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# **PEER, or How decision-making destroys the possibility of being hospitable**

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## PEER, or How decision-making destroys the possibility of being hospitable

### Introduction: Peer

I have a friend about whom I want to tell you. She is the mother of three years old Peer, whom I include in our friendship. Peer lives on a farm in Northern Germany, together with his parents, with another couple and their two children, with a big dog, several cats, chicken and old apple trees in a beautiful garden. However, winters are cold and wet in Northern Germany. Therefore, Peer enjoyed it immensely to run around bare foot and naked in our well heated little apartment in the city center of Bremen when he visited me with his mother three months ago.

Peers mother, who is a close friend of mine since we got to know each other as students, tried to put the little boy in bed so that we would have some time to talk in peace. No way. Peer played hide and seek, laughed at me and enjoyed running away from his mother. Finally, he got so tired that he surrendered, throwing himself happily in his mother's arms.

Peer is a special joy every time I see him. A year ago he was growing a little slowly which worried his parents, but when I saw him next time he had become a little boy who has a big appetite for sausages and tells you long stories about the world in his own language.

### Decision-making versus hospitality

Why did I start telling you about Peer and his mother? A new kind of ideology about choice and freedom makes the world inhospitable for children like Peer. The illusion that you know something about a person and his fate by testing and probabilistic predictions destroys the readiness to be surprised, the openness for the unknown, the courage to dare. Statistical critters and diagnostic categories such as "life expectation", "Risk for heart disease", "mentally retarded" etc. are serious obstacles to what Ivan talked about last time: A concrete situation, face to face with another person.

Ivan talked about the surprise, the unpredictability of what might come out of acting as a neighbor.

He said, it is an irrational act, you cannot justify it. The Samaritan was moved in his *splanchna*, in his guts, and acted. He did not weigh the possible consequences before he turned towards the Jew and did not try to rationalize his behavior. He saw him, and knew what he had to do.

In the following 30 minutes, I want to tell you what I think prenatal testing and counseling has to do with the loss of hospitality. First, I want to argue with Barbara Duden that until last century pregnancy has been a special stance toward an uncertain future, toward something coming but yet unknown. Then I want to show you how modern prenatal care destroys this special stance for the sake of supposed "security" and "freedom of choice".

### Pregnancy as symbol for a stance towards a not yet known person

Being pregnant historically was the symbol of a very special and culturally very fundamental kind of uncertainty.

First, "pregnant" meant that something was already there, but not yet revealed. Today, you still say "pregnant with meaning," - you know that there is something, but you cannot yet grasp it or see it, it has not yet revealed itself. Barbara Duden has done a lot of work on the meaning and the experience of pregnancy in history. She shows that in former times only birth could reveal the truth. She has documented an unbroken tradition in Hippocratic medicine according to which no physician can be sure that a pregnancy was a "real one" until the birth of a child has provided the proof. People knew that nature could bring forth not only children, but also moles, mooncalves and other creatures.

Barbara Duden refers to the report on a midwife who attended a woman on the point of giving birth. No child ever came. Believe it or not - step by step her belly dwindled and nine months later, it had flattened out. (I think, we shall not judge on these stories, trying to find out what "really" happened. )

The abundance of such stories Barbara Duden takes as a sufficient proof for a certainty that we have lost: pregnancy. Pregnancy referred to a woman's anticipation of a child, not to a physician's diagnosis, to her hope rather than to a verifiable developmental process.

So, only birth retrospectively gave certainty about the truth of having been pregnant. In German, you can say: going pregnant, "schwanger gehen", which beautifully expresses the intransitive nature of the business the woman is engaged in. It was not a physiological state, the technical verification of the

existence of certain hormones and fast growing cells, but something the woman *did herself*: It was a stance towards the unknown, towards birth that hopefully would bring a healthy child.

Today, the onset of pregnancy is the result of a test. Being pregnant does not mean hoping for a child anymore, but it now names a physiological state assigned to a woman after a hormone test. This hormone test is supposed to verify something that is already there - Ivan suggested the formulation of "diagnosis of successful infoetation - the im-plantation of a fetus". The sense of the "not yet" has been lost. All kinds of tests have been invented to assess the quality of the "product" to be expected, and its "environment" - the becoming mother - that, in the view of medicine, is a potential threat to the fetus. Risk figures, ultrasound pictures, chromosome counts, gene tests - they all seem to tell us something about the coming. The anxious expectation of test results has substituted the hope for the birth of a healthy child. The crucial "revelation" today is brought by the lab technician. Barbara Duden speaks about the "public fetus": The coming child once grew in the dark, beneath the woman's skin. Ultrasound and fetal photography have transgressed the woman's skin that once was the threshold between inside and outside. Now, her inside is publicly visible.

I see this break in the meaning and understanding of pregnancy as a symbol how in our society we deal with the unknown, with the unpredictable, with the surprise another person, not yet known, can be.

