qualitative study on women with physical disabilities and leisure, women with disabilities defined leisure as free time to do what they wanted at their own pace (Henderson, Bedini, Hecht and Schuler, 1995). They described leisure in much the same way as non-disabled women but most referred to their disability as a reason for modifying their leisure.

Although disability, which varied from woman to woman, had an impact on their leisure, it did not affect their desire to take part in a particular leisure activity (Henderson et al., 1995). Therefore the meaning of leisure for them did not differ from other women, but the manner in which an activity was carried out may have been different (Henderson et al., 1995).

Women with disabilities share some of the same constraints as non-disabled women. "Energy deficiency, time shrinkage, lack of opportunity and choices, dependency on others and concern for physical and psychological safety" were seen as the leisure constraints for these women (Henderson et al., 1995, p.23). Although these are constraints that are experienced by women in general, living in a body that is disabled has additional implications for these constraints. For example, it often takes much more energy for woman with disabilities to carry out an activity than it would for a woman without a disability.

Anticipation of a barrier to involvement could also influence a disabled woman's desire to participate if she felt she could not successfully overcome that obstacle. The ability to deal with impediments depended on life circumstances and the "inherent motivation to find meaning in leisure" (Henderson et al., 1995, p.29). Perhaps this "inherent motivation" or personal desire suggests an aspect of leisure that is situated in the body and informs one's experience of leisure activity.

In summary, the literature suggests that men and women experience leisure unequally due to the fact that activities are often organized by men around the time tables of men. This neglects the domestic tasks that women often perceive as their responsibility alone. Women are often objectified in the leisure activities of men as well (e.g. pornography). Women with disabilities and those without disabilities participate in physically active leisure for the same reasons; pleasure, stress reduction, relaxation and to improve fitness. They differ in their opportunities to take part in leisure. Many of these differences have to do with the inaccessible environments, time constraints, transportation problems, lack of information and available programs. The results suggest that women with disabilities have lower levels of interest in competitive and organized forms of leisure (GCFAS, 1988) and that their subjective experiences (both physical and cultural) are not being recognized in existing programs.

Conclusions

Theories of disability have concentrated on either biological, economic or social-political implications of disablement. Feminist analysis allows for alternative ways of looking at the social world by introducing the subjective experience and a woman-centered approach.

The problem with much feminist analysis is that it is also driven by non-disabled culture. Much value is placed on how social attitudes and constructs affect women's experiences, while ignoring the manner in which the physical sensations of the body affect the subjective experience. Within the subjective experience of the body, one finds the social and cultural experience of living within a particular body and the physical experience of bodily sensations. The major dilemma for persons with disabilities in western culture is that they must live in a world organized around norms of a healthy, strong, body; a body that has been objectified. They are not only treated as different, they are also treated as separate and distinct from other people. In other words, we concentrate on controlling our bodies to fit within a certain social context. This manipulation of the body alienates us from the experiences of the biological body, its limits and its knowledge.

This type of understanding of subjective experience necessitates the integration of mind and body where the body itself becomes a source of experiential knowledge and has a knowledge of its own. The incorporation of the body beyond its cultural ramifications is important when studying women with disabilities because it is the bodies of these women that affects their total subjective experience both biologically and culturally. When forced to live embodied as a female with a disability, within a society which places positive values on health and beauty (according to medical, male-informed, non-disabled standards) the experience of the body's relationship to the environment provides a unique understanding of the world.

I have argued that the awareness of the relationship between the mind and body can be accomplished through the experience of self-directed leisure activity. In our culture, leisure activity is often mechanically organized, male oriented and non-disabled oriented. Most women with disabilities are not as involved in these types of physical activities. Is it because they have not had much exposure to these activities or have they lost the desire to participate due to the anticipated constraints associated with them?

Women's insight regarding leisure activity is often based on self-education through experiential adaptation. This is a more process-oriented way of participating in leisure activity. Women with disabilities are often forced into being aware of how their body moves within biological and cultural limitations. Since women with disabilities are forced to experience their bodies, perhaps they experience leisure activity differently than non-disabled women. Moreover, women have different physical sensations than men due to differing biological features which might suggest that disabled women experience leisure activity differently than men with disabilities. These women also move within a cultural context that devalues the physical attributes of their bodies. Their unique vantage point is formulated through the intersection of the lived experience of the body and the mind; of living within a biologically female and physically impaired body within a specific cultural and historical context. This may suggest alternative approaches to leisure activity which are informed by subjective experience which is both biologically and culturally based. In order to examine these insights, I will investigate how they experience the body during leisure activity, in relationship to time, to their physical and social environment, to themselves and to others. They may hold a key to balancing the biological and cultural components of our subjective selves and inform the development of more appropriate programs or activities.

CHAPTER 3

THE METHODOLOGICAL APPROACH

Introduction

Two methodological priorities became apparent on reviewing the research literature regarding women with disabilities and their leisure involvement. First, subjective experience involves exploring both the biological experiences of the body (or the "body one is") and the socially constructed and objectified body (or the "body one has"), in relation to the environment in which individuals live (Connelly, 1994). Thus, to approach an understanding of subjective experience, the immediate experience of living within a particular body and the experience of living in that body within a particular social context or culture must be explored. Second, women with disabilities are different from other women due both to their physical attributes and to their cultural positions as persons with disabilities. They also share with other women the cultural positions associated with living in a female body. These priorities determined that the method used to understand the subjective experiences of women in leisure must give value and voice to their unique vantage point while simultaneously accommodating their commonalities with other women living within Western culture.

This approach was important because previous research had often overlooked the differences that existed both between women and between types of disabilities. Disability research has too often been informed by a non-disabled perspective and/or perspectives that are insensitive to female issues (see Cassidy et al., 1995; Morris, 1993; Oliver, 1990; Wendell, 1989).

On the level of praxis, expanding the connections we have with other human beings has the potential to make known to us both our similarities and our differences. While the intent of this research is primarily to explore the subjective experience of women with disabilities in movement, it had another purpose. That was to create a textual account which speaks to all people, instigating change at an individual level while informing the collective social consciousness.

Qualitative Versus Quantitative Approaches

This research employed qualitative methods because, while quantitative research is beneficial in revealing behaviours and attitudes that exist among particular groups within society, it is less concerned with meanings and the social context in which social phenomena may exist (Reinharz, 1992). This is particularly important for feminist research because it helps reveal interpersonal operations of power (Reinharz, 1992). Although the brevity of the statistics in quantitative research make social problems easily communicable and accessible to more women, she warns that statistical data does not take social context into account (Reinharz, 1992).

Berg (1989) argues that quantitative, statistical research techniques count and measure a phenomenon while qualitative research assesses the quality and essence of a phenomenon. He describes quality as referring to "...meanings, concepts, definitions, characteristics, metaphors, symbols and description of things" (p.2).

Qualitative research methods, for example, can prompt recollection of "half-forgotten" experiences of the senses which may lend themselves to memories and meanings that quantitative methods cannot convey (Berg, 1989, p.3). This was of signal importance to the current research which incorporated the meaning that the sensations of the body had in regard to the leisure activities of women with disabilities.

Some have criticized qualitative methods using small samples because the results are not generalizable to the larger population. Although this does have some merit on the face of it, the criticism misses that the intention of qualitative research is to better understand subjective experiences within social contexts. If the intent is to investigate distributional issues; for example to establish the gender distribution of athletes at the Special Olympics, then quantitative techniques would be appropriate. Qualitative methods were better suited to the current study, however, because I was interested in understanding the experiences of women with disabilities within the social context within which they live.

In the last chapter, I discussed the results of the GCFAS study on Physical Activity and Women with Disabilities (1988) which emphasized both the strengths and weaknesses of qualitative methods. While the study provided some useful findings, the results also homogenized women with disabilities such that differences among the respondents were overlooked. The meaning of physical activity to different participants was not the focus. Rather, the study was about the respondents perceptions of how they fit into existing structures of physical activities. The study only provided information on how disabled women might be incorporated into existing structures. They did not explore options for alternative physical activity models. In the current study the focus was on the subjective leisure experiences of women with disabilities as defined by the women themselves. At the present time there is only a limited understanding of this issue.

The definition of women with disability used in this study is taken from the World Health Organization's Classification of Impairments, Disabilities and Handicaps (1980). It included any woman who was restricted or limited (due to an impairment at the body level) in her functional ability to carry out activities within the manner that is considered normal for a human being without either personal or technical supports (Bickenbach, 1993, p.10; Hutchinson and McGill, 1992, p.51; Jones, 1994, p.8; World Health

Organization, 1980, p.28; Department of International Economic and Social Affairs, 1990, p.1) This definition is important because it emphasizes that impairment occurs at the level of the body and that disability is the loss of ability to carry out activities in a socially accepted manner. This suggests the possibility of conflict between what the body is able to do in light of the social expectations placed upon it.

There were several categories of disabilities. Women with mobility disabilities were the focus of this study meaning they were limited in their "ability to work, move from room to room, carry an object from 10 metres or stand for long periods of time" (Ministry of Citizenship, 1990, p.3).

This group of women were chosen for a number of reasons based on their socially disadvantaged position with regard to both gender and ability. For example, regardless of age, females report more limitations in mobility than males (MSS, 1990, p.7). Also, in comparing this group of women to other women with disabilities, they were more economically disadvantaged due to the greater barriers they experience in educational attainment, and long term employment (MSS, 1990). Since financial status is an obstacle to many leisure activities, this would suggest that they are a particularly vulnerable group within disabled women as a whole.

This research included women with congenital and acquired disabilities. A congenital disability is one which a person is born with and an acquired disability is one which an individual has acquired after living for a period of time as a non-disabled person. It was important to have women from both categories of disability to gain insight into their differing standpoints. One group is informed by experiences in both a non-disabled and a disabled body, while the other group of women are informed by a disabled body alone. There has been relative silence in the feminist literature on the latter group of women.

During the course of the research it became clear that there was another group of women who fit neither of these categories. These were women who have progressive disabilities (for example, multiple sclerosis or muscular dystrophy) which meant they were moving from a non-disabled state to a disabled state over a period of time. This provided them with the opportunity to prepare, to a certain extent, for their inevitable decline in ability.

The definition of leisure for this research was extremely broad, eventually defined by the women themselves. Leisure included activities that were defined by the women as leisure. They could be passive or active, recreational or not, and structured or unstructured. Any movement needed to carry out an activity (e.g. walking, wheeling, stretching, turning on a radio or T.V., visiting) was of interest for this research.

A Phenomenological Approach to Qualitative Research

One way of doing qualitative research is through a phenomenological approach. Phenomenology studies the meaning of lived experience and attempts to generate an indepth, robust and rich description and interpretation of meanings (Van Hanen, 1990). The researcher asks what is the essence of a particular phenomena, in order to determine the meaning of a phenomenon as it is lived; not the meaning that is particular to a social group, historical period or culture (Van Hanen, 1990).

Phenomenological inquiry presents a description of experience and lets the consequences of that description evolve as they resonate with the reader. It does not attempt to solve anything as much as recapture it (Van Hanen, 1990). As a communicative guide, it involves sensations, perceptions and mental processes (Zaner, 1970). Thus, it is not used to affirm that a particular reality exists. Rather it makes "explicit what has hither to been implicit" (Zaner, 1970, p.50). In other words, when the reader of this type of inquiry notices that they have taken some belief for granted, what has previously appeared as obvious has become transformed and changes the way they view the world. Through this shift in attitude, change is instigated. In the removal of taken-for-granted perceptions of realities, the objectification of other realities is also changed. Van Hanen (1990) explains phenomenological inquiry as an instrument of change in this way:

> Lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of essence in such a way that the effect of the text is at once a reflective re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience. (p.36)

This type of inquiry is not particular or universal but lends itself to both which was important to this thesis because women with disabilities are both unique and similar (Van Hanen, 1990).

In this research, the phenomenon in question was leisure. Although women with disabilities have a different relationship to leisure than other women, my research focus lied in what it was that constituted leisure for them. The intent was to approach a better understanding that would possibly resonate with other women in general and challenge taken-for-granted or normative definitions of leisure.

Obtaining descriptions of a phenomenon requires that the focus be on how the subjective experiences of the narrator express the essence of a particular phenomenon (Van Hanen, 1970). For example, it was just as important to find out what it was like to be a women with a disability involved in leisure as it was to have these women tell me about taking part in leisure while being embodied as a woman and as a disabled person. The difference was that the narrators were being asked to articulate their immediate leisure experiences from within rather than by looking at themselves from outside of those pursuits.

Van den Berg (1972) explains that the difference is that in asking a narrator about her/his "introspectively, accessible, subjective account" of his/her own observations is like asking the narrator to tell us about the world as it appears to be on "second thought" (p.38-39). When the researcher asks the narrator to describe activities which she/he calls her/his own, we get more information about the person's character, subjectivity, essence and condition.

Van Hanen (1990) states that life-experience needs to originate in what is being experienced in the present or within the body. For example, if a woman with a disability focused on a leisure experience that stood out in her mind, it was important to have this incident described from the inside; how she felt, her moods and emotions, what her body was experiencing at the time. Therefore, a phenomenological approach to gathering information not only explores the facts and activities of the narrators life but their feelings and emotions as well (Anderson, Armitage, Jack & Wittner, 1990).

Indepth descriptions can be made in terms of the relationship between the basic components of the "lifeworld"; lived body, lived space, lived time and lived others (Van den Berg, 1972; Van Hanen, 1990). The "lived body" refers to the manner in which the body reacts to experiences and what it is experiencing physiologically (Van Hanen, 1990). This was a vital component of this research as the manner in which the lived body was experienced by a woman with a disability transformed her being-in-the-world and particularly her being in leisure activity (Toombes, 1992).

"Lived space" is not measured space rather it is one's felt space or personal space and the person's relationship to it. It refers to the physical environment in which we move and how certain experiences relate to specific spaces (Van Hanen, 1990).

"Lived time" refers to subjective time as in a person's past, present and future (Van Hanen, 1990). It can also refer to clock time as in the amount of time it may take for a woman with a disability to carry out a particular movement.

"Lived others" refers to relationships within interpersonal space (Van Hanen, 1990). The meaning of our relationships with others as well as object is explored. For example, the relationship between the women studied and object such as mobility aids, was very important in their leisure pursuits. It is the relationship between these four components that gives a better understanding of a phenomenon.

In sum, phenomenological inquiry involves the description of a phenomenon as it is, without judgment or interpretation (Van den Berg, 1972). It requires the researcher be in the body as it is (or in the present) during conversations, and not let the mind wander to interpretations of the description. This was particularly important for this research as the literature review suggested that a mind/body duality exists within activity and persons with disabilities are forced to confront this. After indepth descriptions of the total subjective experience of movement for women with disabilities have been accumulated, only then can their stories categorized and thematized. It is only then that the researcher asks critical questions. This is because something cannot be critiqued until it is understood, and description brings understanding (Zaner, 1970).

Oral Histories

This study gave voice to women with disabilities and in so doing it also created the opportunity for progressive change. To hear their voices I chose to collect and analyse oral histories.

As a research technique, oral history has had difficulty being fully accepted by some social scientists because it is seen as a historical method. However, oral histories lend themselves to phenomenology because they strive to capture a deeper understanding of a particular phenomena. They involve case studies, indepth interviews, life histories, stories, biographical interviews, and/or narratives (Reinharz, 1992). Oral histories allow for the concept of time and since this research focused on how leisure was related to time, this allowed for reflection on changes in the experience of movement over time as well as in relation to immediate time.

The purpose of the oral history is to write a history of those who have previously been silent in the literature. (Gluck, 1983; Anderson and Jack, 1991; Reinharz, 1992). The responsibility of the oral historian is to produce this written document through the collaboration between her/himself and the person with whom she or he is speaking. Both the narrators and researchers are subjectivity intertwined (Anderson and Jack, 1991). Key to this method is that the history is written from the narrators perspective.

Reinharz (1992) cautions, though, that this approach might be viewed as problematic because people may view social/ political problems in individualistic rather than contextual terms. However, viewing social problems on an individual, subjective level does not necessitate the exclusion of placing this phenomena within the larger social context. In fact, recognizing a social problem on an individual level may create the basis for recognizing similar experiences in others. In terms of women's studies, the ability of oral histories to bring the experience of women into history through a tangible written format presents a foundation upon which the common experiences between women can become apparent (Reinharz, 1992). Therefore, the implications of such research is an expansion of a knowledge base which is informed by both explicit and implicit messages which may resonate with the larger population of women. This means that the reader may be able to identify with the narrators words with little interference by the researcher. It is this identification between women on an implicit level regarding their similar positions within a particular social context which will promote social change (Reinharz, 1992).

Reinharz (1992), Gluck (1983), Gluck and Patai (1991), and Thomas (1983) state that group oral histories reveal the shared characteristics of women despite their different lifestyles and cultures and therefore adds to the collectivity of women. This is important for the current research which recognizes both the differences and similarities between women with disabilities and women in general. Reinharz (1992) suggests that by collecting oral histories in groups, one can hear the individual woman while seeing patterns in the study of a larger number of women. Although group oral histories may have been beneficial for this research, instead it involved individual oral histories because no interest was expressed in group meetings among the women.

This kind of research would be particularly important for women with congenital disabilities. In particular, since I wanted this paper informed from a disabled point of view, it was important to listen to women who have always been disabled. Most of the disabled feminists who are researchers in the area are women who acquired disabilities after living a non-disabled existence. Women with congenital disabilities have not experienced a non-disabled body and they have no other lifestyle with which to compare their disabled existence. A person with an acquired disability or a progressive disability can compare her non-disabled existence with her disabled existence. As a result, these women come from a position of comparison unlike women with congenital disabilities.

Collecting the Data

Reinharz (1992) and Gluck (1977) suggest three types of oral history; topical, biographical and autobiographical. The topical approach was utilized in the current study as my interest was in the specific topic of leisure activity. This type of oral history method is similar to the open-ended interview technique (Reinharz, 1992). Below, I will first discuss the benefits of the open-ended interview as a method of collecting oral histories. Then I will outline how oral histories complimented the objectives of this study.

Interviews, in general, are important to research into the daily lives of people because they give researchers access to people's ideas and thoughts as described in their own words. They are conducive to helping the narrator become actively involved in the research being carried out (Reinharz, 1992). Open-ended interviews are a method of data collection which encourage interconnectedness between narrator and researcher, meaning power imbalances between the two parties have more opportunity to be levelled out (Reinharz, 1992).

The open-ended interview is less structured than some other interview techniques and the information gathered is that which is generated by the narrator. The benefits of open-ended interviews for data collection in oral histories are that they allow researchers to describe and discover people's view of reality while simultaneously generating a theory (Reinharz, 1992). Questions are not structured according to the researcher's agenda, rather they are structured according to the narrators response. Thomas (1983) suggests that this approach to oral histories requires flexibility because questions are not static, rather they evolve during conversations from the statements of the narrator. There are no fixed procedures or techniques that determine the research (Reinharz, 1992; Van Hanen, 1990). The researcher uses clarification questions that probe into cliches, or taken-for-granted statements given by narrators. Thomas (1983) and Van Hanen (1990) suggest that a cue for the researcher to use probing questions occurs when the narrators seem to give socially acceptable responses. The open-ended interviews will allow the researcher to go beyond the socially defined boundaries of what is acceptable and privileged. Thomas (1983) describes this as getting back to the "nitty-gritty".

> And the thing that I think is real important about doing oral history is to not stop with the socially accepted response, but keep going until you...find out what was the reality of her situation, not what she thinks you want to hear was the reality of her situation, or not how it's always been described, or not what

> makes the local community or family structure more comfortable to describe it as. (p.51)

The flexibility of oral histories was also beneficial for this research. First, it allowed narrators to direct the flow of information and the researcher could probe deeper into the narrators statements to obtain a deeper understanding. Flexibility was also important because the physical abilities of the narrators determined the type of conversation, where the conversation took place, and/or how the information was relayed to the researcher. For example, most conversations took place in the women's homes as transportation was a problem for them. Also, one women who had difficulty relaying information verbally typed out her own oral history for me. This research needed flexibility for very practical reasons.

Oral histories were conducted with nine women; three with acquired disabilities, three with congenital disabilities and three with progressive disabilities. I had originally planned to speak to twenty women but I had difficulty finding women who wanted to participate. I placed requests for participants in newsletters and sent them to different agencies associated with disability issues such as the local Independent Living Centre and March of Dimes (See Appendix A1 and A2). I sent a request for research to the special needs department at a local college. I did not get one call as a result of these requests. I met two women at a DisAbled Women's Conference and one through a colleague. The remaining women were located through personal contact and the snow ball effect. I did have two women who expressed interest in participating but after several attempts to contact and/or set up appointments, it became apparent that they were either too busy or lost interest.

A letter was drafted to explain the nature of my research. It soon became apparent, though, that I needed to make changes in this letter to accommodate different needs and abilities (see Appendix B1, B2 and B3). For example, I needed to write this letter in different formats so that some had larger, bolder print or more spaces between the lines. I had not previously considered the possibility of motor impairments to the muscles in the eyes or other visual impairments. It was important to me that the information was easily accessible to the women involved and this meant a range of choices. I also had to ensure that it was easy to understand. I often explained what I was doing and left the letter for the women to read on their own time. This I feel is something that researchers need to be aware of, not only for this group of women, but for any group being studied.

Conversations with these women needed to be flexible as well (the term conversation is preferred over interview as it gives a more personal and less power-imbalanced connotation to the meetings between the researcher and the narrator.) Flexibility was necessary around not only where the meetings took place but also who would be present during the conversations. For example, one woman who's speech was difficult to understand used someone she knew well to help her communicate with me when I had difficulty understanding.

Open-ended interviews are important in hearing the stories of people's everyday lives. This research approached oral histories through the use of open-ended stories about the lives of women with disabilities as told by them. One objective was for the researcher to do more listening than setting an agenda of issues to talk about. My desire was to ask for clarification of phrases and not assume that I understood what they meant (Reinharz, 1992). This aspect is potentially problematic because of the possibility of subjective biases influencing the researcher. These can be limited with strategies suggested by experienced oral historians regarding effective listening skills.

The Art of Listening

> In the language of nature, working and listening are the same. Working and listening means sensitivity. To be sensitive is to be aware, to listen with the body, which is really our ears, and to perceive what is going on around us with

> our listening mechanisms rather than our seeing mechanisms. This is because our seeing mechanisms can be illusionary. If we see without including that inner sensitivity, we do not get the clear picture of what is occurring. (Rael, 1993, p.65)

Reinharz (1992) notes that what is most important to oral histories is to get at the experience, not the facts. This means it is important to listen to feelings. The benefit of good listening skills by the researcher is that the narrators are provided with an opportunity to reflect upon their own words and develop ideas and associate meanings to their previous statements (Anderson & Jack, 1991; Reinharz, 1992; Thomas, 1983). This means that it is important to be patient and accept periods of silence between researcher and narrator as a time for reflection by narrators (Thomas, 1991; Van Hanen, 1990).

