

# Childbirth Support for Women with Disabilities

*A Report of the Equity Committee of the Interim Regulatory Council on Midwifery*

*Le Comité d'équité du conseil intérimaire sur la réglementation de la profession de sage-femme est un groupe mandaté par le gouvernement de l'Ontario depuis 1989 pour réglementer la profession de sage-femme. Ce rapport discute principalement des questions de soutien pour les femmes atteintes d'un handicap qui doivent accoucher.*

*The Interim Regulatory Council on Midwifery is a group which was appointed by the Ontario government in 1989 to regulate the profession of midwifery. The Council's Equity Committee was set up to ensure equal access to midwifery services by all women in Ontario and to heighten cultural sensitivity amongst practising midwives.*

In November and December of 1991, the Equity Committee of the Interim Regulatory Council on Midwifery (IRCM) (now the Transitional Council of the College of Midwives of Ontario) met in Toronto with women with different disabilities. The meetings were fruitful and important ones for the IRCM in making contacts with the community of women with disabilities. We heard stories of tremendous courage and resourcefulness in these women's experiences with childbirth, in spite of major systemic and attitudinal barriers which they faced.

In any discussion of people with disabilities, the question of accessibility is paramount. But accessibility does not just mean having wheelchair ramps for those using wheelchairs and sign-language interpreters for the deaf. One woman pointed out that those types of access issues are relatively easy to identify and, when the will and the resources are there, they are easily rectified. Attitudes toward people with disabilities are much more problematic and harder to correct. Many examples were cited of negative and stereotypical attitudes displayed by health care professionals. One woman without an arm was asked on the maternity ward "How are you going to raise that baby?" Jan, a woman with polio, when learning from her doctor that she was pregnant, was told at the same time that she had been booked for

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an abortion. She felt that the alienation caused by comments like these can lead women with disabilities not to seek out prenatal care. This same woman went on to have her baby, and when he was first born, the doctor held him up to her proclaiming, "His legs are fine." (Polio is not a hereditary condition). Tracy, a woman with a form of muscular dystrophy, recalled that when she had her first child, "I had to wait awhile before someone said congratulations."

Another woman who has a rare metabolic disorder wasn't able to attend the meeting but spoke with one

of us extensively by phone. She remarked that in her days (the 1950s and 60s) "it was even a no-no to get married." She added that, "on the whole, as soon as our doctors found out we were pregnant, they said we should have an abortion." She recalled nurses and doctors asking, "Who's going to raise it?" and remembers one nurse calling out "Have fun," in a sarcastic tone as she left the hospital with one of her babies in arms. She became friends with a group of women with a similar disability, and they all supported each other through the years they were bearing and raising children.

Pat, a long-time activist for disabled women, added that for women in institutions, there is an expectation that they aren't sexually active and therefore are not going to get pregnant. When they do, there is often shock and outrage on the part of their caregivers. And yet pregnancy, birth, and lactation can be extremely important and validating experiences in the life of a woman with a disability.

Negative stereotypes of women with disabilities who are contemplating pregnancy, pregnant, or with children are based on a belief that people with disabilities should not reproduce. This notion is further based on one or two other beliefs: 1) that we do not need more people with disabilities in our society, and 2) a person with a disability is incapable of doing a good job raising their child. Although it is difficult to gauge how widespread these beliefs are, we need only look at the widespread acceptance and use of prenatal diagnostic techniques (ultrasound, amniocentesis,

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chorionic villi sampling, etc.) for some indication of the lack of acceptance of people with disabilities in our society. This issue is one which has been struggled with for a number of years by disability rights advocacy groups. We asked the women we met with whether any of them had had genetic counselling or any prenatal diagnostic techniques when they were pregnant. One woman responded that she wouldn't even consider not wanting to have it. She added, "We either accept disabled people in our society or we don't."<sup>1</sup>

Ann, a diabetic woman who suffered numerous miscarriages before she decided to adopt a child, found that getting reliable and realistic information during her pregnancies was extremely difficult. She was told that getting pregnant and holding the pregnancies would be the only problems she would face, and was not told, for example, that the sleep loss which most pregnant women face during pregnancy and in the early years of a child's life can have a tremendous impact on the blood sugar levels of a diabetic woman. She feels that women are done a disservice by not being told what is common or uncommon to particular disabilities during pregnancy. Women reported that they also find it difficult to get accurate information both about the effect of pregnancy and labour on their condition (i.e. will it worsen their condition in any way, either temporarily or long term?), and the effect of their disability on pregnancy and labour. They specifically mentioned being concerned about the impact of hormones and weight gain on their respective conditions.

