

Who Do We Think We Are?: Self Image and Women with Disabilities

"WE HAVE TO IMAGINE OURSELVES DOING SOMETHING BEFORE WE
CAN DO IT, AND IT IS VERY HARD FOR US TO IMAGINE OURSELVES
DOING SOME THINGS."

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FEBRUARY 8, 1989

For all women, imagining one's self as a competent, capable, strong, attractive and loveable person is a challenge.

Indeed, this very constellation of characteristics contains qualities which are seen by many to be contradictory.

In a conservative, patriarchal world view, women cannot be competent, capable, and strong and at the same time, attractive and loveable. Despite two decades of 'New Feminism', the resolution of that contradiction remains a dilemma for many women. How then do women who are born with disabilities, or develop them later in life, imagine their own strengths, learn to love themselves and others and express their full potential?

Seventeen women with disabilities came together in Ottawa in June, 1985, for the founding meeting of DAWN Canada. They identified self-image as a key concern, together with sexuality and parenting, violence, employment equity, isolation and lack of access to the women's movement. Self-Image was ranked as the most important issue overall by the 245 women who participated in the 1988 DAWN Canada: Disabled Women's Network Canada research project, on which this position paper is based. A strong self-image is essential to gaining access to the world of work, to developing strong, egalitarian intimate relationships, to effective parenting, and to resisting the violence that pervades our society. As one woman I interviewed for the project told me, 'You've got to start with self-image. If we can learn to feel good about ourselves, everything else will fall into place.'

Indeed, but again, how do we learn to feel good about ourselves? As women who do not necessarily fit our society's limited definition of beauty, trapped in a double-bind in which our sexuality is both denied and exploited, how do we learn to accept and explore our sexuality? As women with a high rate of unemployment and poverty, how do we come to value ourselves, in a society that values people for their ability to make money?

All these questions are linked, in some way, to self-image. What factors lead to the development of a strong self-image? Surely, unconditional love in childhood and acceptance by one's peers are instrumental. These do not come easily to girls with disabilities. Media images which project positive role models with which we can identify are essential. Yet such images are rare for women with disabilities.

This paper will explore the problems which impede the development of strong and positive self image for women with women with disabilities. DAWN Canada research on the subject included the development of a questionnaire, its distribution to 1200 women with disabilities, analyzing the 245 returned questionnaires, and interviews with approximately 50 women during travel to the Atlantic provinces, Alberta and the Yukon.

Although the findings here will hopefully pertain to the disabilities. It is important to note that the respondents and the women I interviewed are no doubt an elite group among women with disabilities. They were contacted through DAWN Chapters and other disabled consumers groups, through women's centres and organizations working with people with disabilities. Among them are more women living in major centres than in remote areas, partly because they were easier to contact and partly because people with disabilities often are forced to move to cities to access services.

There are no women who are currently living in institutions in the sample, though there are some women who spent a part of their lives in one. This is an unfortunate omission, which bears blunt testimony to the isolation of many women with disabilities; it was simply not possible to cut through all the red tape that isolates women in institutions. So the evidence is obtained from a select and relatively fortunate group of women with disabilities. Yet if this select group experience barriers in developing a strong self-image, those barriers must be at least as high for other women with disabilities.

Because violence, employment equity, and parenting by women with disabilities - all of which are connected to self-image - will be discussed in other papers, this paper will focus on four areas: early experience; experience in the educational system; sexuality and relationships; and role models and media images of women with disabilities. In all these areas, there will be differences among and between women with disabilities.

Our experience is not uniform; it varies vastly with the type of disability, our age at the onset of the disability, the resources available in our communities, and other factors. While I will attempt to point out these factors throughout the

paper, some will be implicit. For example, the remarks on early experience obviously apply to women who came into the world with disabilities. They apply to women who become disabled later in life only to the degree that they apply to all women in a sexist society.

Early Experiences

Gwyneth Ferguson Mathews states in her article, "Mirror, Mirror: Self-Image and Disabled Women", that in general, women born with disabilities face 'even greater, more complex difficulties' than women who are disabled as adults. Although the time of disability for our respondents ranged from birth to "only three months ago", 93 women or 38% of the respondents were women born with a disability. They constituted the largest group of women who responded to our questionnaire.

The first influence for women with disabilities, as for all humans, is our parents, and primarily our mothers. We know those children need unconditional love in order to thrive and mature into adults who are spiritually and emotionally strong. Jessica Benjamin points out that 'In order to become human beings we have to receive recognition from the first people who care for us.' For a girl born with disabilities, there are many barriers to unconditional love.

Her birth may create a crisis. It is not uncommon for families to fall apart when faced with the reality of coping with the physical and emotional demands of a disabled child.

The caring parent - almost inevitably the mother - may never have time for herself, and may feel uncomfortable leaving the child with a sitter or caregiver. Yet she may resent the responsibility, the long term dependency, the toll on the rest of the family. Fathers often walk out the door never to be heard from or seen again. Though far more rare, mothers have been known to do the same. Faced with the very real demand of giving up their child or their husband, mothers will usually choose to support the child, but not always.

A mother may see her disabled daughter as evidence of personal failure. The 'second stage' of the women's movement is still new, and its' principles are not yet universally accepted. Our parents, like ourselves, grew up immersed in the patriarchal culture. The women who mothered us were brought up to understand that a women's sphere was within the family. Most of them, and most of us, were exposed to their model families of 'Father Knows Best' and "Leave it to Beaver", or their equivalent in another patriarchy.

In traditional families, the mother is the one charged with the responsibility of keeping the family stable and its members content. Her husband and her dependent children give her identity; she is 'Bills' wife', Carol's mom'. The mother of a child born with disabilities is the producer of a child who does not fit the perfect model. She is the one who carried the child.

The child's presence may be seen as a constant reminder that the mother has failed to achieve perfection. As children, we may add to this burden. We expect her to be perfect. To a child, a mother is the one who can 'make it all better', who eases our pain.

Why can she not then heal us? As pain and salves our wounds.

Jane Flax points out that daughters resent their mothers impotence, for not possessing the sort of power that could free both of them from dependency." (Flax 1987:34)

As any child grows up, she learns to distinguish herself from her parents, and to see herself as a distinct and autonomous being. But what happens then when the girl child born with a disability seeks to affirm her autonomy? If her disability is sever, and other supports in the community negligible, she is forced to recognize that she will never be completely autonomous; she may never be able to completely differentiate herself from her parent(s) or her caregivers. Teachers, doctors and social workers may discourage efforts at autonomy, seeing the disability before they see the maturing child. The mother realizes that her child, like her in so many ways but 'imperfect' in society's eyes, will need a degree of nurturing for many years, perhaps throughout their common lives, or beyond the parent's own death. Given the lack of community supports for the disabled and their parents, the cost of caring for the daughter in time, energy, and personal autonomy will probably be borne by the mother. She will receive no pay and little recognition for that work. Her only power may seem to be the control she holds over her child, based in her daughter's dependency on her.

Mothers may foster the dependency that sustains their power. They may undermine a child's self esteem by suggesting that she will never be attractive, that no man will ever want her, that she shouldn't go out and play because she might hurt herself, or other children might make fun of her. A child like this is doubly disabled; rendered powerless by her inability to see herself as an independent, separate being.

Small wonder that women with disabilities often have difficult relationships with their mothers. Women that I interviewed as I traveled, especially those who have been disabled all or most of their lives, frequently spoke of this tension.

Mum is bitter. She blames herself for my disability. I try not to get frustrated in front of her, because it sets her off on a guilt trip. (Interview with woman who has Cerebral Palsy, 1988)

I'll call this woman Shirley, because that is not her name. I have changed the names of all women quoted in this paper out of respect for their confidences. When Shirley was 16, her mother developed Bursitis, and refused to get outside help for herself or for Shirley. Shirley blamed herself. She went to visit their family doctor, who told her that her mother only had six months to live. Shirley went to live in a group home. Her mother recovered and is still alive. That was eleven years ago.