Van Hanen (1990) states that to be a good listener, one needs to learn the art of being sensitive to the subtle undertones of language. Listening is something one does with more than their ears. I am referring to the importance of the body as a vehicle through which the senses are activated and present us with a knowledge of its own. For my purposes it was important to listen to what my body was telling me while I was involved in the conversations and to what else was transpiring non-verbally between the narrator and myself. As a non-disabled person, I wanted to avoid naming the meaning these women were giving to their experiences in leisure. Otherwise, it would be possible for me to name it in non-disabled terms, defeating the purpose of doing this type of research.

I also became much more aware of my own senses, like what I was seeing, smelling and hearing and how it related to the context in which I was situated. I realized that this taxing of the senses of the researcher is an important part of the experience. I realized this particularly during transcription of the conversations. Somehow the words alone did not capture the entirety of what I experienced when I was actually with the women. It was the lived moment that could not be transcribed so as to relate the entire experience. I tried to write these experiences down so as to capture some of this essence. For example, in several homes, televisions were on with the volume turned low more for background noise than to watch.

To help ensure that I was a good listener and enable me to present the narrator's story rather than my own subjective orientation to the women's stories required listening on my part with my entire body with careful attention to my own reactions. This helped to abdicate some of my non-disabled definitions. The less talking I did, except for clarification purposes, the less opportunity I had to incorporate non-disabled attitudes that may have guided the conversation in my own direction. The purpose was to keep me from over-generalizing statements made by narrators.

The conversations in this research did not end until the women involved felt there was nothing more to say regarding their leisure activity. Van Hanen (1990) refers to this as the silence that ends the interview; not an empty silence, rather a "fulfilled silence" (p.99).

Analysis and Action

All conversations, except two, were tape recorded and transcribed. One woman wrote her own oral history because she was a writer, speaking was difficult for her and because her speech was difficult to understand. The other woman was concerned that her voice would not record and she was uncomfortable with the tape recorder. She said that she had more time to reflect and answer when I was making notes. She felt this reflection made her think of things she had not thought of for years.

I had originally planned to transcribe all of the recordings myself so as to give me an opportunity to reflect on the conversations. Due to time constraints I was forced to have someone transcribe for me. In keeping with my political stance, I wanted to hire a transcriber with a disability and because I thought there would be a certain measure of empathy between the transcriber and the narrator. For logistical reasons, this did not happen. I hired a non-disabled woman. This had a positive effect because she became interested in the women on the tapes and enjoyed learning about them. She asked about the location of some of the activities that had been discussed during conversations because she had a relative that might benefit from such pursuits. This relationship proved to be an opportunity to share the insights and issues that women with disabilities face, to a small degree, with non-disabled society.

I also gained written information from the women themselves (e.g. newspaper articles featuring them and their active involvement in the community, work they had published, prose they had written, information on issues they felt to be important). This too gave me insight into their daily lives.

I asked the women to sign release forms stating that they would allow me to use their conversations. Following the method used by Thomas (1983), I asked the women to sign the release forms following our conversations. The reason for signing them at this time met an ethical issue as it allowed them to make changes or withdraw if they were uncomfortable with information they had relayed to me.

As with the description of the research letters, there were several formats for the consent forms so as to accommodate individual abilities and to offer choice for the women (see Appendix C1, C2 and C3). One problem did emerge from the consent forms which raises methodological questions for future research done with persons with disabilities. One should be careful not to assume that everyone can sign their name to give consent. A majority of the women had difficulty with this task and two women could not sign their name at all. Consequently, I needed someone to witness their signatures. The inability to write a signature was a concern for four of the women I spoke with. In future research, in order to preserve independence and dignity, alternative modes of giving consent are important.

The women were also asked whether they wanted to have their names used in the research or not. The concern was that removing the name from the experience could somehow remove the experience of the phenomenon from the woman. Also, from past experience in a study on mothers with disabled children, the confidentiality of the mothers' names was not important to them. Rather, a concern was to have their experiential knowledge made known. Having their stories put into tangible, written form somehow bestows validity on these experiences. I wanted to give the women in this study the same opportunity. Also, I sent these women a final draft of our conversations so they could have a piece of their history in written form.

The analysis involved three stages. First, the analysis of the data involved listing responses to particular requests for information such as age, residence, income, definition of leisure, education, employment if applicable (see Appendix E). It was like presenting the data and making "obvious what is obvious" (Connelly, 1994). Then information from the conversations was further analysed by categorizing it into how it related to the lived body, lived time, lived space and other, making note of any categories that overlapped.

Next was the thematic analysis. Themes are the elements that occur most frequently giving the dominant messages from the text. Van Hanen (1990) refers to them as structures of experiences. They are the umbrella terms or metaphors. To find the theme, I looked for clusters of patterns, differences, recurrences around certain statements. Van Hanen (1990) suggests that the researcher looks for wise or prophetic sayings that capture the meaning of the text or highlight statements that are particularly revealing about leisure activity. A theme occurred when categories were coalescing and the theme or message was what was found in all of the broader categories. This process involves "making the hidden obvious" (Connelly, 1994).

The final step of analysis was the critical analysis. Here the "obvious is made dubious" (Connelly, 1994). This was the section that questions why and examines the social context in which these themes had developed. It examined the relations of power that made this thematic statement viable. This was to ensure that taken-for-granted assumptions were questioned and presented as such.

In summary, this research involved conducting nine oral histories with women who had a variety of disabilities in differing degrees of functionality. Demographic information was analysed first. Then themes were developed around repeated issues raised in the conversations. These themes were then related to past research and present research. It was also analyzed in relationship to the models of disability presented in the literature review in an attempt to place it within a social context.

CHAPTER 4

PRESENTATION AND ANALYSIS OF THE DATA

This section will discuss the findings of the research. The differences between labels given to disabling conditions and functional abilities will be discussed. The women's description of their own disability will be used throughout. Biographical sketches of the women will be presented at the very beginning to give the reader a human face with which to make connections. The data will be related to previous findings and the analysis of that data will be presented. This analysis will be in keeping with the issues raised in the literature review. Definitions and experiences of leisure will be discussed as well as the constraints experienced by these women with regard to leisure, both physically and within their social environments. A final section will discuss the manner in which these women adapt their daily lives to meet their leisure needs and desires.

Biographical Sketches

The following are brief descriptions of the women in the study. They refer to their disabilities, how I came to meet them and the environments in which they lived.

Ada

Ada has had fibromyalgia, as part of an arthritis condition, since she was fourteen although she felt she had it since eight or nine years of age. It is unusual for one to have the disease so young. Her main functional disability involved muscle weakness along with pain and fatigue in both joints and muscles. She experienced fatigue much more quickly than most people, saying that her "muscles just go heavy" (p.17). She was able to stand for short periods before her muscles fatigue and she has to sit down. Ada used a manual wheelchair which she propelled with her feet and her hands. Because of her physical limitations it was important for her to have flexibility in her work as she tired easily and her physical abilities were sometimes inconsistent.

I met Ada at her place of employment. Her job involved ensuring that the transportation needs of persons with disabilities were met within her city. Her office, shared with several other people, was located in a very large, open room. While visiting with her she moved around the room in her wheelchair, taking me to a bulletin board displaying all the public transportation routes within her city and the places of recreation that were accessible to persons with disabilities. She also showed me a number of reports, some of which she had written, regarding transportation options and obstacles for persons with disabilities. On her chair seat was a piece of equipment that helped her to stand up so that she could reach the reports that were on the higher shelves of her desk.

Louise

Louise had a spinal cord injury about five years ago. She bruised her spine and it hemorrhaged. She was a quadriplegic meaning that all of her limbs have been affected by the injury. There were no broken bones, just a bruise. She stated that she was not as strong as other people with spinal cord injuries. She had weakness in her hands and arms but she felt that they were getting stronger. Her right side worked better than her left side. This presented a problem for her as she was left handed before her accident, so she has learned to use her right hand for writing. Louise talked a lot about her abilities with regard to the weight of objects. She could not lift, because even though she had the use of her bicep muscles, she did not have the strength in the tricep muscles which she needed for lifting. She also had difficulty grasping objects, especially if they were heavy. She also stated that she had feeling in her hands but they felt "slippery and soft, like butter fingers" (Louise, p.78).

She lived on her own with access to twenty-four hour attendant care if and when she needed it. She used an electric wheelchair. She had a spacious living area with wide hallways. What I remember most about getting to know Louise was her ability to figure out ways to adapt gadgets in her life to make it easier for her daily living. I met Louise at a DisAbled women's conference. We sat at the same table during lunch. She had a positive attitude about her disability in that she spoke of how she was getting more and more ability back.

Debbie

Debbie described herself as a "class six person with cerebral palsy" which meant that her cerebral palsy affected at least three of her limbs anywhere from moderately to severely (Sherrill, 1993, p.629) She also had severe balance and co-ordination problems. Debbie used other medical terms to describe her abilities. She said she has some athetosis and ataxia. Athetosis means that she has fluctuating muscle tone so that there are involuntary, unpredictable, constant muscle movements (Sherrill, 1993, p.625). Ataxia is a term used only for people who can walk unaided. It has to do with a disturbance of both balance and co-ordination (Sherrill, 1993, p.626). People with this condition often over-compensate for their unsteadiness of gait by making extreme movements of their arms to help with balance. Debbie could walk on her own, either using her arms or a cane to help balance herself. She also had spasticity which meant that she had muscle tightness and stiffness during voluntary movement. She had surgery to release her Achilles tendon which affected her ability to jump. Along with these motor impairments, she had a visual impairment which made it very difficult for her to read small print. As a result, she needed specialized equipment to help her with her university studies.

I met Debbie at her home where she lived alone. She used public transportation to go to university where she was working on a degree in recreation with special emphasis on persons with disabilities. She was also in the process of starting a consultation service for persons with disabilities regarding recreation and leisure activities. We sat at her kitchen table and talked about her leisure experiences and her expertise around issues of recreation and leisure for persons with disabilities.

Carol

Carol had a form of Muscular Dystrophy. She was told that it is Friedreich's Ataxia, but she thought it was another form. She experienced poor muscle co-ordination due to weakness in her muscles. This made it difficult to transfer herself from her chair to another seating position. While she said her stamina and health were good except for the ataxia, she knew it was a progressive disease. Although she was able to stand for short periods of time, she could not walk and used a manual wheelchair.

I met Carol at her home where she lived with her husband. She was sitting at the kitchen table holding her dog on her lap. Our conversation was held at the table. There was a television or radio playing in the background. It was a relaxing atmosphere.

Pam

Pam was a quiet, congenial woman who was always willing to help in any way during the process of the research. She also gave me leisure contacts that I could share with other women in the study. Pam was in a near fatal accident twenty years ago. The injuries sustained in that accident were extensive. She injured her head, her jaw and her hip in the accident. Now, she has poor balance due to problems stemming from injury to the inner ear. She has double vision and cannot look up as this throws her balance off. She could walk on flat surfaces but sometimes used a cane or other people for support. She also used an electric scooter for mobility. She experienced pain in her left leg more than her right leg. Her right arm and shoulder were painful too. Formerly left handed before the accident, she did everything right-handed.

Her whole left side felt like it was asleep - it was tingly up to her waist. She also got hot at times, felt sick and would possibly pass out. Subsequently, she felt cold. Although she had been treated for this, she did not know why it occurred.

I met Pam at her place of residence. It was spacious with wide doorways and hallways. She owned a cat and her house contained artifacts indicating her love for animals, particularly horses.

Ann

Ann, a humorous woman, suggested that sociability was important to her life. She liked to write and has written a book of poems that reflect on her personal experience with her god and her coming to accept her disabilities. She had already lost one leg to amputation and she had been told that there was a possibility that her other leg would also need to be amputated. She could stand on one leg and pivot, but she generally used a manual wheel chair. Along with restriction to her movement, she had other health problems. She was diabetic, had angina and chronic obstructive pulmonary disease which she said affected her breathing. She stated that she had little stamina and limited upper body strength. She felt that her health is deteriorating.

I met Ann at her residence, an open space with few obstacles in the way of the path of her wheelchair. She lived there with her pet dog. The television was on when I came in, but Ann turned it off when we sat down to her kitchen table to talk. She lit up a cigarette (a part of her leisure) and we began our conversation.

Renatta

Renatta was a very social woman and liked to visit others. She had cerebral palsy and used an electric wheelchair. Her legs and her right hand were affected. Her right hand was weaker than her left and she did not use it much. She used her left hand most of the time to carry out daily activities including driving her electric wheelchair. She said that she sometimes experienced uncontrollable muscle movements, but not always. She had difficulty writing. She could move her arms better than her legs but she was unable to walk.

I visited Renatta at her home where she lived with her parents. Her mother was there during our conversation. This was an interesting situation because I was able to hear a caregivers viewpoint as well and the struggles that Renatta and her mother have undergone over issues of dependence and independence. Although Renatta's mother expressed opinions for her daughter, I was confident that they were not her mothers point of view alone. This was due to the fact that Renatta was a straightforward woman and she did not hesitate to verbally disagree with her mother. During our conversation, Renatta was clear that leisure pursuits were important for social contact.

Irene

I met Irene at a conference for women with disabilities. I was intrigued by her communication system. She used a sheet with words and letters on it and from it spelled out what she wanted to ask the presenters. I was interested in meeting her and introduced myself.

Irene had cerebral palsy (CP) which was due to the use of forceps during her birth. She described CP as brain damage that affects physical movement. She explained that no two people with CP were alike. Some were slightly affected where their disability was hardly visible while others had difficulty controlling the muscles that held up their heads, moved their arms and legs or their ability to speak. She described herself in this way:

> I have a speech impairment, so I use a communication board or the computer that has a voice. I can walk when someone holds my hand. For long distance, I use a manual or electric wheelchair. (Irene, p.3)

I visited Irene at her apartment where she lived with her husband. Her apartment building was spacious with wide doorways, hallways and automatic doors. When she met me at the door she was sitting on a desk seat that had wheels. I was impressed with how she moved around the apartment on her chair by propelling it with her feet. She showed me her voice output computer and communicated with me through it. Through our conversations, I discovered that Irene was a writer who published both a column in the local newspaper and articles for magazines. Since I had difficulty understanding her speech, she suggested that she write her oral history for me. I described the type of information I was looking for and she responded in writing. When at first I inquired about leisure she laughed and asked "What leisure"? This was actually a common response that I received from about half the women.

Annette

I met Annette at a meeting for women with disabilities. I remember noting her sense of humour and love for animals. Annette had been diagnosed with Multiple Sclerosis (MS) since 1975. She stated that MS affected her vision first when she started to see double. Later she lost mobility in her arms and legs. Consequently, she did not walk at all. By nature, MS often goes into remission but then it gets worse once the remission is over. Such is the unpredictability of the disease that people can die suddenly with MS. Annette had limited use of both hands but she was not able to do things like needle work. Her hands shook when she tried to do things like answer the telephone.

I met Annette at her apartment where she lived independently with the help of full-time attendant care. Her building has wide doorways and open concept rooms. She let me into her apartment with hand held controls. Like many of the women, Annette had a cat which, it became obvious during the conversation, was important to Annette. By the end of our conversation I realized that the process had been tiring for Annette. She yawned throughout the conversation and this progressively got worse. In retrospect perhaps dividing our conversation into sessions might have been more comfortable for her.

Making the Obvious, Obvious...Demographics

During each conversation I asked for background information from all of the women. They were asked about the nature of their disability, their age, their marital status, their educational level, their source of income, whether or not they were employed and where they were currently living. The following is a summary of the responses to these questions.

I was able to place the nine women into three categories of disability. There were three women with congenital disabilities all of whom had differing degrees of cerebral palsy. Cerebral palsy is caused by damage to the motor areas of the brain and can lead to a number of neuromuscular conditions (Sherrill, 1993, p.27). Three other women had acquired disabilities. Among these, one had a spinal cord injury, which can be defined as some form of injury or disease to the spinal cord and/or spinal nerves (Sherrill, 1993, p.557). Another woman in this category was an amputee, which involves the absence of an entire or partial limb due to "trauma, cancer, infection and vascular conditions like gangrene" (Sherrill, 1993, p.611-612). The third woman had an accident that resulted in limited mobility.

The final group of women had three different types of degenerating disabilities. One woman had fibromyalgia. This disease, which can be severe, affects women more than men and it is associated with extreme fatigue and REM (Rapid Eye Movement) sleep disturbance (Epps and Stewart, 1995). REM sleep occurs three to four times each evening. It occurs during periods of light sleep when the eyes move rapidly under the eyelids and the brain is very active (Faraday, 1975). There is aching and pain in the muscles, tendons and joints and it often affects the back so that there are multiple tender spots on the spine and or extremities. Sometimes the pain is in the form of a tingling sensation (Epps and Stewart, 1995).

One woman had multiple sclerosis. This is a disease of the brain and spinal cord and can lead to paralysis and tremors (Havard, 1990). This episodic disorder is caused by an abnormal immune response that destroys the insulating sheaths of the nerve fibres (the myelin sheath) so that the nerve fibres are bare (Epps and Stewart, 1995; Havard, 1990). One of the women was told she has a form of muscular dystrophy called Friedreich's Ataxia. This disease causes degenerative changes in the nerve tracts and nerve cells in the spinal cord and the brain (Havard, 1990). Symptoms include unsteadiness of gait, loss of the knee jerks, difficulty with speech, tremors in the hands, head and eyes, deformity of the feet, and curvature of the spine (Havard, 1990). It is also a disease that begins in childhood and can affect brothers and sisters (Havard, 1990).

The women ranged in age from 25 to 49. Two of the women were in their mid-twenties. There were no women in their thirties. Five were in their early forties and the remaining two were in their late forties.

Only two of the women were married and living with husbands. The rest of the women were living on their own. Three of these women were single and the other four had been married and were now divorced. This pattern is consistent with research findings that state, when compared with non-disabled women, women with disabilities are more likely not to marry, marry later or divorce. One author has suggested that "when women become disabled the divorce rate is 99 percent" (Cassidy et al., 1995, p.54).

One woman had elementary school education. Four had secondary school education, one of whom was taking college courses at a local community college. Two women had college diplomas. Two had university education, one of whom was finishing a recreationist degree at university and the other already had a Bachelor of Science degree.

Therefore, over half of the women had some post secondary education. This differs from the national HALS statistics through the Ministry of Supply and Services (1990) which reports that only 11.2 percent of women with disabilities as compared with 16.2 percent of men with disabilities had post-secondary education. The survey also found that women with disabilities and women without disabilities are similar in that both disabled and non-disabled men are more likely to have post-secondary education than their female counterparts. Cassidy et al. (1995) suggest that opportunities for educational advancement reveal gender inequity. Women with disabilities are less likely than men to be encouraged by families and school systems in terms of academic achievement (Cassidy et al., 1995). As a result, they more often receive job training preparing them for less visible, part-time or home-based occupations.

Source of income varied among the women. Some had only one source of income while others had several. The sole source of income for five of the women was a provincial disability pension through Family Benefits. The Ontario Family Benefits Assistance provides financial assistance to families who need help with living expenses. Persons 18 or older with disabilities are included under this legislation. The definition of disabled includes: "a major physical or mental handicap that severely limits you in carrying out normal living activities" (Ministry of Community and Social Services, 1987). The final stipulation is that this disability must be of a permanent nature.

Three women received money from the Canadian Pension Plan (CPP) in conjunction with other sources of income. Among these one woman supplemented her income with funds from disability insurance and with her husband's income. Another woman used CPP to supplement her employment income. A third woman received both CPP and the provincial disability pension through Family Benefits.

The Canadian Pension Plan pays a monthly pension to people with disabilities who have contributed to the plan for two of the past 3 years or 5 of the past 10 years, who are between the ages of 18 and 65, and who have a physical or mental disabling condition that is severe and prolonged. The disabling condition must prevent regular work at any job and be long term (Human Resources Development Canada, 1994)

Whether the women received CPP, Family Benefits or a combination of these two, there was a maximum amount of money they could receive each month. Statistics suggest that almost 56 percent of persons with disabilities have a total income of under $10,000 (Minister of Regional Industrial Expansion, 1990)

At the time of our conversations, eight women were not working outside the home. One woman worked in her home as a free lance writer. Five of the women had been employed at one point in time. Studies by the Canadian Minister of Supply and services (1990) and White (1993) found a similar pattern nationally where more women with disabilities in Canada are unemployed (61.7 percent) than men with disabilities (40 percent). These gender differences reflect those in the general population, but to a greater degree. Women without disabilities are also more likely to be unemployed (31.1 percent) than men without disabilities (11.9 percent).

The woman who was employed outside the home worked flexible hours to accommodate her physical needs. Ada spoke of the importance of flexibility in work to her physical needs:

> ...And I've arranged my work life...I'm a research assistant, so if I miss a deadline that's okay. I'll get the next one. And I work when I can. If I can't work I don't. (Ada, p.18)

In a HALS survey (1990) found that of 40 percent of employed disabled adults in Canada, 53 percent indicated that they are limited in the kind and amount of work they can do.

Some of the women lived in their own homes while others lived in residences provided by other organizations. Four of the women lived in Supportive Living Units (SLU) provided by the March of Dimes. One of these women lived in one of these units with her husband. Supportive Living Units are part of the Supportive Housing Programs operated through the March of Dimes and are built as accessible, self contained apartments for person with disabilities. To be eligible for an SLU one must be 18 or older, have a long term disability, have a stable medical condition at the time of service, must be able to direct one's own care and be able to remain unattended in her/his own apartment (Ontario March of Dimes, n.d.). Twenty-four hour attendant services are available to the individuals in these units (Ontario March of Dimes, n.d.). The objective of this program is to promote independent living for person with disabilities.

Two of the women with acquired disabilities lived in accessible units in Co-operative Housing. Co-operative housing is a program that provides financially supplemented housing for persons on lower incomes in exchange for their services in the maintenance of the building. A specific number of accessible units are built for persons with disabilities.

One woman lived in her own home with her husband and had Home Care come assistance to help her with her daily care. One woman lived in an apartment on her own. The other woman was living at home with her parents where her mother and brother helped her with much of her daily care. The Minister of Supply and Services (1990) reported that the rate of disabled females living in private households was higher for women with disabilities than for men.