### Pregnancy and prenatal care

When my friend got pregnant, she underwent routine medical pregnancy care. In her fourth month of pregnancy, when her belly started to grow, her doctor sent her to a routine sonography. She never considered having an amniocentesis - back in our student days, we had all night discussions about the eugenic implications of prenatal diagnostics and the social changes these techniques might provoke.

After the sonography, the doctors told my friend that they had to reveal something about her coming child. On the basis of her age, a blood test and the sonography, a computer had calculated a high probability of the child having Down syndrome. They urged her to undergo amniocentesis - because only a chromosome-count could give certainty if the child in fact had trisomy 21, the laboratory result corresponding to Down syndrome.

When my friend got the news, she was shattered. She remembered our discussions when we were students. In our group of friends, we had all shared a decisive "No" to prenatal selection. But now, many years later and herself being pregnant, she felt that she was not prepared, not ready for the decision the doctors urged her to make: They asked her to test the number of chromosomes of her hoped for child, and then, depending on the result, consider an induced abortion.

#### Genetic counseling facilitating a decision about pregnancy

I think not only my friend was shattered, but no woman is prepared for that kind of decision. In a concrete situation, you sometimes just know what to do. But the only thing concrete in the situation in which my friend found herself was her growing belly and her hope for a child. The physician urged her to take abstract information about test results and risk figures more real than her hope and her well-being.

In order to soften a woman up for this impossible decision, women are sent to a genetic counseling service since the 80s of the last century. You might know about these services, since they are routine in the US. I have just finished a 300-page work on genetic counseling in Germany. For this work, I listened to more than 30 counseling sessions where geneticists urge pregnant women to make something called an "informed decision" about their pregnancy. The encounter takes 60-90 minutes. The procedure resembles a ritual. There is almost no difference between counseling sessions in Germany and in the States. The counselor tries to persuade his client to project her coming child onto the intersection of risk curves. The woman is pressed to take statistical concoctions for "knowledge", knowledge about the person to whom she prepares to give birth. And in turn, this illusion of factual knowledge generates a sense of power, of controllability by which she is made responsible for the outcome of her pregnancy.

Genetic counseling for me serves as an instance for the multiplying incentives persuading us to make management like decisions in every day life. As Barbara Duden wrote in her book "The woman's body as public space", the genetic counselor talks about the fetus as a management consultant talks about shares. Depending on risks and chances, it will be kept or disposed of. Genetic counseling is a course in how to make a management-like, economic decision about your child-to-be.

#### So called "rational decision-making" as a threat to the remnants of hospitality

This kind of so-called "rational decision making" is in my view the most recent threat to the remnants of hospitality. Last fall we tried to get a sense for the profound difference between sharing a place and inhabiting space. We asked how to make place in the space age. Last week, Ivan argued that hospitality can only be practiced by one who can open the door and lead a guest over the threshold into a place. He stressed that no rules, no calculus, no norms limit the kind of hospitality he wants to practice. And he contrasted hospitality with access to professional care. He showed how the presence of professional services, from childcare to first aid or to gerontology, has destroyed being hospitable to children, to the old, to the crippled and the sick. Professional services disable by telling us that there is always somebody else licensed to be a better helper. The rise of professionalism made it possible to conceive of the gynecologists ultrasound pictures as something better than the midwife's haptic or hands on examination, and to consider intensive care units as an advance to the deathbed at home.

But Ivan also suggested that the very essence of professional services has changed during the last two decades (this is something Sajay Samuel and Jean Robert will discuss next week). As you realized, home-birth, dying at home and alternative healing methods are more and more in vogue. There is a trend toward a new "do-it-yourself" - a "do it yourself" that is facilitated by counselors and therefore should perhaps better be called "serve yourself". We are now asked to serve ourselves after we have learned to recognize our options, to gain a preestablished information package, to calculate our risks and benefits and to take responsibility for the outcome of our decisions. These courses in so-called "rational decision-making" promise a new kind of freedom and "autonomy" from expert control. "Get the necessary information, and make an autonomous decision", goes the slogan. I picked out genetic counseling as an extreme example of such kind of courses in autonomous decision-making.

#### An example of a genetic counseling session

Before I can give you an example for a genetic counseling session, I want to make one clarifying remark about a crucial concept in management-like decision-making: Risk. In economics, "risk" has become the main concept to turn the uncertain future into calculable possibilities. But "risk" does not tell what will happen in an individual case. It is a concept that is based on statistical populations. It measures the frequency of certain events in large populations or in long series of experiments.

Imagine throwing dice: each side has the probability of  $1/6$ . But it is only after several hundred throws that the relative frequency of each number starts to tend toward  $1/6$ . Strictly speaking, there is nothing like an "individual risk". Therefore, for an individual, acting on the basis of risks or probabilities is like gambling - facing probabilities you still do not know what the future holds.

