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The Only Parent in the Neighbourhood: Mothering and Women with Disabilities

In truth, our society is not adequately supportive of any parent. There is not real training for parenthood, so the reality comes as a surprise to most of us. Parenthood is the hardest job anyone will ever have. Yet the physically limited parent may be the only parent in the neighbourhood toward whom the community directs its anxiety about the difficulties of the job. Joann Lemaistre, "Parenting", [With The Power Of Each Breath](#)

As Lemaistre indicates, surviving as a woman who has both children and a disability in a society that sees our disabilities before it sees our womanhood requires ingenuity and strong survival skills. However, a discussion of the issue of parenting for women with disabilities must be broader than a simple discussion of such skills. The means of coping must be discussed and the women who have done it must be celebrated other issues must also be discussed: the right to choose whether to have a child or not; the right to adopt; the right to have disabilities and keep our children; the right to community support in our mothering.

This position paper is based on the results of DAWN Canada's 1988 survey of women with disabilities. The project included the distribution of 1,200 questionnaires, which were returned by 245 women with a variety of disabilities and meetings with approximately fifty of the respondents from the Atlantic provinces, Alberta, and northern B.C. and the Yukon who volunteered to be interviewed. Through this project and this paper, DAWN Canada hopes to increase awareness of issues affecting mothers with disabilities and to point out areas for further discussion and research.

Reproductive Rights:

In the first two papers in this series, "Who Do We Think We Are: Self-Image And Women with disabilities" and "Beating The 'Odds': Violence And Women with disabilities" (both Ridington 1989) we mentioned the urgent need for truly accessible sex education materials and birth control information. Our sexual relationships should be ones that we choose, out of our own needs and desires. They can not be so if we have been denied information about sexuality. Similarly, a choice to be a parent must be an informed choice.

We must have access to appropriate birth control information and materials so that our pregnancies can be planned and chosen. Beyond that, should birth control fail, we must --like all women --have the right to terminate a pregnancy when **we** decide that abortion is necessary.

For women with disAbilities, the term "reproductive rights" encompasses more than the right of access to birth control and the right of choice. It also includes the right not to have fetuses taken from us against our will, and the right to retain our wombs, our ovaries, our fallopian tubes.

It includes the right not to have our bodies used as a testing ground for unproven contraceptives and questionable new reproductive technologies, and the right not to be injected with harmful hormones that disrupt our normal bodily functions in order to "simplify" caring for us.¹

Medical science uses us as the objects of tests, but it also strives to keep us from replicating ourselves. Practitioners seek to interrupt pregnancies which could perpetuate us; they seek to destroy what we have created, if it is formed in our image. New reproductive technologies have simplified the identification of foetuses with disAbilities; our society's concept that disability is abnormal and undesirable has created an expectation that identification must result in elimination. We would reiterate the question disabled activist Marsha Saxton posed to conference examining the concept of a "handicapped-free society": "why should a pre-natal screening revealing a disabled foetus be automatically followed by a systemic abortion?" (see Barile 1988). Certainly, we should be informed about all available medical tests, and told the results of all the tests we choose to undergo. We should also be put in contact with parents of children who have the same disability and with existing support groups. We can then consider all this information when making our decisions.

As feminists, we know that a woman's right to control her body is fundamental to women's equality. Yet other feminists have been slow to support the right of women with disAbilities to control our bodies. Perhaps now that chorionic villi sampling (cvs) can be used to detect the sex of the foetus in the first trimester, making abortion for the purposes of sexual selection possible, feminists will come to understand the issue from our perspective. For it is not women on our own who are choosing to abort foetuses that will become female infants. According to a doctor who performs such tests and appeared on CBC-Radio's Cross-. Country Checkup, on March 12, 1989, it can be "couples from mid eastern backgrounds, where men need sons as heirs." all women must have the right to make informed decisions as to whether we mother, and under what circumstances. As Barile notes, (1988:5) we must ensure that, "freedom of choice will mean that all women will have access to all the available information that will permit them to make a choice that is truly their own." neither men wanting heirs nor doctors who see us as producers of "undesirables" should make that choice for us.

Some "reproductive technologies" may be new, but forced sterilization is not. As Anne Finger points out, compulsory and coerced sterilization of the disabled began in the late 19th century. Its most enthusiastic practitioners were the Nazis. (Finger 1985: 294-297). Women with mobility impairments and those of us who have epilepsy and other neurological disorders have been sterilized. So have individuals who are deaf: they were seen as "incomplete" humans because they "had no language."²

Sterilization of women with disabilities remains a common medical procedure. It is a manifestation of the attitude that persons with disabilities are asexual, or should be. (see Ridington 1989a) we lose our right to choose when our reproductive organs can be removed at the will of caregivers, lawyers, parents, or medical practitioners.

In the interviews conducted with women with disabilities during the summer of 1988, several women told of their pain at having had their right to parent removed. A young woman i will call "Shirley" lost that right when she was only seventeen. She has cerebral palsy and uses a wheelchair. She is in her mid twenties, well-groomed, articulate and attractive. She loves babies. She would like to have her own children, but has had a hysterectomy. During the interview, she said, "i would adopt if the right man came along." he came along once and they planned marriage. He was killed in a motorcycle accident four years ago. She has not met his like again. The hysterectomy was done when Shirley was living in a group home. At the time, her menstrual flow was very heavy. They put her on six different kinds of hormones but nothing worked so then they removed her uterus.

Shirley would love to work in a day-care, but has been told that her disability precludes it; she can't lift children. But she does look after the children of friends ranging from small babies to a hyperactive eight-year old. She told us a long story about a friend whose wife had left him with a very small infant while she went away for the weekend. Within hours, he was pounding on Shirley's door asking for help. She went home with him, warming the cold, damp baby under her shawl on the way. She found clean diapers, blankets and food, and had both father and baby calmed down in short order.

