

“I CAN FEEL IT-MY BABY IS HEALTHY”: WOMEN’S EXPERIENCES WITH PRENATAL DIAGNOSIS IN SWITZERLAND*

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Synopsis—Prenatal diagnosis allows for the detection of genetic anomalies. In interviews with 10 women in Switzerland we wanted to know how they had arrived at their decision “prenatal diagnosis yes or no”; what role doctors played and how their social environment had reacted to the offer of prenatal diagnosis and the women’s decision. We asked about their feelings and anxieties and about the psychological mechanisms which led to the women’s decisions. The interviews revealed that prenatal diagnosis is a tool with which the discriminatory practice of social selection takes place, but that this is hidden behind liberal ideologies of so-called “self-determination.” Women’s fear of giving birth to a handicapped child; the social stigma attached to bring up a disabled child, the urgent need for resistance against prenatal diagnosis as a eugenic control mechanism —these are topics explored in this article.

Synopsis—Pränatale Diagnose ermöglicht das Erkennen genetischer Schädigungen am Embryo. In längeren Gesprächen mit 10 schwangeren Frauen wurde ermittelt, wie die einzelne Frau zu ihrem Entscheid pränatale Diagnose Ja/Nein gekommen ist, welche Rolle die Aerzte/Aerztinnen und die Medizin spielte und wie die soziale Umgebung reagierte. Den Gefühlen und Aengsten wurde nachgegangen und die psychologischen Mechanismen ergründet, die zum jeweiligen Entscheid führten. Anhand der Interviews wird aufgedeckt, dass mit dem Instrument der pränatalen Diagnose ein gesellschaftlicher Selektionsprozess stattfindet, der hinter Selbstbestimmungsideologien verborgen wird.

Die Angst ein behindertes Kind zu gebären, die gesellschaftlich desolate Situation mit einem behinderten Kind zu leben, die Notwendigkeit des Widerstands gegen die eugenischen Massnahmen – das sind Themen dieses Aufsatzes.

This is an account of our study into the firsthand experiences of pregnant women —women who have had to come to terms with the problem of prenatal diagnosis. What we wanted to know was *how* these women decided whether to undergo a test or not.

Recently, both of us, over thirty-five years of age, became mothers. Despite the fact that we belong to the so-called “high-risk” group of older pregnant women, we refused to have an amniocentesis. (This test takes place in the 16th to 19th week of pregnancy.) In Switzerland, doctors routinely recommend this test to pregnant women over 35 for a genetic examination of the foetus. It is for this reason that for our research on prenatal diagnosis, we chose pregnant women in this age group.¹

We conducted interviews with ten women in Switzerland, from rural as well as urban

environments and from various social backgrounds. Four of the ten women were expecting their first child, however, not all of them were pregnant for the first time; the other six were expecting their second or third child. Six of the women had agreed to genetic testing and one of them received a positive test result: in the 20th week of pregnancy, her future child was diagnosed as having Down’s syndrome and she decided to terminate the pregnancy. Another of these six women is the mother of a four year old daughter with Down’s syndrome and was pregnant with her third child at the time we talked with her.

In our interviews, we wanted to find out the motives which cause a woman to say yes or no to prenatal diagnosis. What we were able to see was that the very existence of genetic testing significantly influences pregnant women’s lives. Almost all of the women knew about the existence of prenatal testing before their pregnancies, and all were confronted with the tests during their medical examinations.

The following thoughts and ideas have been crystallised out of the many, sometimes

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emotionally charged discussions which resulted from the enormous amount of material we gathered in the interviews; they are a condensing of our encounters with the ten women, of our own experiences and our talks with other feminists.

YOU CANT ESCAPE IT

“Genetic testing is so taken for granted—you just don’t have to think about it any more” said Serena who was expecting twins and decided to have a test.² Most women were confronted with such foregone conclusions: prenatal testing appears to be generally accepted, both by the media and society at large.

I was in a frightening quandary. Everywhere I heard: have you had your genetic test yet? You must have it, since it is now possible . . . and what if you have a handicapped child? You’ve already got two children, you must think of them and of your husband! It was terrible what my acquaintances and family said to me. I only met a few women who didn’t think the test was absolutely necessary.

Livia finally decided to have the test, after direct pressure from her husband and doctor.

