

Stress in Mothers of the Disabled

By Jennifer Hoyle

Les mères d'enfants handicapés sont susceptibles d'éprouver beaucoup de stress en raison d'un sentiment d'aliénation conjugué au manque de soutien social de la part de la parenté, des conjoints et de la communauté. Le présent article préconise que l'on reconnaisse le travail des mères d'enfants handicapés en leur offrant un soutien véritable et en mettant fin à la tendance qui veut qu'elles assument de plus en plus de responsabilités de l'État en accomplissant du travail non rémunéré et dévalué.

CASE STUDY

On an early morning in February 1979, something happened that penetrated the very essence of my being; my first child was born. She was a beautiful, bald headed, blue eyed, miracle and I was overwhelmed with a feeling of joy.

My daughter was not a content baby. She was breast-fed, rocked, read to, taken outside and loved. I could not help wondering what was wrong. The doctor would tell me that she was colic and I accepted that until she was about four months old. The strangest part was that she would turn her body and her head to her left; ignoring that her right side existed. She was unable to sit alone until she was about nine months old because she did not use her right hand to help hold her up. She did not move around because crawling meant using both sides of her body. To top it off, she was not sleeping day or night.

Doctor's visits became times filled with mixed emotions. It was difficult to watch the other children doing the things that my child could not and dealing with the stares of other mothers. Most of all I became anxious about my visits with the doctor himself. Every check up I would tell him what she was not doing and he would tell

me that she may just be slow and not to worry. I felt like I was being an overprotective, first time mother but inside I really believed that something was wrong with my daughter. He would not label her and it was not until my husband and I together asked him to refer us to the Children's Centre for an assessment, that he gave us the referral.

My suspicions were confirmed at the Centre. Although my daughter was never labelled there, she was immediately treated with physiotherapy and occupational therapy. I remember the anger and guilt I felt when the therapist told me that she felt she could have had more success with Amy had she been there before sixteen months of age. Amy was not labelled until the school board sent her through a battery of testing some seven years later in order to find a placement for her within the school system. She was then labelled a child with hemipalagic cerebral palsy caused by a porencephalic cyst in the mid-right fossa of her brain. The label was important to me. It confirmed my credibility as a concerned mother, if not to the doctors, at least to myself. It gave me a basis upon which I could start to do what needed to be done in order to give her the best possible life.

These years taught me a lot. I no longer believed that doctors were Gods but I also knew that I had trouble standing up for what I believed was right. I questioned myself all the time. Why can't I do all that these experts are saying I should be doing? Why don't I want to do some of those things like physio and speech? Well, another major event in my life provided me with an opportunity to answer some of these questions.

In July of 1983 our second daughter was born. This pregnancy had been plagued with sickness, sadness and fear

that something may be wrong with this child, even though I had been assured that the chances of that were almost nil. By now I was sensitive to anything that appeared to be unnatural behaviour for a child and when I saw my daughter there was something that made me question whether or not she was okay. She had a worried look on her face and her eyes looked as though they were covered with an opaque film. They were not bright like Amy's. For some reason I associated it with mental retardation. Family, friends, doctors, nurses and my husband assured me that they did not see this and that maybe I was looking for something abnormal since I had had a bad pregnancy and a long labour.

By this time I had changed to a general practitioner who was very accommodating as far as my requests for referrals. He also spent time with me during visits, listened to what I had to say about my daughter and gave it credibility. I was not so lucky with some of the professionals to whom he referred me. My experience was that the more specialized the professional, the less power I felt I had in making decisions about the care of my daughters.

Caring for this child became a nightmare. She continued to have trouble eating, cried all the time and slept very little. This brought back memories of Amy and I asked to have her referred to a pediatrician. I'll never forget the day I took her to see him. He looked at me and said that Jessie had neurological problems and would not lead a normal life. He was sending her for tests at the hospital. I remember driving home from the doctor's office with Jessie crying in the back seat. I was crying in disbelief. How would I cope? I felt so alone.

The tests confirmed a micro-cephalic diagnosis which means a small head and

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a small brain. I was given the diagnosis and sent home to cope. I was in shock. I now had two children with special needs but because I was getting no sleep, I had no energy to deal with the situation in any sane manner. My husband and I had no life since my life centred around the needs of the children and instead of working in a partnership he tended to deal with things by going out with his friends. I was even more alone.

The turning point came when Jessie was about one and a half years old. I went to her physiotherapist and told her that I did not know if I could keep the care up and that I was frightened. Thank goodness for her insight as she gave me a number to call; a family support worker. She thought that under the circumstances, maybe Jessie could start in the nursery school program at the centre, even though she had not yet reached the mandatory age of two. She listened to my concerns and did not increase my load by telling me what else I should be doing for my daughter. I will never forget her. She opened doors for me when I did not think there were any. The onus wasn't all on me. The responsibilities could be shared, if not by my husband, maybe by some social services. There seemed to be hope.