Shirley talked of caring for children with the same enthusiasm and caring that a poet or a fine craftsperson has when she speaks of her work. It was obvious that it was what she would choose to do, above all else. But she grew up with a disability, and went to a special school within a children's hospital. She had learned to be compliant, and to accept the verdicts of physicians. Shirley was just entering womanhood when her womb was taken from her. Would the doctor who made her barren at the beginning of her reproductive years have sterilized a non-disabled teen-ager who had the same symptoms?

"Janet" also lost her right to parent, not at the hands of doctors, but at the fists of her ex-husband. He beat her when she was pregnant. When i worked at Vancouver transition house, i learned from the residents that when a woman gets pregnant, the pattern of her husband's battering might change. The blows do not hit the face any more; they land on the belly.

It's been called the "poor man's abortion." like Shirley, Janet was still in her teens when she became sterile.

I lost the only child i had a chance of having. He was still within me after five months. Then my husband was abusing and battering me around. When it came to the baby, i carried it for almost five months, and then it died. It was dead inside me. ..., i could never have kids, and i was told this right from the time i was 20 on. And to me, it's always been painful, like. When mother's day comes around. If you are told at 19 that you can't have kids for the rest of your life, it just throws a cold damper on your insides. I have the pain every now and again

of realizing i can't have kids. .. For my own gratification, knowing the hell i went through. ..its not that i don't feel complete, i just feel the hurt and the pain of not being able to be a mum. (from transcript of meeting with a group of women with disAbilities)

Adoption:

When i talked with Janet and her group, her friends suggested that she adopt. "whether it is natural or adoption, you can still be a mother." but Janet had tried that route, and been denied that possible avenue to motherhood as well.

I found out i cannot because i am on a disability pension and they will not allow it. ..they will not allow my husband and i to have a [foster] child in the home because of the very same reason. You have to have a working income and "a good home environment." (from same transcript)

Janet has a disability that she terms "brain damage" as the result of a bus accident in her early teens. Perhaps the adoption agency saw that as a barrier to good parenting. We know that other women with disAbilities have had difficulties in adopting. Those that have been successful have been told they would only be given a child who is disabled. We are concerned about the number of children with disAbilities who are not placed in permanent homes. In many cases, restrictions on giving out medical histories make adoption difficult or impossible. We would urge that such restriction be lifted.

However, we believe that the decision to parent a child who may have special needs should be up to the adoptive mother, rather than the agency. If the agency is concerned that the prospective mother's disability may cause her difficulty in parenting, it would seem logical that they give her a child they consider easy to parent. It is that they Value children with disAbilities less, or are simply glad to get rid of "difficult" children?

In recent years, some people with disAbilities --generally couples in "stable marriages" --have been successful in adopting, with no restrictions as to whether the child has or does not have a disability. Valerie Richardson, who is mobility impaired, and her husband tom, who has epilepsy and haemoplegia, spoke at the "parenting" workshop during the 1988 conference of the Alberta Committee of Disabled Citizens (ACDC). They have an adopted son, now four, and are applying to adopt a daughter. They found a friendly social worker and were given some help from the government. Unfortunately, it was cut off after the first year. Still, the Richardsons have been successful parents. Their son has adapted well; as his dad. Said, " Brandon doesn't know how not to adapt".

Surely, applicants who seek to adopt children should be judged on their ability to give a child a caring home. Disability should be reason for providing any necessary support services to adoptive parents. It should not be a reason for refusing them a child.

Pregnancy:

For those of us who choose to become pregnant, and are successful in conceiving, pregnancy can be an affirmation of womanhood. Donna Hyler described her feelings in her article in [With The Power Of Each Breath: A Disabled Woman's Anthology.](#)

...the possibility that i might be pregnant awakened in me a growing sense of joy that i had never before felt. A previously dormant part of me spiritual, physical and psychological was heralding its existence and making friends with the rest of me. (Hyler 1985: 280)

Pregnancy can bring back a pride in our bodies that has been negated. It also can be problematic. Girls with disAbilities and adolescents who become disabled frequently are told not to expect to become mothers. When they find out that motherhood is impending, they may doubt their ability to bear a child, and to parent her. There are few role models and fewer support systems. Friends, relatives and health professionals may be critical and overly solicitous. Megan Kirshbaum, executive director of a support group for parents with disAbilities in San Francisco , points out that:

...some of the most successful relationships with medical providers involved a kind of collaboration in which the woman's knowledge of her own body and functioning was acknowledged and respected."

(Kirshbaum 1988: 9)

We are, after all, the authorities on the workings of the bodies we live in, but this is not recognized in most doctor patient relationships. Physicians who can collaborate as Kirshbaum suggests are great allies; unfortunately, they are rare. Many doctors may have difficulty dealing with women who are both pregnant and disabled. We blur their categories. Physicians lack models for dealing with us. Many have a hard time saying, "i don't know how to deal with this, but i'll try to find out as much as i can and help you as best i can." their lack of knowledge may trigger insecurities, which become expressed in authoritarian behaviours. Their dogmatism then reinforces our own doubts about our abilities to mother. Rather than deal with us honestly, they may urge us to abort, or be unsympathetic. "Ruth", who is post-polio, told me of her pregnancy. When she needed an emergency caesarean, her doctor accused her of "wanting the easy way out." she went on to have two healthy boys, and to be a foster mother to 13 kids.

Although a new "female procedures chair system" is being manufactured,³ most gynecological examining tables are not designed for use by women who are mobility impaired. Transferring on to them is difficult, and sometimes dangerous.⁴ maternity wards may be full of hurdles: transferring to the trolleys that carry patients into the labour room; getting access to the baby in a lying-in arrangement; using an inaccessible washroom. Kirshbaum tells of a pregnant paraplegic woman who was asked to stand for "just a minute" on a scale, and of interference with the role of an interpreter during labour. (Kirshbaum 1988:9) although proportionately we may well spend more time in them than non-disAbled womens hospital facilities are not designed with women with disAbilities in mind.

Pregnancy may exacerbate our disabilities. For example, multiple sclerosis, which generally becomes apparent in young adulthood, often involves bladder problems. Pregnancy puts strain on the bladder. The result can be toxemia. "Ilz," who also participated in our interviews, had two small children and was pregnant with a third when her ms manifested itself. She became extremely toxic and gained sixty pounds. She was in and out of hospital for the last six months of her pregnancy. The pregnancy went on for ten months. She is Catholic, and wanted more children. She decided it was too risky.