I talked to my family doctor about an amniocentesis because I was going on 36. He didn’t think it was really necessary. But my husband maintained that one should take advantage of these tests since they now exist. When I had to have an ultrasound he came with me to the gynaecologist. We could see quite a bit on the screen, as I was already in the 15th week of pregnancy. My husband asked the gynaecologist for his opinion about an amniocentesis and he replied that for a woman of my age, the answer definitely should be yes. From 35 onwards, he said, one *had* to do it. Although my husband didn’t make the decision for me, I felt pressured. This really bothered me as I felt I was being coerced into having the test. I said to him that I’d have the test, but only because he wanted it.

Another gynaecologist expressed his opinion just as directly to Elvira. Despite his strongly-worded advice, she decided against the test.

I went to my family doctor when I was three or

four months’ pregnant. At first, it was completely clear to me that I wanted to have an amniocentesis, because I was soon going to be forty. I hadn’t really thought about it carefully, though. My family doctor (a woman), thought the test wasn’t really necessary. Nevertheless, she arranged for me to have an ultrasound at a gynaecologist’s in order to determine the exact date of birth. The specialist expressed his opinion quite strongly. He said that if I were his wife, he would have the genetic testing done immediately.

On the basis of these reports from women who had been examined by many different doctors, both female and male, three “types” of doctors emerge:

1. The TECHNOLOGY type. He or she advocates the official medical position which is “prevention”: prenatal diagnosis is a “neutral” tool to prevent sick off spring. This opinion is communicated without any doubts to the pregnant women.
2. The TRADITIONAL type. This kind of doctor sees giving advice as an obvious part of his or her role. They are critical of the prenatal genetic testing, especially because of the possibility of an abortion, which doesn’t fit in with their attitude to life. They are pleased when women refuse to have the test and do not shy away from mentioning that abortion for them equals murder.
3. The ALTERNATIVE type. This category includes the unconventional doctors who are critical of the official medical position. Dutifully, they explain the various tests to the women and ask them to carefully consider their decision, because, in the end they say, the question is an ethical one. This “objectivity,” which leaves the decision in the hands of the women, may reflect their own uncertainty and indecision about the new technical developments.

THE TECHNICAL ASSAULT

In the seventeenth and eighteenth centuries in Europe, midwifery, the last domain of women healers, was taken over by man-made medicine. The new medical-technical developments caused changes in the instruments and methods used to control the pregnancy. The tests developed from a

simple diagnosis by touch, to ultrasound examinations to genetic analysis. The health of the pregnant woman, the development of the foetus in the womb and an uncomplicated birth were originally the main reasons for medical supervision. In medical terms: the aim is prevention. It has always been the claim of medicine, not only to cure illnesses, but also to prevent disease from occurring. Even before the introduction of prenatal diagnosis there were cases of recognising “diseased” embryos. In these cases, functioning preventatively, medicine advises that the carrier of the disease, the embryo itself, should be eliminated. For example, if a pregnant woman becomes sick with German measles, a discontinuation of the pregnancy is legal even without completely proving that the child is indeed “deformed” as it is a case of a so-called “medical indication” necessary in Switzerland to grant official approval for an abortion. (Approval is also provided if there is a so-called “social indication”: proof that the continuation of the pregnancy would be harmful to the woman’s psychological, social and economic well-being.) What then is so unusual and new about the prenatal tests of today?

Qualitatively new is that medicine, armed with the necessary technology, sees it as desirable to eliminate genetically “damaged” embryos. Routinely, and still packaged in the medical terminology of “prevention,” the *systematic discriminatory selection* of life is being pursued: judgement about what “kind” of embryo is “worth” or “not worth” being carried to full term is becoming socially acceptable. The act of elimination itself is being institutionalised.

The development of these technologies was ushered in by ultrasound examinations for diagnostic purposes. Ultrasound is used today as a routine examination to check the development of the foetus. Some doctors have become so specialised that they claim they can recognise deformities on the early embryos, so that ultrasound has the same consequences as amniocentesis or chorion villi sampling (another prenatal diagnosis test, performed at 7–10 weeks of pregnancy). Because of their selective precision, these newly-developed medical techniques and tests have rekindled the eugenic ideology that sick people can be systematically eliminated before they are born.