In many ways nursery school for Jessie meant a life for me. She cried at nursery school and I felt guilty but I knew that I needed a break and I needed to be with other moms in similar situations. Some of my closest friends came from that time in my life and I found a new strength within myself to persevere.

Not all parent support groups proved to be so supportive. Some parents added to societal prejudices and I felt even more alone. I remember a parent making a comment when I was working to integrate Jessie into a kindergarten class. Jessie is non-verbal, totally dependent but very social. My intentions were to use her

social skills with other children to aid in her development of a communication system. Although these parents had disabled children who were in wheelchairs too, their children had purposeful movement, could talk and learn more traditionally. These parents could not understand why I would not send Jessie to the Children's Centre for school, implying that Jessie did not have the right to belong in the same system as their children.

The family support worker informed me that I was entitled to handicapped Children's Benefits for Jessie as well as Amy. I was angry that I had not known this before as we had paid for everything prior to this point for both girls, e.g. braces, glasses, transportation to and from appointments. She told me about a Parent Relief program that meant trained individuals would come and sit for parents, for a minimal fee and the government subsidized the rest. Special Needs at Home was another option for us. According to this program, we would be able to have a worker come in up to twenty hours a week to help. All of this was welcome news, but I did not realize the implications of getting involved in these programs.

Handicapped Children's Benefits is means tested, which means that in order to receive it we were required to give our financial status to substantiate that our annual income was within the given limits. The application for both girls meant that I would have to spend an afternoon with a worker stating what I spend on my children's needs over and above what a family with a "normal" child would. This was difficult as neither of my children could be placed in the category of "normal" so I had nothing to compare it to.

The Parental Relief Program involved a long case history of both girls, a visit with the co-ordinator to go over the history of the girls and then visits with the people who wanted to do relief sitting.

Each prospective employee had to be taught the things that I do with the girls every day. All this took several weeks. Also, sitters came and left from this program regularly which meant this process of training and informing was ongoing.

The Special Services at Home Program depended upon whether or not one was willing to label their child as developmentally handicapped because this program, at that time, was only available to this group of children. Developmentally handicapped was a nice way of saying mentally handicapped. Jessie fit this category but I was not about to label Amy in this way as it could have implications for her future school placements. I felt this label would be detrimental to a child who was close to the norm both physically and mentally. This program ran on a six month contract basis between workers and clients so every six months a new application needed to be filled out with no assurance that it would be accepted. Therefore it became important to have support for your application and the goals therein. This meant letters from the experts (e.g. doctors and therapists). I had to prove that my child was disabled enough to warrant her a worker. Recently, the Special Services at Home Program was expanded to include the physically disabled. This means that Amy may be able to take advantage of the program, but it means more applications, more workers and more red-tape.

The bottom line in taking advantage of these programs was that our private life became an open book, with people always going in and out of our house. Perhaps even more frustrating, was trying to find the time in an already busy life to do the paper work and accommodate the visits from the program co-ordinators.

In all this, I have become frustrated with doctors and other health practitioners who view me as an overprotective

mom. I am a mom who knows her children because I work with them every day and must always be alert to changes. I am also frustrated with a system that puts more work on the mother. Ultimately, since I was at home (out of necessity), I took care not only of the girls but of all the services and workers that were involved with them.

As Jessie gets bigger and her needs increase I am starting to question how long I will be able to continue to care for her. Although I have taken advantage of the many services available, most of the day-to-day activities are left up to me. These thoughts lead to guilt and much sadness. I want her to live with me but nothing comes easy. Caring for her physically is only a small part of the problem. I get more frustrated organizing the services available and getting letters of support from professionals. Accessing these services is not just a matter of one telephone call. Sometimes it takes many phone calls to ensure support. There is no certainty whether workers will be able to remain with my family for any length of time as these jobs from government services are part-time and low pay. This created a major problem for me as far as searching for employment and getting my education were concerned.

The bottom line for me becomes a matter of trying to educate friends, family and the government (by means of advocacy), that my children are people first with strengths and abilities like everyone else. They may not be successful in the eyes of mainstream society, but the way I see it, maybe we as a society need to view success in alternative terms since it means different things to different people. Any social policy concerning mothers of the disabled must address this issue if my children and all other disabled persons are to have a valued existence. Perhaps at that time, mothers as caregivers will be valued too.