Making mothering accessible:

Eighty-eight of the 245 women who returned our questionnaires indicated that they have children. Not all of them had been disabled at the time that their children were born. Thirty-eight women, or 43% of the responding mothers, gave birth (or adopted) before they became disabled. Nine had children both before their disability became apparent and after. Forty-one (47%) became mothers while they had a disability.

The highest number (31) were mothers of two children. Twenty-eight had one, and twenty were mothers of three. Mothers of many children responded as well. Three women had four, two had five, and there was the mother of six. Most respondents were mothers of children already grown; 78 children were listed in the over eighteen years category. Only 9 of the children listed were still pre-schoolers, and thirty-five were of school age. This does not mean that women with disabilities are no longer having children. In fact, the likelihood that we will parent probably is increasing. As Megan Kirshbaum points out, the fact that young adults with disabilities are: ...integrating into the community, forming relationships, becoming sexually active, expecting a full life [is] leading to a rapid increase in the number of disabled parents." (Kirshbaum 1988:9)

The fact that our respondents are more likely to be mothers of older children in all likelihood reflects the fact that young mothers with disabilities are over-burdened. They have no time to get involved with disabled consumers' associations and organizations of women with disabilities. These organizations were a primary source of names for the distribution of questionnaire.

The mothers who did respond had not found motherhood easy. Question fifteen of our questionnaire asked "were any of the following a problem when you were raising your children" and listed six items. The percentage of mothers who answered, "yes" for each item is as follows (many mothers checked more than one item):

- Housing 25%
- Transportation for yourself 36%
- Transportation for children 25%
- Child care 33%

- Household tasks 32%
- Lack of social/medical workers who understood your situation 33%

Because there is a dearth of information, of resources and of support services, each new parent has had to resolve her problems on her own. Val Richardson adopted her child and then found that the manufacturers of baby gear have not yet realized that parents with disabilities exist. She designed an appropriate crib, and had a tray built onto her wheelchair to facilitate feeding and diaper changing. Parents notice that their children adjust to their parents' disabilities very early. As Val Richardson said in her workshop, "Brandon sensed that he had to do things for himself. It was sometimes tough, but every time you go through a tough time, you learn you can get through it."

We do get through it, but resources would certainly make it easier. "Patsy", a mother of two, is mobility impaired and lacks upper body strength. She is very competent; I met her in her office where she manages a centre for people with disabilities. But she had a hard time when her children were little. She could not carry them. She had no knowledge of any support system and no awareness of how to deal with the babies; "I just groped through myself." she went on to say:

I was scared to be alone with the babies until they were walking, then when they were I couldn't get things like cleaning supplies out of the way, so I could never leave them alone, had to watch them 24 hours a day. A man would never understand. With the first one, I felt extremely burdened, then guilty. By the second child, I had a better attitude. But the support simply isn't there for disabled mothers. (from notes of interview)

Despite the lack of resources, we not only survive, but find creative and effective solutions. "liz" also encountered problems as a mother of three when she developed MS. She began to lose her sight, "but never in both eyes at once until later." she found that "carrying the kids was hard." child care was another problem, as was transportation. She could not drive because of her eyes. Her husband drove her places when he could but she had to do a lot of things when he was not home. Like many of our respondents, she relied on her children for help, and then felt guilty about it. In her words, "the six-year old looked after the house and the 3 year old and the dog. I had to work on letting them still be kids."

Like Valerie, liz invented solutions. In the winter, she made the girls red parkas so she could see them easily against the snow. Her problem is a common one. It is difficult to keep track of active children when you cannot see them clearly, or when you cannot run after them. Children of two learn that they can outrun a wheelchair. They sense that their mum cannot find them if they sneak into dark corners. When it suits their purposes, they take advantage. For this reason, the pre-school years can be the most difficult.

Gail, who developed ms at sixteen, found that things got more difficult when her daughter got too heavy for her to lift.

I went through the pregnancy, no problem at all. In fact for the first two years I was able to carry her around, it

was a normal situation. It was just when she was turning about 3 and a half, 4 years old, I was finding it more of a problem. My balance started going; that was my problem from the beginning but it started to be a little more than usual seriousness. She was taking swimming lessons from about 4 months old, but after she was about 3 and a half years old I could not continue on because I didn't feel safe with her. I couldn't lift her up, I was always afraid of falling over. In fact I did do that a couple of times, fell over on top of her. And that wasn't in swimming, that was just getting out of the car and walking up to the bank. ...I guess I was relieved in a way, she still held together even though I fell on her, she took it in stride. (from transcript of tape of interview)

Lack of knowledge and information forces parents to develop their own ways of coping. Fortunately, we seem to be brilliantly adept at doing that. It seems that our children are also resourceful. They follow our lead, and the process becomes reciprocal.

Megan Kirshbaum and her organization, "through the looking glass," have studied and videotaped the interaction of parents with disAbilities and their infants during the babies' first year. They seek to "describe the dance between disabled mother and infant --the mutuality, reciprocity as it occurs in caretaking and play." (1988: 10) for example, their videotapes show the co-operation between a mother with paraplegia and her baby. The mother's problems with balance meant that she had to lift him with one hand; at one month of age, he would adapt by curling up like a kitten and remaining very still during the lift." as time progressed, the co-operation intensified. Kirshbaum and her co-workers also found that infants were more patient with their disabled parent than with other caregivers (1988: 11).

Having access to such information is vital. We need to know how other mothers and children have choreographed their "dance". At present, there is no compendium of knowledge that can help us when we are struggling. The dance is redeveloped step by step as each new mother comes on stage.

Communities and governments provide few resources. In most regions of the country, some services exist for parents of children with disAbilities. Yet there is little awareness that people with disAbilities are also parents.