For women, it is important to recognise that the

application of these techniques doesn’t take place in a personal, perceptibly verifiable environment, but somewhere in a laboratory. Given this physical alienation it is difficult to question or doubt the clinically clean and supposedly unequivocal answers one receives. Where it is only cell tissue that determines whether a foetus is “worthy or unworthy of life,” the brutal law of clean, discriminatory selection is already being exercised.

The offer to undergo prenatal diagnosis is put to the woman at a time in her life which is psychologically stressful. Most probably, to every pregnant woman occurs the thought that her child could be born sick or handicapped. Women have always protected themselves psychologically against this disquieting thought in different ways. Pregnancy allows space for a variety of feelings and mental attitudes to cope with such fears. For example, women from Nicaragua refer to magical fantasies which say that a pregnant woman should not look at a sick child in order for her child to be healthy. Other women demonstrate rationalised hope: “in my family everyone was always healthy” or display a pure and simple hope for the best attitude. When these fears are balanced with the basic gut feeling “my child is healthy,” they are easier to bear. All the women we interviewed underwent these thought processes, which we’ll call “wishful thinking.” Also, we ourselves during our pregnancies experienced this wishful thinking. The psychological state of a pregnant woman – based on hope, belief in fate or successful rationalising to ward off fear—is put under great pressure by this technical assault.

This tension became very clear in our discussions. We felt a lot of empathy and understanding for the difficult decisions faced by the ten women, whether they were for or against the tests. Worrying, however, was the fact that the problem of taking part in a discriminatory selection practice played only a minor role in the thinking and decision-making processes of most women, whether they were in favour of the tests or against them. Their decisions and opinions were formed within a small, private circle: doctor, husband; perhaps a girl friend and family. Two of the women decided against the tests primarily because of religious reasons. Other social frames of references, especially the emerging public debate about genetic engineering or feminist perspectives on pregnancy and motherhood, were totally absent

or only of slight importance. With the exception of one woman, no one expressed the need to discuss the impact of these technologies on women as a social group. Subjective biographical criteria and factors specifically relevant to their personal relationships played the main role in their decision-making.

YES TO THE RISK

The women in our study who refused to undergo prenatal diagnosis were sustained by their intrinsic feelings that “my baby is healthy.” As Elvira put it:

Somehow, I believe in destiny. I had my first child at thirty-six. Before that I’d never been pregnant, so I’d never had an abortion or a miscarriage. I believe that I can trust my feelings. Since the beginning of my pregnancy, I’ve had the good feeling that everything will be all right with my child and I continue to believe that.

Another woman, Rosa, had lost her first husband to an incurable illness when she was still quite young. Despite or maybe because of this experience she had decided against the tests. She said:

Before this pregnancy, my present husband and I were instructed about the tests and had already decided against them. We realised that what we wanted was to have this baby, and that, in any case, you can never say if a child will stay healthy throughout its life. We did consider that it could be handicapped, but the hope, that it would be healthy, was stronger.

It is important to understand in what way the introduction and general propaganda about the genetic tests has changed things psychologically for women. Women today could opt for knowing what the technologies can say about their children-to-be. To refuse prenatal diagnosis means not only the refusal itself, but to reject the additionally accessible information as well. The optimistic thought “my child will be healthy,” that women formerly trusted in, has become questionable and seems in need of strengthening. Not to inform yourself means that women must psychologically put more energy into warding off fear. Women

seem to feel that. For example, Rosa suspected this. When asked if she had never considered having an amniocente-sis so that she could perhaps prepare herself to have a sick baby, she answered:

I thought about it, but decided it would be early enough to know at the time the baby is born. Otherwise, I couldn’t have enjoyed my pregnancy any more; I would have worried too much ahead of time.

Women see themselves confronted by a medical-technical logic which threatens to put them psychologically out of balance. With a lot of energy, they have to construct a counterbalance. Of the women we talked to who refused to have the test, besides the previously mentioned religious motives, it was positive professional and personal experiences with handicapped people that were most useful. Personal values and life experiences—a very individual frame of reference—for them were more important than fear promoted by those in favour of the tests.

Women who refuse to have the tests done, do not wish to have a handicapped child, but they do accept the possibility of this risk. This may sound banal, but is psychologically crucial. As Elvira put it:

Of course, I don’t wish for a handicapped child. But I can imagine coping with such a child.

And Fiorina, who “had missed” the right moment to have the genetic test done – probably not accidentally – said:

If I gave birth to a handicapped child ... yes it would be difficult for me and no one would be happy . . .

