Visually Impaired Women as Mothers

by Ruth Bieber-Schut

L’auteure, une femme aveugle, compare et contraste ses expériences de mère à celles d’autres mères qui présentent elles aussi des déficiences visuelles. La plupart de ces femmes font partie d’un groupe de soutien pour mères malvoyantes que l’auteure anime.

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Before I became a mother, my instincts and common sense told me that raising a child would likely be the greatest challenge of my life. After all, how often had I heard the phrase, “children are a lot of work,” and being legally blind certainly wasn’t going to help. So, when I became pregnant I tried to be prepared. I bought season’s tickets to the theatre because I knew there would be less time to spend with my husband. Little did I know that my husband was not interested in theatre, and I would be too tired to care. I planned to attend a class at the University towards my Master’s degree, and although this turned out to be a positive move, no one warned me about how difficult it would be to squeeze the class in between breast-feedings, or how tricky it would be to complete assignments while caring for a child who never seemed to sleep. I joined exercise classes and post-natal support groups, only to find them virtually impossible to get to. I plaintively warned my friends and relatives that I would likely be needing extra support only to find after the baby arrived that they were all busy and committed to other responsibilities. Then, to top it all off, the first year of our son’s life was to be the most financially devastating period that my husband and I had seen in almost eight years of marriage.

By the time my baby was six months old, I was exhausted, overwhelmed, and, quite simply, frazzled. The walls of our small home seemed to close in on me, yet getting out with an infant seemed to take more energy than I possessed. I was isolated and I felt trapped. I wondered why I was finding motherhood so difficult. Was it just me? Some kind of postpartum depression perhaps? Did it have something to do with the fact that I was legally blind, or was it just that motherhood itself was difficult?

In a desperate attempt to understand my plight, I called a local rehabilitation agency for blind and visually impaired individuals and made two inquiries: first, what if any support services were available for legally blind parents; second, could I obtain a list of visually impaired mothers who might be interested in speaking with me.

Available support services consisted primarily of volunteers. I did not take advantage of this service, however—mostly because I was still too bewildered by my own situation to know exactly what I would ask a volunteer to do.

Before long, however, I had accumulated a list of other mothers with a visual impairment. I knew I had to reach out.

I began by calling each mother to request a personal interview. I simply wanted to explore each woman’s motherhood experience, and to see if she had any words of wisdom for me. The willingness was evident, but the process was arduous. All mothers were, I discovered, if nothing else, busy people. By the time I had completed only two interviews, I suspected that a support group for visually impaired mothers would be of great benefit to me and to others in my position. Needless to say, I jumped at the opportunity when I was asked to lead such a group, and the twelve sessions which we spent together over twelve weeks were both enjoyable and enlightening.

I shouldn’t have been surprised to discover that my experience was not unique to me, nor was it solely due to the fact that I was legally blind. On the other hand, it was not exactly like every other mother's experience. As simple as this may sound, it was an important revelation for me.

Description of group

There were nine group members, plus two interviewees who were not a part of the group. Nine of these women were homemakers while two worked outside the home, one of whom was myself. The ages of our children ranged from months *in utero* to sixteen years, with the majority being of pre-school age. Each mother had between one and three children. The marital status of the women ranged from single parent, to common-law, to married, to divorced. All of their partners, save one, were or had been sighted. In one case, the married couple were both totally blind. Visual loss for each woman was of varying degrees: no light perception, light perception only, legal blindness (an acuity of 20/200 or less in the best eye after all possible correction, or a visual field of less than 20°), or low vision (an acuity of greater than 20/200). The women also experienced different eye conditions: juvenile macular degeneration, retinopathy of prematurity, retinitis pigmentosa, glaucoma, diabetic retinopathy, and detached retinas. Although several of the women had hereditary eye conditions, none of their children were visually impaired.

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The support group met weekly for twelve sessions on Friday mornings from 10:00 a.m. to twelve noon. The program was sponsored by and located at a local rehabilitation agency which was easily accessed by all forms of local transportation. The centre provided transportation for those women who needed it, a babysitting service at the centre while the mothers met, a spacious and comfortable meeting area, as well as coffee and muffins after each formal session. All of these concessions were greatly appreciated and, in my opinion, added significantly to the success of the group.

A college student who was using the centre for a practicum experience assisted in the organization and ongoing maintenance of the group.

Each two hour session consisted of one-and-a-half hours of structured discussion followed by one-half hour of socialization with coffee and snacks. I was responsible for choosing a theme for each week and leading the discussions which ensued. Because my approach was phenomenological in nature, it was critical that similarities as well as differences in opinions be embraced and that each woman was able to share her experience comfortably. Topics of discussion included: child-rearing, issues of safety, asking for help, mobility, social support and myths, prenatal and hospital care, and, finally, the ups and downs of mothering. To round things off, we invited a father who was totally blind to attend one of the sessions to share his story. As his children were all young adults and he had been their primary caretaker, he too had a wealth of information which he presented with candid humour.