Child care is expensive, and the best care is very expensive indeed. Many good centres require parent involvement, and no parents want to leave their child in a centre they have not examined carefully. We have all heard or read reports about children who are abused and neglected by caregivers; we do not want that to happen to our child. However, many centres are inaccessible. Few provide accessible transportation to enable mothers to accompany their children. Child care activists have only begun to address the needs of parents of children with disAbilities. The concerns of parents who themselves have disabilities were not mentioned during the Canadian Day Care Advocacy Association's 1988 conference. ⁵

The "neighbourhood hub" model, which was mentioned during that conference, ⁶ is one that with input from mothers who have disabilities could provide a good resource. It combines a child care centre with a library, a drop-in centre, a toy library, a newsletter, and conferences and workshops. Videotapes like those made at "through the looking glass" and other information could be included in the library. Infant-care items adapted for specific needs could be rented or traded there. If made physically accessible, and with information provided

in all necessary formats, the "neighbourhood hub" could be a source of information and relief.

At present, community services used by most parents - community centres, family drop-ins, swimming pools and parks, or even schools --may present barriers to parents in wheelchairs or parents who use guide-dogs and canes. Most of us cope, struggling by ourselves or relying on friends and relatives. Some, like Liz, have supportive spouses.

Even where services exist, many mothers cannot get to them. As Rawnie Dunn points out in her "discussion paper on parenting", (1988: 6) transit services for the disabled may not allow small children on board. This makes it impossible for mothers with disabilities to take their infants and toddlers with them, even when a child requires a medical check-up. In parenting, as in so many things, it is not our disabilities that create difficulties; it is the barriers presented by an inaccessible world.

The resourcefulness and the endurance of mothers with disabilities illuminated the answers to another of our questions: "if you resolved any of these problems, please take a minute to tell us how you did this." one woman mentioned that she had started a mobility bus and is still on the board that runs it. Others wrote:

I read as much as I could on the subject, and experimented with various common sense solutions. Practical experience from my work as a nurse came in handy, and I helped with formation of a self-help group in the city.

I became aggressive and learned how to vocalize my concerns and I became adapted to most situations.

Fortunately, I own and drive a car. There have been times when I couldn't even open a car door without severe pain, but I have persevered and managed to get through the difficult times. I have refused to give in to the disease and try to live an active life, no matter how severe the pain and the desire to give in to it. (mother of two school-age children; she has arthritis)

I insisted that my child be provided transportation from kindergarten to day-care even though seats were reserved for social service clients -- stubbornness on my part.

Many mentioned the help they got from their kids. Married women on the whole seemed to find it easier. They generally had more money; some of them could hire help. One "adapted living - house, car, homemaker help." three learned to drive and bought cars (one of them was planning to leave, but waited until she had her license). Some married mothers spoke of the help and support they received from their spouses. Yet there were more whom, despite the presence of a partner, gave answers that indicated they resolved things on their own. One answered, "made special arrangements with playschool, hired my own, never did solve it," one stated simply, "they grew up, thank god."

Although women who were in relationships were generally less poor than single mothers, some women

found marriage a financial impediment. Wives are seen as dependents by many government social services, so wives of men who are themselves on pensions or in low-paying jobs suffer. One woman is struggling to make her house accessible, but lacks money:

I have made a few' renovations for access when I could get money together for it. Husband's income is too high to qualify for help -- no disability pension - catch 22 situation."

Some women became resigned, and stopped seeking assistance. " I didn't do tasks I was unable to do," one wrote, and another just "did what we could with what was available --used neighbours and friends or did without." some were forced to give up for a while:

I left home and went to an institution in 1981 because township would no longer pay for my homemaker attendant to come in and my husband at the time worked 3 shifts. .. I could not be left alone.

(this respondent is now remarried, and living at home.)

For others, the struggle continues; " I'm still trying, still fighting with Yukon home care services." from another:

While I found no ideal solutions to above problems, I managed to make arrangements. ..hired domestic help, relying on friends, mate, public transportation, taxis ...the hardest part is finding someone (anyone) who understands enough to really help one cope. Perhaps this is simply asking too much? Sometimes the solution must come from inner strength.

Single Parenting:

Mothering isn't easy; single parenting hardly ever is. Mothering with a disability is always difficult, and single parenting when you have a disability is tough indeed. Yet over half of the mothers in our sample (48/88) are, or have been, single parents? Their problems are the same as those of women who are partnered, but they are more likely to be exacerbated by poverty.

As [graph 1](#): "Income Level Of Mothers By Relationship Status" (see Appendix A) shows, similar numbers of single parents and mothers who are partnered have low incomes. In both groups, ten women report incomes under \$5,000. However, [graph 2](#): "Source Of Income Of Mothers By Relationship Status" (see Appendix B) shows that 25% of partnered mothers are supported by their spouses and the total family income in many cases may be higher. The median income for both groups of mothers is between \$10,000 and \$15,000 and eleven of these women have incomes of over \$20,000. Only 30 of the 40 mothers in relationships answered the question on income; only one single mother did not report her income.

Seventeen single mothers (36%) have incomes of under \$10,000 and 25 (53%) earn less than \$15,000. Only 17% earn over \$20,000. This group of mothers, which includes widows, separated and divorced women, and

never married women, support themselves and, in many cases, their children, on their low incomes.

When asked to give their main source of income, many women note more than one category. For this reason, the information contained in graph 2 is based on a higher number that used for graph 1. Fifty-six answers were given by the 20 mothers living with a partner and 53 were received from single women. This basis, 20% of single mothers work full-time while only 12.5% of partnered mothers do. Fifty-eight percent of the single mothers (31 of the 47) rely to some extent on government

Assistance (pensions, welfare benefits, etc.), while only 23% of mothers who are in a relationship receive government payments. Out of 35 divorced and separated mothers, only 3 receive support payments from a former spouse. One widow survives on insurance payments.

The single mothers cope with poverty and with other difficulties. They get very few support services from governments or from their communities. In their replies to our question, "if you resolved any of these problems, please take a

Minute to tell us how you did this," single mothers proved Lemaistre's point: communities and governments do little to help parents with disabilities meet challenges, "yet the physically limited parent may be the only parent in the neighbourhood toward whom the community directs its anxiety about the difficulties of the job."