Rosa, in turn, told us:

My husband and I thought, simply, that if we had a handicapped child, we’d just have to learn to accept it. Our second child was not a surprise, we had planned it. In the case of a pathological test result, I don’t think we could have decided against it.

To say “yes” to the risk means to learn to accept a handicap or a sickness which one doesn’t wish on anyone as a part of life that can’t be influenced. In

this sense, it's a "yes" to the unpredictability and, by extension, to the diversity of life. We think that these considerations are essential, not only for individual women who have to make such a decision, but also for the formulation of strategies for resistance and opposition to these technologies. As women we must work together to strengthen ourselves, so that the refusal of the tests counts as a "yes" to the risk and a "no" to the institutionalisation of discriminatory selection.

INTUITION vs. INFORMATION

It may be surprising to learn that women who were convinced that their child would be healthy agreed to have an amniocentesis. A few of them realised the contradiction in what they were doing. Stasia, who was confronted with the existence of prenatal diagnosis for the first time during her pregnancy, told us:

In the end, I went to my next consultation with Dr. X and said "I want to have the test" even though I was really sure – inside of me – that my baby would be healthy. I hadn't had any complications and felt good. From this moment on, I knew that my "intuition" and my "intellect" were not in complete agreement with each other. It then all went quite quickly: when I saw the baby on the ultrasound screen, I knew it was healthy. I wondered what on earth I was doing there. My intuition spoke out loud and clear but I couldn't turn the clock back and undo the test.

During her pregnancy, Hortensia, a medical doctor herself, was confronted by unexpected contradictions:

For me, the most difficult conflict was about whether to have an amniocentesis or not. Before my own pregnancy I knew the official guidelines: after thirty-five pregnant women should have an amniocentesis. I had always informed women about this, believing that every woman in the end had to decide for herself. Before my own pregnancy, I thought about this question rationally . . . but about four weeks before the amniocentesis, as I began to make my own arrangements for the test I realised that I had become unsure about the

necessity of this test. And these feelings increased . . . I asked myself, whether this test was really necessary. I felt that my developing child was not handicapped, yet I wondered whether I wasn't repressing something, whether there was something I didn't want to know . . . But deep down I *knew* my baby was healthy . . .

Hortensia ended up having the test and was told that everything seemed fine.

All the women we consulted experienced the insertion of the needle and the long wait for the test-results as unpleasant and distressful to varying degrees. But it was precisely their original feeling "my baby is healthy" which helped them to control their fears before and during the test. This feeling also helped them to deal with their fears regarding the heightened miscarriage risk of an amniocentesis and with the punitive waiting period. Sereina explained:

I knew that there were more risks of a miscarriage with chorion villi sampling than with amniocentesis. I found the actual procedure very, very unpleasant but I accepted the risk of miscarriage. I was worried that I might play with destiny because I was expecting twins. But I decided that if these two wanted to live then they'd have to be able to take this too. I was sure that these two babies wanted to be born.

Stasia described the following breath-taking situation:

The long-awaited for envelope with the test report came after about fourteen days. It took me till the evening, till my husband came home, to open the letter. As I was waiting, suddenly I was gripped by the thought: "what do I do if the results aren't normal?" but then said to myself I would have had a telephone call telling me that. The first sentence of the letter read: "Diagnosis: normal"! The details of the diagnosis were mentioned underneath. I needed a bit of time to really *believe* it ... I was relieved, even though it had always been clear to me that the child was really healthy.

All of the women who had decided to have the test done, told us that they would do the same thing

in the next pregnancy. Given their unpleasant experiences in connection with the genetic examination and with, as had been observed by a few of them, the discrepancy between their feelings and actions, we find this astonishing.

But it is understandable. The dynamics of the situation develop in the following way: fears that the future child might be handicapped appear in every pregnancy. Pregnant women have always found the psychological means to neutralise these fears and make them bearable. Now a testing procedure is introduced which through an exclusively pessimistic point of view increases these existing fears. They are thereby manipulated into a narrowed down problematic. The medical world suggests that all fears are quite unnecessary once the test has revealed the genetic "normalcy" of the embryo. Complete silence is maintained about the fact that the majority of handicaps occur during the long-term development of the child, namely at the time of birth or in childhood, for instance through accidents. The women we interviewed who had submitted to the tests confirmed that they experienced the rest of their pregnancies without anxiety: for them the promises of the medical world were successful. The women who refused to have the test were continually confronted with the possibility that their child might be disabled: a psychologically troubling, but unavoidable process, which moreover helps to prepare one for a possible reality which is very often less than perfect and harmonious.