Because every disability and every woman with a particular disability is an individual, it is important for women to have the kind of care which will pay close attention to the needs of that woman. A number of women commented that they tend to be the ones who know their condition best and yet they frequently encounter health care personnel who feel they know what's best for them. Tracy, for example, was going to be given muscle relaxants without her knowledge to prepare her for a Cesarean section. Although she caught the mistake before any harm was done, she remarked that the health care worker should have

known that, "giving muscle relaxants to a person with muscular dystrophy is like putting a plastic bag over their head." As a further point of clarification and perspective, she added that,

*The consequences of certain interventions may be annoying for non-disabled women (e.g. giving Valium post-surgically), but can be life-threatening for a disabled woman.*



Sensitivity to other practical issues may also be lacking. For example, one woman who uses a wheelchair commented on the importance of making sure that a person's wheelchair is very close by when they have been transferred to a bed or gurney, not on the other side of the room or out in the hallway.

Women who have had their disability since childhood are usually quite familiar with all the particulars of their history and what drugs and procedures are recommended or contraindicated for them. We were told that, in general, women with disabilities may tend to be less trusting of the medical profession (at the same time as being quite dependent on them) because of their long-standing involvement with doctors. The women we spoke with felt strongly that health care personnel should give more credit to women with disabilities for the knowledge they possess about their particular condition.

Women who have had their disability since childhood have usually become familiar not only with dealing with a number of specialists, but also with being treated like a guinea pig, particularly if their disability is rare. They become "someone on whom the doctors can learn." Pat noted that it was not uncommon in her childhood to be told by a doctor to strip to her underwear and walk in front of a group of interns and residents so they could observe her gait. She became "condition X" and felt invisible, like she wasn't a person. A growing body of literature about the experiences of women with disabilities attests to similar experiences by many women, an experience which can carry over into pregnancy and childbirth. Women with disabilities often feel conflict about their care. They want doctors to understand more about how women with their condition

experience pregnancy, but, at the same time, do not want to have to be guinea pigs on whom doctors can practise and learn.

In our meeting in December, which was attended by two deaf women, a hard-of-hearing midwife, and a woman with spina bifida, we learned in particular about some of the unique problems which deaf women encounter in pregnancy and childbirth. One of the deaf women, Mary Anne, had had two of her children in a birthing centre, one at home with a midwife, and one at home with her husband because she was unable to find a midwife. The second deaf woman had had two hospital births. The primary problem which both women identified was the lack of services and resources in the health care system for the deaf and hard-of-hearing. The effect of having no sign language interpretation for deaf and hard-of-hearing clients quite simply means that they are left out, that there is no or minimal communication, and that they must rely on fellow deaf people and written material to get information. The myth that all deaf people can read lips was quickly put to rest by Mary Jean Rumball, a nurse who has worked extensively with the deaf community and who was our sign language interpreter for the meeting. She pointed out that "lip-reading is a particular skill and not everyone can do it." She emphasized that one should never assume that a deaf or hard-of-hearing person can read lips. Nonetheless, whether reading lips or not, deaf people tend to observe facial expression with more acuteness than hearing people. Mary Jean noted that the tendency to turn away and speak in hushed tones when a woman is in labour may be well-intentioned, but it can only cause worry for a deaf woman who does not have a sign language interpreter since she relies on seeing facial expression to get a sense of what is going on.

Access to interpreter services is very limited, which we learned first hand in organizing this meeting; we spoke to half a dozen agencies and freelance interpreters before we were able to find one who was available at our meeting time. Hospitals, as a rule, do not offer services for the deaf or hard-of-hearing and the women we spoke with were not aware of any hospitals, public health departments or health units which would pay for private interpreters. They argued strongly that we must consider this service in the planning of any public meetings and in the proposed school of midwifery.<sup>2</sup>

#### **A role for midwives working with women with disabilities**

One of the most important things we learned from the women we met with was that they tend to exclude themselves from being candidates for midwifery services because of the emphasis on the use of the word normal (normal pregnancies, normal childbirth, a normal process). Long conditioned to believe that what they are is "abnormal," women with disabilities tend to believe that they must automatically have high risk care and that there is no room for midwives in that care. As our discussions progressed, however, it became clear that midwives could play a critical role in the care of women with disabilities. The support and advocacy which is so often missing in some high risk care and is characteristic of midwifery care would be a tremendous help for some women with disabilities. As Heather, a woman with spina bifida put it, "a disabled woman usually best knows her disability; what she doesn't know is the childbirth part." A midwife who has gotten

to know a woman and the details of her disability could be an important bridge between the woman and her other caregivers. The continuity of care and the personalized attention which a midwife provides can be invaluable in helping a woman to establish breastfeeding, an activity which takes on particular importance for some women with disabilities. A woman with a disability who is not high risk could be made to feel more confident and reassured through a midwife's care. One of the women asked that we request exemption for women with disabilities if the regulation of midwives determines that midwives cannot offer care with high risk women.