Self-will and determination to stay active and I was able to accomplish [as] many projects as I possibly could. I relied on myself, it was difficult. (single mother of 5, mobility impaired)

Re: housing --not resolved; just continued to pay 1/2 to 3/4 of monthly income for housing while raising my children alone. Re: child care; my parents looked after children from divorce for five years; then I packed their lunches and phoned them after school at home daily to check up on them.

Emergencies are the dread of every mother. For women who have restricted mobility and live alone with their children, they are a nightmare. In 1985, I interviewed a young mother I called "Melody" for an article that appeared in Resources For Research (Ridington: 1985). She told me about the night her youngest child had acute bronchitis, and needed hospitalization.

I was just out of the rehab centre. I had no money, couldn't afford an ambulance. I had my mum's car outside, because I'd been being chauffeured around in it, but it didn't have hand controls. But I had to get her to the hospital. I carried her over my shoulder, balancing her while I tried to crutch my way to the car. You can imagine me trying to put her in the car, trying to get the door open with her and my crutches, and my no-good hands. Then I drove with my feet on the controls, but no real idea of how much I was pressing on the accelerator. I was scared stiff somebody was going to drive right through me. But I got her there.

Housing that is livable, affordable and accessible is a problem for all people with disabilities. There isn't enough

of it. For single mothers, it can be an insurmountable problem.

Many apartments that are supposedly accessible have only one accessible bedroom. How does a mother in a chair reach her children to tuck them in? To take their temperature or clean up their vomit? Or to get them out in an emergency?

Melody lives in a so-called "handicapped" suite with her two daughters. She explained why the suite didn't meet her needs:

There is an assumption that disabled people will live only with an aide. A spouse, a relative, or kids -you're not expected to have those. And the garbage, the laundry rooms, the fire doors are all-inaccessible. When you're holding a small child, it's hard to hold one of those heavy doors and push your chair through. There's a three or four inch step up to the laundry room, and you have to open the door with a key. So I can do only laundry if Terri [her daughter] is around. (Ridington 1985)

Many of us require services, like medical specialists and rehabilitation centres, that are only available in the cities. As housing in major cities becomes more and more expensive, choices become fewer and fewer. The trend to "user pay" philosophies and privatization of social services is making it still more difficult to get access to resources. No wonder many mothers spoke of survival rather than resolution.

Help with my son was never available so he had a hard childhood.

I really didn't [resolve], just had to struggle with the situation.

Never! Long term care threatened to take my child away; also said he had to quit boy scouts to look after me. L. T.C. would not let homemakers cook, clean or wash for him (he was eleven).

Kept seeking assistance through various agencies. Live the best I can under any condition; close my eyes to the rest.

Several sent a succinct message; "I struggled until the kids grew up", or "I survived as best I could."

Single parents who are native or members of "visible minority" groups as well as having disabilities, may feel the "anxiety of the community" most directly. Edna coffin is a native woman with a mobility impairment. She was a single parent for several years. Her "demographics" are the kind that seem to push social workers' buttons. In a workshop on parenting at the Alberta committee of disabled citizens conference in September, 1988, she spoke of the pressure that social workers put on her to abort, or to have her children placed for adoption. Once they were born, she was the target of unannounced visits and general harassment at the hands of social services.

Such stories are common; cases where single mothers with disabilities received thoughtful support are not.

Some single mothers got involved with agencies that could help, or formed their own groups when none existed. "I solved [my] housing problem by getting involved with Ontario Housing." wrote one;

From another, "I lobbied and organized for housing access."

Some didn't make it; others had very difficult times indeed. One woman answered, "My sister adopted my son." Another stated, "I was in a mental hospital for a nervous breakdown for a while."

Coping with Violence:

More than half of the single mothers with disAbilities who responded to our survey not only had to deal with problems of transportation, accommodation, child care and the like; they had to deal with the residue of violence in their own lives and in the lives of their children. We did not ask women who were separated or divorced why their marriage broke up. Our data, however, allowed us to compare the rates of violence experienced by mothers when compared to women who had never parented. We found the rate of violence for all mothers (40 out of 88, or 45%) to be somewhat higher than the overall rate of reported violence for all respondents (40%).

We also compared violence experienced by women who were currently in relationships with that experienced by those who had separated and divorced for mothers who were in a relationship, the rate of violence was 23%; the rate of abuse by a spouse was 13%. Mothers, in contrast, had a 47% rate of abuse by a spouse. Overall, 64% of them had experienced violence, whether by a spouse, a parent, or someone else. Eleven

Women listed more than one assailant. One mobility impaired mother of two listed four assailants: parent, spouse, service provider and caregiver. The rate increased for those who were not currently in a relationship: almost two-thirds (30 out of 48, or 63%) have divorced, separated, widowed or single (never-married) mothers had experienced violence.

Regardless of their relationship status, sixty-five percent of all the mothers who reported violence (26/40) named a-spouse or ex-spouse as a perpetrator. Divorced, single, remarried and widowed mothers all had higher rates of spousal abuse than did women currently in a relationship. But five mothers continued to live with a partner or spouse who had perpetrated violence against them.

The high rate of abuse by spouses suggests that many mothers with disAbilities left --or were forced out of -- violent relationships. Re-integrating a life after violence, even when the difficulties are not increased by the lack of resources for mothers with disAbilities, is an arduous task. Children who have known violence can be difficult to mother. In "beating the 'odds': violence and women with disAbilities", we met Clare who is blind. Her husband's sexual abuse of her two young daughters broke up the family. Clare is very poor and says she feels very isolated; "i have no real social life." the kids are now in school all day, but they still show signs of the abuse. The younger daughter is having petitmal seizures. She is in a "special" class, and feels a lot of stress

"she just blanks out, and she gets very high temperatures."

Isolation:

The lack of social contacts and support that Clare lamented is a real problem for many mothers with disabilities. Mentioned the need for community, for a chance to learn from those who have passed along our path before us. Some mothers we have spoke of another kind of isolation: they told us of estrangement imposed on them by those we should be able to trust. Such neglect is a form of psychological abuse. We can be isolated even when we are surrounded by people, if they are insensitive and neglectful of our needs.