THE SUPERVISED FEMALE BODY

We know from our discussions with the pregnant women that they usually did not know to what end the various unknown and unexplained examinations were being done during their pregnancies. They hardly knew, for example, what tests their blood was taken for. Therefore, they could not really deal with the consequences of the various examinations. Fiorina, who described herself as being critical of the medical world, felt:

I don't know exactly which tests were being done; they just sent my blood to a lab. Also at the beginning of the pregnancy, routine ultrasounds were made. I was rather worried. I wanted to inform myself and read quite a bit about it, but I wouldn't find anything that said

that ultrasounds could possibly be harmful. Only in one book was mentioned that ultrasounds are not advisable at the beginning of the pregnancy. I continued to go for ultrasound check-ups every six weeks. I asked other women if that was normal, and I heard that they were all doing it. But in a way, that's really no argument.

Stasia was eventually given some information:

After a long talk my gynaecologist told me what tests she was doing. She explained, rather quickly, what the blood was being tested for: syphilis, gonorrhoea, AIDS, and other diseases. I took it in and thought, "Oh well, it has to be like that."

One could talk about the unquestioned faith women seem to show for medicine. But we remembered our own helplessness when seeing the doctor during our pregnancies mainly because of the confusing range of diagnostic tests and therapeutic techniques offered and the pressure of time during check-ups. Under these conditions, it is almost impossible to make sense of these technologies. With regards to the sense or nonsense of the tests we felt that we were totally at the mercy of the medical information system, which is the *same* medical system that is also promoting this technology! Even more blatant is the interdependency in the case of pregnancy and birth which of course are not "diseases" but are being treated as such by the doctors. This individually experienced dilemma of loss of direction is the price women have to pay: the responsibility for their own bodies has been taken out of their hands – usurped by a male dominated medical world.

Elvira told us about the following observation which was crucial for her decision *not* to have the tests done:

I was with a good friend who underwent the tests. What really shocked me was the long waiting period, the wait for the test results and the fear that she experienced during this time. I realised that she couldn't build up any kind of relationship with her future child. Instead, she had to distance herself from her pregnancy.

Another aspect to consider in this medical (mis)management of women's bodies and lives is

the fact that *nowhere* are these tests described as the drastic attacks on the body they usually are. The women themselves do not know what to expect. Stasia remembered her experience with chorion villi sampling:

I couldn't get rid of my apprehension and anxiety. I didn't know how far away the foetus was from the placenta or from the top of my belly, I mean, literally, in centimetres . . . The question of whether there might be something wrong with the baby was displaced by a panicky terror that the foetus could be injured during the test. I wanted to communicate my fears to the doctor, and asked direct questions, for example, if the foetus could be hurt by the needle. Word for word, he said to me: "If I wanted to do that, I could." What a cruel, cynical answer. He poked the needle in the top of my belly and went on with another, even bigger needle to retrieve some tissue. The whole thing was awful: he dug around and I could hear that the needle was blocked and that he'd picked up too little tissue. He needed to go in three times. I stared continuously at the monitor, saw everything on the screen and interpreted it in my own way, based on my fears. I could always see what was the placenta and what wasn't. Then there was a panicky moment. I saw something appear in another colour and I figured it was the foetus. I can't tell you how wretched I felt —I forgot everything else —the analysis of the tissue and the result of the diagnosis became completely unimportant. I could only think: the foetus is injured. I just about went mad. After that I had to take the tissue sample to the genetic institute myself. It was lunchtime and I had to wait. Everything got delayed, I wandered around as I was trying to deliver this thing ... In the next few days, I couldn't do a thing. The idea that my baby had been injured, did not leave me ...

Because of the difficulty of assessing the consequences, that are an integral part of the medical technologies, the "wishful thinking" of the pregnant women becomes thus focussed very specifically. This basic fear "did it hurt my baby?" in our opinion removes from the women the responsibility of thinking through what they would actually *do* should the results indicate an anomaly.

Livia described this dilemma:

I said to myself that if the baby wasn't disabled too badly I could accept it. My husband, however, said he couldn't; we never agreed on this. I don't know what we would have done if indeed there had been something wrong with the foetus.