Definitions of Leisure

The women, in general, had a very clear sense of what leisure meant to them without formulating specific definitions. Choices for leisure were individual but definitions of leisure were similar among the women and in relation to those given in the literature. Louise, for example, described leisure in very general terms:

> Well leisure to me is just relaxing. Like I'm having a leisure time right now just talking to you. Relaxing. Yeah. Something that relaxes. Something comfortable. Something that's fun. I mean leisure is going out as well. But I

> mean reading a book, that's leisure or sitting in front of the T.V. Sitting in a hot tub...To sit in a hot tub. THAT'S LEISURE. (Louise, p.88)

All of the women saw leisure as involving experiences that are pleasurable, enjoyable and fun. It also involved free time to do things without obligation:

> Okay, well the term itself just means time to do something other than what I have to do. If I'm not committed to something that I have to do, then it's filling in time that's left. (Ann, p.46)

> There's no sort of definition. We (referring to her peers at school) defined it as something that is free time, without obligation, something that we want to do. Leisure can be any kind of activity or it can just be thinking, expressing, having coffee, whatever. I think leisure is a very broad statement and everybody wants to equate it to an activity because that's what makes it meaningful and that's what makes it less frivolous or whatever. Well, it is frivolous, it's leisure for god's sake (we laugh). It's not supposed to be structured or it doesn't have to be structured. (Debbie, p.10)

When describing the difference between sport and leisure she suggested that sport is exclusive of some abilities but leisure on the other hand is not. It was just for fun. In her case, she quit sport when it stopped being fun:

> D. I was so driven...Because you're so driven it kind of takes away the pleasure of the whole thing.
>
> J. So to you leisure means pleasure? What's the difference?
>
> D. Well I mean you better enjoy what you do or else why are you doing it. It came to be more driven, more achievement based than it was before and all of a sudden the enjoyment of it started to fade from it. (Debbie, p.17)

Leisure was also specific to the person involved in it. Debbie explained that activities become leisure or recreational activities because they had meaning for the person involved in them:

> Any sport that I do is a hobby. Any competing that I do is a hobby because I've finally come to the point in my life where I can say that I am striving for MY personal best, not the person beside me, not the person in front of me or

> whatever. See, I was always striving to win, to beat other people, to be better. Now, psychologically, I can say I'm doing my best for me, not anyone else.

She introduced the importance of leisure as an integrating force in personal growth. Ada's views agreed with this, indicating that leisure helped to round out an individual's life so that one gained a wider view of the world beyond work, school, and family:

> J. What do you mean by rounding out, when you say rounding out?
>
> A. Well, I think with work, you sort of have a tunnel vision of life. Like usually, no matter what work place it is...there's a different life somewhere else...In your work life, or...your home life, you can get so that you think that's all the world is. I like to do things where I meet different people. Do different things...get a wider view of the world. (Ada, p.52)

Leisure also integrated the aspects of a person's life by integrating the processes of the mind and the body. Carol used her mind to experience what she could not with her body. She told me that she used her mind to experience the leisure that she could not experience with her body:

> I love to dance but I can't. I do it in my mind. I've never told anybody about that. I'm afraid people would think I'm nuts. I'm always dancing in my head. All kinds of dances like tap dancing, not ballet, I love jazz...I skate and walk sometimes in my mind. Everything that I can't do (physically), I do it in my mind. (Carol, p.107-108)

Pam also referred to the mind/body connection necessary in leisure pursuits. Pam's decision to take part in leisure involved being in tune with physical and emotional needs: "Deciding to take part in leisure involves recognizing what my body is capable of doing and what I need emotionally" (Pam, p.91).

The mind/body link also had connections to self-identity. For Debbie, leisure was a place where one formed self identity. For example, through leisure pursuits she reached a turning point in her life where she examined herself, her wants and her needs: "Leisure allows me to figure out what I like, who I am, who I want to be around and what I do with those people. So it's all interwoven" (Debbie, p.18).

Leisure also was seen as helping to integrate persons with and without disabilities. It provided persons with disabilities with a view of normality beyond therapy and the trials experienced in daily living. For the non-disabled, this provided a taste of life from a disabled point of view. Ada addressed this:

> (For) some people, just getting up in the morning and getting themselves dressed and fed, is such an ordeal. And then maybe you have people coming in for (your) therapy...You've gotta make sure that by getting out and having recreation areas...you're getting out to where things are normal. And also, it forces the rest of the world to sort of get a wider view, cuz they get to deal with you. (Ada, p.53)

Leisure was defined very broadly. It could be carried on indoors or outdoors. It could be both passive (i.e., requiring small, slow, movements) or active (i.e., large, quicker movements), structured (i.e. being on a floor hockey team) or unstructured (i.e., needlepoint). If it was structured, it was important not to medicalize it so as to ensure that leisure activities remained fun. Several of the women suggested that recreation programs should be fun and not therapeutic. Debbie explained that therapeutic recreation programs often eroded a sense of autonomy:

> I don't even know that much about therapeutic recreation. I just know it comes from the medical model that says 'I'm the one in control. You are the recipient. This is what we do. These are your choices, choose one.' No sort of free expression. (Debbie, p.22)

Ada, in reference to a class she took in a regular recreation setting, suggested that there were differences between segregated and non-segregated programs where segregated programs tended to be more therapy-based: "It's in the regular program. It's not medicalized. It's in the Y...It's a regular program...There is the difference. It's for fun" (Ada, p.5).

Although the choice of leisure pursuits was seen as individual, leisure was important to the social well-being of the women. The importance of the social component of leisure was evident throughout the conversations. All of the women spoke of the importance of doing things with people, although some found it more important than others. Ann supported the view that leisure had an important social component. She suggested it was a time to share accomplishments with others:

> ...I mean, I may enjoy sitting here writing the poetry but then I distribute it. Then I do speaking on it. You know, things like this. So it has an impact other than the fact that I've done it...The same with music. I mean, I'll sit there and I'll learn a new song and I might sing it at church. (Ann, p.48)

The social component of leisure was also vital to Renatta because she saw it as a starting point to the pursuit of other leisure activities. She believed that other components of leisure would follow from social contact. Renatta's mother expressed it this way:

> I always had in mind saying, 'Renatta there is some sort of social club where you meet once or twice a week.' Not every two months or three months...Meet friends, maybe meet someone special, have a relationship or something like that. From there they would do sports, music, go out together and do shopping because to me that's leisure for Renatta. (Renatta's mother, p.29)

In conclusion, the women in this study saw leisure as free, non-obligatory time that was spent in pleasurable pursuits. It could be active or passive, structured or unstructured but not necessarily therapeutically oriented. This was not to say that physical needs were not salient. Rather, therapeutic aspects were not a central reason for taking part in a leisure activity. The activity had to be fun. It was specific to the person involved and provided an opportunity for personal growth. Not only did it integrate the personal aspects of being, it also integrated the personal and social components of being. This was one of the most important features of leisure for these women. Most of the women wanted to socialize with others whether they were disabled, or non-disabled.

In comparing the definition of leisure offered by these women to other definitions it becomes apparent that they are quite similar. Kelly (1987; 1990) and Hutchinson and McGill (1992) describe leisure as something that integrates an individual's mind and body and promotes personal growth beyond the activity itself. They also suggest that it is freely chosen and brings pleasure. The women in this study also defined leisure similarly to other studies on women with disabilities in that they too saw leisure as free time to do what they wanted to do at their own pace (Henderson et al., 1995). Mowl and Towner (1995) and Smears (1996) state that leisure pursuits are also affected by the manner in which the physical body reacts to the activities. Although the women in this study stated that the physical needs of their body were important, leisure choices were not solely constructed around physical abilities.

Their definition differed from other definitions in that they felt leisure for them was usually constructed by a medicalized view of the disabled body which focused on the impairment. However, their definitions were very broad so as to incorporate personal choice and different functioning abilities. The women in this research supported the suggestions by other researchers (see Hutchinson and McGill, 1992; Kelly, 1987, Kelly, 1990) that gave recognition to the social component of leisure where people can share their gifts, talents and build relationships. What follows is a discussion of the leisure experiences reported by these women.

Experiences of Leisure

When looking at the leisure experiences of the women, the similarities and variations among them depended on factors such as age cohort, functional ability, association with an agency or institution such as school or independent living centre, whether or not the woman was born with a disability, whether the symptoms of the disability progressively became noticeable or whether the disability was acquired later in life.

Early Childhood

All but two women spoke of spending time with friends and family as an important part of their childhood leisure. For Irene this was particularly important. She explained the importance that friends and family members played in her leisure as a child. They were a means of mobility and a socializing agent for her:

> My brother George and I had two good friends, Margaret and Mary Ellen. They took me everywhere that they went in my little red wagon. We went uptown to the Dollar Store (we drove the manager crazy by exchanging things). We had a drink stand. My parents took us on day trips to the beach and we visited our family and friends. (Irene, p.3)

Among the other respondents, all but two were physically active as children. Physical activities, ranking from the most popular to the least popular were: swimming and baseball, team sports, dancing, skating, tobogganing, racing, hiking and as Irene put it, "the things kids do" (Irene, p.3). Five of the women were in Girl Guides as children.

Adolescence

All but two of the women maintained or increased their physically active leisure during adolescence. Irene became less active due to the removal of important social relationships in her life. Her brother started spending more time with his friends and her girlfriends moved away.

The other woman who became less physically active did so for physical reasons: "I was very athletic until I reached puberty and started putting the on weight. But even then most of what I did was physically active" (Ann, p.30).

Some women became more physically active due to affiliation with organized groups or social institutions in their communities. For example, the school system often provided opportunities for those women born with a physical disability to take part in physical activity particularly when in segregated school settings. For example, until her late teens

Renatta went to a segregated school separate from the public and catholic school systems, and housing only children with disabilities. Renatta reflected on her active role on school teams:

> M. When she (Renatta) was at the Centre, they had a hockey team and it was serious business...and she loved it. They did trips to Toronto, played against other teams...and they went all over.
>
> R. I even had a boyfriend at that time too. He was the captain of the team so I could do anything I wanted (we all chuckled). I loved the captain of the team. He was gorgeous.
>
> J. So is this one of the things you did as a teenager?
>
> R. Yeah. Floor hockey and I loved it. (Renatta and mother, p.51)
>
> M. When she (Renatta) was out of the Centre, it all just disappeared like overnight. (Renatta's mother, p.52)

Her activity level changed when she entered a public high school where the focus became therapeutic:

> ...It was physio, physio, physio. Everyday it was physio. I didn't mind the physio but he (her teacher) did it eight times a day. I was constantly sore and I used to come home crying in tears because he used to pressure me about this physio thing and I said 'Physio ain't the be all and end all of my life. I mean I do have a social life. I do have a personal life. So leave me alone.' (Renatta, p.32)

Debbie on the other hand became very active outside of school in the local sport facility for persons with disabilities:

> That's a sports facility that specifically catered to persons with disabilities and also we had able-bodied members as well...I used to go in there and run track and just various different things. And of course I joined a team in (city name)...It was people in chairs and people ambulatory like myself. We used to just run track and do different games, basically just get out for fun. Then, of course we got good as a rugby team and we went out and competed and I won some medals and stuff. (Debbie, p.16)

Not only did these settings provide opportunities for physical activity, they also ensured the opportunity for relationship building:

> My favourite thing was, I think was hockey because with hockey, I got out. I made her (referring to mother) drive all over town of course but I enjoyed it. We had real games with real people and it was real fun. (Renatta, p.54)

For two of the women with degenerative disabilities it was during their physical activity in adolescence that they became aware of their failing health. This was sometimes problematic because their disability was invisible to others. When Carol first noticed her disability she was seventeen and subsequently it became difficult for her to do certain things in physical education, particularly in gymnastics. Since the teacher did not understand about her disability she kept pushing her to improve. Consequently she struggled and suffered injuries that were rationalized by insinuations that she was too weak or was overweight:

> The teachers would force me to do it. I would come home black and blue. I just knew it in my heart. I had trouble with balance and my walking...I always felt unbalanced and with my coordination. No one could tell but I knew it. (Carol, p.106)

For most respondents, physical activities during adolescence included many of those associated with their childhoods. They were involved in team sports like baseball, rugby, swimming, floor hockey and volleyball both in segregated institutions and in public institutions depending upon whether or not they were born with a disability. Two of the women were on travelling teams which they enjoyed immensely.

Involvement in passive leisure activities remained similar from childhood to adolescence, increasing for one woman in particular. These types of activities included watching television, listening and/or playing music, writing, needle point, rug hooking and telephone conversations. For Irene, her leisure activities became less active physically but more active politically:

> I had an office upstairs in the house, so I spent most of my time in there. By this time, I got myself involved on Committees and Boards to improve the lives of persons with disabilities. Plus I started writing my monthly column in December of 1976. (Irene, p.3-4)

A number of women expressed that they were more involved as children and during their youth in outdoor activities like tobogganing, horseback riding, hiking, going to the beach, canoe trips and just doing things in nature. Annette liked the outdoors and nature for both active and passive leisure activities. Annette described her outdoor activities as an adolescent. She would meet with her cousins at grandma's house where:

> We played baseball there. We used to play around the trees. There was a lot of trees then.....I sat and read Gone with the Wind under the tree but the tree got taken out because it got Dutch Elm disease. (Annette, p.41-42)

Adulthood to Present

During adulthood distinct patterns emerged regarding women with disabilities and leisure. First, most of the women participated in leisure that was slower moving than they had previously experienced in their lifetime. Second, it became more important to spend time with other people during leisure. Third, those involved in leisure activities outside of the home were usually involved in segregated activities. Fourth, their desire for leisure activities was comparable to that of non-disabled women but their means of attaining them were often dependent upon circumstances often beyond their control. Finally, they desired leisure because it was important to their physical, emotional and social health. These themes are explored below in detail.

All but three of the women were involved in more passive leisure pursuits than earlier in their lives partly due to their geographical location. Among the more active, Debbie's education gave her access to courses in movement and resources for participation in physical activity:

> ...I'm involved in the recreation programs at Brock because I take courses and the phys. ed. program because I take courses there as well. As far as structured intramural stuff I don't do that. I work out with a guy two times a week weight training and stuff. (Debbie, p.25)

Similarly, Ada lived in a larger city where there were more options for transportation and leisure. This will be addressed later in a section on environmental constraints.

For most respondents, typical leisure activities included watching television and movies and listening and/or playing music. Ada was the only woman who stated that she did not watch television: "I don't watch T.V., I don't have a T.V. I decided I don't have time" (Ada, p.49-50).

Going out to dinner and movies with friends and spouses was also a popular activity although frequency depended upon factors such as finances, a companion, transportation and weather. For example, in the summer Carol went with her husband on her scooter to a local restaurant where they could sit outside the restaurant because it was accessible (Carol, p.20).

Many of the women also went shopping, usually to malls. Other leisure activities cited involved needle point, knitting, and rug-hooking although for some these activities are physically difficult. For example, Annette showed me a partially finished piece of rug-hooking which she had been unable to complete.

At least half of the women read for leisure and some liked to write. Writing took different forms. For example Irene wrote a variety of things including a newspaper column. She was presently trying to publish her autobiography and took night courses on publishing. The process of writing was arduous for Irene. On top of her computer board was a board with holes in it which went over top of each of the keys and served as a guide for her fingers to access the hole corresponding to each key. She typed her text and pressed a key and the printed message was retrieved.

Debbie was writing her memoirs and Ann wrote occasional articles, music and poetry. For her, writing was a mode of expression as well as something enjoyable:

> ...Most of what I write is poetry although I do write letters and things like that...I go off on things cuz I've got such a weird sense of humour. But, with doing the co-op newsletter...I put an editorial in every month and anything that's particularly on my mind that might relate to other people in here (referring to the co-op) and stuff like that, I can do that kinda stuff...I enjoy writing. I don't know, I've just always enjoyed self-expression. (Ann, p.35)

Pets were also an important aspect of leisure for six of the women. They were not only seen as companions and a source of enjoyment, but also as helpful. For example, Annette talked about how her cat was helpful in getting the attention of others if she needed help:

> He (her cat) watches television. He listens to people talking. I don't know how much he understands but I'd like to know. He knows if I call (yawn) during the night...call the attendant...he's right there, he goes right to the door and waits for them to come. (Annette, p.35)

Pets also provided comfort: "Animals know if you need something or need them. If you don't feel good they will come around" (Annette, p.38).

Ann trained her dog to be both a working dog as well as a pet:

> ...The dog is a real blessing because there's times when you feel alone to make sure you don't...and being a working dog, she's a real blessing...Oh, she picks things up off the floor. That's the main thing that I need her to do for me. She can turn lights on and off. That's something I don't really need her to do but that's part of her training. She does anything. She picked up a cigarette for me when I dropped it. (Ann, p.4-5)

Another passive activity was using the telephone which will be discussed in the section on equipment.

Finally, there was a generally expressed desire for more leisure although their desires were not always attainable. For example, five women would like to be more physically active, believing it would be physically, socially, and emotionally beneficial. Ada, though, explained that for active leisure one needed a balance. She showed me a book that described exercises which she thought would be helpful for her. She also felt exercises alone were not enough:

> ...And I know I'm supposed to do it (exercise) and it's painful (for) muscles and joints. And so I don't wanna be (in pain), so that's why I...(tried) Tai Chi...then I'd get bored and move on to something else. But, for the first time, this aerobics thing...I'm finding I found something where...it's fun to do. (Ada, p.11-12)

Not only did activities get more passive for most of the women over the years, they also became more segregated in most cases. That is, leisure became an activity that was carried out in settings with other persons with disabilities only. If the activities were inclusive they were marginally inclusive. Inclusion means including people with disabilities in community programs in a way that is meaningful for them so that they can make choices and have the supports and connections they need to become full active members of the community (Dattilo, 1994). Debbie described marginal inclusion as a less than meaningful activity:

> Just because someone is a human goal post, and yes I have been a human goal post, it doesn't mean that it is a meaningful experience...you don't change the entire program to fit the person with special needs. That's not inclusionary. That's just tailoring the program to one person or a few people or whatever. I am committed to everyone having a positive experience with that person (with the disability) involved. (Debbie, p.1)

Therefore, inclusion did not mean physically placing a person with a disability into an existing program and changing that program to meet the persons needs. Rather it meant finding out what the person needed (physically and socially) and finding a way to incorporate it into the existing program so that everyone involved benefits.

Another attempt at an inclusionary program was one that would be part of the regular recreation program for a non-disabled service but would be also be specialized.

Examples of this included Irene's "Yoga for Persons with Disabilities" at the local YWCA. These segregated programs could be seen as beneficial because they meet the physical needs of disabled people that other mainstream programs do not:

> ...they found that people with this (fibromyalgia) do better if they've got a good aerobic work-out...I was trying to find some kind of recreation so I could move and keep from getting stiff. So the doctor sent me over to this (aerobics) class and the instructor who is knowledgeable about me, and if you get into troubles he knows, 'Okay, do it this way'...So the recreational leaders have to be more knowledgeable too. (Ada, p.3-4)

To be involved in a regular leisure program, then, it had to also match the needs of individuals. For example, special equipment, a slower pace and any other needed supports may be required. Ada did Tai Chi and canoeing because they moved at a slower pace, there was opportunity for rest, and there were supports (people and equipment) in place.

In sum, some of the findings here shed new light on experiences of women with disabilities over time. The women described leisure as children and adolescents to be mainly outdoors and more physically active. Adult leisure activities were more passive and segregated. The most popular activities were enjoying pets, reading, writing, television and music. Organized activities were mainly carried out in segregated settings as previously cited by Hutchinson and McGill (1992). For the most part the women participated in slower-moving activities. Their desire to be more physically active was reflective of the findings in the study by the Canadian Government (1988) on physical activity and women with disabilities.

In terms of desire to be more active, not only did physical ability constrain involvement, a number of other factors were also influential: the physical body and the activity involved, time, relationships, environment, transportation and equipment, funding, and policy options. These were similar to the findings by Henderson et al. (1995).

Therefore, other aspects of daily living affected leisure experiences and these constraints will now be addressed.

Context and Constraints

An aspect that must be considered when identifying leisure constraints is the fact that leisure cannot be viewed as a separate entity for women with disabilities who had to continually juggle other components of their daily living. Leisure opportunities were not always readily available to them and participation required much energy for planning, adapting, creating and making connections between what their bodies needed and what they needed emotionally and socially.

This section will describe how women with disabilities encounter obstacles to leisure involvement. I will address (i) the effect that the physical ability of the body had on leisure choices, (ii) the availability of time, (iii) transportation, (iv) the location of leisure activities, (v) the need for personal space to carry out activities, (vi) equipment and articles providing physical supports that help with the pursuit of leisure activities, (vii) supports that derived from their relationships with other people, and (viii) other constraints related to economic issues and policies.

The Biological, Gendered Body and Beyond

There was a large difference between the actual functional ability of the body and perceptions connected to labels given to physical impairment. While the impairment label objectified the body, looking at what one was functionally able to carry out personalized the condition. This was an important distinction made by women in this study:

> And really it doesn't matter what disease you have, it's whether you can lift your arm (that's important). And in arthritis, maybe some people can lift their arms and some can't. So it doesn't mean anything, it's just a label for disease...And you might function differently at different times too. I mean, people think that if you have arthritis you're in a wheelchair. This isn't true. And people with cerebral palsy, there's a broad range of functionality. (Ada, p.1-2)

Debbie's description of and focus on her functional ability rather than her disease label told me more about what she was able to do as an individual:

> J. Okay earlier you said you have athetosis and ataxia as part of you CP. What does that mean?
>
> D. Now let me hope to remember this. Which one is which? One has to do with balance. I know that for sure. My balance is certainly a factor. And one has to do with involuntary muscle movement. I always get the two mixed up. That's very slight, the involuntary muscle movements, but sometimes I'll be sitting here and you'll see my shoulder go (shows me a shoulder movement) and my head (shows me a head movement) and some of that I can't control. But in varying degrees, sometimes it's worse. For me, what is the worse is not the spasticity. It's more the balance problem. (Debbie, p.7)

Thus, respondents indicated that it was important to be sensitive to differing levels of ability within diagnostic labels and how these labels can misconstrue lived reality. Louise referred to her impairment and how it differed from others with the same type of impairment:

> I bruised my spine and it hemorrhaged. I didn't break any bones I just bruised the spine. That's what is so frustrating with me because I meet people with spinal cord injuries with broken bones and they have a lot more strength and they can do this and they can do that. It's really strange and when you hear about someone talking sometimes it's ...they have a spinal cord injury and they are paraplegics. There's hardly any quadriplegics. I'm a quadriplegic. (Louise, p.76-77)

These experiences of impairment and disability had a direct affect on the type of activity and the manner in which it would be carried out. Impairments, of course, affected the ability to carry out activities of daily living (ADL). In turn, ADL affected leisure because they consumed energy and left less energy for leisure activities. Pam gave me her morning routine to give me an indication of what she does physically:

> ...Okay say I vacuum and dust and all that and I've done his (the cat) litter box, I've made the bed, maybe I've done a load of laundry, I've taken a shower, I've washed my hair, I've got dressed. I'm tired. (Pam, p.80-81)

It was not just the activities of daily living that took energy, it was also the energy needed to concentrate on those tasks. Carol referred to how using the bathroom tired her mentally:

> To go to the bathroom, I have to be precise, the wheelchair has to be in the right spot...It takes a lot of energy to concentrate and I have to rest after. (Carol, p.111)

Renatta talked about the energy needed to dress herself:

> I can try to put on my slacks. I've done it before and I've changed myself and done whatever I've had to do, but it takes I would say about two to three hours just to dress myself if I were to do it on my own. Okay, not that I've ever taught myself but I know how long it takes me because by the time I'm finished, I'm bushed and I don't want to do anything else. Dressing myself takes a lot of energy but I can do it. (Renatta, p.48)

Louise emphasized the importance of caring for the physical functions of her body, which she could not do on her own, to ensure that her leisure time was enjoyable and relaxing:

> Making love is leisure too. That's leisure. That's very relaxing (we chuckle). It can be very tense for me sometimes, especially if I've had a problem where I haven't been able to go (have a bowel movement). Then I worry I'm gonna have an accident. That's why I always hope that I can go before the weekend and so I can have a good weekend. (Louise, p.92)

Thus, although non-disabled women also referred to low energy levels as constraints to leisure, this was often associated with their perceived domestic responsibilities rather than physical impairment.