Shirley now lives alone, in an apartment in a co-op. Her relationship with her mother remains distant.

Another woman, 'Rose', is post-polio. She said, 'My mother was afraid to get close unless I was sick.' Rose spent seven or eight years out of her first 18 in the hospital. At one point, only her arms were not paralyzed. Her parents weren't allowed to see her. Her routine got to be 'Hospital in summers, school during the school year.' At times, she wanted to stay in the hospital; it had become home. She is now in her thirties, and a mother herself. Her relationship with her own mother is just starting to heal, 'She came to Post-Polio's Mothers Day picnic, and that was great.

Siblings, particularly sisters, can be a good support system for girls and adolescents. However, for girls with disabilities, relationships with siblings can become difficult. Shirley mentioned above, has one younger sister. She is able-bodied, and used to resent having to care for an older sibling, and the extra expense of Shirley's disability. Now, they are friends, and go out together. But, like many other women with disabilities, Shirley was denied some of the joy of first sisterhood, of sharing experience with another like you in sex and genes, who will always understand where you are coming from because she came from the same place. Able bodied siblings squabble, and resent each other, but they also care for each other. A first born may subsequently be given responsibility for a younger child, but that burden is balanced by their previous opportunity to be the only one, the special child. A child who remains 'special', who needs more time and care, is resented by the

baby who sees her share of attention, her own 'special time' atrophied by the demands of her disabled sister. The girl with a disability feels the resentment, and experiences it as guilt. 'I am a nuisance, a burden, this family would be better off without me.'

Child abuse takes many forms. It leads to a 'fundamental lack of self-confidence and self-respect.' (Forward and Buck 1988:23) For most women with disabilities, psychological abuse and verbal abuse is a fact of life. When a child feels resented and comes to understand that she is in some way less than perfect, she may come to see herself as unlovable, worthless, and potentially dispensable. All children have a fear of being abandoned. For a child born with severe disabilities, the fear of being abandoned or sent away to an institution may be very real. There are more children with disabilities in need of good foster homes and adopting families than there are homes that are willing to take them.

For many of our respondents, banishment was a frequent, verbalized threat; for some, it was carried out. If parents find it impossible to cope with their disabled daughter, and place her in an institution, feelings of abandonment and rejection are inevitable. Hospitalization for necessary medical treatment, or being sent away to board at a special school, can seem like banishment to a child. A child who is 'sent away' tends to think that she has been banished because she is bad and unloved. The parent-child bond can be irreparably damaged.

In recent years, there has been a trend towards keeping children with disabilities in their homes and communities.

But women now still young have been subjected to decades of institutionalization, for no good reason. One example is 'Diane', a woman I interviewed in the Atlantic Provinces. She has had seizures since she was 14 months old. When she was six, she was put in an institution in Montreal. She has blocked a lot of her memory of the time, but recalls, 'I spent a lot of time scrubbing floors.' At twenty, she went to a convent. The nuns taught her, at long last, to read and write. She is thirty one now and active in local disabled consumers' groups. She still takes a lot of medication for her epilepsy, but seizures are infrequent. She works in a sheltered workshop, and makes \$4 an hour sewing aprons, and other goods. She is back living with her mother and stepfather. It seems she has few alternatives but to get along with her parents as best she can. She told me she would like to get an apartment on her own, but she has tried before with little success. Her wages are too low to cover

expenses on her own. With her poor educational background, more highly paid work is not available.

Abuse may also take the form of emotional neglect. A parent who has been told her child may die before she reaches the age of two, or twelve, or twenty may be understandably cautious about giving of herself and loving the child fully. 'After all,' she may think, 'what is the use of loving a child, or putting energy into a child, who may abandon me?' A parent who is convinced - or wants to convince herself that the child would be better off in an institution may also remain aloof; the decision is easier that way. In such circumstances, and in many institutions, physical needs may be met, but emotional needs go unmet. Self-esteem cannot blossom. Clare, who's mother had measles during pregnancy, was visually impaired until age 27. Now she is blind. During our interview she said, 'I always felt my mother hated me, that she couldn't look at me without feeling guilty. She seemed not to want me; it was like I was a reminder of something imperfect in herself. She wanted to forget about me.' Clare was sent to a boarding school for the visually impaired in Ontario at age seven. She describes it as, 'a nightmare. I had bad eczema, and the nurse used to slap me around and give me very hot baths in baking soda.'

Some women with disabilities take on the role of the family clown, believing this the only way to be appreciated or loved. Fearing banishment, a daughter will learn to deny her own needs and feelings in order to make her parent's lives easier. We stifle our own needs, our own anger. We will do anything to prevent disharmony and possible banishment. We learn to laugh when called 'freak, retard, gimp', rather than show our hurt. Yet these epithets are devastating, particularly if they come from our parents. Abuse - whether sexual, physical, or verbal, or in the form of neglect - has a debilitating effect on self-esteem. Our research indicates that verbal abuse is a reality in the lives of the majority of women who have a disability. One hundred and fifty-four of our two hundred and forty-two respondents, (64%) had been verbally abused because of their disability, 19% could not recall whether they had or not, and only 8% stated they had never experienced verbal abuse. 9% did not answer the question.

Childhood abuse leads to lifelong vulnerability; women come to accept the verdict that they are worthless. We become targets for more abuse. I interviewed a woman I will call Janet, who is now living under an assumed name. She suffered what she calls a 'brain injury' in a bus accident in early adolescence. Janet recently escaped a long-term marriage in which she was subjected to rape, severe beatings, and other abuse. She describes her adolescence.

When I was a kid. My mum automatically saw me as retarded, as like one of those retarded children, like a mongoloid or someone who can't look after themselves or can't do anything for themselves. She automatically did that. And she said that, well, my brother and I are christians; he told me that she had said, 'this is God's way to punish me, by letting me have one child who is now mentally retarded.' I knew darn well, deep down inside of me, I'm not that way. I've got the capabilities of doing everything like everybody else. I have a right to be a human being and treated like a human being. And I went through a struggle for years, and because my mum um wouldn't listen to me, she at one point was going to have me put into a Catholic home or a Convent, away from her, so she didn't have to look at me, she didn't have to talk to me, or anything. (From transcript of tape made during interview)

The cruelties of shaming, blaming, name-calling can also continue into adulthood; one woman I interviewed mentioned that her father had recently sent her an advertisement for a full length body-brace. Perhaps he was trying to be helpful, but it showed that he had ignored her real situation and the efforts she is making to learn to accept and love her body as it is.

Generally, the women I interviewed described themselves as being closer to their fathers than to their mothers. Perhaps it is easier for a father, who is away at work for much of the day, to be patient and loving for a few hours in the evening; he does not have to cope 24 hours a day. He comes to represent the longed-for autonomy, the connection with the desired but feared - and perhaps unattainable - outside world. Shirley, who moved out at sixteen to save her mother's health, remains very close to her father. Although she sees her mother infrequently, her dad drops in, 'just to visit and to keep me company.' Shirley told us that she got her sex education from her father, 'we learned part of it at school, then I'd come home and we'd talk about it.' There is no disclosure of overt incest here. Yet the fact is that the normal mother-daughter relationship is skewed. It is possible that in some cases such father-daughter interdependency could lead to an incestuous situation.