And Stasia said:

I ought to have thought about the consequences, in case the result wasn't positive. I couldn't come to a decision . . . I tried to avoid thinking about it or talking about it with my husband. We discussed it only for about half an hour. The only possibility for me was to make a "head" decision . . .

The question, what I would have done in the case of an abnormal result came back to me when you asked to talk with me. It *bothers* me that I can only answer it in a speculative way: I really don't know what I would have done.

The results of Fabiola's tests —which revealed abnormal cell tissues — highlighted the way in which women experience conflict between their intuitive wish — "my baby is healthy" — and the world of reproductive medicine:

The beginning of the pregnancy was perfect, I never felt sick, it was clear to me that I would have the amniocentesis . . . I wasn't ever bothered by the discussions about the risks and wasn't worried about the complications. Dr. X told me that only 2% of the cases turn out to be positive, but, he said, we'll do the test anyway. I never thought for a moment that I might be among those 2%. Instead, I believed that the test was just the smallest of hurdles. If I felt so well, then everything had to be all right . . . So I had the test done on the basis of a rational, unemotional decision. I told everyone that I was pregnant. When I came back from a holiday one Sunday, I found a letter saying that I should call Dr. X. He told me that the foetus had Down's syndrome. I should come for a check-up immediately, because I was already twenty-one weeks pregnant. I had to make a decision right away. I was put under a big time pressure; for him the decision to have an abortion was clear. He said that the baby would probably start moving around that week and then it would be

harder to decide. Perhaps I'd also let him believe that it *was* clear to me, that we didn't have to discuss it ... In any case, there was no discussion. I had the termination.

Hardly any woman knows, that when the diagnosis of her foetus reveals abnormalities and she decides to terminate her pregnancy, that she must then go through an artificially induced, excruciating act of birth that lasts for hours – that in fact she must deliver her baby to death.

With the development of chorion villi sampling, which can already be done in the eighth week of pregnancy, women do not have to undergo this traumatic experience. For the individual woman this is a great relief. At the same time this technique hides the act of selection which takes place even more. A prematurely induced birth turns into a scraping of the womb: a regular surgical procedure.

ANXIETY SEDUCES

Because of our worries about giving birth to a handicapped child, women are easily seduced into having a genetic examination. None of us are immune to this. Women from all political and social backgrounds feel bewildered by the new medical procedures which on the one hand legitimise their worries, but on the other pretend to know how to eliminate such anxieties. The women we interviewed told us about various types of fears: from the fear of the *unknown*, for example, which led them to imagine that they couldn't possibly cope with the demands of a child with a disability. As Fabiola said:

I couldn't imagine having to care for a handicapped child twenty-four hours a day, day after day for twenty years or more.

In addition, some women mentioned the social discrimination and the financial worries. Natascha, whose financial situation is tight, spoke about this. She decided not to have the test but then experienced a pregnancy full of worries:

... above all the gossip of the people. One sees families, who because of a handicapped child, had to completely change their lives. Since we haven't got a car, I asked myself, how would I get the child to therapy. More generally, how would we manage

... ; we'd have to move, since this house isn't suitable for a wheelchair because it has so many stairs ... I imagined all these things ... I was also worried about paying for all the necessary aids. And I thought about the restrictions that we'd have to face: no more hiking, no more holidays in the mountains.

The mother of the four-year-old girl with Down's syndrome said:

... until now there have been no difficulties, but we are quite aware that there will be problems — later, when she's twenty. Someone will have to be legally responsible and take care of her. Also, as time passes she'll be less sweet and less accepted by other children in her age-group. The changes will come step by step for us. Up till now I've had no problems.

Most women we talked to were also afraid that having a handicapped child would force them into the traditional female role of caretaker and nurturer which they would never be able to grow out of. Hortensia, the medical doctor, said:

The main reason why I decided to have the test was because I have a profession that I wanted to continue practising. I can determine myself how much I want to work and my partner is ready to take care of the child for a certain amount of the time. Thus I am not forced to take the traditional female role. Perhaps I'll have to assume the main responsibility for a few months, but that'll be over soon. With a handicapped child I'd be stuck at home for years. I've been working to get myself out of the traditional female role for many years and I don't want to slip back into it. The idea of having a child with Down's syndrome means taking care of it for twenty years or longer, taking care of a baby that never develops past the level of a small child. Because of that, one is once again forced into the feminine role. It's also clear to me that I'd never put such a child into a special home. I'd have to bear the consequences myself.