All of the women referred to how they carried out leisure activities differently than non-disabled people as a result of their physical impairments. For example, Ann had to play table tennis on one leg and knew what was required so as not to over-exert herself:

> ...But if I take a sprits of nitro before I start, then I can play a couple of games before I get into any problem at all. And because I can stand on the one foot...it gives me a little bit of, you know. I don't have any balance mind you...I'd get the chair the right distance from the table and I would warn everybody I'd be playing with 'Please don't be nasty and serve way back here'...But I can stand hanging onto the table...(Ann, p.7)

A decline in physical ability also meant fewer leisure options. Annette wanted to write but was physically unable to do so:

> J. Is there something that you would like to be able to do that you can't do?
>
> A. Write. That's hard to do.
>
> J. That would make a big difference for you?
>
> A. Yep. (Annette, p.47)

This is consistent with the findings in the 1991 HALS survey on the leisure and lifestyles of persons with disabilities in Canada. When there is an increase in the degree of severity of the disability there is a decrease in the percentage of cultural activities outside of the home and the less likely persons with disabilities are to be satisfied with the frequency of their participation in cultural leisure activities (Statistics Canada, 1991)

The movements involved in some activities were more physically beneficial than others. For Debbie, being physically active had a positive impact on her impairments:

> I think I am stronger. I deal with various medical things everyday like migraine headaches and muscle spasms, stiffness and soreness. Imagine how much worse it would be if I wasn't constantly moving around. If I wasn't constantly getting out and doing whatever. (Debbie, p.12)

Ada referred to reasons why swimming is so beneficial to people with physical limitations:

> ...there have been times when I've been weak. I couldn't even move, so somebody would do a range of motion for me. It's not very satisfactory. You really need to do it and really swimming for me is a way to do it...because it's

> buoyant. So anybody with a disability it buoys you up...It's kind of like an anti-gravity work-out. You're not working against gravity which makes it difficult. (Ada, p.60)

In this sense, the body itself reacted to the leisure activity and the environment in which it was taking place. The recognition of the importance of physical activity for the body was also found in the 1988 GCFAS survey.

Physical limitations meant that the mind and the body had to work together to carry out even the activities of daily living:

> As a person without a disability, you do not think of anything you do. You don't think of picking up a glass, how heavy that glass is or how hard it is to put your fingers around that glass. You do not think of things like that...I've learned, being disabled, everything's heavy and because I have problems closing my fingers it's (a glass) very hard to get around. (Louise, p.78)

This connection between the mind and the needs of the body carried over to leisure activities. For example, Debbie used imagery in a game situation in order to feel safe:

> I imagine that there is something that prevents you from touching me. It's not that I don't like to be touched, but I need that space for assurance that you're not going to knock me right on my can. (Debbie, p.6)

Debbie expressed how she was self-reflective in order to make necessary changes in her life situation: "I like to constantly challenge myself and look inward and be reflective and see what it is that I need to change and that sort of stuff" (Debbie, p.25).

Physical inabilities affected the ability to work and consequently the economic status of these women. This in turn affected leisure options. This is consistent with the findings by the Minister of Regional Industrial Expansion (1990) which reported that of the persons with disabilities who were not in the labour force, 69 percent said that they could not work because of their disability. Women with disabilities are less likely to be employed.

Renatta's mother addressed this issue and expressed how Renatta's disability affected her job prospects. She compared the reality of Renatta applying for the same job as me (a non-disabled person):

> They're (potential employer) certainly not gonna pick her. They're gonna see her in a wheelchair, not just because of the wheelchair. Why would they hire her when they can hire you? You walk. You can take yourself to the bathroom. You don't need help to go to the bathroom or have transportation. All the little things that add up to a big picture. (Renatta, p.33)

Watching the deterioration of one's physical ability was frightening. There was a fear of the impact their disability would have on their economic future and their ability to purchase the equipment and drugs they may need: "...It's scary to think about of the future. I've gotta make sure that I can provide these things for myself, or in any other situation" (Ada, p.21).

Part of this fear was focused on the ramifications of their bodies. Carol was concerned about losing her ability to sign her name: "It is like you are losing a part of you and you can see that you are losing your ability to do a simple thing" (Carol, p.112).

For Ann, this fear had to do with losing independence and feelings of vulnerability:

> My biggest fear is if I go into a nursing home, that's permanent...And it's something...I have no control over. I can lock the door if I'm afraid of (someone breaking in)...There are things I can do to prevent that. There's not necessarily anything I can do to prevent this (losing her abilities). And that's what's frustrating. You have no control over this. (Ann, p.40)

There was also fear of the pain associated with an activity. For example, Pam referred to a painful experience she had horseback riding shortly after her accident. This was an activity she would like to pursue but she was afraid the pain may be worse:

> But I mean like this was when I was say 27 or something. And it hurt a little bit then but it wasn't so (bad) it would have killed me. But I don't know like it might bother me now and I don't know if I would be able to stand it long enough. (Pam, p.73)

Fear of the unpredictable nature of disablement has been reported in other studies (see DAWN, 1995). The findings of this study suggest that fear was associated with loss of functional ability which translates into loss of independence.

It was not just the biological aspects associated with disability that had implications for the leisure of these women. Being biologically female sometimes exacerbated physical impairments or accentuated their feelings of vulnerability. For Carol and Annette the biological process of giving birth dramatically affected their diseases. Carol stated that after her daughter was born she could not get her strength back: "I had trouble with my legs and knee joints. I had weakness that I never had before" (Carol, p.110).

Annette expressed the same concern with the weakness she felt after her daughter was born. She was not aware at the time that having children when you have MS affected one's physical health in a negative way:

> J. Did you find that it got to be...did it (progression of MS) change after the baby was born?
>
> A. Oh yes. (When) the baby was born I was so afraid I was going to drop her. Then I found out...you have children, it's no good with MS...You're not supposed to have children. (Annette, p.28-29)

Female biological processes at times required more assistance depending upon the degree of functionality of a disabled woman. Louise suggested:

> Well, there's a lot more things that woman always did that men don't. Men don't have periods. Women do. I have my period. I have to call down to have them (the attendants) come and clean me up when I want to change my pad. (Louise, p.103)

Similarly, being female put women with disabilities at higher risk than men when moving about in public. Pam referred to a friend who rode the city transit system who was often alone at transfer points. In a survey conducted by DisAbled Women's Network in Toronto, 31 percent of disabled women had been sexually assaulted as adults compared with 23 percent of non-disabled women. Their likelihood of being physically or sexually assaulted as children was 33 percent higher than that of non-disabled women (DisAbled Women's Network, n.d.).

While disability was central to the body image of these women, norms associated with gender also affected body image.

> It (disability) is central to my whole body image thing, but it is not the only thing. It is something that I am constantly reminded of and something that makes me a little uneasy in social situations - my whole body image and my disability and how that is presented...Or you know, you'll see this really good looking person, and I say person because it can be a man or a woman, and you say to yourself 'Wow. I wonder if they know they're so good looking (chuckle).' And then in that split second you'll say 'Oh they'd never be interested in me.' (Debbie, p.15)

Annette addressed the issue of how her disability affected her perceived role as a woman. She referred to dating and the impact a disability had on it:

> A. I think men do not like women to have disabilities. They'd rather have a normal woman because they want...to be cared for by the woman.
>
> J. Do you think that would then be different for disabled men?
>
> A. Yea, because they want to be taken care of. (Annette, p.74)

Several of the women internalized the norms of the normal body. Debbie described the social norm for the body as that of the healthy body where this type of body was seen as superior and permanent:

> ...They (non-disabled people) are looking at life from their temporarily able bodies (chuckle) and the reason I say temporarily able is you can go across the street and get hit by a car in ten minutes, not that I wish it upon you, but it can happen and you could be a disabled woman. And what I'm saying is appreciate what you have now and do with it what you will but remember, you're not superior...You as an able-bodied person aren't superior. (Debbie, p.20)

The ability of one's body affected one's perception of it:

> D. My body mechanics isn't gonna change. I thought it would but it isn't because I work out. I mean certain things do happen. Yes, I am stronger and I do have more muscle mass than fat, still my appearance still looks the same...
>
> J. It's interesting because when you are talking about being attractive you don't refer to you disability...Do you see it (your disability) as something unattractive?
>
> D. That is I guess primarily the reason I think I'm unattractive. Yeah. Though I would never ever or hardly ever say that in public though I guess I am now. (Debbie, p.13)

This internalization was taken into social settings and the women tried to control their image. Interacting with people in social settings was affected by disability. Carol referred to her concern about how she looked to others. She had a heightened concern for her physical appearance:

> When people look at me I wonder 'Is my coat on straight? Is there something in my teeth? Is my hair straight?'...I'm concerned how my body looks, like sitting up straight. I always ask my husband 'How's my hair?' (Carol, p.108)

Mirror and photographic images were also touched upon by three of the women. For example, during one of my visits with Irene, she asked me if I wanted to see her wedding pictures. I found that sometimes she did not like her pictures. Her husband said she has a hard time smiling. She laughed because she was frowning in the pictures.

Debbie shared this dislike of looking at images of herself. She did not like to look at her body in the mirror: "Oh I just hate it. I just hate it (chuckle). I really do. I don't mind looking at my face but if I was looking at the rest of my body, no...I don't like pictures" (Debbie, p.15).

Self-image was influenced by body-image. Cassidy et al. (1995) suggests that women with disabilities receive constant messages from peers, social institutions and media that give them a negative body image. These images create feelings of inferiority, worthlessness and inadequacy (Cassidy et al., 1995).

In Frank's (1988) case study of a women with a quadrilateral limb deficiency, she found that this woman was able to find a balance between cultural expectations of the body and the functional abilities of the body. She too evaluated her body in relation to normative standards of appearance and function, but she also had a drive to carry out everyday tasks in accordance with her functional ability. This is similar to the women in my findings.

Ada, felt that women with disabilities should look in the mirror so they can see their bodies and how they move. It would be helpful in the acceptance and celebration of their bodies and the care of their outer appearance. This was one of the benefits she sees to her aerobics class:

> ...We've got a big mirror in the aerobics class...and I look differently, different than other people and I can see the differences whereas I don't usually see them...People with disabilities need to see themselves too and have nice clothes, not necessarily expensive but clean and repaired. A nice hairstyle. I see that a lot with people with disabilities. If they were to go out and join a class where there's a mirror, a ballet class, they would see themselves more. (Ada, p.58)

Looking at oneself was also important for the acceptance of others: "... they're reflecting on what other people are seeing...and part of the acceptance of society is looking clean and neat. It's too bad we don't live in another century..." (Ada, p.59).

When the disability was visible to others the disability often became the defining feature of the women. Renatta suggested that one of the problems she had was that people saw her lack of physical ability and made negative assumptions about her mental ability. She explained that when shopping, store clerks sometimes assumed her to be mentally incompetent and talked to her mother instead of her at the check-out.

When the disability was not visible others tended to disbelieve it existed. Carol explained how that invisibility of her disability and her gender led family members to trivialize her concerns about her health. She explained that it was different for her brother who had a disability since he was a boy and therefore not expected to do all the things that she was:

> So if he was complaining it wouldn't be seen as him trying to get out of responsibilities but it did seem that way when I complained. He was the baby boy and was babied. I was the oldest. Also, he couldn't hide his disability like I could. (Carol, p.107)

This defining of abilities according to visual clues obscured similarities between people with disabilities and non-disabled people and made the former separate and distinct:

> When you look at something in a medical way and that's your primary focus, medical, this person is like DIS-abled. When I think of disabled, I think of 'dis' and then I think of 'abled' and I make that distinction and I make that hyphenated disabled thing. (Debbie, p.22)

When these women were seen as separate and distinct then they were not recognized as having the same desires as other members of society. "I think that nobody really thinks that anybody with a disability...has feelings and needs - dating and being close and that stuff. I think that's really overlooked by a lot of society" (Debbie, p.14).

Renatta stated that she was also seen as delicate and weak, particularly by extended family members who did not see her very often. Renatta and her mother explained it this way:

> M. They don't have very much to do with her (Renatta). They're walking around on eggshells. They think they have to be very careful because they think she's retarded because she's in a chair.
>
> R. Even when they pick me up they have to be so delicate and I'm like 'What are you being so delicate for?' (Renatta, p.40)

This type of pity and low expectations placed on persons with disabilities is suggested by Mastro et al. (1988). Such perceptions are also commonly associated with women in general (Sherrill, 1993).

As a result of not seeing beyond disability and of attributing dependent attitudes to women with disabilities, little respect was given to the knowledge they had of their own bodies. For example, for Carol, it was not only her teachers who did not believe she was experiencing some physical discomforts. Her parents and her doctors also questioned her experiences of her body. She knew that she was sick but her doctor said that she was not: "Doctors do not consider what's going on in my body. The doctors thought it (her mother's disability) was all in my mother's mind and my parents might have thought that of me" (Carol, p.107).

This lack of consideration for the affects of impairment in relation to other body parts was also mentioned in the 1995 DAWN survey. A number of the women suggested that non-disabled people take for granted their physical abilities: "...before I was (disabled), I didn't have any need to think disabled. All the years I worked in the bingo hall, I didn't realize they didn't have any accessible bathroom until I was in the wheelchair" (Ann, p.37).

Although norms of femininity were important to the respondents, their disability was more an issue than their gender. In other words, they talked about constraints due to their disabled status rather than their status as women. They attributed constraints to leisure to their disability more than to their gender. They desired to be seen as a person first. Their bodies became objectified, pitied and in need of special treatment due to impairment and handicapping perceptions of the ideal body. This was an overwhelming sentiment by the women: "I just want people to accept disabled people for what they are, and quit complaining about what they think we want because it's not what we want, it's what we need" (Carol, p.111).

Sometimes, a new identity was created based on experiencing physical and cultural limits of the body:

> To a certain extent it hurts that people can be so superficial not to be able to look beyond the shell. Really your body is just a way for you to transport you around the earth. After you pass onto the next life, and I do believe there is a next life somewhere, your body is not going to be all that important. Who you are, what you mean, how you treat other people, that's going to be a hell of a lot more important than if your body is beautiful or defective or whatever. (Debbie, p.12)

In sum, the findings suggest that the body itself affected leisure pursuits. The women made clear distinctions between their disabilities and diagnostic labels. The latter objectified the body and concealed the differences in functional abilities which occurred within the parameters of those labels. Due to physical impairments, the mind and body had to work together to carry out activities but that did not negate the fact that these limitations affected economic status, emotional state and body image. They evaluated their bodies according to social norms associated with the female and non-disabled body. The visibility of a disability affected the manner in which the women were treated. At the same time, they had to carry out activities in a body that did not meet these standards. They wanted to be seen as a person first because when the impairment and/or the disability was seen first they became defined according to their disablement. This separated them from non-disabled culture because their impairments were viewed as negative (e.g. costly, weak and individuals in need of pity). They felt their physical differences gave them a devalued status.

It's All in the Timing

It became obvious through the course of this research that non-disabled and disabled societies have very different conceptualizations of time. This difference manifested itself differently throughout the lifespan. For example, there were problems for those who were unable to physically reach those developmental stages at the appropriate times in life. Many never reached those stages. This was of particular importance to women with congenital disabilities as their childhood experiences differed from the women who experienced childhood as non-disabled. Debbie referred to the manner in which a lack of past physical experiences informed the present physical experience:

> Well, it was interesting because I never had very much experience on the playground as far as climbing, moving like most children do. I just never did any of that because people didn't want me to hurt myself, and I didn't know how to do it. I found when I went into the educational gymnastics course, when my peer helper would be helping me to go through the movements, I wouldn't know what he was talking about until I saw him do it...I had no recollection of how to do some of that stuff because I hadn't done it before. (Debbie, p.4)

The difference in development levels affected the type of leisure pursued by persons with disabilities. For Debbie, the inability to move quickly in a game situation with non-disabled participants made involvement difficult: "I don't have the reaction time. I don't have the balance. I don't have the co-ordination to do it successfully" (Debbie, p.6).

For Ada, the pace of the activity within non-segregated recreation programs was a determinant of whether or not she would take part in that activity. Ada referred to Tai Chi as one such activity: "With the Tai Chi it was all slow movements...I didn't need the specializing so I could join the regular class" (Ada, p.9). A study by Henderson et al. (1995) supports this finding. They found that women with disabilities wanted to do leisure activities at their own pace.

Care for the physical body also affected access to spontaneous leisure. It took longer to take care of the activities of daily living like bathing and dressing:

> And I think, most of my limitations are the bathrooming, the changing, the getting ready to go out is a really big thing for me. Getting my coat on...like I can get my coat on if you give me half a second (said sarcastically) but my mom's always in a rush and she won't let me try anything. But when I'm home by myself and have to change myself, I can do it. It takes me a little longer than the average...well it just takes a little longer for me than it does for you. (Renatta, p.49)

Louise reported that feeding took her longer. "I like to take my time. I eat when I feel like it. I don't eat when I have to. Being fed, you have a certain time and you have to eat at THEIR time" (Louise, p.79).

This meant that the women must plan their leisure activities according to their physical needs. Planning and organizing also took time: "You've gotta plan. You always have to plan ahead. You know, like to make sure I can get the help" (Pam, p.4).

The time of day in which an activity was to occur and the frequency of an activity also affected leisure choices. Sometimes, energy levels were higher at certain times of the day:

> But, just the concept for me with the fibromyalgia, a lot of muscle pain and fatigue. That's why I'm saying I can't go to anything that's in the evening...But, fatigue and the muscle weakness is my functional disability. (Ada, p.16)

Ada also referred to the frequency with which she could carry out an activity comfortably: "So I can do almost anything, but just once. I can reach up, but try and do a couple at a time and I start to shake. Whereas, normally you'd be able to do that" (Ada, p.17).

Decisions to take part in particular leisure activities revolved, at times, around their care schedules. Louise referred to her schedule for bowel management:

> I used to have it on Fridays so I could have Saturdays and Sundays my whole weekend, but now it's Saturday evenings. They (the attendants) were just too busy around here so it changed to Saturday evening. (Louise, p.79)

But the women also hesitated to change caregiving times because they feared losing the care they depended on. Carol talked about quitting wheelchair dancing because it clashed with her time scheduled with Home Care: "I guess I can change it but it's not always good for Home Care and I have to depend on them for getting in and out of the shower" (Carol, p.109). Louise said it best:

> Your (referring to everyone in general) whole life you go on a schedule but being disabled, you're always on a schedule, especially if you're not able to do it yourself. You're on that schedule. I mean I have to have a schedule to go to the washroom. That's very frustrating as well. (Louise, p.80)

Other studies have suggest that a major factor affecting participation of women with disabilities in leisure activities is time constraint, whereas persons without disabilities do not see it as a major obstacle (GCFAS, 1988; Shaw et al., 1991). According to these findings, time constraints were not necessarily associated with lack of time, rather they were due to time spent planning and carrying out ADL. This involved fitting in with the time schedules of caregivers, transportation providers and programs. Time of day affected energy levels and women often chose leisure with this in mind. Constraints of time affected leisure activities inside and outside the home and this was directly related to the care of their physical needs.

Transportation

Related to the issue of time constraint is transportation since it is seen as a means to get to a destination faster (Zola, 1989). A general lack of transportation was a leisure constraint identified in differing degrees by all of the women. Transportation availability was dependent upon functional ability, budgetary factors, geographic location, and accessibility.

Public transportation was available in all the areas where respondents lived, although it was often not accessible. Buses or taxis were present although women who were unable to walk or climb steps could not use them. Thus, transportation for persons with disabilities tended to be segregated and specialized to meet their needs alone. Even then, segregated transportation did not meet the needs of all of the women.

Segregated transportation was also more expensive because the women had to pay each time they got a ride. There was no bus transfer on buses for the disabled:

> Well, the expense of the bus is no big deal. It's only $1.75 and that's not that expensive, but it can be. It costs me $8.00 for five tickets. It's a pain when you come and go and you have to pay. Like if I go to three places, I have to pay for three places. So it can be expensive when you go all over the city in the bus. (Louise, p.96)

Due to the cost of transportation and limited funds the women were forced to prioritize their leisure choices:

> ...so it's $30.00 a ticket, so it's gone up $3.00 and I use about one and a half tickets a month, so it's about $45.00 a month in transportation, you know....It's (referring to a ticket) twenty trips, so that's 10 trips there and back. And like I go to church every Sunday morning with chair van and I go Wednesday evening for Bible Study. So right there is my twenty (trips) and then some. (Ann, p.15)

Ann also suggested that private interests were problematic for transportation for persons with disabilities; it was not just a service provided for a minority group, it became a money making endeavour:

> I'm sure that the demand is there,...but again, it would probably end up being so costly if it was a profit-making thing, that nobody could go anyway. Not on our (people with disabilities) income, you know. (Ann, p.17)

This reflects an economic approach to disablement where the cost to the service provider is weighed against the benefits to the persons with disabilities.

Even if cost was immaterial, availability was an issue. Much of transportation availability was determined by policies, procedures and scheduling. On the day I interviewed Pam she was waiting for a call from the bus service. Even though she had been told by the bus company that her request for a bus would be confirmed by a 4:00 p.m. that afternoon, her time request was still unconfirmed when I left at 5:00 p.m.

The rigid schedules in transportation, limited leisure spontaneity for these women: "I have to book for a week ahead...if I haven't got a booking by Friday I can't do nothing on weekends" (Louise, p.94). Also, in order to plan outings, accessing buses frequently required anticipating the schedules of other riders. This anticipation of transportation needed limited flexibility. Spontaneity opportunities for leisure activities were consequently limited:

> No. There's not spontaneous buying, there's not spontaneous going out...you have to fit, yeah. Like you have to fit into...(the schedule of the transportation providers.) (Pam, p.5)

While it may be true that there were more flexible modes of transportation for some women (e.g. taxi), they were not available to all the women and they were more expensive. Thus, while there was the possibility of more spontaneity in leisure with alternative transport options given that many of these woman were on low incomes, choices were often limited: "Well I mean, I can get the taxi but that costs too much. That costs about triple what bus fare costs" (Louise, p.94).

Inequities were also apparent according to differing abilities. Ada referred to restrictions placed on the transportation system in her area for persons with differing disabilities: "Recently there's been restrictions on the DARTS register...if they (persons with disabilities) don't use a wheelchair or walker, they can't get on DARTS" (Ada, p.85).

She went on to explain how this decision did not consider the different functional abilities of people: "Well, we have a big problem because Alzheimer's patients can't use the regular taxi. There are people who need dialysis" (Ada, p.85).