Isolation and despair led "Louise", a mother with ms and asthma, to try to commit suicide three times. Her body, her home and her family life were deteriorating. Improper medication had exacerbated her disabilities to the point where she was "having seizures, talking nonsense, feeling burning sensations," she went down to 62 pounds. It was painful to eat; her bowels were so backed up "my feces were up around my heart." she was paralyzed for two years, and in bad shape for five. When she could no longer walk, she was put on a couch in the basement; she spent years down there, in a room with no windows. She felt very isolated and did not understand why she was put there, "I don't know where my husband's head was." her boys were afraid of her dying, "I don't know how the people around me put up with me. " it seems they put up with her by isolating her.

Her children have been damaged by it all. Her 12 year old is "mentally disturbed" and can't read yet. She is still in the marriage. Now she is walking, struggling to keep her home care, and insisting that the boys have a year off housework to make up for the years when she had to rely on them for survival.

Children as Helpers:

Mothers spoke and wrote of their fears about the effects of their disabilities on their children. They worried about being dependent on their kids for care. They thought they were denying their children a proper childhood. They were concerned that their children's friends would tease them about their "weird" mother. They wondered how to deal with kids who felt responsible for the disability, as many did.

The question of whether it harms children to have to do more chores than their peers is a moot one. Most parents at the ACDC parenting workshop felt guilty about making demands on their children. Certainly, kids must be allowed to be kids. They should have time for school work, time to form friendships, time to lie on their bellies and dream, if they want to do so. Childhood must not be denied them, and they should not be used as servants and 24-hour attendants. The presence of children should not be an excuse for social agencies to refuse to provide needed help.

However, if children know they are loved and that their efforts are appreciated, it surely does no harm for them to learn early in life that others must depend on them, and that they must take as well as give. In a world where individualism and selfishness are seen as prerequisites for "success", our children have greater

opportunities to learn to be responsive and responsible. In a world of hierarchy, we can show them the need for the web of interconnectedness. These are qualities that women traditionally value, and rightly so. They result in the non-hierarchical world view that Carol Gilligan has described in her book, In A Different Voice (1982: 62-63).

Since relationships, when cast in the image of hierarchy, appear inherently unstable and morally problematic, their transposition into the image of web changes an order of inequality into a structure of interconnection. ... the experiences of inequality and interconnection, inherent in the relation of parent and child, then give rise to the ethics of justice and care, the ideals of human relationship-- the vision that self and other will be treated as of equal worth, that despite difference in power, things will be fair; the vision that everyone will be responded to and included, that no one will be left alone or hurt.

What better vision to give our children, to allow them to grow into the kind of human beings who can solve the social and environmental problems that exist now and which will no doubt get more complex as they mature?

Adolescence:

Mothers with disabilities may find their children's adolescence trying. Most mothers do, and having a fifteen-year old six-footer tower over your chair as you tell him he's grounded doesn't make it easier. As "Susan" put it during our interview, "it is hard to stand up to them when you're sitting down all the time." she has a degenerative and genetic disability, and has been in a chair for three years. Her daughter is solicitous, and wants to stay home and help all the time: "I have to push her out into the world." but her sons are different. They are struggling to come to terms with the changes Susan's disability has made to their lives. She remarked;

I truly think it is harder on them than on me. I would like to find a support group for them. I think a lot of it is that they are afraid they might get it. Right now they've both been tested and they are all right. But that doesn't mean they won't develop it somewhere down the line. There is no test for the gene. They don't know enough about it."

Young people who must confront the fact that a disability is genetic may bear resentment; "what did you do to me, giving me this to cope with?" Susan continued:

They have a lot of anger, because their mother can't do so many things. They see the TV moms and expect that, you know, bobbing around like Clare Huxtable, law degree in one hand, vacuum in the other. It's not very real. They want everything other teen-agers have, in families where both parents are working. My husband is unemployed. They can't understand why I can't go out and work. They look in the paper and say, "hey mum, there's a job for you." but I have really low energy because of my disability. If I don't feel good, they have to cook for themselves. They get mad. There is no support; unless you can contact someone you know who's been through it.

We have to be very secure in our identities and in our parenting skills to respond to our children's anger and

their concerns without feeling guilt or grief. Again, support groups and knowledge of the way other parents have handled such situations would be helpful. Again, such resources are rare.

Role Models:

We heard and read stories of success as well as the stories of struggle. We talked to "Gail", who chose to leave her marriage because she had outgrown it. She and her former husband share custody of their daughter, and they have made it work very well. We talked about her parenting during our interview. I felt admiration for the way she had handled a situation that affects many families, and is always difficult for children and parents. When she decided to leave the relationship she said,

"Do whatever you want, you can hate me, but don't do it in front of [daughter]." Because I have a six year old daughter now. And I said, she is our priority, we've got to focus on her, and never mind what problems we have. I've found since then, as far as my ex goes, we get along better now, we just couldn't live together. . Because now we have that one focus, our daughter. She was there when he moved out. In the truck and wherever they went, driving to his place, which is maybe five minutes from where we live, in a vicinity that is really familiar to her. The thing that really pleases me is that our friends, the majority of them, as far as the kids and such they sort of continue on acting just like we had been before, except that [ex-husband] doesn't live here. I think that helped a lot with my daughter, the fact that they took it in stride. I talked to the day care worker at the time, the fact that this was happening, that she might have a bit of change in her reaction. And actually I was told that the day after [her dad] moved out she was colouring by herself and very quiet, not too much mingling with the other kids, but that was only for one day. She can phone him whenever she wants, there's very good accessibility. There's no "no, you can't come over this time." in fact she's with him now, his cousin's getting married. (from transcript of tape of interview)

Our children can accept us, and will, if we accept ourselves. Fathers with disabilities who spoke during the ACDC workshop on parenting worried about their children's reaction to their disabilities. They grieved the loss of physical strength which they saw as being necessary for interaction as a father. It may be the only role model they know. One queried, "how do i deal with my kids when i can't play hockey with them?" he might have been reassured had he read the results of Frances Buck's study which compared the psychological health of children with fathers who had and did not have disabilities. As cited by Rawnie Dunn, he might have found that 97% of the children with disabled fathers reported that they had benefited from having a disabled father. Many expressed appreciation that their fathers stayed home and taught them patience, Values, coping skills, and sensitivity to others. (Dunn 1988:2)

The fathers who worry because they can't play sports have failed so far to realize the infinite capacity of kids to adapt and to love. Edna Coffin is athletic, and spoke in the ACDC workshop about how her kids were "surprised that other parents walked, and that basketball was played without wheelchairs." Gail's MS has developed to the point where walking is not always possible, and she recently got a scooter. Her six-year old daughter loves it.