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Stress occurs when individuals have to deal with demands over and above the usual level of activity. As stressors increase, there is an increase in the possibility of health problems. Health depends upon a person's ability to adapt to the changes in their environment and still remain relatively stable (Clarke, 1990:

109-10). There are three main stages of adaptation: the alarm reaction, resistance, and exhaustion (Selye, as cited in Clarke, 1990). The alarm reaction involves the body's production of hormones for fight or flight. Resistance is an adaptive stage where the body starts repairing itself after the stress has been applied. Exhaustion occurs if the stress continues, as the body tries to keep up its defenses and runs out of energy. Continued exhaustion can lead to "diseases of adaptation" (Selye).

The impact of stressors on an individual depends on evaluation of the stress, coping strategies, control and available social support (Clarke, 1990: 112). This article focuses on how mothers of the disabled are affected by the degree of control they are able to feel and the amount of social support they can draw on. My aim is to reveal how it is those forces outside of the mother, rather than the forces within her, which compound her stress.

The traditional view of women as caregivers is one source of stress for mothers of disabled children. Women do not have adequate social supports for what are understood to be their "feminine" roles. The disabled persons they care for are also an oppressed group who receive little social support. These mothers are more alienated and have less social support than other women.

How are mothers in general alienated? Alison Jaggar argues that as a result of the industrial revolution and the 'science' of child development, mothers' control over childrearing has been reduced. Men have come to determine how children are raised while 'experts' dictate scientific methods of childrearing (Jaggar, 1988: 311). Scientific methods of childrearing are based on judgments and studies that take children to be products produced according to specific criteria, and assume that mothers need instruction on how to raise children (Jaggar, 1988: 312 and Rosenberg, 1988: 388-389). As a result, mothers question their ability to raise children and become alienated from them in much the same way that wage labourers are alienated from the products of their labour (Jaggar, 1988: 312).

Women as Caregivers

To understand caring, we must take account of the social relations of gender

and privacy which place those who care in a private prison to cope alone with responsibilities (Graham, 1985: 48).

The caregiver role is understood by both men and women as a 'natural' one for women (Bem et al., 1984: 13, Bullock, 1990: 70). Both sexes view child care work as part of maternal devotion (Bullock, 1990: 70, and Graham, 1985: 36). Attitudes about which gender should do the childrearing support an unequal division of labour between mothers and fathers. Mothers have the major responsibility for health care in the home (Clarke, 1990: 28 and Cook, 1988: 43).

Mothers are also the mediators for professional services outside the home. This role takes them outside of the private realm and into the public realm. Responsibility for health care places mothers in contact with doctors, social workers, district nurses and, as in our case study, therapists and social support programs (Graham, 1985: 26). Mothers become the link between the informal health care system and the formal health care system of the state. It becomes obvious that the major responsibility for nurturing the ill child and co-ordinating his or her treatment falls in the laps of mothers (Cook, 1988: 43, Bullock, 1990: 72, and Burke, 1987: 1).

With the movement to de-institutionalize care for the disabled child, the mother is now required to form a mini-institution within the home environment (Bullock, 1990: 72). Our case study reveals how one mother became the sole caregiver for her children by trying to co-ordinate all the aspects of their health care, including therapists, doctors, advocates and taxis. A study by McCubbin (1988) confirms that it is mothers who usually accompany their chronically ill children to clinic appointments and health care services. Mothers of the disabled have more and more responsibilities associated with their caregiving role, and are therefore more and more susceptible to burnout. Burnout is usually associated with workplace stress. It is found in frontline workers like teachers and nurses and is the result of continuous demands, little time away from concentrated personal interaction, shifts and having the responsibility of two or more things at once (Rosenberg, 1988: 390). Mothers of the disabled take

on many of the roles of frontline workers. They are highly involved in the child's life, keeping watch over every detail. They spend more time in caregiving than mothers of non-disabled (Burke, 1987: 1).

The home care demands placed on these mothers often add to financial worries. Mothers of the disabled are often unable to work outside of the home to help with the financial burdens (Bullock, 1990: 73, and McCubbin, 1988: 28). This may isolate them even more from the public realm.

It is assumed that a mother will take on the role of caregiving but there is no recognition that she may need social support because caring for a human being is not viewed as work, only as a "private, natural and essential enterprise" (Rosenberg, 1988: 386). On the one hand, women are contributors to social reproduction, providing labour for industrialized society. On the other hand, their work is a "biological necessity" and it is not viewed as 'real' work; their role has a low status (Rosenberg, 1988: 36).

Social Support for Feminine Roles

The first social supports to consider are those associated with the family. Support from husbands has already been explored; there is little—if any at all—because child care is assumed to be a 'natural' role for women. In industrialized society, women are isolated from other women. There are no longer extended families, boarders and maids to help mothers with child rearing (Jaggar, 1988: 312). Mothers have little chance to learn caregiving skills from others within the nuclear family (Rosenberg, 1988: 388).

A child with disabilities places greater demands on the family. If mothers are left with the role of caregiving without family support, stress is increased. Lack of extended family support, lack of adaptability within the family to changing demands and lack of fathers' involvement in health care are major sources of stress for mothers of disabled (McCubbin, 1988).