There were regulations around what equipment could go on buses and taxis. The type of equipment a person used dictated the transportation options available to her: "They take electric chairs,...they don't take scooters" (Pam, p.24).

In one city, the needs of the persons riding the bus were prioritized so that transportation to and from medical appointments took precedent over leisure activities:

> If someone calls in there on Thursday and has something more important than me going to visit someone, okay, say they have to be at the doctor at a certain time...they can bump me, like they can take my space. (Pam, p.16)

Even activities that were necessary for daily survival, like shopping, whether it be for clothes or for groceries, could be considered 'social':

> J. You were saying about shopping. That's not considered a necessity?
>
> P. Yea. That's not. Shopping period. Any sort of shopping. It's considered...a social thing. (Pam, p.12)

The categorization of social activities as not being a necessity, overlooked the significance of leisure for emotional health: "Therefore, church is considered social, I don't consider it social, because it's a very major bearing on my emotional and spiritual health" (Ann, p.14).

This may suggest a difference between disabled and non-disabled worlds. Persons without disabilities may not consider social activities as being as much of a necessity for their emotional health as the women in this study.

The process of being transported could also be arduous. Ada spoke of the experience of taking a bus trip to the nearest heated pool:

> I found that I was so tired by the time I got dressed and the long bus trip, sometimes we'd stop a lot of places, that the transportation prevented me from the trip...it was such a long trip you know. It wasn't like I could go to the neighbourhood park. (Ada, p.3)

One of the biggest complaints was the lack of transportation between communities. This was a problem for women whose friends lived afar: "I would also like to see the transit...It only goes here. I would like to go out of town to maybe visit (her friend) or something and it won't go out of town" (Renatta, p.57).

The availability of accessible, affordable public transportation was also variable between regions. Ada lived in a different city from the other women but also in a separate region. This facilitated a clear comparison between her transportation experiences and those of the other women.

Ada had a more varied leisure life than the other women. This was in large part due to a relatively new program called a "taxi script" that allowed for more spontaneous riding by persons with disabilities. It was subsidized 25 percent by the provincial government, 25 percent by the municipal government and 50 percent by the riders themselves. This made a relatively inexpensive alternative to the busing system:

> What the taxi script program does, it enables people to get out on the spur of the moment, instead of calling DARTS (busing system for persons with disabilities) system. It (the busing system) takes a few days ahead of time to book it...a taxi script gives you some flexibility. (Ada, p.7)

Ada referred to a woman who found that this program provided her with more dignity by not emphasizing her disability:

> This older woman...did a bridge club that always came to her house because she wouldn't go on the DARTS buses. She didn't think it was dignified, these big, big, buses. She didn't want them to drive up to her friend's house and she just wasn't comfortable getting onto them. So when the taxi script program started, right away she was down here (at the city transportation centre) because this made the trip affordable...so now she takes a taxi to her friend's place so she can go out with these bridge clubs. (Ada, p.13)

Although the program limited the number of books of tickets that a person could buy in a month and was slightly more expensive than the segregated bus system, the taxi system could be economically beneficial for people with disabilities. This depended on their destination:

> If you're going out everyday that's not enough...if the rec centre is close to you, that's good because it would be a short ride. That won't cost much and it might last you a whole month. If the rec centre is far away, then you might use up more of your taxi scripts. It is more expensive than DARTS but if you're close by it's less expensive. (Ada, p.8)

It was also less expensive if a person required assistance because the rider was paying for the use of the whole taxi and not just a seat in it as was the case with the bus: "...the other thing is the taxi...if you're taking your child with you or your partner or friends, the taxi still costs the same where on a DARTS but, you have to pay extra fares" (Ada, p.14-15).

It was suggested that personal transportation (e.g. a car) was the best options, to ensure flexibility, but none of the women owned a vehicle. Only one woman had the use of her parent's vehicle. Louise and her husband owned an unconverted van, which due to the high cost of putting a lift in it was not accessible to her. Funding for such a conversion is not covered through the Ontario Health Insurance Plan. Even if some of the women could drive vehicles, they did not have enough money to adapt them to meet their physical needs: "I would like to have the kind of money I'd need to get myself a van with hand controls and a lift...to have that independence back, because I've had a car" (Ann, p.14).

Physical limitations were also problematic when using cars. This was especially true of those who had very limited upper body strength who also needed to be able to transfer from a wheelchair to the seat of the vehicle and to fold the chair for transporting it in the car: "If I could get into a car, I could go anywhere" (Louise, p.93).

Louise suggested that the less the functional ability, the less likely transportation was available:

> Well, I'll tell you one thing, transportation is the pits. Being disabled, you cannot come and go as you please because you have to depend on transportation. As when you're walking, you just walk. When you want to go into a car you (as someone who is non-disabled) can get into a car. Being disabled, especially when you haven't got movement like I do, like I got nothing. I can't move myself and being in a power chair is even worse because you can't fold a power chair and you just can't go anywhere. You have to depend on the bus. (Louise, p.98)

Being transported in private cars often required the presence of another person. For example, Irene travelled with her husband. She was able to walk to their vehicle, but he helped her into it. For women who were unable to walk, this meant that they had to find someone who was willing to help them into and out of the car. None of the women owned vehicles that were converted to meet their physical needs.

Past research suggests that transportation is a problem for women with disabilities (see DAWN, 1995; GCFAS, 1988). The findings of this study expanded on understanding transportation constraints. In sum, there was no universal transportation system for persons with disabilities. It was often specialized and separate from non-disabled modes of travel. Available transportation did not always mean equitable transportation. Regulations, policies, costs and procedures varied from town to town, city to city and region to region. They were based on cost and convenience for service providers and were not flexible enough to accommodate differing abilities and equipment needs. They were often founded on the biomedical model of disablement which focuses on impairments so that medical appointments took priority over what the women saw as necessary social activities. In addition they reflected handicapping definitions of disability which treated all persons with disabilities as having similar needs.

Unless there was access to personal transportation and the supports that were needed to use it, these women were restricted to leisure activities within their communities or within their own homes. The schedules of transportation providers constrained spontaneity in leisure because they often had to rely on providers in order to participate in leisure outside of the home. This required prior planning which was a problem when leisure options were already limited. The lack of inter-city transportation also affected their social networks to the extent that women with disabilities became isolated from other women in similar situations. This differs from women without disabilities who often transport themselves in private cars.

Environment

Environmental constraints were physical obstacles faced by women with disabilities as they moved within the personal and interpersonal space around them. It also referred to the social environment or setting where leisure activities and programs took place. The environment was an important factor affecting leisure and disability because disabled women often needed extra space to manoeuvre their bodies and/or equipment. Spatial designs were generally constructed around assumptions that certain body postures, positions and strength are normative. For example, Ann pointed out that businesses assume that the vertical position was the norm. Stores are set up to reflect this assumption: "Is it necessary to put a display in the middle of an isle?...Grocery stores aren't a problem for the most part. High shelves, yeah, but then that's kinda hard to avoid" (Ann, p.11).

Even if publicly owned, environmental considerations for differing mobility needs were often neglected. For example, it was seen as important to have accessible pathways for anyone who had difficulty with mobility. Accessibility increased opportunities for leisure activities whether it be walking or going to an activity:

> If you get the streets accessible, then people can walk with their friends in their neighbourhood to the rec centre. If we get the buses accessible, we need to have (the sidewalk between) home and the bus stop accessible. (Ada, p.37-38)

Ann talked about the dangers of riding her scooter to the local shopping mall afforded by the curbs and sidewalks she has to negotiate:

> But now if I don't see it (referring to traffic) it doesn't scare me as bad. So I just go with my back to traffic. But then I get down to (name of a road) and there is a ramp sidewalk, so I get on that ramp sidewalk, go all the way down to the muffler place and there is a curb. There is no way for me to get off that ramp sidewalk. So they make a lot of sense. Ramp it at one end. (Ann, p.62)

Also, the surface on which the women rode and walked affected their pursuit of leisure activities. Pam talked about the importance of the surface on which she walked due to her balance: "Being on a stone driveway wouldn't be good at all (and) walking on the grass isn't good because...grass has bumps in it" (Pam, p.1).

Ann's love for her dog led to an opportunity to train dogs for persons with disabilities. Her involvement, though, was dependent upon the accessibility of the training area: "Oh, I'm more than willing (to train the dogs) as long as where she (the trainer) trains them is accessible" (Ann, p.52).

Aspects of accessibility not addressed by legislation also restricted leisure opportunities. For example, inaccessible homes of friends and family affected the ability to visit for leisure:

> I could get the bus, but I can't go visit anybody because they aren't accessible. My family...well, I used to go and visit. It makes me think sometimes, and I know it's not that way, it makes me think 'Do they really like me coming to visit?' Cuz now I can't go visit and they're not doing nothing about it...(Louise, p.95)

It is important for persons with disabilities to have physical access in and out of their homes because this means they could spend more time in community activities (Zola, 1989). This is important since persons with disabilities are often disconnected from their communities and from opportunities to build relationships with non-disabled persons (Hutchinson and McGill, 1992).

Leisure activities outside the home depended heavily on organizations. Most of the segregated leisure activities were linked with organizations such as Centres for Independent Living, DisAbled Women's Network, Multiple Sclerosis Society and March of Dimes. For Ann, much of her leisure activity was associated with her church. For example, she occasionally played her accordion at the church:

> ...(the) Pastor this year...asked me if I would do a song for the Christmas program. And I said 'I haven't played since I was like twelve years old.' and I said 'I don't have an instrument' you know. So another fellow from the church said 'Oh, I've got one you can use.' And I said 'That's cuz you Polish (laugh). So anyway, I did it. (Ann, p.32)

Ann warned, though, that these settings were only useful in leisure pursuits if they had the resources to meet her physical needs: "I'd love to be in the choir but I can't get up on the stage, so that's out of the question" (Ann, p.57).

The understanding of organizers in such settings was important too:

> I'm going to have a little chat with him (the pastor) about this one day cuz ah, you know, there's gotta be a lot of areas that can be used and I just have a feeling like he's fairly new Pastor, and I think that he's trying to kinda do everything himself. It's not even (a) delegating (problem), it's who wants to be in control I think. But, I think he needs to understand that we have needs to be met and we could do that if he'll allow us. (Ann, p.57)

In the Government of Canada Fitness Survey (1988) the ability for program leaders and organizers to adapt programs according to individual needs is a limiting factor to the participation of women with disabilities in physical activities.

Leisure activities were sometimes combined with the activities of other minority groups such as the elderly. Carol had done wheelchair dancing at a seniors centre and had lots of fun. She has not gone for a while because mainly seniors were at the dancing: "I feel out of place with everyone being older. A lot of older people stay to themselves" (Carol, p.109).

This type of combination, while recognizing similarities between the elderly and persons with disabilities and the specialized attention that must be given to their bodies, ignores individual preferences. This gives the impression that these groups have homogeneous needs which are based on health care needs alone.

Segregated programs for persons with disabilities often included all age groups making it difficult to develop peer relationships. Renatta's mother referred to this problem for her daughter:

> Well, that was the only time when they (an organization for persons with disabilities) invited her (Renatta) to this get-together and these people were all senior citizens except for two or three. (Renatta, p.56)

The women expressed positive and negative feelings toward segregated settings for leisure pursuits. For example, Debbie stated that sport programs for the disabled were not always equitable since they too were built upon a hierarchical system like non-disabled sport model:

> Well, there again you have a classification system where every disability has a classification system. And those classification systems would be so wide ranging that I could be, yes, running against someone who was a CP 6 but, much more capable of doing those things than I was. (Debbie, p.17)

Segregated sport programs placed persons with disabilities in special categories, setting them apart from other non-disabled athletes due to their perceived lack of physical capabilities:

> ...it's because at all the sporting events for the disabled, you've got the cameras...And it's all on the six o'clock news and this is wonderful. And all these needy, pathetic, wonderful people who are now finally achieving something (said sarcastically) and it's just so interwoven...I think that's where it comes from, that systemic oppression. 'If they can't do anything else, at least they're good at something.' (Debbie, p.19)

Some programs were more inclusive than others and provided the opportunities for increased activity, travel, and meeting disabled and non-disabled people. Debbie referred to a sports facility that specifically catered to persons with disabilities:

> Then when I was fourteen I joined (name of facility)...it had able-bodied members as well. I used go in there and run track and various different things. And, of course, I joined a team in (name of city). It was people in chairs and people ambulatory like myself...and I went to a national league when I was

> fifteen in England and I competed in swimming and did a little rugby for Canada. (Debbie, p.16)

The social setting in which the women lived often affected leisure options. Renatta suggested that in a larger city she had access to a more inclusive type of community centre that met many of her needs. Renatta and her mother explained:

> M. There were all kinds of people. Not only handicapped but regular people. It's all mixed in. It's wonderful. They had a wonderful pool and you could go anytime, day or night, and swim to your heart's content and not say 'Hey in forty-five minutes you've got to get out of here.'...And the programs that are run there are just fantastic...
>
> R. ...They had things there for my mom too. So she would leave me to have my fun and I would leave her to have her fun. So it was great. (Renatta, p.63-64)

Community recreation centres were often too rigid in their scheduling, costly, and did not include persons with disabilities. Renatta experienced this at her local YMCA:

> M. They are so restricted, so limited, and they have actually nothing...What do they do? They have people go in there to have exercise classes to lose weight. They have a day-care centre...They have the pool for an hour for every group that comes in. What else do they have? Zero.
>
> R. They (the Y) have zero for me except for the pool but the pool timing is not long enough...the membership (fee) is phenomenal. (Renatta, p.65-66)

Even within larger cities, recreation centres accessible to persons with disabilities were often far apart or not on major transportation routes:

> One of the problems with scattered sites, is accessibility...I think having (recreational) sites scattered is a good idea because you're playing with your neighbourhood kids. It's just the accessibility...normal kids (can) walk to the site...if the neighbourhood isn't accessible...people with disabilities (can only) go to...three or four larger recreation centre in their (city) that are accessible. But then they have to get the transportation to get there. (Ada, p.71)

Also, the composition of a community and whether or not the means of transportation was accessible, affected availability of leisure programs. For example, Ada lived in the large city with major centres for health and rehabilitation care. If there was an increase in the number of people using these services, planners for transportation and recreation had to be more innovative:

> J. The reasons why there is an increase in demand?
>
> A. Age of the population, and the people that are already on the service are aging and their demands are increasing because of this. There's rehab centres here (in her city) so you get people from (names of other regions)...Part of their rehab is to get out into the community, get on our services and a lot of times they see that they can have the freedom of travel and other things...in our area. They sometimes stay. (Ada, p.10)

The disabled body itself often required more physical space when taking part in leisure. For example, Debbie talked about her need for non-disabled team mates to respect her need for space for her to be comfortable during a game situation:

> It's like, I say to people 'Just don't get too close to me.'...It's not that I don't like to be touched but I need the space for assurance that you're not going to knock me right on my can. (Debbie, p.6)

Equipment often took up more physical space than the body. It required more space for mobility. This left even less space for the women to move in: "The wheelchair seems to be so much bigger than the human body" (Carol, p.111).

The spatial needs of the body were affected by the type of activity the women were involved in. Some activities were easier due to their nature. Ada referred to canoeing as an activity which was conducive to her physical needs: "Otherwise, it's really quite a smooth motion, like swimming or bicycling and you can rest when you want. And I love canoeing" (Ada, p.32). Renatta referred to the therapeutic qualities of the pool: "I love the pool. I love the water. It's very therapeutic plus it's very relieving. I relax in the water plus I love the water in general" (Renatta, p.62).

There were often aspects of the physical environment that were beyond the control of decision-makers and/or the person with the disability. These included the issues surrounding the weather. The women were able to get outside more during the summer. Being able to get out and about also brought more independence: "That's why I like the summer a lot better because I can just go" (Pam, p.81).

Winter weather often affected their physical bodies. Ada referred to using her scooter in the winter and how the length of exposure to the winter temperatures affected her: "It was a long way. It would take me about twenty to twenty-five minutes. But in cold weather I'm not supposed to have much cold weather. It affects me terribly" (Ada, p.18-19).

Snow and ice made walking difficult. Debbie addressed the problem of balance and how she envied those with CP who have more balance: "You know, I can just imagine winter, being a CP 7 or 8 being out there on the ice. Not having such a difficult time standing up (laugh and pause)" (Debbie, p.5).

This in turn directly affected leisure involvement. For example Ann could not get out with her dog in the winter: "I wish I could get out more just to take the dog for a run or something like this because she needs the exercise for one thing and I can't get out in the snow to take her" (Ann, p.47).

Women with disabilities expressed a need for an environment that accommodated equipment and the movement of their bodies, but policies, both private and public, placed restrictions on the environment. Leisure programs were often inflexible and combined people from all age cohorts and types of impairments and functional abilities. As a result, individual preferences were ignored in exchange for more therapeutically and economically informed programs. More inclusive programs were available in larger cities and provided more opportunities for meeting people, but recreation centres within larger cities were often few and far between. Also, composition of cities affected whether or not leisure activities outside the home for persons with disabilities were supported by the community in which the women lived. Outside of the social environment was the physical environment which had an impact on leisure pursuits as well (e.g. weather, terrain). They could make leisure inaccessible and unavailable.

Equipment, Gadgets and Gismos

Equipment was defined as any device that helped the women to be more independent and increased their functional ability. This equipment was sometimes specifically made and sometimes adapted to meet the needs of the individual. Other pieces of equipment were devices that could be used by any person but they were often used differently to meet a specific functional need of a woman.

Equipment had social and physical ramifications. It could be physically beneficial, ameliorating the effects that impairments had on the body: "The modern technology has helped a lot and the mouse is easy to use. And this (referring to the lift in her chair) helps with the pain" (Ada, p.21).

Wheelchairs enabled the women to be more mobile by maintaining the strength they had in other body parts. For example, Carol needed it for upper body strength which she used for transferring during ADL and subsequently activities associated with leisure: "I don't want an electric wheelchair because a manual wheelchair keeps my arms strong so I can get on the toilet or in bed" (Carol, p.111). Equipment also helped with basic functions:

> ...A wheelchair is good, but if you go in shopping or anything I can't carry parcels and move too, and wheel the wheelchair. I could have an electric chair

> but it would be like a little easier because then I would have one free hand where I can hold the stuff and do things. (Pam, p. 3)

It also had the opposite effect since a wheelchair can be both difficult to manoeuvre and energy sapping: "It's not a normal thing to be sitting all the time. I think it's hard on the body" (Carol, p.108).

Equipment also affected daily choices. Pam had to plan her shopping trips around the limits of her scooter:

> ...you have a grocery cart and you can put quite a bit of stuff in that...now the other night I went over to (name of a grocery store)...that's connected to (name of another store), I went into (the latter store), and I got my laundry soap, and fabric softener and...bath stuff and that, and holding the basket (in the scooter). I already had quite a few things, so then from there I had to go into the (first store). Well, I couldn't get all the groceries I wanted to get out of (first store) because my basket was full. (Pam, p.4-5)

Equipment was also seen as dehumanizing. Some women felt that they 'became' the chair to people: "I try to be normal but the wheelchair gets in the way. It's part of me. I don't like the way it looks" (Carol, p.112).

Equipment that helped mobility could not always be accommodated in certain situations and this, too, was dehumanizing. Ada explained how uncomfortable it was to have to use the lift on a special bus because it made her stand apart and be seen as separate:

> A. It's so humiliating (referring to going on a bus with a lift).
>
> J. How does that make you feel?
>
> A. Centred out. Up in the air. Exposed. (Ada, p.26-27)

Physical ability affected ability to use equipment and therefore some of the women required assistance. For Annette, the television was a piece of equipment that required help:

> The other time the T.V. was on and I thought they (the attendants) were coming between eight and eleven-thirty. Nobody came. The T.V. was on all night. And there was no control. The remote control wouldn't work. (Annette, p.20)

Also, some equipment was not very portable and limited mobility in other ways: "Being in a power chair is even worse because you can't fold a power chair...and you just can't go anywhere" (Louise, p.98).

If assistance was required to use equipment for leisure, choices were limited. Renatta's mother compared Renatta's ability to go out with that of non-disabled persons:

> They (kids with disabilities) can't get up and put on their coats and say 'Let's go to the bar.' Well it's not just, 'Come on let's put on your coat and go to the bar and have a drink.' It's to get her up into the wheelchair, get her dressed. Somebody has to lift her into the car and lift her out of the car, get her there. (Renatta, p.34)

Several of the women felt that the equipment they needed in order to carry out activities affected the important process of friendship building:

> ...who would want to fold up my wheelchair and help me in the car...A lot of friends want to go out and party and to the bar and they want men and don't want to take a wheelchair into a bar. It will scare the men. (Carol, p.111)

Equipment was not always specialized. Sometimes an everyday device was particularly useful to a person with a disability. Ada also used gadgets so that she could canoe:

> I got knee pads and I got this (thing) to go around my waist to support me, and a neck brace. And wrist brace. You should see me canoe. I look like I'm wearing armor. But that's what I need in order to be able to paddle. (Ada, p.32)

The telephone was also seen as an important piece of equipment as it provided an important link to the outside world. I found that the telephone often rang during the conversations. Respondents frequently talked about the different features of their telephones. Telephones with number display and speaker phones were among the features

I heard about during our conversations. It was a means of keeping in touch with other friends in the disabled community when they were unable to physically visit with them. Carol talked about a friend who lived in the same city and how the telephone facilitated their friendship. She talked to that friend almost daily until she moved away and long distance changes became prohibitive.

Ann, however, said that even though the telephone was her only medium of social interaction, it was not the same as personal contact:

> ...sometimes three or four days go by where I don't have 'people' interactions. Phone, Yea...But, I'm not really a phone person, not one who likes to just sit and chat on the phone...I like to see the person I'm talking to. (Ann, p.45)

The telephone was also an important safety device: "This is 24 hour care. So I've got a number I can call, if I need somebody during the night" (Annette, p.20).

Television was seen as having therapeutic value. Louise found some programs on the television to be a useful source of information:

> Well some people get uptight. They say you know how some people really react to the soap operas and we think it's real and stuff like that. Well, at the time it's real, but when it's off, it's off...to me the soap operas help my life. I've learned a lot by watching a soap opera. (Louise, p.89)

Videos were also used by five of the women as a leisure activity. All but one of these women spent most of their time in their homes. Louise missed her VCR. She sold her VCR when she was hospitalized and does not have the funds to purchase another one:

> Leisure for me was my VCR. I used to tape movies and I used to take the commercials out. I'd get another VCR, I'd borrow my girlfriend's and I'd spend a day taking the commercials out of the movies that I taped. Or I'd rent movies and put them on a tape. (Louise, p.89)

In sum, equipment could make activities easier physically and could help maintain physical ability. The use of equipment could also tax limited energy resources as well as access to certain leisure environments. Equipment could be dehumanizing so that people became defined by the piece of equipment they used rather than as the person in control of the equipment. The assistance of other people, and portability of equipment limited the leisure choices both inside and outside of the home. Since there was a decrease in one-to-one social interaction with friends overtime, for most of the women, the telephone, television and VCR proved to be important pieces of social equipment.