I know when I got this scooter here, she thought it was the best thing since sliced bread. She ran off to the park across the street and said, "my mum's really good now, she's got a scooter, she can come now," and she was happy that I could come, because for a short while before I got this, I wasn't able to get across the street, I just couldn't. She wasn't held back, but I couldn't go with her. So she was very pleased when I got the scooter, she could ride on my lap. She's getting a little taller now so its going to be not too much longer before she can't; I'm always moving her head to the side so I can see around the corner. (from transcription of tape of interview)

The Gifts We Grant Our Children:

As we learn to cope, as we resolve our dilemmas, as we demand our rights and the respect we should be accorded, we are giving our children this knowledge as well, our children have opportunities to acquire skills that are rare in the non-disabled populace. There are practical examples. Mothers who are deaf told me of their children who are growing up bilingual, learning American Sign Language (ASL) from their mothers and spoken language from friends and television. Such children grow up to be wonderful interpreters; many professional signers are the children of a deaf parent.

Knowledge of the complexity and diversity of the ways in which humans gain and express knowledge, and communicate with each other is a gift we are perhaps particularly able to give our children. Joann Lemaistre has made this point well.

To our children [parents with disAbilities] can give a zest for human contact and the examples of myriad ways in which it is possible to get going productively when the going gets very tough indeed. To have a hand in producing emotional resilience, compassion, and the willingness to set reasonable goals for oneself is a very fine expression of parental love. Joann Lemaistre (1985: 291)

DAWN Canada Mother's Caucus:

At the "parenting workshop" co-sponsored by DAWN Canada, the Coalition Of Provincial Organizations Of The Handicapped (COPOH) and the Canadian Association Of The Deaf (CAD) March 25-26, 1989 , mothers with disAbilities asked dawn to create a mother's caucus. Caucus members will include delegates who attended the conference from across Canada and three were elected to the board of directors. They identified many issues of concern, including many discussed here (see recommendations).

Recommendations

The following resolutions brought forward from the parenting workshop held on March 25 -26, 1989 were carried unanimously at the annual general meeting of DAWN Canada on Monday, March 27, 1989:

1. That DAWN Canada form a mother's caucus to review the issues identified by the parenting workshop and further develop specific proposals.

2. That the mother's caucus act as a liaison with other national consumer groups on issues of concern to disabled mothers, especially those identified in specific recommendations of the parenting workshop.
3. That DAWN Canada apply for and administer a grant for a three to five year project that would facilitate the resolution of the issues identified by the mother's caucus/parenting workshop as prioritized, including:
 - o mother's support groups -information and referral
 - o technical aids and attendant services -access to daycare and other services -lobbying for increased funding -lobbying for improved legislation

This work may include activities such as:

- o research
- o position papers
- o a resource handbook -community outreach worker(s) -travel
- o advocacy work

(the mother's caucus was formed at the annual general meeting and' out of a possible six members, four positions were filled: two other positions were provisionally filled and three members of the mother's caucus were consequently elected to the DAWN Canada board of directors.)

Notes

1. The most controversial tests and administration of harmful drugs involve Depo-Provera to women in institutions, and others. For information, contact the Canadian Coalition on Depo-Provera, c/o Health Sharing - 101 Niagara St. - Toronto, Ont. Finger's article (see references) is also good, but the discussion is framed in an American context. The history of the Depo-Provera issue is very different in Canada
2. Roger Carter cited this and other examples of the 'Eugenics' arguments to sterilize individuals with disabilities during his presentation in the 'Parenting Workshop', Alberta Committee of Disabled Citizens, Edmonton, Alberta - September, 1988.
3. The Midmark Corporation, Medical Products, Versailles, Ohio, USA 45380 - Manufactures a 'Female Procedures Chair' that is designed for easy transfer from a wheelchair, and adjusts to accommodate '98 out of 100 women'. See Cassady, June 'Chair for comfort and convenience' in Accent on Living Winter 1988. The chair costs \$11,000 Canadian. Pat Israel of the DAWN Canada executive is working to get it placed in women's health centres in Ontario.
4. In the first paper in this series, we described the problems encountered by one woman because of a fall off an examination table. See Ridington, 1989A: 22. See 'Proceedings, Child Care: Meet the Challenge' April 21-25, 1988, Ottawa, Ontario. Ottawa; Health and Welfare Canada.
5. As note 3; Discussion of neighbourhood hub model is on p. 41.
6. Thirty-eight of the responding mothers are currently living with partners or spouse; four had divorced and are remarried; eight are widowed; three are single (never married); thirty-five are divorced or separated.

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 and we owe them many thanks for their hard and creative work, without which this original research would not exist.