Many girls with disabilities lack information about sex; they know only what their parents choose to tell them. Unfortunately, many men cannot conceive of intimacy with a female that does not include sexual contact - even when she is their own daughter. Daughters who have disabilities may require personal care that requires touching of the genitals long after the father of an able bodied child would have reason for such touching. The meaning of such touches may be unclear to an uninformed daughter. Fathers may find the child an easy outlet for a need to dominate; they may be overtly abusive, and use sex as a tool of power. When the daughter is very vulnerable and lacks

sophistication, she is an easy victim. It is easy to see why girls and women with disabilities are frequent victims of incest and/or sexual abuse by male relatives and caregivers. A study done by Joanne Doucette for DAWN Toronto found that 47% of a sample of 30 women with disabilities had been sexually abused, compared to 34% of non-disabled control group. Our study did not separate out sexual abuse from rape and assault, as will one we are now undertaking, but our findings are consistent with Doucette's 43% of our respondents had experienced violence; 53% said they had never experienced violence, and 8% did not answer the question. For most, (a total of 52% of those who had experienced abuse) The abuse was a person in a position of trust; a spouse (37%) a parent (15%) or a caregiver (10%). Doucette also found that parents and caregivers were frequent abusers, her sample was small, and only 7 women in it were in a long term relationship, so abuse by spouse was not as high a category.

Abuse is more common among girls and women who were born with a disability, or who became disabled early in life. Table 1, compiled from the responses to our questionnaire, indicates that women born with disabilities and those who become disabled in their early years are more likely to be abused than are women who become disabled in adulthood. Table 1 shows the incidence of abuse among women who responded to the DAWN Canada questionnaire, by age at onset of disability.

TABLE 1

Disabled women who have experienced violence by time of onset of disability (DAWN Canada Survey, 1988) Compiled November 1988; some late questionnaires which were incorporated into other statistics were not included here)

Onset of DA	# violated	# Respondents	Percentage
Birth	32	67	48
Early Childhood	18	28	64
Over 10 yrs. ago	17	55	31
5 - 10 yrs. ago	12	35	30
Less Than 5 yrs.	6	11	55
Overall	85	196*	43.3

*Does not correspond to total sample because not all women answered questions about violence.

If we disregard the figures for those who were disabled less than 5 years ago (a very small number of women), it seems that there is a significantly higher incidence of abuse of women who have been disabled since childhood.

Girls and women with disabilities may put up with sexual and other assaults out of fears of abandonment, fears that they will not be believed, fears of breaking the family apart. Those were all reasons given by women who told us that they did not report. Their fears are well-grounded. Disabled victims of violence, particularly sexual abuse, often have a difficult time being believed. The accusations are denied. Often there is no witness. They may be labeled crazy, and no charges will be laid against their assailants because the woman is not a credible witness. When it is a matter of the word of a woman who may have difficulty communicating or be poorly educated against that of an adult who is respected in the community, the adult invariably wins. If the abuse damages our self-esteem, disbelief diminishes it further.

A doubted victim feels powerless and invalid. We may be doubted because we lack the words to describe what happened to us. We may be isolated from our peers, and denied the giggling gabfests when girlfriends share what they have learned about 'it'. because of the myth that women with disabilities are asexual, we are denied good sex education.

Society still believes for the most part, that girls and women who use wheelchairs, who have learning disabilities or hearing or speech impairments, cannot possibly be attractive to the opposite sex. Thus, our reports of sexual abuse may be discredited because of the attitude, "Why would he bother? Why would he want her?"

Our problems do not stop if we are believed. A girl with disabilities who reports sexual abuse, and is believed, is likely to be banished to an institution or to a foster home. Banishment fosters the guilt that all incest victims bear; it is not the guilty that are sent away? Our choices are limited; abuse or banishment. Since children in foster homes and institutions frequently are violated by foster parents and caregivers, we may end up with the worst of both worlds, banished and abused.

Less than half the women who reported abuse in our questionnaire (43% of women who were abused) had told authorities about the abuse. Those who had been silent cited dependency (55%) and fear (64%) as the major reasons for their silence. We learn to deny our own reality in order to survive.

Discredit our own anger and learn to live with the guilt - we learn to take it and take it and take it some more. We come to think we deserve it, we come to see ourselves as unable to control our lives. Disabled victims of childhood sexual abuse and incest grow up to be adult victims of sexual abuse, or ongoing incest. Our vulnerability becomes evident to those who seek out victims, and we find ourselves victimized again and again. "Janet", the woman who was verbally abused as a teen, described the abuse she was subject to during her marriage.

It was only a few days after we got married that he became violent with me, and said, "Janet, if you leave the house, I'm going to kill you." Shortly after, my husband raped me a few times. But the raping I went through was pretty severe. That's when he had me at gunpoint. I never knew from one moment to the next when I was going to have him beating me up. I've been beaten on my face, he tried breaking my back, he's done damage to my legs, had my back out in four places. He tried biting my arms a few times. It wasn't until he just turned over one morning and said, 'Can I call you Mummy?' that I realized he was having a nervous breakdown.

Experiencing Education:

For many girls with disabilities, school years turn an impairment into a disability. The need for medical treatment, isolation from other kids at a 'special school', or the inability of the standard school system to deal with them, means they are denied a proper education. This in turn handicaps them financially and socially for the rest of their lives.

In 1987, Pat Israel of DAWN Toronto did a cross-Canada telephone survey of 24 people with disabilities. Her first question addressed the effect of 'diminishing language or patronizing behavior', and asked 'how important has this been to your quality of life, as a child, teenager, and at the present time?' Twelve of the 17 respondents who had disabilities as a children stated that their childhoods were difficult.

They found little acceptance either within their families or at special schools. Older people were often perceived as trying to be 'too helpful' while peers ridiculed or shunned the disabled child. "Kids laughed at my funny shoes". (Status of Disabled Persons Secretariat 1988:23)

Although things may be changing now, some of our respondents were educated at a time when children with visual, aural and multiple disabilities were segregated, often in schools far from home. Because they were not seen

as potential members of the work force, the education they received was minimal. Shirley spoke of her education at a 'special school' in a children's hospital. In her opinion, her education there was 'not good.' The emphasis was on 'social skills,' so that people with disabilities would know how to act.' She also had to spend a lot of time in physiotherapy and missed classes as a result. She feels cheated: If I'd had more help academically, I would have my grade 12. She was forced to quit at 18, with only her grade 10 because she was no longer eligible to be a patient at the children's hospital.

Currently, she is taking a computer course that is free for people with Cerebral Palsy. She is also taking an advanced ceramics course. She would like to go to a vocational school, to upgrade and get her grade 12. Shirley is not an exception, women who are born with a disability or who become disabled in childhood are over-represented among those with less than high school education.

Overall, however, our respondents have high average education but among them are women who's education precludes their full participation in society. Lack of information and skills that are common knowledge for most people can be devastating to self-esteem. Eleven women stated that they had no formal education and 8 of these women were born with a disability. No formal education does not mean 'none' since many of these women had special tutoring. They simply did not enter the education system.

Another 28% had only elementary school education while 30% had some high school, or high school graduation. However, a large number were very well educated. Forty six women (19%) are university graduates, and 22 of these hold post-graduate degrees. The balance of the respondents have some university or college or training certificate. This group is large overall, but women born with a disability or disabled in childhood are underrepresented. Early disability seems correlated with either very high or low education - once we get the opportunity, we go with it.

Whatever their education level, most women wanted to get more: 62% expressed this wish. For 21%, however, handicaps related to their disability are a barrier to further education. In most cases, inaccessibility, lack of transportation, or lack of special facilities create the barrier.

Even for those women who did get their education, the process was often painful. Remember Clare and the scalding baking soda baths. 'Mainstreaming' - integrating children with disabilities into regular classrooms, may resolve many problems, but it can create difficulties for children who are seen by their

peers to be different. Children with mild or moderate disabilities can also be scarred by ridicule from their peers or teachers.

My mind went back to my own years at Crofton House, a school for young ladies in an elite Vancouver neighborhood. The polio I had in early childhood left me with weak ankles and pigeon toes. I had to wear orthopedic oxfords. One day I was called out of the queue of grade 2 girls and told to walk up and down in front of 30 giggling seven year olds. "That," said the teacher "is how a Croftonian does not walk." My spine still crawls at the memory, four decades later, my self-esteem has yet to recover completely.