Prenatal and hospital care

Most of the women agreed that prenatal classes and information was of the utmost importance. The more information the better was the main conclusion, especially given the potentially vulnerable situation of having a baby in a hospital. Group members acknowledged that we had come a long way since the days of flat operating tables and stirrups, but, for the most part, the medical model remains intact. In the stories told there were examples of nurses and doctors who were all too ready to take charge of a women in labour, never mind a woman in labour who could not see.

Most participants agreed with one woman who stated:

> *...the prenatal classes were just that, too little. We got to see pregnancy, labour and delivery, but suddenly, there we were—the mother of a child and you were supposed to know what to do. Somehow it was supposed to be all natural and normal, never mind that you couldn't see and that you'd never had a baby before. You were simply a mother and your instincts were supposed to take over.*

Breast-feeding, in particular, seemed to be one of the most frustrating and hopeless obstacles for many of the mothers in our group. It became apparent to all of us that mothers and babies didn't automatically know the ins and outs of nursing. To make matters worse, there seems to be a major visual component in the breast-feeding process. It was one thing to not know what to do, it was another to not be able to see and not know what to do. Heaven help you if you had an infant who refused to latch on. The stress could be enormous.

That, in fact, was my own experience. Only sheer determination and the supportive knowledge of a breast-feeding consultant after I came home from the hospital led me to success. I knew then that if I had another child, I would ensure breast-feeding support before the baby was born, as well as in the hospital and at home if necessary.

Many of the women in our group ended up bottle-feeding their babies due to a lack of support and out of total frustration. Some women carried residual anger over this issue months and even years after their babies were born. Breast-feeding, they felt, would have been better nutritionally, and a potentially marvellous way of tactually bonding with their babies.

In my experience, not informing people about my legal blindness has only led to confusion. As a teenager I made a career of hiding my disability from my peers. The misunderstandings which that led to, in the end, hurt me more than anyone else. Since then I have opted to inform others about my disability. I have noticed this aids in easing tension and avoiding misunderstandings.

This decision is supported by the hospital experience of some of the other visually impaired mothers. One woman who was partially sighted, and did not inform the hospital staff ahead of time or communicate her ability to them, was not allowed to hold her first-born child unless the husband was there. Another woman, who had night blindness but could see well during the day, was accused of being lazy during the wee hours when she asked for assistance with her baby. A third woman, whose vision had deteriorated since her first baby was born, was given inadequate help from the nursing staff after the birth of her second baby. As usual, they thought she was an experienced second-time mom, and did not know that she was in fact coping with and adjusting to her decreasing vision. Another woman, who was diabetic and had a propensity for premature births, found herself at one point surrounded by a multitude of specialists, all of whom she felt she had to educate regarding her unique situation. Her experience seemed to sum it all up: "some medical professionals were helpful, and some were not...just like anywhere else." What was critical, we concluded, was that this woman had educated herself about what she needed, and had learned to communicate those needs to others when appropriate.

Asking for help

Asking for help was possibly the most arduous aspect of my early motherhood experience. My independence had suddenly been challenged and the list of requests seemed endless. Like so many others, I had bought into the patriarchal myth that "doing it yourself" was better. I had not yet understood that, in fact, independence itself was a myth. Instead, like countless other women with a disability, I felt I had to prove my worth. When sighted individuals would long ago have asked for help, I would still be struggling to show the world that I could do it on my own.

Then I found myself responsible for another little life, and doing it all myself no longer made sense. It wasn't safe, and it certainly wasn't practical. Asking for help did not come easily to me. There were days when I resented my dependency so deeply that I likened my situation to that of a beggar on the street corner—only I felt obliged to be polite and forever grateful. The state of constant indebtedness to others only increased my resentment. I frequently vowed that if my sight ever returned I would never ask anyone to do anything for me again.

One mother who had been totally blind all her life expressed minimal concern about requiring and seeking assistance. She seemed to be well aware of her own personal strengths and needs, and cared little about what others thought of her competencies as a blind person. In my estimation, she possessed two of the most critical components necessary for successful living: solid ego boundaries and a solid support network. Reliable friends and family members did not hesitate to lend a hand when necessary, and her identity was not threatened by their assistance. It is possible that because she had been totally blind from birth she was unencumbered by the personal crises which occur as a result of sudden or gradual vision loss. In any case, the message is clear. Motherhood under any circumstances is not meant to be endured alone and, as blind mothers, it is important to understand our need for connection.