Caregivers, Friendships and Relationships

Women with disabilities often struggled with issues of dependence and independence. Although they strived for independence, they often needed assistance with their physical needs. Depending on others for activities of daily living often meant foregoing leisure activities and working within caregivers' schedules.

This relationship involved concern for the comfort of caregivers. When Carol was remodelling her home to make it more accessible for herself, she took into consideration the comfort level of her husband and daughter. In compromising, not everything, like the components needed to make coffee, were accessible to all family members.

Paradoxically, dependence on caregivers often meant more independence. For Carol, being able to live at home gave her independence because she had someone to take her out: "If I wasn't married I couldn't be in this house because I'd be here alone" (Carol, p.112).

Louise mentioned her concern for caregivers who were not family members a number of times. She felt that since they were an integral part of her life, and they must share the same environment with her for extended periods of time, there needed to be a balancing of needs in order to accommodate the needs of both parties:

> I mean you've got to think, you're having a caregiver but you've got to be comfortable with that caregiver. The caregiver...you've got to think of their health...like them hurting their backs. Or if they are standing too long you've got to make things easier...you're not thinking of just you. (Louise, p.84)

For Louise, the Supportive Living Unit (SLU) program gave her the best of both worlds: and she addressed this when she described the SLU program:

> ...It's an apartment where you live in your own place. You live in your own apartment but if you need somebody for anything...an attendant is here all the time to help you with what needs to be done. (Louise, p.71)

There were no clear preferences for participating with disabled or non-disabled persons in leisure activities. This finding is consistent with the findings of the Canadian Government survey (1988) which suggest that women with disabilities have a flexible attitude toward leisure activity. Some women preferred to be with other persons with disabilities. Pam explained that she liked segregated leisure activities run by organizations and people who have an interest in the disabled. They helped to make her leisure experience enjoyable by removing some of the obstacles to involvement:

> On a tour...It's always 35-40 people that are going. So you're getting to go to places like that (Canada's Wonderland) say for like $35 which includes everything. Like that includes any attendant services you might need. Anything...There was people always willing to help...they always have the attendant people. (Pam, p.62-63)

Pam liked being with this group because the people in the group were disabled too:

> I'm comfortable. I find comfort in that because, you're lucky you're with disabled people and you're with people you know don't mind helping you...And whereas if you're with people (those who don't want to be there)...you're not really sure if they're just there because you want them to be there. (Pam, p.65)

Others, like Louise, wanted to be with non-disabled persons so as not to be separated from the non-disabled community and to maintain her former non-disabled identity:

> Well, my problem is, okay I'm disabled but I don't want to be around disabilities all the time. Because, to me if I'm around people who are disabled constantly, I'm gonna think of myself as being disabled. Okay, I have a disability but I have friends that are walking and they're not in wheelchairs and I'd like to be surrounded by them just as well as being surrounded by people with disabilities. That's just the way I feel. (Louise, p.73)

The physical ability of people who helped these women in leisure activities was less of an issue than the desire for the activity itself. This was evident with Ada who recognized the importance of leisure to one's social life. She explained that she went to aerobics classes for the exercises she physically needed. Even though they were physically difficult to carry out due to a medication she was on, she was motivated by other members in the class:

> ...they (her peers) watch you, and I think that might be the difference, I'm doing it with people I like. And that's what recreation is. But when you have to do it on your own, it's exercise. (Ada, p.13)

At the same time she scouted out activities that fit her desires and physical abilities. The social component became an added feature. For example, she took part in a canoe trip run by an organization that mainly serviced persons without disabilities. To expand this service to include persons with disabilities they worked in conjunction with a service organization for persons with disabilities. Therefore the program was not specialized, but the needed help was available:

> A. I went on a camping trip.
>
> J. Now was this a specialized camping trip or just a group of you that wanted to go?
>
> A. Well, I'll tell you what it is. It fulfilled my criteria. It wasn't a special camp. (Ada, p.27)

This trip was a collaboration between an organization that serviced persons with disabilities and one that traditionally serviced non-disabled persons:

> (It's) an integrated disabled and non-disabled canoe trip...It's with a regular company...the March of Dimes and this travel company (The Canadian Wilderness Trips) got together and decided 'let's see what we can do with it.' (Ada, p.27)

That there were both persons with and without disabilities involved in this canoe trip made it possible for it to be inclusive for persons with disabilities. At the same time, Ada expressed some concern that the non-disabled persons on the trip were present more as caregivers then as peers. This concern could be problematic.

Friendships were important to the women I spoke with, although the type of relationship depended on the basis upon which it was built. There was a distinction made between peers as friends and friendships with professionals and volunteers in their lives. Several of the women cherished friendships with professionals and/or volunteers over the years:

> Tanya was a physiotherapist at the (rehabilitation centre for children) and she was very good at what she did. And she cared and that was the big difference, she cared. It wasn't just a job. (Renatta, p.31)

Annette referred to a volunteer who she felt went beyond the call and duty: "She helps me with banking. Things like that. She, I gave her my money I got back from the Income Tax and she's putting it in the bank" (Annette, p.11).

The problem with these friendships were that they were temporary because professionals sometimes moved on in their lives and careers. Renatta remembered a physiotherapist who socialized with her as a friend:

> She would talk and knit and just general conversation. She was very good for Renatta until she moved to Toronto. For a while she wrote letters and kept in touch and then we just lost touch. (Renatta's mother, p.31)

Also, because of the underlying nature of professional relationships, there was sometimes a sense that it was emotionally difficult when caregivers moved on or do not want to build friendships:

> Sometimes when you work with someone on a professional basis..., you connect with someone not on that professional basis because you're able to look beyond...I'm able to look beyond and find the individual...Because of who I am

> and what I do, I have to find the person before I can trust them with the most intimate things or the things on my mind...But it's really very difficult because I know this person as a professional, but I also know them personally and how can they turn their backs. (Debbie, p.27-28)

Ada suggested that there were problems with having volunteers as friends because there was uncertainty in this type of relationship. Ada referred to a man in her apartment building who depended on his volunteers and becomes friends with them:

> He needs a volunteer to help him do the archery, you know, pick up things...but he does it (plays archery). But he said to me a little while ago that he's gotta be very careful about making friends with the volunteers because he gets hurt. The volunteer stops being a volunteer. I mean friends do that too, but at least you can argue with friends...The volunteer, it's a different relationship, not a friend friend relationship. (Ada, p.54)

Friendships with peers seemed to be very important relationships because of shared interests:

> I met a woman called (name). We became good friends. We went out a lot to shows, bowling, dinners and plays. Our favourite thing to do was go to the park, lock all the car doors, and talk for hours and hours until one or two in the morning. (Irene, p.4)

The most important aspect of friendships and leisure activities was trust. Debbie explained the importance of going out with someone you know:

> Like for instance, when I go to a bar, I always make sure that I know the people very well and that they know when I need an escort to the washroom. I'm just asking to hang onto them to help me through the crowd. And the different ways that we have to make it through the crowd is often kind of funny. Often times I'll say 'Well, you walk ahead and I'll take hold of your torso here and we'll walk through.' But, I'm okay with the fact that I can't always do different things with the body but they've got to know that that is what I need. So, I can't show up at a bar and be with a bunch of people that I don't really know or trust. (Debbie, p.11)

Reciprocity was an important aspect in a meaningful relationship for these women. It was important that relationships be non-obligatory. The best friendships were those that involved give and take for all parties involved:

> ...you can't have a normal relationship until you're friends first and then friends help each other. And she'd (referring to a woman who was looking for a friend) have to find some way that she can help the other person too. She's gotta think about what is my part in this? (Ada, p.55)

Ada gave an example of how she contributed to a relationship on her canoeing trip: "On that canoe trip, I couldn't do a lot of lifting, but what I could do, like I knew the stars...You've gotta dig sometimes for your talents" (Ada, p.56).

It was important that expectations not be excessive. Carol referred to having friends visit and what made it relaxing: "Having someone else present is relaxing especially if it is someone who is not expecting to be waited on, like making coffee. It is important that I know I don't have to wait on them" (Carol, p.108).

Friends also needed to be able to accept the physical limitations of these women and recognize that they may be required to assist them. This meant a certain level of understanding on the part of friends, particularly non-disabled friends, who may need to do physical work in the friendship.

Most of the women revealed no preference concerning the physical ability of friends as long as they had similar interests. For Renatta, it was helpful to have non-disabled friends for her physical needs, but it was just as important to have similar interests:

> ...I want to go out with more people ya know. Like people my age range. You know the person you have for your children (referring to my respite worker), now I would love to spend a week with her...she just fits me like a glove. She looks like she would fit me like Diane did. And we would have a lot in common because she likes to go out and party and do all these other things. Somebody like her is what I'm looking for on a social level. (Renatta, p.34)

A number of the women felt that it was difficult to meet peers. Renatta's mother wondered where she could find other people with disabilities that were Renatta's age:

> I'd like to know where all these people are on a social level. There are lots of handicapped boys and girls in the same situation as Renatta. The same age. Where are they? We certainly don't know any. (Renatta's mother, p.34)

The logistical reality of socializing and the desire to do so were problematic. Three of the women expressed the desire to date but meeting people was difficult. A number of women stated that there was no place to go to meet others. Renatta expressed her desire to date and eventually marry while her mother expressed the concern about places to meet partners: "Where do you meet people that have something in common with her in a wheelchair? On the same level? Where does she meet a nice boy" (Renatta's mother, p.29).

Annette suggested that it was not only lack of opportunity to meet potential partners, it was also perceptions of disability: "Nobody wants to go with anybody who's disabled."

Almost all of the women desired to be seen as a person first. This desire is also reiterated in other research (See DAWN, 1995; Frank, 1988). They did not view themselves as much different from others. Debbie felt that person with disabilities, given their low social status, were placed in the position where people felt pity and animosity:

> ...And we're (people with disabilities) always gonna be seen, I always think of it as we're sort of one rung below single mothers...Just draining the system. 'These poor pathetic', and I put down in quotations, 'disabled people'. I don't think of myself as...well I am poor, but I'm not pathetic (we laugh). (Debbie, p.8)

Also, along with the desire to date comes the fear of pity and aggression:

> The dates were just like, 'I feel sorry for you'...Of course you always have to deal with those over aggressive people. I mean you want to go out on a date and you want to feel something for someone but often times that's misunderstood. You know you get in positions where you're not wanting things to happen but they are and you're saying 'Hold on a minute'. (Debbie, p.14)

The desire for interdependence in relationships with friends was affected by dependence on caregivers, meaning the women wanted to have friendships that were based on reciprocity of sharing of needs and interests. Renatta depended on her mother to take her to leisure activities and this affected her independence:

> J. So you don't have any transportation there.
>
> R. No, unless she drives me...on the other hand I don't want her to drive me all over town. If I can get somewhere myself then I'll get somewhere myself but right now there is nothing. (Renatta, p.58)

Social isolation was a major issue for a number of these women, because of where they resided and limited financial and transportation resources. Renatta's mother felt that she was isolated from her peers because she lived at home. Renatta's mother compared Renatta with three of her friends who did not live at home:

> They seem to have friends...the three that I'm thinking of all happen to be in group homes. So they make friends...Renatta lives in the home with her parents so she's isolated. (Renatta, p.35)

Ann also talked about the isolating effect of living on her own:

> You find that there are a lot of days that seem to go by when you almost don't feel anything. It's like you want to shut everything out cuz there's nothing out there for you. I don't know if that makes any sense to you or not. (Ann, p.44)

The women in the study desired independence but their physical needs often required some degree of dependence on others for ADL and leisure activities. This need for assistance often meant concern for the comfort of their caregivers often at the expense of their own comfort. In a related case study, Frank (1988) found that much importance was placed on independence by women with disabilities and the desire not to have to wait around for the help of others.

Friendships were important to the women but those friendships with professionals and volunteers differed from those with peers. Professionals and volunteers were often temporary and filled with uncertainty of commitment. The latter type of friendship was based on shared interests, understanding, trust and reciprocity. Friends and family were often helpful with physical and financial needs.

The women cited benefits to participating in leisure with both disabled and non-disabled persons, but their available choices to participate depended more upon the activity itself than on the other people involved in the activities.

In sum, opportunities to build relationships were constrained by the fact that many of these women lived in isolation. Their relationships often revolved around care. They were unable to get out into the social environment due to lack of transportation, program availability, accessibility, and funds. Moreover, except for one woman, they were all unemployed and lacked the opportunity to meet people in the working environment.

Funding and Policy Options

All the previous constraints had one thing in common. They were all affected by economic constraints and policy restrictions to some degree. This section will address the implications of low incomes, funding options and policies that regulate the physical and social environment, transportation, and time schedules.

Whereas past studies recognize that leisure for persons with disabilities is affected by economics (see Mastro et al., 1988), this study reveals reasons for this. Part of the reason these women did not have access to leisure opportunities was because they lived on limited incomes. Only one woman did not discuss economic restraints, perhaps because she had a husband with full time employment to help support her needs.

Often the women were on disability pensions through Family Benefits and/or Canada Pension Plan. These pensions gave them fixed incomes in the sense that there was a maximum amount of money they could receive each month before their pensions were decreased. This amount was minimal. Pam explained the difficulty of dealing with a limited income:

J. Well, you pay your rent, cable, phone, hydro, Visa and Sears and all you have left...is $86.20 a month, that's for food...

P. Yep. I think that's what I got.

J. ...that's for clothing, that's for transportation, you're not even including up here your transportation.

P. No.

J. So you have to take that out of that too?

P. Ummhmm

J. There is nothing left.

P. No, there is not.

J. I can see why there's nothing for leisure. And your transportation can run you more than what you're telling me, your $27.00...

P. Yep...usually a card (for transportation) lasts a month. (Pam, p.19)

One woman said that due to her poor economic position, friends where a vital component of her survival: "It's not easy. Some months if it wasn't for my friends and church family, things like that, I don't think I'd be able to survive" (Ann, p.13).

Lack of funds meant that even the simplest leisure pleasures could not be accessed. For example, Louise said soaking in a hot tub would be leisure for her but she did not have the funds to purchase an appropriate lift:

> With the commode I can't have a tub because there is not a lift that can get me in the tub unless I get the track that goes over the tub. That's expensive. It can be done. Like I can get it done in here but it's expensive. It costs money. I don't have it. But I really miss that (soaking in a tub). (Louise, p.87)

Limited incomes also affected access to equipment that would increase mobility for leisure pursuits. Irene and her husband owned an unconverted van. Due to the high cost of installing a lift, they did not have an accessible van. Funding for such a conversion is not covered through the Ontario Health Insurance Plan. Even if some of them could drive a vehicle, they did not have enough money to adapt it to meet their physical needs: "I would like to have the kind of money I'd need to get myself a van with hand controls and a lift...to have that independence back, because I've had a car" (Ann, p.14).

The majority of the women were unemployed and those who were employed only worked part-time. This meant they had no health benefits beyond those provided by the Ontario Health Insurance Plan which is restrictive in what it covered. Although Ada liked her job because it had flexible hours to meet her physical needs, it did not necessarily meet her long term financial needs: "I just get paid by the hours I work. I don't get any benefits or anything which is a downside" (Ada, p.18).

Due to the fact that all the women were dependent on some amount of financial assistance from the government in order to live, the government controlled the decisions regarding how much money they would receive and what they were to spend that money on. They decided what equipment, transportation and environmental needs would be publicly funded.

Ann argued that those who controlled her financial situation defined the parameters of leisure for her. She referred to how budget cuts to services made by the present provincial government affected leisure in her life because it neglected to recognize the important role it played in her life:

J. Do you see your social activities as part of your necessities?

A. Oh yes. Definitely...I wrote a letter to Harris back when they were doing this (making cuts) saying that the things that they (the conservative government) consider social, I don't. Like I said, my church for instance wouldn't be considered social, 'cuz their idea of necessary is work, education, medical. (Ann, p.14)

The women expressed concern over the low value that was placed on their needs by both public and private funding sectors. Debbie suggested that decisions to adapt and develop social and physical environments that met the physical needs of persons with disabilities were based on a cost/benefit analysis where cost to society versus the benefit to persons with disabilities:

> It's a whole sort of scenario. If one person is in a wheelchair do you widen the hallway because it needs widening? You say 'Well, yes you do.' But then it's money or 'It's just one person' or whatever... (Debbie, p.8)

Decisions to fund recreational programs were based on perceptions of what was considered important and necessary for persons with disabilities especially if an activity was already available in the community:

> In some things, funding is a major issue, you know. It's like with the ping pong, for instance. Nobody will fund something that is already available in the community. But, what's available is not accessible. (Ann, p.59)

The respondents also perceived that segregated programs were first hit by cutbacks in public funding: "I do not do too much anymore at the senior centre because of funding cuts. There are not as many activities available" (Carol, p.108).

Even when the women were able to access more inclusive leisure environments, they were often costly. Renatta expressed this as one of her concerns regarding her local YMCA: "The membership (fee) there is phenomenal" (Renatta, p.66).

Government subsidies to transportation companies also influenced leisure options by affecting the fares charged to users. Partial funding by the provincial and municipal government for transportation needs of persons with disabilities had the potential to be beneficial. For example, taxi scripts provided the opportunity for more spontaneous and often less expensive transportation depending on where the passengers were going and how many would be riding in the taxi. It also provided a less segregated transportation option for people with disabilities, eliminating some of the dehumanizing aspects of segregated transportation. The problem with this program was that it depended mainly upon governmental grants for its operation and therefore was not necessarily a permanently provided service. It was vulnerable to funding cuts on a regular basis.

When considering other modes of transportation available to the women some expressed concern about the effects of funding cuts to the bus systems. Others felt that even if there were no cuts there were also no increases: "The province is giving the exact same amount so they can say, 'Hey we haven't reduced it but, with the increased demands, the costs goes up of course'" (Ada, p.7-9).

Government and private funding policies for specialized equipment affected mobility because of their limitations and inflexibility. Pam pointed out that regulations surrounding the Assistive Devices Program through the Ministry of Health did not allow her to have a scooter and an electric wheelchair:

> Now if I get Assistive Devices I have to trade my scooter in because the lady that's in charge of that, now she said that I should have thought of it before I got my scooter. Like I shouldn't have got them to fund me for a scooter, because I knew they (scooters) weren't allowed on the chair van. So, even though I would really wanna keep it (scooter) for the summer that's my problem, not their's. (Pam, p.56)

In order for Pam to have both pieces of equipment she had to wait another three years for possible funding from Assistive Devices.

Private insurance companies were another funding option but they frequently required prior payment which was difficult for women with low incomes. Pam could not get the walker she felt would be best for her mobility needs:

P. ...even though my insurance will pay for it, you still have to come up with the money for it up front.

J. So...you had to get the cheaper one, because how else would you come up with the money up front?

> P. ...like it's always been like a game...Like it boils down to what they consider is a necessity for your life. Well, how do they know. Your life is your life, not their life. They're telling me I don't need this stuff. (Pam, p.59)

Recoverable costs for equipment were sometimes partial. For example, the pump that was required to keep the fluid off of Ann's legs was covered by Home Care but the stockings that she needed to help prevent fluid build-up were not:

> And I have to get that (elastic stockings) cuz as soon as you take the pump off (and) you put your leg down, you've kinda undone any good it does because the fluid's going to start going back into your leg again....they cost $24.00 a pair...nobody wants to pay for this. I asked Home Care. Home Care was willing to pay $150.00 a month for two months to rent the pump; $300.00. But they won't pay $24.00 for the stockings. Like where is the sense to any of this? (Ann, p.66)

Carol felt that decisions based on costs and benefits by public and private sectors reflected an internalized ideology. She interpreted a case in western Canada in which a father murdered his disabled daughter as an example of the low value placed on persons with disabilities and how economic costs to care for persons with disabilities affected perceptions. Her own family members reflected this attitude:

> If he (Mr. Latimer who killed his disabled daughter) couldn't accept his own daughter...Can you imagine what society thinks of disabled people. They must think 'You cost too much money. You shouldn't even be here. We should send you to Mars.' I know that's what they think. My own sister even says that's why our taxes go up 'because of you guys'. Even if she's just kidding she shouldn't say that. (Carol, p.110-111)

This suggests that decisions to fund leisure activities for persons with disabilities hinged on economic decisions. Crawford (1989) referred to this problem of funding dollars as being the result of biomedical approaches to disablement where funding dollars were more likely to be given to programs that had a rehabilitative component associated with them. Under this approach to disablement, leisure activities are seen as necessary mainly because they were possible avenues for making persons with disabilities employable and therefore less costly to society in general.

Non-existent or inappropriate policies were partially explained by economic considerations but they were also affected by the lack of sensitivity on the part of those formulating them. Policies and regulations regarding transportation, scheduling, the environment, equipment and caregiving were often written from the perspective of people who were non-disabled. This often resulted in the treatment of persons with disabilities as a homogeneous group.

Much of transportation availability was determined by policies, procedures and scheduling. For example, pick-up and drop-off locations and times for persons with disabilities infrequently met their needs:

> ...they've (the bus company) has come out with this rule that they will wait three minutes for you and I've been...over at the (shopping mall)...and I've been real close, I could see the bus outside. And I don't know how long he had been there, but I knew I was late...and like, I mean I'm talking two, three maybe four minutes late, and I'm not like real late...but I've seen the bus and I've been right there, just as they pulled away. (Pam, p.12)

Policies and procedures governing the extension and restriction of space within leisure environments reinforced non-disabled norms regarding the body:

> When I used to go to (name of mall), when they had the grocery store there, you used to be able to go into the grocery store, no problem. Well, then they got so they didn't want to be losing their carts all the time, people were taking their carts out into the mall and not bringing them back, so they put this fence up, all of a sudden you couldn't get through...And they had a chain part and they said 'Well you know, all you have to do is get someone to unlock the chain for you, they could do it.' The people that had the key were behind the deli. That's fine when somebody's there. (Ann, p.11)

Renatta had a similar experience in a video store. Her mother explained the difficulty in getting a membership for Renatta:

> Jumbo Video. She (Renatta) wanted a card...And she (the woman at the counter) says 'No you can't have one because you don't have a valid driver's license, you don't drive and you are in a wheelchair'...We went back four times and talked to the four different people and do you think she could get a membership?...It was the principle involved. They wouldn't because she didn't have a valid driver's license and because she was in a wheelchair. They were saying that she couldn't get in and out of their door by herself. (Renatta, p.68)

Renatta did finally get her membership to Jumbo Video.