Almost universally, those of Israel's respondents who had a disability in childhood and adolescence found that the cruelest experience occurred in the teen years. As they put it, emerging sexuality and identity issues made it hard to accept my disability - a lonely time. (Status of Disabled Persons Secretariat 1988: 23) For others, school was a time of social ostracization: children and adolescents can be devastatingly cruel to a child who is 'different'. Rose, whom we met earlier, had a lot of surgery and had to move to a General Hospital. At a time when most adolescent girls are adjusting to their developing bodies, she was in a brace up to her neck. Her lungs were affected. As a result, she didn't have many friends, 'I didn't fit anywhere.' She left home at 18 because her self-esteem was low, and she had to distance herself in order to prove that she could succeed without her mom.

The adolescent who becomes disabled also has a trying time. Gail, who has Multiple Sclerosis, told me in our interview about her experience in high school. The MS had already been diagnosed, but her parents were told not to tell her.

So her incontinence, the stumbling and falling, the numbness in her limbs all seemed like manifestations of clumsiness, something that was wrong with her that she was somehow responsible for. She tried to cope as best she could. At sixteen, an age when we feel all eyes upon us, when any divergence from the norm seems terminally embarrassing, Gail found that difficult.

As a teenager, sometimes there was no success, there was just too much to accommodate at that point, as far as the leaking, as far as the bowel and bladder. I became very adept at going into the washroom cubicle, and using a lot of toilet paper. After I flushed the toilet to get cold, clean water, I'd sort of sponge my panties, and then use dry paper towels or whatever to soak up the moisture. Usually about half an hour later, I'd be ready to carry on, so to

speak. It was hard as a teenager, and it hasn't really got much easier. (From transcript of interview)

Gail might have found those years easier if she had known what she was dealing with. However, a doctor had advised her parents that she shouldn't be told. All her friends knew, and found it hard not to share their knowledge.

As it worked out, all my friends in high school knew that I had MS, but they had been told that, "Mrs. Smith does not want her daughter to know." So they went around carrying this thing. It wasn't until I was married, I think around 22 then, coming back for a visit with all these people, my friends, that a close friend said, 'You know Gail, everyone wants to come over to look at you, to see how you are.' I said, "What do you mean?" and she said, - like this girlfriend, her mother worked in a bank that my parents did business with and she knows my mum quite well, and mum sort of opened up right there in the bank and told her that I had MS and she didn't want me to know because this is what the specialist had said, and you do not go over a doctor's head, but a specialist's head, no!

Gail's experience points to another source of feelings of powerlessness for women with disabilities. Although we are more reliant on the medical profession than are our able-bodied sisters, in many cases, doctors do not respect us. The doctor who insisted that Gail be kept ignorant of her disability is not atypical. Not telling women what is going on with their bodies is only one form of medical abuse that women and children with disabilities must cope with. We frequently run into other forms of abuse from the medical profession. As Debra Connors explains in her essay 'Disability, Sexism and the Social Order.'

Common notions of disability continue to objectify us as patients. We are the failures of modern medicine, the 'cases' whose births could not be foreseen and for whom there are no known cures. We testify against the omnipotence of medical science and represent a frightening truth. We are feared and hated and viewed as hopeless patients in all of our daily environments. (Connors 1985:79)

We are often denied our right to know what is wrong with us. We may not be consulted about medication and treatment. We may not be allowed to control our own reproduction. We can be sterilized and forced to have abortions against our will. We may be denied the right to safe birth control, and the right to have our questions answered clearly and correctly. Women report being consistently misdiagnosed, and treated in extraordinarily patronizing ways.

"Hilda", a young and beautiful woman who has a rare bone disease and is very tiny, told me about an episode when she went with her boyfriend to see her doctor. She mentioned birth control, and the doctor looked at her in astonishment and demanded, 'what do you need birth control for?' telling me this, Hilda laughed and said, 'And my boyfriend was sitting right there, right!' But such incidents undermine our confidence in ourselves as sexual beings.

Doctors often allow a disability to overshadow a person. Symptoms that indicate sexual abuse and incest in able-bodied women are overlooked by many physicians. Such symptoms are even more likely to be overlooked in women who are not seen as women, but as a 'case' of Multiple Sclerosis or Cerebral Palsy. Women, in general, are seen by the medical profession to be 'more difficult than male patients'. Their symptoms are often 'dealt with' through over-medication. as April D'Aubin explains: "Their symptoms are reduced; however, the root causes of their problems go unexamined." (D'Aubin 1986: 33)

These attitudes can lead to misdiagnosis, or to no diagnosis.

I interviewed one woman who is mobility impaired. She suffered severe consequences as a result of medical attitudes that see women with disabilities as not having other health needs. During an internal examination a few years ago, she fell off the examining table. She didn't get another exam for awhile, because she couldn't find a doctor who had an examining table that raised and lowered. By the time she did, she had cancer in the lining of her uterus. She had a hysterectomy and other treatment. Her experience shows the importance of such examinations for all women, and the difficulties that disabled women have in being seen as women, and in accessing such normal and necessary health procedures.

Relationships

Gail had friends who stood by her in high school, but any adolescent with disabilities don't. Diane spent her adolescence scrubbing floors; other women also mentioned their shyness, their over reliance on their family. The work load they performed at home, the feeling that they could not attend social events because they were held in inaccessible places, and anyway, if they did, no one would ask them to dance, no one would talk to them. Children and adolescents are extremely susceptible to peer pressure; few of us escaped the devastation of being the butt of jokes. Most adults are ignorant about disabilities, and kids are even more so. To quote "Worthless or Wonderful; The Social Stereotyping of Persons with Disabilities,"

Able-bodied people experience considerable fear, pity, ignorance and outmoded perceptions with regard to disability." (Status of Disabled Persons Secretariat 1988:23)

Whether a girl with a disability goes through a special school, learning in isolation from the able-bodied peer group and without family support, or is 'mainstreamed' with non-disabled peers, it can be hard for her to establish a network of strong friendships. Bonds made with schoolmates who share her disability may be arbitrarily cut off when they are considered no longer the responsibility of their 'special' school.

Difficulties establishing friendships can continue into adulthood. Although 60% of our respondents listed 'friends' as a main source of strength and support (second only to family at 65%) women were split almost evenly on the question, 'Do you feel you have enough support?' forty-two percent did; forty-three percent did not. Even some who answered affirmatively listed 'companionship' as a kind of support they would like to have. It was by far the most common answer.

Some disabilities, like M.S., Lupus and Rheumatoid Arthritis, may become manifest in adolescence or early adulthood, just as we are completing our education, establishing ourselves in careers and in long-term relationships. A toe that 'goes to sleep' may become a leg that refuses to dance, and then limbs that no longer respond to our brains' commands. Pregnancy or the stress of University or a first job may exacerbate pre-existing disabilities, or bring others to the surface. While women born with disabilities may have difficulty seeing themselves as adults worthy of respect and caring, women who become disabled in early adulthood have trouble adjusting to a body they can no longer rely on. Where they have established an identity built on skills that are lost to them, the adjustment can be extremely difficult. "Paula" was a weaver before she developed severe MS; it has affected her eyes, and she is mobility impaired. Her hands are limited in their strength and mobility. She lives on Disability Insurance, from her former job in University Arts Administration. Her interest in art compounds her current difficulties; she has lost the joy art brought her because she can no longer see or use her hands well enough to weave. She has lost much communication with others, because she cannot read or write.

Physical problems like Paula's create barriers to relationships. So can the psychological and social barriers that limit us. Because we are vulnerable, our fear of violence can restrict the mobility we have. Shirley told us that she doesn't go out by herself at night, 'it is not safe.' She will go on the handibus. If

she has to meet someone she doesn't know, she doesn't go alone, but gets a friend to come along. "If I'd arranged to meet you at a strange place, not at my home, even though you are two women, I'd have been worried. I'd have taken a friend along." Shirley's fears are well-founded. They illustrate a problem with accessibility that men with disabilities are less likely to be handicapped by; Street violence is any woman's fear, and many women's reality. The more vulnerable we are, the more we are at risk. A woman in a wheel chair or a woman using a cane is seen as fair game by some men. Shirley has friends who will go with her. Many women don't, and our vulnerability limits our chances to make friends and to meet potential lovers.