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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

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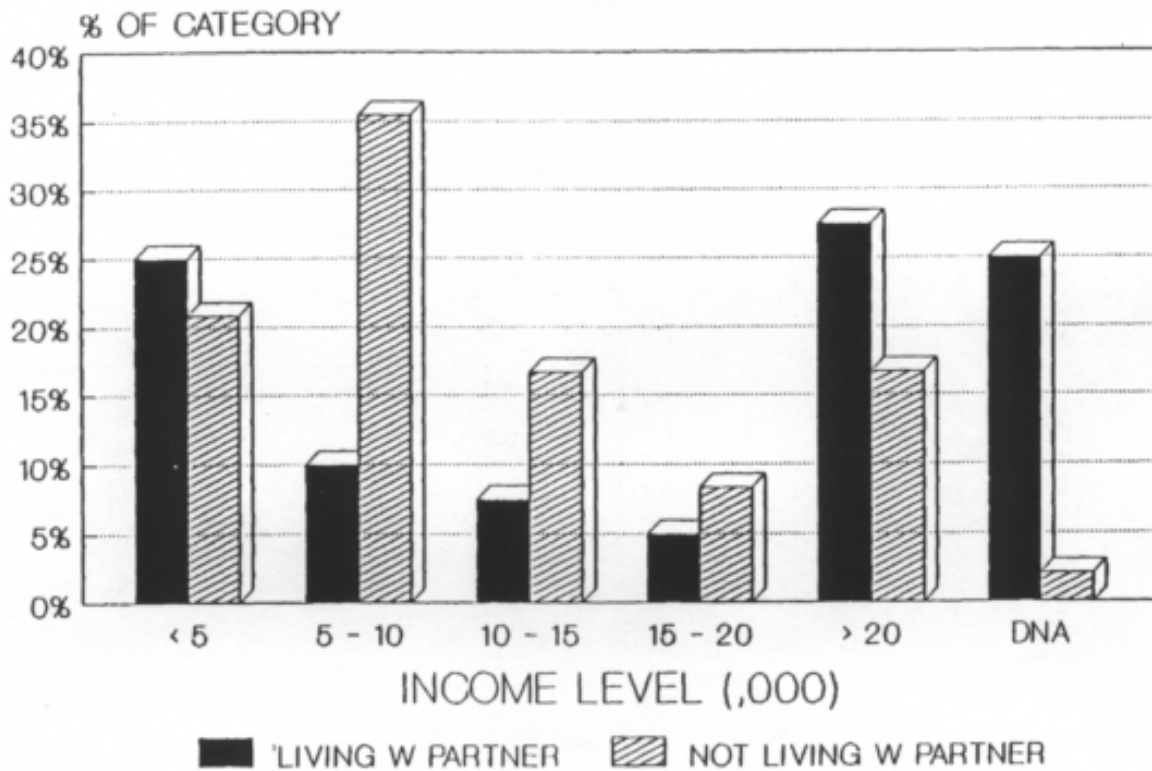
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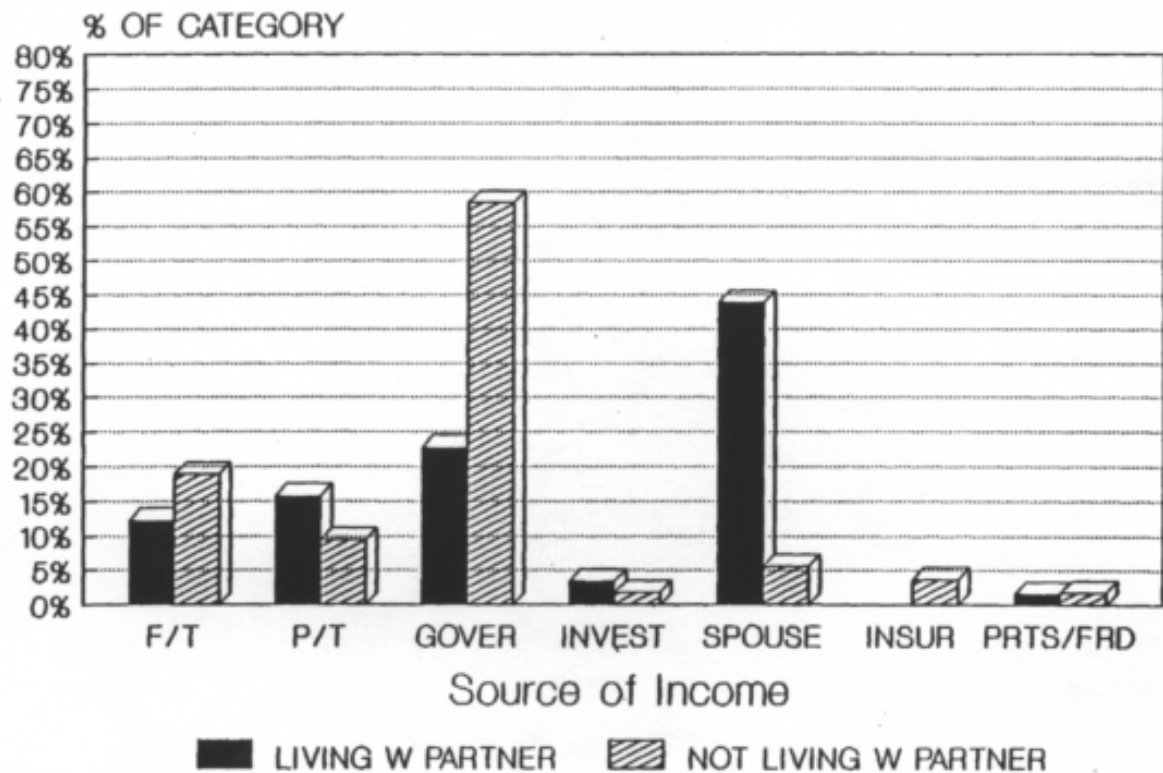
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#1: INCOME LEVEL OF MOTHERS BY RELATIONSHIP STATUS



LIVING W PARTNER = 40; NOT W PARTNER = 48

#2: SOURCE OF INCOME OF MOTHERS BY RELATIONSHIP STATUS



More than 1 Income source reported

DisAbled Women's Network Canada Réseau d'action des femmes handicapées du Canada

110 Ste Therese Road, Office # 005 / 110, rue Ste Thérèse, bureau 005
Montreal, Quebec, H2Y 1E6 / Montréal, Québec, H2Y 1E6

Phone / Téléphone: 514-396-0009 (QC); **Fax / Télécopieur:** 514-396-6585 (QC)

Toll free / Numéro sans frais (Canada): 1-866-396-0074

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