Although some progress had been made to legislate accessibility for persons with disability, policies and procedures often remained exclusive and misleading. Ada suggested that policies could be ambiguous and allow for exceptions. In some research she was doing on pathways and obstacles to the mobility of persons with disabilities in her city, the by-laws seemed to protect the rights of pedestrians using the sidewalks. It stated that there had to be a two metre clearance from obstructions on sidewalks. The problem was that certain obstructions (e.g. hydro poles and lamp posts) were exempt from these by-laws. As roads widen to make more room for motorized vehicles, the space for maneuvering bodies and equipment shrinks:

> So all the extraneous things (that) cars would hit, like lamp posts, hydro poles and parking meters, are squeezed...into the space between the road and the buildings...pedestrians have to have the space to go around these obstructions and the obstructions are not moveable...no not these kinds of things. So you have to go (around them). You don't always have the space and the by-laws we have here say that you can't do that kind of thing (because poles and meters are exempt). (Ada, p.28)

The exemption to the by-laws did not take into consideration the needs of people whose mode of mobility accessed sidewalks. They also did not take into consideration the room needed to manoeuvre the pieces of equipment used to move on the sidewalks. This reflected policies that were based on a handicapping ideology.

There were regulations around what equipment could go on buses and taxis. The type of equipment a person used dictates the transportation options available to her: "They take electric chairs,...they don't take scooters" (Pam, p.24).

Rules and regulations that had to be followed even if they did not meet the needs and desires of the women themselves. This was especially true for women in settings where they were receiving attendant care. Louise referred to how a natural function based on her own knowledge had to be given the okay by someone other that herself:

> I mean like for me, if I'm having a problem for instance and I'm going out, I want an extra fleet enema. My doctors say no problem. I know if I can handle it or not. But they (attendants) have to go through Home Care. Home Care has to say if it's okay. They say it's okay to management and management will tell the caregivers and then the caregivers can give it to me. Otherwise they can't do it unless Home Care says it's okay. (Louise, p.80)

Even though SLU's were said to be consumer driven they are still ruled by someone else (government):

> Like this is supposed to be consumer directed but in my mind it's consumer directed if management agrees and the red tape is cut...As far as (it goes) here, you go to the government first, then the government tells the management, the management will tell the caregiver and the caregiver will tell you if they can do it or not. (Louise, p.80)

During my visit with Annette, I became aware of how her leisure activities revolved around the schedules of program planners. She had a social night planned through the March of Dimes to go out to that evening. She phoned March of Dimes to ask them when she would be picked up. The woman said that Annette would not be able to go to the social that night because she had not decided early enough whether or not she wanted to go. It was too late to get transportation for her now. It did not matter that Annette was unable to phone them to tell them she needed transportation because her phone had been broken. Also, the volunteer who was supposed to be going with her, cancelled leaving

Annette without the assistance she needed in order to go. This made me realize how her leisure experiences depended on everyone else's schedule rather than her own.

Economic considerations and policy implications had a direct affect on how leisure would be accessed, when and how often it took place and what type of supports (e.g. equipment and caregiving) would be available to help it transpire. Limited incomes directly affected leisure options. Since transportation, environmental and equipment needs were dependent on income, if these needs were not met first than leisure participation was difficult. Policies regarding these needs often reflected an ideology which devalued the needs of persons with disabilities. This in turn affected leisure opportunities for the women in the study.

Funding regulations were built on the notion that fixing an impairment was the best way to make persons with disabilities more employable. Therefore, segregated and therapeutically oriented leisure was felt to be encouraged more than more inclusive types of leisure. This meant some leisure options were nonexistent for the women. Policies which reflected an ideology of normality were often inflexible toward their social and emotional needs.

Constructive Adaptation

Despite the constraints described in the last section, most women were adaptable and creative in finding ways to enjoy leisure in their lives. They were often driven to adapt so they could be more independent: "If you don't adapt you don't survive. And I don't mean survival in the sense of physical survival, just being able to get on with life" (Ann, p.42).

They adapted in innovating ways so that they could carry out their desired activities. This was very evident with Louise who was well aware of her ability to adapt: "Like if I want to do something I think 'There's got to be a way I can do this' and 'What do I have to do to do it'...I never had this inventive mind before (my disability)" (Louise, p.82).

Ann also suggested that adaptation was not necessarily associated with the acceptance of a disability:

> Well, I mean, being disabled is a bummer, obviously. Nobody would choose that if they had a choice. But I guess you just...learn to adapt to it...It's sometimes very hard to adapt to something that you're forced into... (Ann, p.63)

The other aspect of adaptation for these women was that it had to be done constantly: "...it's like one thing on top of the other, and every time you find you adapt to one situation something else hits you" (Ann, p.67).

Chronic conditions are permanent but not necessarily static. Therefore, there is no one time adjustment or quick cure for impairments (Zola, 1989). As a result, persons with disabilities are continuously adapting in order to address their needs.

The women had generally learned to accept uncertainty in their lives. Pam referred to being unable to depend on transportation and she put it this way: "Nothing is for sure in your life" (Pam, p.16).

As has been described, meaningful leisure was part of some women's lives more than others. The following section will speak to how women accepted and adapted their lives to undertake the activities they wished to pursue.

First, and simply, there was an air of acceptance of their lives among the women, but not necessarily contentment. Often the women spoke of accepting their situation due to the fact that they felt there were no other options. There was a sense of loss of control and choice over their activities.

But the actions of the women revealed a sense of optimism, hope, and determination. For example, Ada demonstrated a strong resolve in her decision to continue canoeing even though her arthritis was worsening: "And I thought, if I don't go now, I'll never go. And I thought it was over. And then I started canoeing at the cottage with these gadgets" (Ada, p.41).

Louise felt that a strong will was needed for her to succeed at what she wanted to do: "Like, I've always said and this has been my motto, 'Where there's a will there's a way.' I keep on saying that. If you have the will to do something, you'll find a way to do it" (Louise, p.91).

Renatta was an optimist and that was what helped her with her acceptance of her condition. She referred to her mother's thinking that she could not shop independently: "I don't agree with what she's (her mother) saying because I believe if you try hard enough and if you want something bad enough you'll get it. You just have to give it time" (Renatta, p.44).

The women said they learned much through the process of trial and error. Ada expressed this belief in relationship to her specialized aerobics class: "If I think I can do something and I've had experience before,...I'll say 'okay, let me try and see'. So, I...can see and adapt" (Ada, p.3).

They made do with their functional abilities and learned how to use them differently. Ada stated that having a progressive type of disability provided the opportunity to experience several different functional stages. This was useful in understanding what it was like to be someone who fatigued quickly: "...with my disability I sort of weaken gradually. So I went through that, so I understand very well how that feels" (Ada, p.21).

A disabling condition could have emotional consequences too. The nature of these consequences were dependent on whether or not one had the experience of living in a non-disabled body or whether a person was on their journey toward acceptance. Ann described how the conditions of the physical body affected her emotional state:

> ...I find that when situations upset me, I feel worse than I do if I'm having a bad day physically. I can lay on the couch for two hours and put the oxygen on in the afternoon because I'm having one of them days, and yet still feel okay because emotionally I'm okay. I'm there, but those days that I'm really hassling with like...there only a couple of weeks ago he's (the doctor) told me that I could lose the other leg or probably will. You know, it's something. It really didn't come as a surprise to me but I don't want to hear it. You know, don't tell me this. (Ann, p.43)

A study done by a regional DisAbled Women's Network (1995) suggests that positive changes to the emotional states experienced by disabled women is dependent upon personal acceptance of their disability. It also suggests that factors associated with emotional adjustment are due to whether or not a women has a congenital, progressive or acquired disability.

Debbie expressed that she was self-reflective in order to make necessary changes in her life situation: "I like to constantly challenge myself and look inward and be reflective and see what it is that I need to change and that sort of stuff" (Debbie, p.25).

The women also created their own ways of doing leisure. During the summer Carol planted her herbs in clay pots in her back yard. Doing the activity differently often involved breaking down movements into smaller components. For example, being in a limited physical body heightened awareness of the steps involved in an activity:

> If you have strength in your arms you can open that door no problem. I mean they make the handle that you push down. I can push down on that handle. That's no problem, but I can't push that door open. Or you go to open a door. I get my chair in there to push the door and because I'm right handed I have to turn my chair around sometimes because of the way the handle is...but then I'm trying to keep that door open and trying to drive in there at the same time. It's pretty hard. (Louise, p.73)

Sometimes they took part in the activity differently. For example, they took part in one aspect of the activity if they could not do the whole activity. Ada referred to her participation in her weaving guild:

> I spend most of my time designing and little time weaving. I don't do a lot of production weaving for the sales we have, I just can't do that...So I still do it and participate and get the creative thing out of it. (Ada, p.46)

This coincides with Henderson et al. (1995) who found that women with disabilities take part in activities differently than non-disabled women.

Sometimes living in a disabled body meant learning the intricacies of that body. Debbie suggested a technique that broke down movements and helped women to become more aware of what they could do with their body parts. This, in turn, gave new insight into the precise physical abilities of the body:

> So yeah, I think in a very real sense it (movement education) helped me to discover my body and why I move in certain ways and why I do other things and I just didn't know before. It also helped me in my understanding of my own disability. (Debbie, p.5)

Another aspect that helped these women with acceptance and adaptation was connectedness with spirituality. This was particularly important for three of the women (Carol, Ann and Debbie). Carol believed that her spiritual belief has helped her accept her disability. She believed spirit gave her "a second chance to be normal. Or maybe be a super model or something" (Carol, p.108).

Ann suggested that God offered her a different understanding of her disability: "I don't know. It's like new opportunities have come to me since I've been in the chair, just a peace that I never had before. A contentment. And that's only from God..." (Ann, p.3). These findings support those of the DAWN (1995) study suggesting that spiritual practice is very helpful in learning to live with a disability.

Humour was also used for adaptation. I did a lot of laughing with these women. There would be laughter over some of the injustices they experienced, and how the actions of others were sometimes incongruous. During a telephone conversation, Ann suggested that humour was a way for her to be seen as a person first and close the perceptual gap between persons with and without disabilities: "If you don't find humour in things you won't survive...People can see past the disability when I can joke about my disability...If you don't laugh at yourself you won't survive" (Ann).

Adaptations were not always made on the personal level. Often I was told that since there was little leisure available for person with disabilities, a number of the women developed their own leisure programs. For example, Pam was involved in the provision of garden plots for persons with disabilities that were built at wheelchair height making them accessible for those in wheelchairs.

Irene started a drop-in centre for persons with disabilities, although it did not progress the way she had planned:

> There was an opportunity for me to start and run a Drop-in Centre for persons with disabilities. I was dreaming a long time for something like this, so person with disabilities could get out from their houses and do activities together. (Irene, p.4)

She stated that the persons who had used this activity did not like the way she was running it so she was asked to leave.

Some of the women were instrumental in developing more inclusive groups that were based on shared interest. It was an activity that both the disabled and the non-disabled could enjoy:

> I also am a member of a book club...We just read books and meet together once a month. Drink wine. And we go to each other's houses...Well it was a group of people who were sort of rebels in their own way. And we were all getting different jobs and we wanted to see each other still. So, then somebody said, 'Well why don't we get together once a month and have a book club.' So that's what we do. (Ada, p.48-49)

Eight of the women adapted by becoming politically active around disability issues. They joined consumer driven committees, boards, and organizations who fought for the rights of persons with disabilities. For Louise, becoming disabled motivated her to become more active:

> So to me it's a bad thing to be disabled but it's a good thing because it's changed my attitude on life...And I speak up more than I used to. Like now I'm on the long term advisory committee. Someone who know me from my past wouldn't believe that I'm on this committee. (Louise, p.91)

Annette became involved in a committee that was involved with the concerns of the persons using attendant services in her building. Irene was not only politically active through her involvement in committees, she also wrote a column for the local newspaper regarding issues that affect persons with disabilities.

While the women made changes through organized groups, they also made changes on individual levels. Those who were not as politically active were still agents of change. Renatta told people what she thought even though it was not perceived to be behaviour expected of a person in a wheelchair: "You see people aren't used to that. People aren't used to me speaking up...I say it how it is and if you don't like it, that's tough" (Renatta, p.38).

Debbie, wanted to be a recreationist consultant and ensure that persons with disabilities had meaningful experiences of leisure in inclusive settings. She was motivated by her own lived experience:

> Anyone who joins the program that I'm involved with, anyone on some level, will somehow be accommodated, will be safe. That's my commitment to them. And if I'm doing something wrong then I better get out there and quickly self-educate myself. Just to say 'This program isn't for you. You don't fit' will never cross my lips because I know how that feels...You feel that you are second rate. 'Oh I don't measure up, therefore I can't join.' It's not because you don't measure up. It's because it's a shitty program. (Debbie, p.27)

To adapt meant acceptance of uncertainty by the women in the study. Adaptation was constant but it brought a certain amount of independence. Acceptance of their disabilities was fortified with optimism, hope, determination, strong will, spiritual beliefs and humour.

It was through trial and error that they learned how and what to adapt. Some adapted by increasing the awareness of their functional abilities. In other words, through their experience of physical limitations, they became aware of their functional abilities and learned how to use and move their body parts accordingly. Others created their own way of carrying out desired leisure activities through the use of modified equipment or they developed their own leisure programs. Some women became politically active to help with acceptance.

These women learned to adapt themselves and their environments in order to live within a society which is not structured around the needs of persons with disabilities. They tried to make changes on individual levels as well as within social situations. Although they were all women with disabilities, their focus appeared to be on issues affecting disablement rather than issues of gender. They found similarities among people while respecting differences. Carol emphasized similarities rather than differences by bringing everything to two common denominators experienced by all human beings; life and death: "We're all living on this universe together and we're all going to the same place when we die. So we're not that different. People want to think we're different but we aren't. We're all human beings" (Carol, p.111).

Summary of Findings

The women in this research defined leisure time in much the same way as members of non-disabled society, but they placed emphasis on the social aspect of leisure as well as the need for leisure to be based on individual choice and desire rather than therapeutic merit. Leisure was considered to be an important integrating factor in the lives of these women in that it integrated their minds, bodies, spirituality and their relationships with non-disabled persons. Leisure programs had to match the physical, emotional and social needs of the women for them to be meaningful.

Leisure was constrained by a number of physical and social factors. The management of these factors were reflective of one or more of the components of disablement and were often beyond the control of the women themselves. Their physical impairments forced them to be aware of the functional abilities of their bodies. Most of the women evaluated their bodies according to social activities while trying to carry out activities according to their functional abilities.

Other constraints to leisure included the necessity to carry out activities according to the time schedules of others while living in a body that often required a different, slower, pace.

Transportation for leisure activities was given low priority everywhere. It was costly, policies and scheduling were not flexible enough to accommodate differing physical needs that took extra time or required different equipment. Transportation varied from region to region and city to city. Lack of inter-city transportation affected important social networks.

Leisure environments had similar obstacles as transportation. Policies were handicapping in that they negated individual differences. Organized activities were often limited in number and availability, segregated or combined with other populations that would be considered to be in need of a therapeutic leisure program.

Equipment was often helpful in ADL and consequently leisure pursuits as it provided mobility and movement. Decisions concerning equipment were often made according to blanket policies rather than individual needs. Although equipment was often considered helpful in adapting it could also use up limited energy resources. Equipment often required more space and assistance than non-disabled bodies and social and physical environments were often organized around the most efficient use of space. Equipment also had a role in preventing social isolation for many of the women. For example the telephone and the television became social links for women who have limited resources, access to transportation and leisure options outside their homes.

The women in the study desired independence but often required a certain degree of dependence on caregivers, friends and relationships for desired activities. As a result, the women tried to accommodate the needs of caregivers since they depended on them for care in leisure activities. Relationships based on trusting, understanding, sharing and acceptance were important to the women, particularly in friendships. It did not matter if they were with non-disabled people or people with disabilities as long as these qualities were present. Dating was a leisure activity which was nonexistent for most of the women and this was suggested to be due to lack of places to meet people and perceptions of disability by potential dates.

The women were creative in the way they met their leisure desires. If the desire was there for an activity, the women tried to find a way to do it. They became very good at learning through trial and error and adapting accordingly (e.g. Ada used everyday gadgets in order to be able to canoe).

Some women became more aware of their functional abilities and learned how to use their bodies in ways that allowed them to participate. Their determination, optimism, humour and spiritual beliefs were instrumental in both the acceptance of living daily with a disability and in their ability to adapt to meet their needs and desires.

When the women were unable to find a pre-existing leisure program or a way to carry out an activity they often created new activities (e.g. Pam's garden plots) for persons with disabilities. Some of these activities were more inclusive (e.g. Ada's book club). Indirectly, many of the women became politically active so that the needs of persons with disabilities would be made known. Changing the stigma associated with persons with disabilities would also mean changing their leisure opportunities. This is because most organized leisure activities for persons with disabilities are constructed on the ideology that persons with disabilities are separated and distinct from persons without disabilities. As a result, not only leisure programs reflected this ideology, so did all the components needed to make leisure opportunities accessible and available (e.g. transportation, physical and social environments, time schedules, equipment and the funding options that support these components).

CHAPTER 5

CONCLUSIONS AND SUGGESTED SOLUTIONS

Conclusions

This research investigated how women with disabilities experienced leisure activity in relationship to time, to their environment, to themselves, and to others in an attempt to better understand the biological and cultural components of their subjective selves. This chapter will present conclusions and suggested solutions informed by experience.

Leisure was important to the women. It was a necessary force in their lives as they felt that leisure integrated the body, the mind, and social and (for some) spiritual components of being. They defined leisure as free, non-obligatory time spent doing activities specific to their individual desires. Mainly, they emphasized the social importance of leisure when it provided opportunities to share their gifts, talents and to build relationships with both non-disabled and disabled people. For them, leisure was primarily for fun as opposed to the reality that leisure was often constructed for persons with disabilities mainly for therapeutic reasons which focused on their impairments.

Their definition of leisure was broad incorporating differing functional abilities. It became evident during this research that perceptions of physical activity were variant for people with disabilities, often blurring boundaries between physical and passive leisure. Definitions of passive and active leisure activities were seen as relative to functional ability. For example, for the non-disabled individual an activity such as weaving might appear to be relatively passive. For Ada though, the physical activity involved in working on the loom was taxing. She had to find an alternative mode of weaving that would better suit her physical ability.

This research adds a new component to the study of women with disabilities and leisure in that it began to examine leisure over the life span. Leisure activities changed over their life span whether the women were born with a disability, acquired a disability, or had a progressive disability. Their leisure during childhood and adolescence was more physically active and often occurred outdoors. They were active with non-disabled and disabled children, not always in segregated settings. Adult leisure activities were more passive and were often done alone (e.g. enjoying pets, reading, writing, television, and music). They often took place in segregated and/or private settings.

The desire for leisure, which was specific to the individual, had not changed for the women over time. Only the physical limits and the social ramifications associated with those limits changed. The women desired to be more physically active, as was suggested in a national study on women with disabilities and physical activities (GCFAS, 1988) but they were constrained by biological and social factors (e.g. impairments, time, transportation, environment, equipment, relationships, income and policies). These were constraints that they faced in their daily lives as adults which might suggest that these constraints were not as important during their childhood and adolescence. This would be especially true if the women acquired a disability later in life. Perhaps this also suggests that adults with disabilities are treated differently than children with disabilities with regard to leisure.

This research supported the suggestion that leisure is affected by both the biological and the socially constructed body. Physical impairments had a direct effect on leisure choices, often because they affected energy levels. Previous research indicates low energy levels as a constraint to leisure is not uncommon for non-disabled women as well

(Henderson et al., 1995). Also, impairments made it difficult to carry out leisure activities in the way they were "intended" (e.g. according to non-disabled standards).

The findings suggested that living with physical impairments and disabilities affected the creativity and adaptability of these women. This was particularly true of persons who had experienced living without a disability. These women spent much of their time finding a balance in their lives between the desire for an activity and their ability to participate. For example, they had to decide how much they could do without depleting their energy and their desire to carry out an activity. They were women who have learned to live in the present, meaning each activity required them to be aware of their impairments and functional ability. They were constantly reminded of their body at each point in time when trying to carry out any activity.

Gender, although a significant factor in the lives of these women, did not have the same impact on them as their disability. Many had internalized social norms associated with the female and the non-disabled body. For example, some expressed concern with how they appeared physically to potential partners because this made them stand out as different from other women. But, they were forced to carry out activities in a body that did not meet the social standards associated with health and beauty. Although they were conscious of cultural norms associated with gender (such as female body image) their concern for their needs, as persons with disabilities, were more intensely expressed.

This study also added a new dimension to previous research suggesting that women with and without disabilities share time constraints as an obstacle to leisure opportunities. This research differed in that time constraints for women with disabilities were not necessarily associated with lack of time in general as much as they were associated with the time related to the care of their physical needs; the length of time needed for ADL, the schedules of service and care providers, and the time of day in which an activity occurred.

Since leisure revolved around their physical care and the time schedules of others who were non-disabled, this often meant that women with disabilities had to wait for their needs to be met. Their personal timetables were not the norm and was perceived by them as being given lower priority than those of caregivers.

Transportation options to accommodate leisure choices were a major complaint by the women. This is similar to other research on women with disabilities (see DAWN, 1995; GCFAS, 1988). Transportation was often unavailable, inaccessible, expensive and informed by inflexible policies. Transportation problems were experienced in both segregated and inclusive situations, with some geographical regions being more inclusive than others. It had an isolating affect on the lives of many of the women such that their leisure options were confined to those available in their own homes and immediate communities. Therefore, transportation problems limited the development of important disabled and non-disabled social networks and relationships which the women perceived as an important component of leisure.

Cultural environments (e.g. recreation programs) and the physical environment (e.g. buildings, pathways, geographical terrain, weather) affected the types of leisure the women participated in and where they participated. Environments were often inaccessible, costly, segregated, and designed by decision-makers who were perceived to be lacking in disabled consumer input. As a result, buildings and leisure programs often reflected an ideology which suggested that all persons with disabilities have the same functional abilities and should be treated as a separate homogeneous social group.

This kind of special treatment for persons with disabilities also brought into question the best type of environment for leisure. There were experiences of solo leisure activities, where the women were carrying out the leisure on their own in their own way (e.g. watching television, writing), or segregated leisure where they were with other persons with disabling conditions (e.g. wheelchair floor hockey, rugby). There were also examples of women who, to some degree, were carrying out their leisure activities in more inclusive environments with other non-disabled people (e.g. Ada and her Tai Chi and aerobics, activities carried out with non-disabled spouses, partners, and friends). Although there were advantages to segregated environments for persons with disabilities, some of the women felt that this kept non-disabled people from getting to know the person behind the disability. It also kept them from building social relationships with non-disabled women.

Equipment necessary for leisure often determined where leisure occurred. For example, due to the fact that equipment occupies more space, it affected access to leisure environments. Equipment was not always portable or easy to manipulate so it often meant depending on someone else for help (e.g. to put the wheelchair in a vehicle to go shopping or out for the evening). On the other hand, it was important for mobility, maintaining physical ability, and encouraging social relationships (e.g. keeping in contact with friends through the telephone).

Since equipment was expensive or was not available for the functional needs of each individual woman, the women sometimes adapted by purchasing gadgets that were available at stores who served the general public (e.g. Ada purchased objects from a local hardware store to enable her to go canoeing). Equipment was not always funded by private and public health insurances which suggests that decision-makers may not recognize that persons with disabilities have differing functional abilities.