Adjusting to reduced strength, accepting a body that sometimes seems like an enemy and gives more pain than pleasure, and coming to terms with the image in our mirror that will never again resemble the one in the high-school yearbook are things that happen to all women with time. But for women who become disabled, these can happen in the late teens or early twenties. Our span as 'desirable' may be shortened. Whatever we may thin of traditional sex roles and traditional relationships, most of us would like to feel 'chosen,' to be beloved. Sexual intimacy for the long-term may elude many of us. Many women with relationships; 43% of the women in our sample were single. For others, relationships end when they become disabled. 34% of the women who became disabled after childhood stated that their relationship status had changed since they became disabled. 16% were divorced and 4% separated.

For a woman whose disabilities mean that she must have help for personal care and household tasks, being single can mean spending time frustrated, or neglected. Paula's attendant problems have increased as she has become more and more disabled. She has no choice but to rely on students, about there is a great deal of turnover, and she finds this instability difficult. Shirley, too, must rely on the unreliable. She sees neglect as a form of abuse, and she has suffered from neglect. She requires an attendant to help her get up, and to assist her in getting ready for bed. On occasion, the attendant hasn't shown up. She has had to phone someone else. Luckily, she has other people to phone.

Our study did not include a sufficient number of women who identified themselves as lesbians to provide insight into lesbian relationships among women with disabilities. Only 22% of our sample and about the same percentage of the women I interviewed were married. The married women I spoke with affirmed that equal relationships between men and women are still a goal, rather than an actuality for most Canadian women. That goal can be much harder to reach when the attitudinal, educational and financial barriers

to full-participation that our society places before people with disabilities are added to the still-unequal position of women in Canada. For heterosexual couples in which the woman is disabled, marriages seem to operate on a very unequal basis. While some women said they got both respect and caring from their spouse, more spoke of the difficulties their men had in coping with their disability. Rose's husband finds it hard that she can't dance; she tried, but broke her ankle due to osteoporosis, which is hitting her early because of her polio. Another woman I interviewed, who is in a wheelchair, said, 'My husband treats me like I'm able bodied; he sees me as completely competent. Sometimes that's difficult to live up to. "Many women with hidden disabilities find the same thing. We look ok - are we just trying to get out of work when we say we are tired all the time?"

I talked to married women who were expected to do the housework despite their disabilities. They must fight with their husbands, or fight with homemakers and social services if they cannot do the chores themselves. 'Brenda' has a husband, a lovely home, and two adolescent sons; we talked in our interview about her ongoing battles.

Last Monday I cried all day because the girl wasn't doing anything. I'm afraid to complain, because they will just take more hours away from me. I had 30 hours, now I'm down to 6. I've been in the program since day 1 and now they are trying to throw me out. (From notes taken during the interview)

The message Brenda is getting from her husband, her sons, her homemaker, and social services is 'You should be doing it yourself.' Brenda has MS and is in a period of relative remission, but is not strong enough to handle all the housework. Her internal knowledge of her own strength is incongruous with the messages she is being given. Again we are disbelieved.

Parenting

Parenting can be a source of joy, but also a source of frustration. The problems of parenting for women with disabilities will be the subject of another paper, but it seems important to touch on those that affect self-image here. Kids want a mom who is normal, who can make things for them and fulfill all their needs. Very few women can be perfect mothers, but the struggle is even more difficult for women with disabilities. Often, children are called upon to help at an early age, and expected to look after their siblings or take on household tasks before their friends must do these things. Mothers must deal with their own anger, and their own feelings of failure and frustration. Part of Brenda's anger lies in the fact that she feels guilt about the demands she

made on her sons when she was bed-ridden for two years. Now, she wants them to have a bit of the childhood freedom she believes she denied them.

Normal teen-age rebellion can be particularly difficult for a single mother; it can be very hard to discipline a child who is much more physically able than you are. Without support, parenting for women with disabilities can be a struggle that undermines rather than enhances their self-esteem. Mothers in our survey identified child care and transportation for their children as major problems in bringing up their kids; these are problems that could be rectified with good social services. Asked how they resolved their problems, the largest number answered that they 'struggled'.

Getting Older

The graph, "Age of Respondents" (see appendix A) shows that the women in our sample are a relatively young group. Over half are under 40. The largest group (46%) are women aged between 25 and 39 years of age. 31% are between 40 and 55 but only 12% are over 55.

These statistics reflect our sample and its sources, not the incidence of disability among all Canadian women with disabilities. DAWN Canada is an organization which focuses on issues of concern to women with disabilities not dealt with by other organizations such as parenting, sexuality, employment, self-image, access to the women's movement and violence. Parenting and employment are of greater interest to women under retirement age. There are also many seniors' organizations which attract older women.

However, this does not mean that DAWN Canada and its members are not concerned about mature women with disabilities - most of us will get there. Our disabilities may become more severe as we age and we are more likely to have more than one disability. According to Statistics Canada - 30% of individuals with disabilities who are over 65 have two disabilities, while only 23% have only one. Among those under 34, 55% have only one.

For some of us, our disabilities accelerate our aging. One respondent who has a spinal cord injury finds this difficult. She is in her late thirties but looks a decade older and men her age see her as too old. Fortunately, she is well educated and has an excellent, well-paying job. Yet she is still finding it a struggle to maintain a positive self-image in a society that reveres and values youth.

As we age, we again are more vulnerable to abuse and neglect. Elder abuse, called by the terrifyingly accurate term 'Granny Bashing' in England, is not a new phenomenon, although little research has been done on it. None of the women I interviewed were over 50, but some had witnessed elder abuse. Shirley lived in a group home for four years. There were older women there and she told us what she had seen.

I saw a lot of abuse in the group home. People were neglected, some were beaten. They just put my grandma in a home. They wanted to put her in the same one I'd been in. I went down on my knees, and begged my uncles not to. I saw people in there who had 'accidents' and they wouldn't change them all day. If a person annoyed the staff, they just ignored them. (from notes of the interview)

Yet for some of us, maturity may bring acceptance, and increased self-esteem. We may learn to stop envying others, and come to terms with our bodies and our disabilities. WE may accept aids that we spurned during years when we were willing to suffer to appear as 'normally' as possible. As one woman put it, 'I just got a wheelchair, and I use it when going a distance. After all these years of not wanting to be disabled, I finally got a wheelchair and I'm much more comfortable.' We are less isolated in our disabilities as we age; Statistics Canada indicates that rates of disability increase from 5% in children under six to 45% among adults aged 65 and older. Our age mates are acquiring canes and hearing aids and we are no longer stigmatized as 'other'. Everyone gets a pension, so living on one bears less stigma. Our entire age group may not be valued by society, but we are less alone. It may be easier to come to terms with our disabilities and to value our experience and ourselves.

Economic Factors

Whatever our time of life, poverty is a fact of life. The women in our sample were better educated than most women with disabilities, but their incomes did not show it. More earned under \$5,000 (23%) than earned over \$20,000 (21%). The median income was under \$10,000; 109 out of the 188 women earned less than \$10,000. Almost 40% were dependent on their parents or spouse for support; another 50% relied on government allowances or a pension. As NAPO (The National Anti-Poverty Organization) continually points out, it is hard to feel good about yourself when you are poor. It is also hard to be well-nourished, to dress adequately and attractively, to have a pleasant place to live, or to spend money on recreational activities and entertainment, which lighten the spirit and broaden social contacts. Good food is a foundation of well-being, yet welfare rates - and the minimum wage at which many

women with disabilities are forced to work - do not allow a recipient to eat foods mandated on the Canada Food Guide.