Personal and professional experiences with handicapped people influence the decision-making process. For some women knowing how the handicapped are made to live in our society—

solitary, isolated, excluded, unwanted —reinforced their fears. They couldn't imagine being a mother under such circumstances. For the other women, the same knowledge didn't lessen their anxiety, but enabled them to develop ideas and strategies of how to cope with such a reality. These thought processes strengthened them in their decisions to refuse to have the tests.

In addition, we believe that the tests touch upon yet another aspect of fear — an aspect that became barely visible in our discussions, but that we wanted to take up because of our own experiences and a few statements that the women made. To accept that a child, a part of our own body, ourselves and our existence, is handicapped and that this handicap cannot be traced back to an external influence, such as an accident, provokes fears. We have preconceived notions of what our child should be like and it is hard to entertain the possibility that the child could be different, that it could confront us with our own imperfections. We understand Rosa's comments which reflect such thoughts:

I pondered for days and days what it would be like to have a sick child. I probably would have been sad, but would have accepted it, would have had to, in fact, because I didn't want to have the tests.

Fabiola told us her husband's opinion, which also held true for her:

He, my husband, wouldn't have been keen on suffering the financial, emotional or the aesthetic demands and burdens.

The concept of prenatal testing capitalises on this not always conscious mental state: the possible insult to and the uneasiness of accepting a less than "perfect" alter ego. Medical-technical science suggests that handicaps can be prevented and that "perfection" and "normality" can be achieved. By means of emphasising their unconscious fears (which, by the way, can also be real for men), women are easily manipulated and are therefore seduced into using prenatal diagnosis.

SELF-DETERMINATION AND RESISTANCE

Ethical postulates from various political groups

along the line of, "Women just have to learn to live with handicapped children once again," or "Women must, in our opinion, say 'Yes' to a handicapped child" completely ignore the actual psychological state and social position of pregnant women. We do not believe that resistance to these technologies can be built up from such patronising, moralising slogans. Further isolation and divisions among women would be the consequence of this. And not only that: they also push women into making false alliances with conservative groups that have been always categorically opposed to abortion and for whom the situation of the women involved was never considered of importance. Hortensia expressed such fears:

After I had the amniocentesis, if the result had been pathological, I would have probably had an abortion although I couldn't have totally justified it from a moral point of view. The whole issue might also jeopardise women's choice to have an abortion. I think that by emphasising prenatal diagnosis, the perspective of the child is being increasingly brought into the picture; more than the situation of the woman . . . I'm worried that this development plays into the hands of pro-lifers.

The longstanding feminist demand for self-determined motherhood — and we include in it accessibility to abortion and birth control — must not be abandoned by the women's movement. When we took up the question of abortion almost twenty years ago, we defended and formulated the right to self-determined motherhood from the point of view of every woman. An involuntary pregnancy is an emergency situation which can only be evaluated by the women who are themselves affected. This demand for self-determination is opposed to the ruling ideologies of religious, medical and political circles. In this way it must be seen as resistance.

Today the world of medicine is usurping the idea of self-determined motherhood — a notion we had formulated as a collective form of resistance. In so doing each woman is made *individually* responsible as to the question of prenatal diagnosis. Put differently, she now should also bear the responsibility for "quality-control" of our society. The blatant fraud inherent in this so-called "self-determination" becomes evident from the

following example: women, who are advised to have an abortion after a pathological test result, are then forced to take the incapacitating, lawfully prescribed course of going to a psychiatrist for women who want an abortion. Fabiola, who was told that her baby had Down's syndrome, remembered:

The gynaecologist arranged my appointment with the psychiatrist and recommended I go to the clinic the following day for the termination of the pregnancy. I rebelled, I wanted two or three days in between. I was very annoyed that I needed a psychiatrist's report and that I needed to tell him about my family. The psychiatrist said that, of course, I could carry the child to term if I so wished.

When investigated closely, it becomes clear that prenatal diagnosis offers itself as an instrument to reinforce traditional family values, as is already happening in present day political discussions. People who advocate genetic counselling want to make us believe that in the discussion of prenatal diagnosis only the ethical questions about abortion need to be debated. In so doing, the mechanism of discriminatory selection—the core element of prenatal diagnosis — is totally removed from the ethical and socio-political discussions. The ethical problem of prenatal diagnosis as selection is thus reduced to a discussion of abortion, a problem which has always given rise to heated debates.