Relationships for the women in the study often revolved around their care, placing them in a position of dependency. There was an issue of balance between striving to be independent and recognizing that some dependence was inevitable. Not only did they have to depend on equipment, transportation, environments, and funding, they also had to depend on other people to help them with the needs of their impairments. As a result, they often compromised between what they desired and putting others' needs first (e.g. Carol gave up dancing to accommodate the needs of Home Care). This issue of balance also brought some of them to a point of desiring a form of interdependence.

Wendell (1989) suggests that we need to change our social values regarding dependency/independency in order to recognize the value of depending on others and being depended upon. A "model of reciprocity" can be advantageous to both women with disabilities and those on who they depend, in that it teaches recognition of each other's needs, the ability to rely on each other, learning to give and take, learning to ask and receive help, learning to delegate responsibility, and respecting each other's boundaries (Hillyer, 1993).

A number of the women lived in social isolation. Four of the women had little human contact during the day. while others had it daily (e.g. those in the SLU program had contact with attendants, two who were in partnerships, one who lived at home with her family and two who lived alone). This meant that although about half of these women had daily personal contact, it was with professional caregivers and immediate family members rather than in the form of meaningful relationships with friends.

Leisure was perceived as an avenue where meaningful relationships could develop around shared interests. Friendships and more intimate relationships were considered important to the women but it was important that they could give (e.g. share specialized knowledge like Ada's knowledge about the stares on her canoe trip) as well as receive (e.g. Renatta needing help to get in and out of the car when going out). It did not matter to the women if they socialized with disabled or non-disabled persons as long as their relationships were based on trust, shared interest and respect for their functional abilities.

Conclusions regarding funding and policy options have been touched on within discussion of other constraints. The majority of the women were on low, fixed incomes which meant they were limited in what they could spend on leisure and the regulations associated with their sources of income (e.g. Family Benefits, CPP). Funding regulations were perceived to be built on cost/benefit analysis. Therefore, transportation, equipment and recreational setting were often funded if they helped persons with disabilities become more employable. This reflects the economic model of disablement suggested by Bickenbach (1993).

When reviewing the constraints on leisure for them, the respondents often felt that decision-makers did not see leisure as a necessity for persons with disabilities. Decision-makers are those who decide which programs are available, how they are run, how funds will be distributed, the amount of funding (if any) that will be allotted for leisure, and who will have access to transportation, equipment and public space.

Even if decisions-makers tried to make changes (e.g. adapting pathways, providing funds for equipment needed for leisure, flexible funding and transportation policies), it was perceived that they did not recognize persons with disabilities as a group of individuals with varying degrees of impairments and disabilities. Changes were not made according to functional levels, rather they are made according to the perception of what it was to be disabled.

It remained evident that the women believed they were being looked at as a disability rather than people and/or as an economic burden to society. Despite current legislation to ensure inclusiveness, persons with disabilities felt they were still treated as a homogeneous group with relatively invariant needs and abilities marking them as separate from the rest of society.

Limited leisure options brought with them a form of acceptance of the status quo. The women in many ways accepted what was available to them but/and also created new ways of carrying out activities. Acceptance came through determination, strong will, optimism, humour and spiritual beliefs. I was surprised with the way the women often accepted the constraints to their leisure activities. Upon further investigation, I discerned that their resignation was accompanied by frustration and recognition that they had no choice than to accept their limited options. They adapted by creating new types of leisure that accommodated their disabilities. Since functional ability did not always remain the same, adaptation was a constant feature of their lives.

Suggested Solutions

The conclusions of this research reveal that experiences of leisure for women with disabilities often involved a process of balancing options in their lives through trial and error (e.g. finding a balance between desire for an activity and their functional ability, their own personal and social needs versus those of their caregivers and service providers, what they felt were important leisure components for them and what decision-makers felt was important for them, resources needed to carry out activities and limited finances). Therefore, solutions need to accommodate issues of differing needs, while ensuring the treatment of persons with disabilities as persons first. To this end, greater focus needs to be on increased awareness of the needs of persons with disabilities, incorporating disabled/consumer input into decision making processes, and universalizing policies and perceptions so as to encourage inclusion.

To ensure that the needs of the body are met and that people with disabilities are included in leisure activities, a new model of recreation needs to be developed that investigates how the body and its parts move in relationship to time, space, others, and objects. Program designers can develop programs that meet the needs both of individuals and the community. Debbie argued for the development of programs that used the concept of Least Restrictive Environments (LRE). She described it in this way:

> Least restrictive environment can apply anywhere. Where you are removing barriers basically. You are ensuring that those things that you need, whatever they may be, and (it's a very individual thing) are available to you. (Debbie, p.9)

Through sensitivity to the individual's functional abilities and to LRE, programs can be planned that are inclusive and meaningful. It is important to look at the whole person in order plan a good leisure experience, not just what their body can do. This means that the physical, emotional, social and spiritual components of the individual must be considered in order to make the leisure experience enjoyable and beneficial.

On the issue of time constraints, research needs to be done on time, how and why persons with disabilities are affected by non-disabled time norms and the benefits of more flexible time schedules. Instead of having persons with disabilities living their lives under the time controls of caregivers and service providers, their schedules could be made more flexible to accommodate the needs of the persons they serve.

Government subsidies for transportation (e.g. as in taxi scripts) are helpful because they allow for more flexibility of movement, increased dignity and often are more economical. Currently, costs are shared between individuals and government subsidies. However, government subsidies need to be made permanent so this service continues. This is a useful service in other ways because this type of transportation is accessible to both disabled and non-disabled populations helping to eliminate perceptions of separateness.

It was suggested by Ada that decisions about transportation purchases and services need to be made according to the functional needs of the larger population. For example her city was purchasing low floor buses that were partially funded by the provincial government. Not only would these buses be beneficial to persons with disabilities they would be helpful for anyone who may experience difficulty with stairs (e.g. the elderly, mothers with strollers, people carrying larger parcels onto the bus).

This research also reveals the difference between special versus equitable treatment of persons with disabilities. Debbie described equity as something that allows her to be part of the community. A number of solutions were offered to help provide more equitable, inclusive environments. For example, in the process of design and construction of equipment the consumers need to be consulted. Ann also argued that funding to recreation programs should be contingent on inclusivity. Ada suggested that we must get beyond the false dichotomy of disabled/non-disabled in the process of policy formulation, incorporating, instead, the idea of functional abilities. Programs should emphasize differences among people, recognize both impairments and functional abilities, and design programs to accommodate a range of human differences. This makes it more economically feasible to meet the leisure needs of more members of the community. It also challenges the perceptual distinction between persons with and without disabilities by presenting non-disabled people as a group whose needs should be met as well. It is important to consider the functional ability of all people rather than just adapting for the disabled population. Ada explained why.

> It's almost like...it makes more sense to make a decision considering all different functions than considering one, economically it makes more sense. Cuz you might as well do that all at once rather than in bits and pieces. (Ada, p.90)

The construction of barrier-free buildings would also help facilitate leisure for persons with disabilities. This can potentially be more economical because future structural adaptations due to changes in the functional ability of the population would be avoided.

Ada suggested that there needs to be sharing of resources between communities so that information about transportation, equipment and other types of resources would be available and timely. While more resources are available in larger cities, this does not mean they are not needed in smaller communities. This was also suggested by other research findings (GCFAS, 1988; Bedini et al., 1991; Blake, 1992; Block and Vogler, 1994). For example, people in smaller communities would be able to use the information from the studies on transportation for persons with disabilities in Ada's city for their own use. This could increase awareness of the needs of persons with disabilities in other communities and have the potential of encouraging access to leisure options within that community.

Since everyday gadgets were often less expensive than more elaborate pieces of equipment and adequately served the functional needs of the women, perhaps private and public funding policies need to be extended to include such purchases. This would mean that purchases would be disabled/consumer driven. This could also prove more economical for those who provide funds for these purchases.

Persons without disabilities should have the opportunity of interacting with those who do have disabilities so that disability gets a human face. A number of women felt that there was need for an emphasis on sameness rather than difference between non-disabled and the disabled. This may help non-disabled persons begin to connect with disabled persons on a human level based on an emphasis on similarities rather than differences and create an atmosphere of acceptance for women with disabilities. Leisure activities are conducive for this process to take place, providing a chance to socialize with persons both with and without disabilities.

Ann suggested that because persons with disabilities are viewed as a silent minority by decision-makers and that consequentially they need to become more politically active. Oliver (1990) suggests that persons with disabilities need to redefine disablement, build a political movement amongst themselves and develop services that will accommodate their "own self-defined needs" (Oliver, 1990, p.10).

They can do this, too, by joining committees that have an effect on their leisure activities so. This will help create a liaison between management and service providers and the people they serve. Bickenbach (1993) suggests that it is important for persons with disabilities to become politically active in order to challenge the societal framework that defines disablement.

Zola (1989) suggests that we need universalizing policies that recognize that the entire population is at risk of chronic illness and/or disability. Debbie referred to this issue when she suggested persons without disabilities could be viewed as temporarily able-bodied. Age, trauma, advances in technology to prolong and maintain life, and disease are just a few of the things that can lead to a permanent change in one's health.

This research did not suggest that persons with disabilities were totally different from non-disabled persons. The main point was that differences of the body affected ones ability to move in certain ways within specific time frames and environments. This is not a problem unless there is an assumption that there were norms for body movement, time, space and relationships. When these assumptions become embedded in social policies then the policies themselves are written with the belief that people with disabilities are separate and distinct from the rest of society. As a result, disablement becomes socially constructed without regard for the effects of impairment on functional ability. Many of the women in the study found that existing policies are inflexible and static leaving little room for differing needs and perceptions (e.g. policies that did not consider leisure to be as important as caring for impairment needs).

Bickenbach (1993) suggests a multidimensional approach to policy for disablement which incorporates the biological and the cultural experiences of living with a disability. He suggests the need to identify similarities between persons with and without disabilities in order for persons with disabilities to gain respect and encourage society to accommodate difference (Bickenbach, 1993).

Zola (1989) also refers to changing attitudes through universalizing policies which include the personal and social needs of persons with disabilities as well as those of other members of society. Most of the present public and private policies implicitly reinforce perceptions of persons with disabilities as a special group.

This research suggests that in order to make leisure activities more accessible and available to women with disabilities, attitudes associated with disability must be addressed; attitudes that have become part of our social consciousness and social policy. These attitudes reveal an "us" and "them" dichotomy that often exists between persons with and without disabilities.

It also reveals that for women with disabilities attitudinal changes also occur on the experiential level. For women who acquired disabilities, the experience of living in an impaired body changed their attitudes and stereotypes of persons with disabilities. It gave them a better understanding of the experience of disablement. Perhaps what is needed is more research that concentrates on the concepts that are part of the human condition rather than looking at disability issues as being distinctly different from those of non-disabled persons. This could also be incorporated as part of the decision-making process. For example, if one was to look at the experience of physical limitation, most people would likely have an understanding, due to personal experience, of what it is like to be functionally limited in some way.

Also, people in general understand to some extent the frustration associated with time constraints, confinement to a particular area, and being without control in a situation. This is not different for persons with disabilities except that frustration may be accentuated. For example, some of the women in the research, who have had the experience of being non-disabled, revealed that the experience of physical limitations made them more aware of the fallacy of normality and that people are more similar than different. Perhaps, once the human experiences of persons with disabilities are reflected in the experience of all people, similarities may become experientially informed on a human level and leave room for the accommodation of difference. Therefore, degrees of disablement are relative to the individual and it is in this relativity that the answer to embracing difference may be found.

According to this research, any model of leisure for persons with disabilities must incorporate all the components of disablement (i.e. impairment, disability and handicap). Without these components, leisure for them will be seen as separate from persons without disabilities. Definitions of leisure need to be broad so as to incorporate different functioning abilities and therefore include opportunities for the involvement of more people. If this approach was used in all leisure studies then perhaps leisure could be taken into a new dimension. The study of leisure could become an area for exploring the human condition.

EPILOGUE:

REFLECTIONS AND CONNECTIONS

During the course of this research, I became aware of how important the body was to human interaction. I began to reflect on how information infiltrated the body through the physical senses. At the same time, there seemed to be another type of relationship occurring between the body and the environment which transcended words.

While I was doing this research I was reading a book that made me rethink the way I looked at social interactions. It was called Vibrational Medicine by Richard Gerber. According to Gerber (1988), present day approaches to the body are based on a Newtonian paradigm which means the body is seen as a machine controlled by the brain. It is the sum of its parts; an "intricate clockwork mechanism of physical organs, chemicals, enzymes and membrane receptors" (Gerber, 1988, p.41). It is an orderly, predictable, and yet a divine mechanism as well. In the Newtonian model, the human body becomes a reflection of science so the mechanization of the body moves attention away from religious or esoteric explanations of the mystical forces that move people through life. It is understood through a mechanistic view that scientists can understand and manipulate the body (Gerber, 1988). This can be seen in contemporary medical models that consider the body as an object to be manipulated rather than a body that has a life of its own. Therefore, in terms of physical disablement the manner in which one fixes the impairments of the body is through surgery or pharmaceutical intervention. Gerber (1988) argues that these approaches to the body ignore the vital force that gives life to living systems; energy.

Energy is what the Einsteinian paradigm considers, because it views human beings as networks of complex energy fields that interface with physical and cellular systems of the body. Within this approach, all universal substance is seen as primal energy or vibration and all living things are seen as composed of this, including human beings (Gerber, 1988). Vibrational medicine is the manipulation of this basic energy level of substances in an attempt to re-balance the energy fields that regulate the physical body at a cellular level.

It is this subtle energy field that is believed to animate and connect all living things. Therefore, Gerber (1988) suggests that this spiritual element, which is part of human existence, has to be "taken into account if we are to truly understand health, illness and personal growth" (p.32) He goes on to explain that this energy is what programs the nervous system (including the brain) in how to perform and what to accomplish.

If we are beings of energy than we can be affected by energy (Gerber, 1988). It would seem that this interaction may take place on a subtle level (e.g. through people's energy fields). Therefore, we possibly are who we are because of our interaction and experience with our bodies, with others, as well as through the interaction which goes on between the energy fields of individuals.

I have been thinking of the difficulty I have had in explaining what my body was experiencing during my interviews with the women in the study. The Einsteinian approach to the body helped me make some connections. Transcribing the women's conversations gave me verbal information about their experiences but something of the essence of these meetings was lost. It was not something that could necessarily be put into words. I could not help feeling that we were communicating through a means other than words or body language. I have since concluded that my senses were absorbing all that was present. I could describe what I smelled, saw, heard, or felt but it did not have the same quality or essence when described in words as it did during that moment. As a result I felt something that transcended the written word was lost in the research process.

Beyond the senses there was something else that exchanged between the women and myself. Perhaps it is this subtle energy that exists in and around us all. Therefore, even though the senses of the body and the reaction to what was going on were important to the cultural and biological component of this research, perhaps this intermingling of energies was important as well. Perhaps this energy is the knowledge that the body has on its own without cultural intervention. There is still interaction going on between people and the environment, but on a subtler level. This suggests to me that perhaps there is a need for a transcendent sociology which studies social interaction at subtler levels in order to get a better understanding of bodily meanings and social phenomenon.

If we think in terms of energy, then change can occur at a subtle level as well. Changing our own energy fields so as to bring our bodies into a natural balance may offset the energy fields of others around us. It would be similar to a ripple effect caused by a pebble thrown into a pool of water. In this way, change does not have to occur within a collective of people. It can happen between individual people. This may explain individual agency which cannot always be explained in a logical, rational, Newtonian manner and begs to be theorized in new, alternative ways.

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APPENDIX A1

RESEARCH REQUEST
WOMEN WITH DISABILITIES IN LEISURE

I am a graduate student of Sociology at McMaster University. I am also a mother of two adolescent daughters with disabilities. I am currently doing historical research on the experience of women with disabilities in leisure activity. If you are a woman with a mobility disability, between and ages of 20-55 and are interested in telling me about your experiences in leisure, both now and in the past, I would like to talk to you.

Personal or group meetings will be arranged at the convenience and choice of the women participating and will involve at least one session with possible follow-up communication. Confidentiality of information will be the choice of the women themselves. Women may choose to withdraw, wholly or in part, from the study at anytime. My telephone number is ... and if you are interested feel free to call me collect. My address is ... Please contact me before the end of March 1996

APPENDIX A2

ATTENTION WOMEN WITH DISABILITIES: RESEARCH REQUEST

I am a graduate student of Sociology at McMaster University. I am also a mother of two adolescent daughters. My areas of interest are disability the family and how different body types affect our personal experiences within different environments. My current research is a study of how living in a female body, as well as a disabled body, affects a woman's experience of movement or physical activity.

A 1988 survey by the Canadian Government regarding the physical activity and women with disabilities showed that women with disabilities preferred to participate in non-competitive or recreationally competitive/organized sport (Government of Canada Fitness and Amateur Sport, 1988). If this is the case, then I am interested in the reasons why. For example, Do women with disabilities have a different definition of physical activity? What is missing in existing physical activity programs? How does their relationships with other people, places and things affect movement? How does the body affect movement? Perhaps this type of information will help develop new forms of physical activity that meet the needs of women with disabilities.

I want to hear the stories of women with disabilities concerning their experiences in physical activity and/or movement and what movement means to them. Any woman with a disability is invited to be a part of this research as long as you are between the ages of 20 and 45. You do not have to be an athlete you just need a desire to share your stories with me.

Personal or group meetings will be arranged at the convenience of the women and will involve at least one session with possible follow-up communication. Women may choose to withdraw, wholly or in part, from the study at anytime. The results of this research will be available to participants and agencies associated with disability issues. Those interested may contact me at ..., on e-mail at ..., or through correspondence at ... I hope to hear from you.

Jennifer Hoyle

APPENDIX B1

RESEARCH EXPLANATION LETTER
THE EXPERIENCE OF WOMEN WITH DISABILITIES IN LEISURE

I am a graduate student of Sociology at McMaster University. I am also a mother of two adolescent daughters with disabilities. My areas of interest are disability the family and how different body types affect our personal experiences within different environments. My current research is a study of how living in a female body, as well as a disabled body, affects a woman's experience of movement in leisure activities.

Stories as told by women with congenital and acquired disabilities concerning their experience of movement in leisure activity will be tape recorded. The women will be asked to define what movement and leisure means to them. If information is unable to be tape recorded then it will be collected according to the needs of the individual women.

Confidentiality of information will be the choice of the women themselves and the repercussions of choosing or not choosing anonymity will be discussed prior to the signing of the consent forms. Regardless of whether a woman chooses confidentiality of not, she may withdraw, wholly or in part, from the study at anytime and no material will be used.

Personal or group meetings will be arranged at the convenience and choice of the women participating and will involve at least one session with possible follow-up communication. The results of this research will be available to participants and agencies associated with disability issues. My telephone number is ..., e-mail at ..., and my address is ...

Jennifer Hoyle

APPENDIX B2

RESEARCH EXPLANATION LETTER

THE EXPERIENCE OF WOMEN WITH DISABILITIES IN LEISURE

I am a graduate student of Sociology at McMaster University. I am also a mother of two adolescent daughters with disabilities. My areas of interest are disability the family and how different body types affect our personal experiences within different environments. My current research is a study of how living in a female body, as well as a disabled body, affects a woman's experience of movement in leisure activities.

Stories as told by women with congenital and acquired disabilities concerning their experience of movement in leisure activity will be tape recorded. The women will be asked to define what movement and leisure means to them. If information is unable to be tape recorded then it will be collected according to the needs of the individual women.

Confidentiality of information will be the choice of the women themselves and the repercussions of choosing or not choosing anonymity will be discussed prior to the signing of the consent forms. Regardless of whether a woman chooses confidentiality of not, she may withdraw, wholly or in part, from the study at anytime and no material will be used.

Personal or group meetings will be arranged at the convenience and choice of the women participating and will involve at least one session with possible follow-up communication. The results of this research will be available to participants and agencies associated with disability issues. My telephone number is ..., e-mail at ..., and my address is ...

Jennifer Hoyle

APPENDIX B3

RESEARCH EXPLANATION LETTER
THE EXPERIENCE OF WOMEN WITH DISABILITIES IN LEISURE

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Jennifer Hoyle

APPENDIX C1

CONSENT FORM FOR USE OF ORAL HISTORY

The purpose of this research is to gain a better understanding of how women with disabilities experience movement in relation to their bodies, interpersonal and personal space, time and others during leisure activity. It is anticipated that such information could be used in the development of less exclusionary leisure programs or alternative leisure programs. A second purpose is to create a textual account of the phenomenon of movement which speaks to all women, instigating change at an individual and collective level.

I   , have agreed to be interviewed by Jennifer Hoyle of McMaster University as part of a research project to gather information about the experience of women with disabilities in leisure.

The conversations will be tape recorded and transcribed. I give Jennifer Hoyle the right to publish, duplicate, or otherwise use the tape and/or transcript of the taped conversations for publications and educational purposes. I also understand that I may be contacted for clarification of my information during the course of the research.

I have been fully informed of the nature of the research, and the uses of any personal information that I will be asked to disclose. I am aware that I may decline to participate in the study at any point during the study even if I have already started to participate.

I have chosen that my name be used in the typed transcript and in future publications at the discretion of Jennifer Hoyle.

Signature ______________________
Date ______________________

I have chosen that my name not be used but rather that a pseudonym be used in the typed transcript for future publications.

Signature ______________________
Date ______________________

I sign below that I consent to participate freely, without coercion, having completely read this document.

Signature of Participant ____________________
Date ____________________
Signature of Interviewer ____________________
Date ____________________

APPENDIX C2

CONSENT FORM FOR USE OF ORAL HISTORY

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Date

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Signature

Date

I sign below that I consent to participate freely, without coercion, having completely read this document.

Signature of Participant

Date

Signature of Interviewer

Date

APPENDIX C3

CONSENT FORM FOR USE OF ORAL HISTORY

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Date ____________________

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Signature of Participant ____________________

Date ____________________

Signature of Interviewer ____________________

Date ____________________

APPENDIX D

THEMES

Background Information:
- Participant's birth date, place and circumstances
- Description of disability or impairment
- Geographical location i.e. rural or city

Personal Definition of Leisure

Personal Definition of Movement

(Each of the next themes focus on how movement in leisure is experienced in relationship to the body, time, space and others.)

Early Life Experiences in Leisure
- Description of movements involved
- Where? When? Why? Anyone else involved?
- What did they do in the evenings, after school, in summer, weekends. Have them fill the time.

Adolescent Experience of Leisure
- Descriptions of movements involved
- Where? When? Why? Anyone else involved?
- What did they do in the evenings, after school, in summer, weekends. Have them fill the time.

Present Experience in Leisure
- Descriptions of movements involved
- Where? When? Why? Anyone else involved?
- What did they do in the evenings, after school, in summer, weekends. Have them fill the time.

APPENDIX E

CHECKLIST FOR END OF INTERVIEW

Married, Single, Divorced, Widowed, Other?

Age

Employment

Source of Income

Where Living

Educational Level

Acquired or Congenital Disability

Description of Disability