Many women with disabilities find it hard to find apparel that fits and allows freedom of movement when using a wheelchair or walker; when they do, it is expensive. No matter how strongly we may endorse feminist positions that fashion is an expensive trap that oppresses women, it is depressing and demeaning to have no choice but to wear second-hand, ill-fitting clothes.

A lack of appropriate clothing can make it even more difficult for women with disabilities to get jobs. So can the unwillingness of the social services in most provinces to provide necessary services, beyond a basic survival level. When I met with members of women for change, a group of women with disabilities in Newfoundland, they told me that social services there will provide only funds that are necessary for basic survival, 'it has to be absolutely a necessity, and you have to prove that again and again". To illustrate this; Mary, a group member, told me this story;

I'm in the process now of trying to get something, and I've been at it since last October and I still haven't got it. I'm still trying to get what I need, eh. I've gone back every day now for the past two weeks, and I still don't get anywhere, I didn't actually tell you what I'm trying to get; I'm trying to get my front teeth, right. I went for a job interview and they asked me if I was planning to get them. (from transcript of tape made during meeting with Women For Change: June 13, 1988)

Having front teeth in your mouth would seem to be a prerequisite to having a positive self-image to employability, and to good health. It is difficult to smile or carry on a conversation when there is a gap where your teeth should be. As another member of Women For Change pointed out, not having teeth is also preventing Mary from proper digestion, because she's not chewing properly.

Newfoundland is not unique. In Alberta, Clare told me about the Bureaucratic Stupidity she is trying to cope with. She has had a job with 'Santa's Helpers' for a month each year, but she was not going to be able to do it this past Christmas season because she would have earned \$7.50 an hour and over \$100 for the month. That would mean she would lose her disability allowance. As a result, she would not have any extra income to provide a Christmas for her daughters. Clare told me about her budget: She gets \$763 a month, and lives in co-op housing; her rent is \$460; her utilities are \$130; and then there is food. As Clare said, 'it takes it all.'

Women who live on such budgets cannot find adequate housing in any Canadian city. The stock of inexpensive housing is low; much of it is not accessible to many disabled people. If they cannot find an apartment, which is accessible to them in a subsidized project or co-op, they must live with relatives, or in basement suites, or single rooms. Bare bones budgets leave no room for luxuries like 'entertainment' or 'recreation'. Yet it is hard on our relationships with our kids never to be able to take them anywhere, or even give them a few dollars to go out with friends. It is limiting to our minds and our social relationships to have no knowledge of current plays, books and movies because we cannot afford access to them. Sports and other recreational activities can enhance our psychological health and our physical health, yet only 23% of our respondents participate regularly, while another 16% are occasional participants. The most common reason for non-participation is a lack of money; 53% of non-participants cited financial reasons. In denying us participation in community activities, poverty limits our lives and demeans us.

Media Stereotypes

Given all the above, it is miraculous that women born with disabilities grow up to be competent, positive women, and that women who become disabled later in life learn to adjust, and to maintain their self-esteem. There is little in our society to encourage us to do so. As we live our individual lives, cope with our families, our peers, and our educational system; our experience is counter pointed by messages from the media. In western society, the media create a background against which we form our images of ourselves, as individuals and as women. Television and advertising portray women as sex objects, and use our bodies to sell goods. We are seldom portrayed as authorities, as achievers, as decision makers. Women have been resisting these stereotypes for a long time and have formed such organizations as Media Watch to lobby for more realistic and less sexist images of women in the media. We have made some changes; there are more women anchoring news shows and fewer women draped over the hoods of cars in ads than there were a decade ago. On the other hand, television more frequently shows overt violence against women, and more liberal standards now allow for explicit scenes which give the message that all women really need and want is to be taken to bed by any male who has the wherewithal to do it. Pornography, which equates sex with domination, and frequently features women who are disabled, either in actuality or by the wearing of outfits inspired by bondage themes, is available in the video shops which have sprung up on every corner.

The overwhelming majority of women in the media have lithe, perfect bodies. They are white, beautiful, and under thirty years of age. Few women can live up to the media image of womanly perfection, and even those that do can only maintain that image for a small slice of their lifetimes. Further, billions of dollars are spent on advertising goods to improve our complexions, our bodies, and our womanliness and to make us feel that we can never be good enough as we are. As a result, women in general are not satisfied with their bodies. The part of ourselves we see as 'less than perfect' we tend to disregard, to see as worthless. We learn to loathe our physical selves.

All women struggle with the feelings of inadequacy, generated by the images of perfect young bodies, the super mom, the perfectly groomed, yet sexy, professional. Next to the perfect models, compared to the ultra white smiles, we all must learn to accept our flawed features and lumpy bodies. We must also come to terms with the attitudes inspired by sex-role stereotyping and subtle and overt messages that women are sex objects, that our only value is in our ability to turn men on. All women can experience depression and self-loathing until they learn to see media images for the limiting lies they are.

As Susie Orbach puts it, the 'emphasis on presentation as the central aspect of a woman's existence makes her extremely self-conscious. She must observe and evaluate herself, scrutinizing every detail of herself as though she were an outside judge.' (Orbach 1983:7) Feminist theorists have labeled the effect of such concepts as:

...Part of the tool kit of oppression as practiced by patriarchy ... The domination of women, as carried out in advanced western societies is effected not by force, but through the creation of consent, by means of an elaborate apparatus of social conditioning into appropriate sex role behavior. (Eisenstein 1987:XV)

This type of analysis leads to an understanding that society's idea of sexually appropriate behavior does not necessarily comply with perceived biological attributes such as male strength v. s. female weakness. It was developed to overcome a primary obstacle to the full participation of women in all aspects of social life, the belief that women were 'different' and limited by that difference to the domestic sphere. In our society, different tends to mean 'unequal.'

Images that foster feelings of insecurity in able-bodied women can be devastating to a woman who is in a wheelchair, a woman whose disability requires her to repeatedly insert needles in her legs, a woman whose body or brain reacts in ways she can neither anticipate nor control. They can trigger

serious depression in a young woman who has gained a good deal of her sense of self from her physical appearance, and becomes disabled.

As women with disabilities, we may judge ourselves not only in terms of how society expects a woman to look, but also in terms of the socially constructed myths surrounding the disabled; the media which stereotypes women also stereotypes the disabled, or denies our existence. AS stated in the recent first report of the standing committee on the status of disabled persons: No news is bad news (which will from here on be referred to as the 'report').

The media helps to shape public understanding of the disability community. It influences the climate of opinion within which policy affecting disabled persons will be made. The media can facilitate or impede the exchange of information between the policy-makers and consumer or advocacy groups. In addition, the media can perform other roles, such as publicizing available services. It can also influence the self-perception of disabled persons.

Men with disabilities also suffer from these stereotypes. However, women with disabilities are more likely to internalize the identity of the victim, the vulnerable, dependent, incompetent object, because it interlocks with the stereotype of the feminine. All women and girls experience pressure to be humble and complacent, to smile sweetly and be thankful for the help they receive. Women who express their anger or their hurt, are seen as complaining, embittered, as lashing out (Thompson 1985:83), not to mention unlovable, unladylike and just plain 'bitchy'. Women whose disabilities make them dependent on parents, spouses, caregivers or their own children are not free to express their anger; they fear more life-threatening reprisals; abandonment, refusal to provide food or essential care. By gender and disability, we are twice tied into passive roles.