The Equity Committee was pleased to see that a booklet on pregnancy and women with disabilities for the Health and Disabled Women Project includes a paragraph on midwives. The author (one of the women with whom we met) states in a draft of the booklet:

Many women will feel more comfortable with a midwife who can become familiar with their particular situation, and who is able to be with them during the hospital [stay]. The midwife can perform an advocacy role for mothers with disabilities, with hospital staff, and can help interpret hospital procedures to the mother. All in all, it can make the experience smoother, and therefore happier than it has been for women with disabilities in the past.<sup>3</sup>

Our discussions with groups of women with disabilities revealed the importance of outreach to women with disabilities who may not always have a connection (because of poor accessibility) with the delivery of information in the mainstream. We learned from those we interviewed of a number of ways in which the IRCM and future related bodies can best get information out to women with disabilities. They suggested that we could begin by insuring that our office is equipped with a TTY (teletype device for the deaf) and that the names of any midwives who have sign language interpretation skills (we are aware of two in the Association of Ontario Midwives) be made available. Information should be disseminated to the Disabled Women's Network (DAWN), the Canadian Hearing Society, and other associations for the deaf, the Canadian National Institute for the Blind (CNIB) (Braille or tape), schools for the deaf, other disability-specific associations, and the Disability Network. The latter is a television program for which one woman we met with works; she indicated they might be interested in having someone from the IRCM come on to talk about midwifery and childbirth for women with disabilities. The importance of sensitizing midwifery students to the needs of women with disabilities was also stressed.

*Members of the Equity Committee are: Anne Rochon Ford, a writer and policy advisor on women's health issues in Toronto; Pat Legault, a former nurse administrator active with the community health and birth centre movement in southwestern Ontario; Jesse Russell, a policy advisor on Native women's issues in Thunder Bay; and Vicki Van Wagner, a practising midwife in Toronto. When the Transitional Council of the College of Midwives was appointed early in 1993, Pat Israel, a long-time activist on disabled women's issues, was appointed to the Council on the Equity Committee's recommendation.*

This article is one of a number of reports written by the Equity Committee based on consultations which they conducted throughout the province. Additional reports are available for a small fee by calling the Council office at 416-658-8715 or fax 416-658-9532. The address is rccmo, Box 2215, Station P, Suite 285, Toronto, ON, M5S 2T2.

<sup>1</sup>This sentiment is not universally held by women with disabilities. Some, knowing better than anyone else what it means to grow up with a disability in an unaccepting society, would rather not watch their own children have to go through it, while others feel quite strongly that choosing to abort a fetus with a disability is sending a message to society that people with disabilities are not worth bringing into the world. The issues are complex and are not meant to be reduced to simplistic solutions by this account. Any Council members interested in further reading on this issue can get a list of sources from Anne Rochon Ford.

<sup>2</sup>Vicki Van Wagner noted that in many other countries, deaf women are not able to become midwives because of their inability to hear a fetal heartbeat, although there is new technology which would allow them to do this. This is an issue which needs further consideration by the IRCM (the Transition Council of the College of Midwives.)

<sup>3</sup>"You're Having a Baby? Congratulations!", draft of a booklet in preparation for the Health and Disabled Women Project, 1992.

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## See Also...

*The Baby Challenge: A Handbook of Pregnancy for Women With a Physical Disability* by Mukti Jain Campion. London: Tavistock Routledge, 1990.

"Nursing the Hearing-Impaired Patient," *Canadian Nurse*, March 1989, 34-36.

"Pregnant and Diabetic?" a question and answer fact sheet about pregnancy and diabetes available from the Canadian Diabetes Association, National Office, 123 Edward St., Suite 601, Toronto, Ontario, M5G 1E2, tel: (416) 593-4311.

"The Happiest Time of Your Life?", *Soundbarrier*, No.43, December, 1990, 10-11.

"Jane: The Care of a Deaf Woman?", *Midwives Chronicle and Nursing Notes* September, 1991, 251-254.

"You're Having a Baby? Congratulations!", a booklet in preparation for the Health and Disabled Women Project, DAWN Toronto, 180 Dundas Street West, Suite 210, Toronto, ON M5G 1Z8.

"I Want to Be A Mother. I Have A Disability: What Are My Choices?" DAWN Ontario, 1993.

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