If friends and relatives are not readily available, the following sources of support come highly recommended by various group members: local churches, community associations, community health services, post-partum support groups, neighbourhood co-ops, parenting groups—or, form your own group like ours through a local rehabilitation centre. Many of the services used by the mothers were free of charge and supported by volunteers. Paid services should also not be overlooked—a full-time nanny, a daycare, or a qualified babysitter who comes in to one's home for two hours once each week.

A final solution to the dilemma of asking for help involves a change in attitude—namely, the acceptance of the reality of interdependence rather than the patriarchal myth of independence. We became convinced that we deserve to receive help as much as give it, and that children are the responsibility of all of society, not just their parents.

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Orientation and mobility

Virtually all of the women in the support group felt that getting from point A to point B was perhaps the most trying challenge of their motherhood experience. As one woman explained, mobility has always been difficult, and with a young baby, it is just that much harder. Any mother probably has a story or two of how frustrating it is to make it to a doctor's appointment on time in the dead of winter with a two-month old infant, never mind if you can't see.

In the not-too-distant past women commonly stayed home with their children and connected more readily with other mothers in the neighbourhood. Lately, however, mothers have more commonly chosen to return to the workforce out of personal desire and/or necessity. This has resulted in a loss of community and a sense of isolation for many of the mothers who have opted to remain at home with their children. A greater loss of connection was felt by those women who were further hampered by limitations such as visual impairment and no ability to travel freely.

Members of the group suggested requesting assistance from friends, relatives and/or volunteers; using special needs taxi service; using the handibus service for individuals with disabilities; using regular taxi service; pulling a stroller while using a white cane rather than pushing it; and carrying the baby in backpacks, Snugglies, slings. Also, babysitters allow for important opportunities to get out without the children. The most handy and least expensive form of travel for me turned out to be the Snugglie. I always knew where my baby was and my hands were free to manipulate a white cane. I also found taxis to be convenient, especially for emergencies, but, of course they could be very costly. In addition, when travelling to an unfamiliar setting, orientation could be daunting unless the driver was willing to assist. In most cases I have found this to be of little concern if I communicated my needs clearly to the dispatch as well as to the driver.

Finally, the expertise of an orientation and mobility instructor for blind individuals should never be overlooked. These individuals have received extensive training in the art of mobility, and their expertise has been invaluable to countless visually impaired individuals.

The ups and downs of motherhood

When asked what were the favourite and least favourite aspects of mothering, group members mentioned elements common to mothers in general. Some of these included watching the child grow, hearing the child first say "momma," watching the child sleep, and listening to the child's cheerful chatter first thing in the morning. More negative topics also were common, such as not being able to control the child's behaviour and not getting enough sleep. Other comments were less universal and more unique to the visually impaired mother. One woman, who could see relatively well during the day but suffered from night blindness, expressed frustration with her preschool daughter who was skilled at sneaking into the living room in the evenings and watching television with her mother when her mother thought she was tucked away in her bed. Another more common concern was that of not knowing how severely injured a child was after all-too-common tumbles. One mother who was totally blind, and whose child was an extremely agile climber, explained how her daughter ran away from her whenever she hurt herself. This was, needless to say, both frustrating and worrisome.

One of my personally least favourite aspects of mothering was not being able to see my child's face. This came as somewhat of a surprise to me because I had never really seen facial expressions before. What I learned, though, was that how babies look with their adorable faces and subtle little movements is one of the few rewards a mother can receive for all the hard work. This is especially true if the baby cries and fusses a lot, like mine did. Like so many colicky babies, my son would fuss and fret for several seconds, and then suddenly break out in a charming grin, only to return back to fussing and fretting. I, of course, could not see the smile, but only heard what seemed to me incessant complaining. Other mothers were more fortunate of course, and spoke of how much they enjoyed their baby's giggles and googles and babbles. My child was a very early talker, and this naturally was a great relief to me, but those early months of parenting taught me to never underestimate the impact of non-verbal communication.

Conclusion

Four and one-half years have gone by since my first son Eric was born, and now he has a brother, Martin. In looking back at that first motherhood experience, I now know that it was truly more difficult than most, with my visual impairment an exacerbating factor. I also believe, however, that mothers in general have more in common with one another than we sometimes realize. Typically, we are all unique individuals who do our best and simply want the best for our children.

I am also convinced that motherhood is an experience to be shared, and that the need for connection is paramount. However, isolation and alienation for the contemporary mother has threatened to become the norm. Reaching out to reclaim a sense of community, in my opinion, must be seen as a priority—not only for the sake of today's mothers and children, but also for the sake of the future and well-being of our society.

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