The standing committee did an extensive survey of representations of the disabled in the media, and contracted research by Canadian journalists. Their studies included some content analysis of Canadian publications and a canvas of people with disabilities regarding their perceptions of coverage and portrayal by the media. One respondent, Mona Winberg, a columnist with the Toronto Sun, noted the stereotyping that limits public perceptions of individuals with disabilities:

The perception of disabled people goes from one extreme to the other. Either we are noble beyond belief and almost superhuman, or we are useless and only want to collect our monthly benefits and watch television all day. (report 1988:13)

Because 'nobility' is seen primarily as a male attribute, and equated in our society with physical strength and stamina, the 'superhuman' image portrayed in media coverage of Rick Hansen, Terry Fox and their brothers is particularly hard for women with disabilities to live up to. DAWN Canada expressed this in its submission to the committee:

What about all the people who are unable to do anything quite so spectacular? Does that mean that they are any less brave and resolute? Sometimes just getting dressed every morning for some people must feel like pushing from here to Moose Jaw. (Report: 12)

Another respondent commented on another stereotype, that of the 'poor cripple.'

The whole way North America thinks, if something's not perfect, it is not worth it. I'm determined they're going to portray me in the right way. If I am poor, it's society's fault because I can't get a full-time job. (report: 7)

Her comments are reflections on the 'tiny tim' type of journalism, the appeals to charity that so degrade the 'recipients.' Many of these inaccurate reports are 'based on newspapermen's patronizing attitudes. Geared to elicit feelings of pathos.' In newspapers or in the odious 'telethons', reduction to objects of charity dehumanizes individuals with disabilities, and lowers our self-esteem. As the report states:

Our primary conclusion is that persons with disabilities consider themselves to be, first and foremost, individuals. Only secondly do they consider themselves to be disabled. A stereotype or use of language, therefore, which places the disability before the person is not just a syntactical short cut; it is also offensive. (Report: 6-7)

Dehumanization also takes place through a lack of recognition of the differences between our disabilities. While the experience of people with disabilities has elements in common, it is also unique and diverse. A lumping together of the 'handicapped' is a denial of us and a failure to recognize us as individuals. To quote the report once more:

The differences between disabilities are not recognized, e.g. Fact that Deaf see themselves as a cultural minority, with a different language, rather than a disabled group. (Report: 8)

The media concentrate on the most visible disabilities, perhaps because they are the most obvious and most likely to elicit sympathy. Invisible disabilities, particularly those involving the emotions or intellectual development, tend to be ignored. The authors of the report point out that:

Like the community at large, the media are more squeamish in dealing with individuals with psychiatric or developmental disabilities than those who have a physical disability. 'You are always hesitant, for instance, to quote a mentally-handicapped person, wondering if it is fair to do so when the person might have trouble formulating or expressing ideas or opinions.' (Quote from reporter) (Report: 8)

This suggests that women in the media do not offend us in an active way; it can offend by denying our existence. As the report notes:

...Disabled persons who responded to our committee's English language survey feel that they receive the worst quality and frequency of media coverage compared to other groups considered as minorities (women, visible minorities, native people, senior citizens, youth and homosexuals). (Report: 9)

Other researchers (Byrd et al 1980:326 and 1981:80) have remarked that much media coverage contains the usually implicit notion 'that the disabled are unimportant and that society can afford to ignore them.'

Not only are the quality and frequency of coverage of issues relating to disability low, the tone is patronizing. For the report states:

Groups of persons with disabilities or groups representing disabled people were viewed in the same light as any other advocacy group, but with one important difference: Story 'Tone' - the tone most newspaper stories was restrictive and either related to 'injustice' or to sympathy.

The media often refer to persons with disabilities in language that is thoughtless and insulting. The committees' examples of terms used by the media to describe persons disabilities included: cripple, confined to, handicapped, victim of, suffering from, stricken by, invalid, wheelchair bound, sightless, spastic, inflicted with, gimp, deaf as a post, deaf and dumb, falling on deaf ears.

Even such terms as 'special' can be limiting, segregate us, and help to create a ghetto in which we exist apart. Because we are 'special', we are seldom

consulted on issues other than those which directly involve us. To quote one contributor to the report:

I would prefer an integrated approach showing us as part and parcel of society instead of different and therefore special and deserving of the human interest approach (Report: 17)

We are rarely asked our opinions on the issues of the free trade, Meech Lake Accord, and daycare. We are, after all, citizens and voters, interested in all issues, not just 'disabled' issues, to set us apart, to categorize us as interested only in a narrow range of issues is to deny us full citizenship, and also to deny that larger issues affect us. All social and economic issues have impact on individuals with disabilities; indeed, because we may consume social and health services more than our non-disabled sisters, they often affect us more. Further, coverage of 'disability issues' is often inaccurate. It is often reactionary and not reflective of the actual activities and concerns of the disabled community today.

The news media are lagging behind the disability community in the perception of issues the media are not yet sensitive to the changing nature of the disability community with its emphasis on self-help and independence. Also, there has been relatively little coverage of the growing emphasis on the rights, services and political actions to achieve the goals established by advocacy groups of individuals with disabilities. (Report: 45)

One way in which the media denies us autonomy is by asking able-bodied advocates to speak on our behalf. The committee's study found that 'authoritative statements' on disability-related issues were attributed to officials, medical practitioners and individuals in other professions ... disabled persons rarely appeared in their own right'. (Report: 53)

Disabled persons were most often quoted, not as primary authorities, but in describing their reactions to expert and official pronouncements. Daily newspapers tend to rely on experts and community papers on officials. Very few of the disabled persons who were quoted were acting as spokespersons for groups. (report: 55)

On Canadian television, persons with disabilities are most often seen in the 'telethon' context. Celebrities attempt to raise money for charity to help the 'victims' most frequently, 'crippled' children - of disabling diseases. In newspapers, editorials and commentaries on issues relevant to disability were almost completely absent.

The committee asked a panel of persons with disabilities to analyse media images of disabled persons. The panel found that all media tended to describe disabled persons as 'victims' and to emphasize disability rather than ability and common humanity issues.

Such stereotypes have profound, if subtle, impact with disabilities. They increase our feelings of isolation, our sense of being abnormal, 'outsiders'. They make it harder to believe that people will accept us, that we can form good friendships and loving relationships. It increases the fear and avoidance of the disabled that limits us in so many ways.

Bree Walker, a television anchorwoman who has unusual hands and feet has stated, (on the Sally Jesse Raphael Show, CKVU TV Jan 5, 1989) 'I have always been the one who had to reach out, to offer my hand for 'a handshake, because people are unsure of how to deal with me.' For a young woman with a disability already unsure of herself, reaching out can be difficult and once the reaching has occurred, acquaintances may still be wary. Ellen Stohl, a woman with paraplegia who has appeared in Playboy, stated on the same program that, 'everyone I meet has to go through what I went through; they have to adjust.' Bree and Ellen are young and very beautiful. Their disabilities are 'nice' ones; they do not drool, they are articulate. If they have found barriers, those barriers would seem to be much higher for women who are less close to what our culture sees as perfection.

Feminists developed organizations like Media Watch to increase awareness of sex role stereotyping, and to lobby government for initiatives to encourage positive and realistic portrayals of women. The parliamentary committee recommended the creation of a similar organization to work on images of people with disabilities. DAWN BC has a member who focuses on monitoring the media. It is an initiative that DAWN Canada should encourage, and participate in.

Ways to Heal

Whether a woman or child with disabilities is dealing with her parents, her spouse, her caregivers, her therapists, or her doctor, our relationships consistently reflect a power imbalance. Because of these women with disabilities often have a great deal of repressed anger and very few people with whom they feel safe venting such anger. Expressing anger requires trust in our reactions and judging the actions of others. It means we must believe that we are right, that our perceptions are real. It requires the very self-confidence that dependency does not foster (Scheman, 1984: 178)

In order to survive as women with disabilities we must be constantly thankful; thankful to our mothers, fathers, siblings, teachers, therapists, attendants and caregivers, to our spouses. We avoid making clear statements about how we really feel. We do anything we can to focus our energy on others, to protect and preserve our relationships. In such circumstances, it is virtually impossible to develop the assertiveness which is integral to a positive self-image. We may have with good reason, genuine fear of an unaccepting world outside. Since 'the devil we know' is often preferable to the unknown, we tolerate our situations as best we can.