Doctors and clinicians are also a major source of stress for mothers who have

Fact:

Women today spend 17 years caring for their children and 18 years helping an elderly parent.*

**Work and Family: The Crucial Balance, Ontario Women's Directorate, 1991, p.29*

children with disabilities as they exert their power over these women, take away any control over decision-making and once again leave mothers alienated from their childrearing practices. Often these professionals are the perpetrators of mother-blaming (Cook, 1988: 43). Visits are brief and centred around the health of the child with little concern about how child rearing affects the mental health of the mother (Rosenberg, 1988: 389). As if the child gains weight the mother is fine—even if she may be falling apart emotionally. If a mother goes to alternative forms of health care for her child she is criticized for listening to old wives' tales or for negligence (Rosenberg, 1988: 389).

Taking control of the situation is an important issue for mothers of children with disabilities as we saw in the case study. This mother felt that she was lucky to have a practitioner who spent time with her and respected her requests. Being "esteemed and valued" has already been identified as a form of social support.

Dr. Sharon Burke conducted a study of stress and coping by mothers with disabled children and mothers with non-disabled children. The former mothers found medical items, such as talking to the medical staff in hospitals and clinics, reading more about a medical problem and making sure prescribed medical treatments were carried out at home, to be less helpful in managing stressful situations than mothers of non-disabled (Burke, 1987: 2). Perhaps this implies that the medical items listed may be part of the stress; or that true empathy can only be provided by the like-minded. Perhaps mothers of disabled place less faith in the medical profession and what it can actually do for their children.

After the industrial revolution women became the 'community' because they carried out all the positive components of a community in the individual household

(Bullock, 1990: 67). State policy makers build their organization of community work around the assumption that community work and women's work are the same thing (Bul-

lock, 1990: 70). The promotion of community care programs for persons with disabilities by the government is based on the idea that it is a 'humanitarian' thing to do. In reality it creates more inequality for women because their work as caregivers within the community is taken for granted (Bullock, 1990: 68).

De-institutionalization means that disabled children are placed with their families in the community. Government funded community-based support services and allowances for these families are run on small budgets; even though the government actually saved money by closing institutions for disabled children (Bullock, 1990: 74). Families of the disabled must therefore compete against each other for scarce resources because of the lack of proper funding. Accessing available resources for their children also becomes a problem because of bureaucratic red tape (McCubbin, 1988: 209). In our case study, in order for the mother to receive Special Services at Home she needed to obtain letters of support from experts—"to prove that my child was disabled enough to warrant her a worker."

With de-institutionalization, the state meets its own financial and administrative priorities while reinforcing inequality. Women are not only used by the state to help get rid of expensive long-term care responsibilities, but the state also makes women dependent on the male wage (e.g., husband's wage) by confining them to the home.

Many of the resources available to families of disabled persons are supplied by women. These jobs are low-paid, part-time and often done on a volunteer basis (Bullock, 1990: 75-76). This creates special implications for the mothers of these children because their workers are often looking for better paying and more stable jobs. The mothers are constantly training new workers to help them provide care for

their children. This lack of certainty of support and the amount of time needed to train new workers adds frustration and stress.

The Disabled as an Oppressed Group

Mothers of the disabled care for an oppressed group within society. This oppression can be traced to the capitalist system because disabled individuals do not or cannot always participate in the social and economic roles that support capitalism. The disabled are viewed as "social junk" by the dominant class (Spitzer, 1974-75). Their costs to society can hinder the capitalist system's maintenance and growth. Controls, including the medical and social service agencies of the state, are therefore set up to regulate and contain them.

According to Gleidman and Roth (as cited in Seligman et al., 1989) the disabled have a greater likelihood of unemployment, poverty, low education attainment and social isolation—not only because of their disability but also as a result of society's reaction to them. The Statistical Profile of Disabled Persons in Ontario (1988) has produced some proof for these claims. Fourteen per cent of the adult population of Ontario is considered disabled. Of that 14 per cent, 46 per cent do not participate in the labour force (compared to 22 per cent of non-disabled adults not in the work force).

The disabled tend to have a lower education level than non-disabled. Between the ages of 20 and 24, non-disabled are twice as likely to be enrolled in educational systems (Statistical Profile 11). This means lower status, lower paid and lower prestige jobs will be available for disabled individuals. It also suggests that they are less likely to get into positions where they can have some influence on social policy.

Although mothers are important to the maintenance of capitalism (because they produce a surplus of labour), their work as caregivers is unpaid and devalued labour. Why would a social system support a caregiver who is caring for an individual who is not viewed as possessing any economic benefit to capitalist society? Mothers of children with disabilities provide just enough support for their children to let society and its institutions off the hook.

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