It is not that, as women, we need to reconsider women's demands for self-determined motherhood which include abortion — we'll defend these ideas against the old *and* the new patriarchal family politicians — but rather, it is the ideology of discriminatory selection practices inherent in these new technologies which needs to be taken to task vis a vis the women who are affected.

Prenatal diagnosis is a device for population control: in the Western world selection is advocated and is already being carried out with regard to the *quality* of children. And they say it is completely "self-determined" and "voluntary." Women in the so-called Third World, on the other hand, are being forced into sterilisation and the use of harmful contraceptives. There, the number of children, the *quantity*, should be reduced. But only if all women comply with these rules can these goals be achieved. Therefore, it is to be feared that

women will have to face penalties for not complying with these principles of population control in our part of the world as well.

We asked the ten women what they thought about those women who had arrived at a different decision from their own with regard to prenatal diagnosis. "The women should be able to decide for themselves, if they want to have the tests carried out or not," was their more or less unanimous answer. In retrospect, we find it alarming that only a few of them seemed to believe that a general discussion of the issue would help them in arriving at a decision.

Following from our own experiences during pregnancy and what we learned of the plight of the women involved in this coercive decision-making process, we feel that a widely held discussion is urgently needed. Such a discussion must be closely linked to the resistance tradition of the women's movement. Just as in the fight for abortion, self-determined motherhood with regard to prenatal diagnosis would mean collective resistance against the ruling ideologies of medicine and patriarchal society at large. The leading question which *individual* women are often asked by the medical world is: "Do you want to have a handicapped child or not?" But the much more fundamental question for *all* women is: "Through my decision, do I collude with the discriminatory ideology of selection in theory and practice? Do I want to let myself be used for that?"

Resistance against this mechanism of selection means drawing attention to it and openly denouncing it. As well, it means working hard to create a radical feminist ethic as a counterbalance to the superficial *libertarianism* of the medical world. At the same time, we must fight against an inhumane society, where handicapped people are excluded and where mothers of handicapped children are thrown back onto their own resources. It can't be emphasised enough, that women will continue to have prenatal tests and, if need be, abortions, because of social calamities, internal pressures, outside coercions or because of their own specific life contexts. A feminist strategy of resistance must take into account the concrete realities of women's lives as well as radically rejecting systematic, discriminatory selection in theory and practice. Only such strategy will enable a true resistance movement to develop.

ENDNOTES

1. We are grateful to all the women who agreed to talk with us. We want to thank them for their openness and readiness to go through their often painful experiences once again.

2. A short profile of the ten women is included as Appendix A.

APPENDIX A

The women in our study

Elvira: 40 years old, the mother of a 4 year-old child, supports herself on a small farm in the countryside.

Present pregnancy: planned. No test.

Florina: 39 years old, lives in the city, works in the film industry.

Present pregnancy: first child, planned. No test.

Natascha: 37 years old, worked before her marriage as a child minder in a children's home in the countryside. She is the mother of two school-age children.

Present pregnancy: unplanned. No test.

Rosa: 37 years old, handicraft teacher, now living as homemaker and mother of a small child in the countryside.

Present pregnancy: planned. No test.

Dunja: 36 years old, sociologist, now living as a

homemaker and mother of two preschool-age children in a small town. One of her children, a four-year-old girl, has Down's syndrome.

Present pregnancy: planned. Amniocentesis: Yes.

Fabiola: 42 years old, works independently and lives in the city. First pregnancy two years ago, amniocentesis: yes, test result positive (Down's syndrome). The pregnancy was terminated.

Hortensia: 35 years old, lives in the city, works as a general practitioner in an alternative medical practice.

Present pregnancy: first child, planned. Amniocentesis: yes.

Livia: 35 years old, secretary. Lives in the city with two pre-school children and is the day-mother of another small child.

Present pregnancy: planned, amniocentesis: yes.

Sereina: 38 years old, lives in the city, physical therapist, mother of a pre-school child.

Present pregnancy: planned, expects twins. Chorion villi sampling: yes.

Stasia: 37 years old, singer, lives in a small village. Present pregnancy: first child, planned. Chorion villi sampling: yes.