How does a girl or woman who to some degree, may remain physically dependent throughout her life, express her independence, her anger and her frustration, particularly when society does its utmost to make achieving freedom and independence as difficult as possible? Obviously, good feminist therapy would and should help. But, to my knowledge, there are feminist therapists who have disabilities, only a few work in offices that are wheelchair accessible; fewer still know sign language, or understand the realities of disabled women's lives. Further, the majority of women with disabilities cannot afford this sort of counseling.

Group therapy, like the 'anger workshops' organized by DAWN BC can be healing and strengthening. But in some areas, simple act of getting women with disabilities together can prove to be a veritable nightmare. Even if problems of transportation and accessibility are overcome. The group itself must deal with the expressed anger and the conflicts that will be created as a result. One situation that is rarely mentioned but which exists is the:

Hierarchy that ranks people according to the 'acceptability' of their disability. An individual's position in this hierarchy is generally determined by how well that person fits into society's 'norm'. In other words, the less disabled you look, the higher your rank. And this reasoning frequently applies in both the able-bodied and disabled communities. (Thompson 1985:82)

Conflicts may occur when women who have been disabled for a long time confront the 'out of control' anger and frustration experienced by newly disabled women. (Thompson: 81) On the other hand, women who are disabled as adults often express frustration with women who have been born disabled, because many of them have so many unmet needs, many are ignorant of the feminist movement, many have an extremely poor self-image, many lack education and independence. The unstated assumption that 'my disability' is worse than your disability can be part of the group's dynamics as well.

Still, groups are important; they provide a safe place for emotions to be expressed. An understanding of another's inner struggle may illuminate our own. I have described elsewhere (Ridington 1978) how healing can come about when problems for which we blame ourselves come to be understood as common to many women who are like us in many ways. As Naomi Scheman puts it "As long as only you can really know what's going on in your own head, the odds are fairly high you never will." (Scheman 1984: 185)

Scheman suggests that it is important that support groups of any sort work beyond the 'touchy feely' and get to the political that they analyze how the individual is socially and politically constructed. As she puts it:

"Getting in touch with your feelings" free from the influence of other people or of political concerns, is a dangerous myth. To take this position is to stifle the possibility of particular sorts of political change. But it's also to blind ourselves to the truth that we are kin many deep and important ways what others take or at least allow us to be. (IBID)

Our work is two-fold. We must validate each other, and then seek validation in the larger world. Once we have gained strength, we have more overtly political work to do. Suggestions for changes in legislation and in support services, to ameliorate violence against women with disabilities, to promote employment equity, and to assist mothers with disabilities will be made in the other papers in this series. Changing attitudes, which deny us our pride and self-esteem, requires long-term vision and the co-operation of the disabled consumers movement and the women's movement.

That co-operation is coming into being. The coalition of Provincial organizations of the handicapped (COPOH) has begun to address women's issues, and to liaise with DAWN Canada. Published an excellent discussion paper on women's issues (D'Aubin: 1986). The women's movement is slowly becoming aware of the existence of its disabled sisters. It is imperative women with disabilities work with non-disabled women, to bring them toward a greater understanding of our oppression. Though the process is slow, understanding is developing among disabled women, as well as among a larger group of women with disabilities. Women for Change, the consulting committee on women with disabilities, and DAWN Canada and its' affiliates are drawing attention to the ways in which society has stereotyped disabled. They are spotlighting the physical and attitudinal barriers that have protected the majority of people from having to acknowledge the poverty, isolation, and abuse experienced by women with disabilities. Naming the feelings and frustration making people aware of the struggles, the anger, and the

contradictions is the first step to alleviating our pain and isolation. As Naomi Scheman points out, for change to be brought about, it is essential:

... To bring light, clarify, and explain the nature and sources of dimly perceived contradictions in or between our concepts and our social practice. Such contradictions may have been there all along, but their presence causes particular trouble when social practice is changing. One doesn't choose here between explaining the world and changing it: Rather one explains and perhaps facilitates the change by changing the explanations. (Scheman: 1986)

The feminist movement has sought to overcome the boundaries of social categories, and to focus on our common experience as women. This process has been incomplete. There are still gaps and misunderstandings between women of different classes and sexual orientations, and between white women and women of colour. But no larger gap remains than the gulf between women with disabilities and non-disabled women.

As Pat Israel has stated, being a disabled feminist prior to DAWN was lonely and frustrating. (Israel, 1985:1) National organizations have been reluctant or perhaps just amazingly slow, to recognize that they have excluded a large constituency of women. The National Action Committee on the Status of Women, the umbrella group to which most women's organizations belong, had its' first visibly disabled executive member in 1985:85 when Pat Israel sat on the board. Although I was a NAC Vice-President during 1983-84, a time when there was a great deal of internal strife on NAC, I did not find it a safe place to make my invisible disabilities (epilepsy and arthritis) public knowledge. DAWN Canada and some of the regional organizations have joined NAC, and NAC now has a sub-committee on women with disabilities.

NAC still fails to address all issues as they specifically affect women with disabilities. For example NAC is demanding threat the Meech Lake Accord be amended to ensure the supremacy of Section 28 of the Charter of Rights and Freedoms, which is a notwithstanding clause guaranteeing that the rights of women cannot be overridden. This however, would not guarantee the supremacy of the rights of disabled persons, which are covered only in section 15 of the charter.

The Canadian Advisory Council on the Status of Women, a government advisory board appointed to advise on women's issues, has recently prepared an excellent paper on women with disabilities, which is not yet available in English. Its 1987-88 Annual Report carries a recommendation that 'the

Federal Government provide, where appropriate, shelters and/or support services which are designed to meet the special needs of rural, isolated, aboriginal, immigrant, visible minority, teenage, older women and women with disabilities' (Canadian Advisory Council on the Status of Women 1988:18).

Across Canada, attempts to include women with disabilities in local women's events are increasing. However, these still sometimes end in embarrassment, when speakers are invited into buildings that are inaccessible, or wine-up dance is held in an upstairs hall. And if our sisters are insensitive, if they fail to reach out and include us, how can we see ourselves reflected in them and work to enrich each other's' lives - and our own?

Unfortunately, the strains of political work were particularly hard on us; burn-out' is a well-known problem in the women's movement. It will be an even greater problem for us, or our stamina is often less. We must be gentle with the women who take on the tasks of working to improve conditions for all of us; we must all remember that we cannot care for others if we do not care for ourselves. Frustrated with activism, some women with disabilities have come to focus more on their own health. Gwenyth Ferguson-Mathews, whose book *Voices From the Shadows* was the first on the subject of women with disabilities to be published in Canada, is now exploring alternate forms of healing and has had some success. As she said during our interview, "I have shifted from activism to self-image... I am saying, "I am worth it." So she is so are we all. Recognizing that is essential to our self-esteem.

Acknowledgements

Thanks to all of the women with disabilities from across Canada who participated in our project by filling out a long and detailed questionnaire. Some of you needed assistance in getting through it and for that extra effort we are especially grateful to you. Thanks also to those of you who agreed to be interviewed in person and, in this way, enriched the project by sharing even more of your time and the details of your lives with us.

Jillian Ridington, researcher, and Shirley Masuda, Project Coordinator, worked unceasingly. We owe them many thanks for their hard and creative work, without which this original research would not exist.

C.A. Graham and Associates and Pacific National Vehicle Leasing made the graphs possible and for this we are grateful.

Special thanks is due to our funders, the Secretary of State Department's Disabled Persons Participation Program (DPPP), Women's Program, and promotion of Official Languages Branch, whose financial support made this project possible. We are particularly fortunate to have the constant support and encouragement of Glynis Ellerington, our Project Officer (DPPP),

And last but not least, to our Angel, who has supported us in many ways right from the beginning, Thanks!

Joan Meister,
Chairperson,
DAWN Canada