As some of you might know, most of what prenatal tests offer is risk calculations. I remember a genetic counseling session with a young, hopeful pregnant woman whose sister in law had born a child that had died from Cystic Fibrosis. The woman decided she wanted the test because the test was possible. She says: "Since it is possible to make a test and to gain certainty, we decided to have it". Everybody in her family is healthy, and she herself feels well, so that she is certain that the test would be negative and would calm down her worried husband.

The counselor follows a routinized procedure for a genetic counseling session. In order to establish her risk status, he starts to collect relevant data in order to put the young woman in different statistical populations. Because only by making her a part of a statistical population, he can impute a risk on her. The counselor asks for her age, for her health history, and takes the pedigree of her family and of her husband's. Asking questions, he follows a checklist that is the same for each counseling session. The geneticist is not asking personal questions like practitioners still might do in order to get an impression of a new patient, but he screens the woman's history and family history for potential "markers", characteristics that would allow him to create a risk-profile. Each marker puts the woman into a statistical class from which the counselor then derives a risk figure. All these risk-figures are supposed to be basic information for the pregnant woman. Her age, 33 years, puts her into the class of pregnant woman aged 33. And the probability of bearing a child with Down syndrome in this class is one out of six hundred. The counselor turns this abstract statistical model into a "personal risk" by telling his client, that she has a risk of "one out of six hundred" to bear a child with Down syndrome.

After age, "pregnancy" is another marker for the geneticist. The fact that the woman is diagnosed "pregnant" puts her into the class of woman with a positive pregnancy test. The counselor informs his client about the "risks" that are involved in having a positive pregnancy test. From the point of view of the geneticist, childbearing is risky business: He shows her a statistical graph that visualizes the possibility of a newborn being diagnosed with some disease or handicap. He confronts the pregnant woman with a list of frightening possible pregnancy outcomes such as children with heart problems, with hereditary diseases, with spina bifida, or mentally retarded children. There is no reason to

assume that the woman's child would have any of these, but it is the counselor's duty to make her aware of anything that, hypothetically, *could* happen. For some of the frightening diseases and handicaps the geneticist adds probability figures - one in thousand, one in three hundred and fifty, one in hundred.

Now, the woman knows what she can be afraid of. The counselor turns her good hope into bad expectation. The session has already lasted for an hour. Finally, the geneticist takes up the initial question about a genetic test for CF. First, he explains the nature of the disease. It runs in families and has been associated with mutations at a certain DNA-sequence on chromosome 7. The symptoms are very variable, so that some researchers already suggested to talk of several different diseases. Some children die from pulmonary complications, and others grow up without ever becoming aware that they would be diagnosed with CF.

The counselor calculates the risk-status of the couple for bearing children with CF. These calculations are pretty complicated. Even after having studied human genetics for three years, I had to repeat them step by step at home in order to understand them. I'll summarize one of them to give you an impression: The presumed father has a probability of 0.5 to be carrier of the mutation associated with the disease, because siblings statistically share half of their genes and his sister obviously is a so called "carrier". Belonging to the average population, his wife has an estimated probability of 0.04 of transmitting the mutation. Since, according to Mendel's law, two carriers have a probability of 0.25 to have an affected child, the final risk figure is 0.005 or 1 out of 200. "Is this high?" the woman asks startled. "I can't tell", the counselor admits, "you have to decide yourself if you want to consider this number a risk or not". This is verbally cited out of the transcript I made for my thesis.

In case the couple decides to undergo a genetic test, the test results could modify the risk figure. Four different outcomes are possible, and the counselor engages in even more complicated risk calculations to explain what might come out of a test. Only if both, man and woman, would be diagnosed with a DNA mutation, an amniocentesis would be possible to test the genetic status of the child. But the counselor warns: Even if the child is found to carry two mutations, no one can tell what the consequences might be. Genotype rarely translates into a predictable phenotype. As I mentioned before, some people do not even know that genetically they have a serious disease, and others - like the child of the man's sister - die of pneumonia and other ailments.

The woman, now, is forced to make a decision. Test or no test? If she expects advice, she is wrong. The era of expert control is over. In the age of risk and probability, even experts do not know what to do. When the woman overwhelmed by risk figures asks the counselor what to do, he withdraws. "I cannot give you any advice", he clarifies. Each option, to test or not to test, might lead to agony. Is her risk of 1 out of 200 threatening? What, if the coming child is classified as carrier of two mutations? In this situation, there is no advice. In my work, I tried to show how the information about options and risks brings the pregnant woman into an impossible situation. Now, the outcome of her pregnancy seems to depend on her decision. Even when nobody can tell what will happen and how the child is going to be, the information about risks and hypothetical possibilities creates the impression that the woman has to make a "decision" and is responsible for the so-called consequences of her decision.

What ever will happen when the child is born will always be uncertain. But after genetic counseling, the unborn is classified and categorized and the becoming mother is asked to make a decision on the basis of this classification. The child she gives birth to, the person that she will take into her life has disappeared behind a risk-profile.

In my work, I was not concerned about how women decide after such a counseling session. My concern was the decision itself, the fact that after the information they have to make a decision about their pregnancy, a decision on the basis of DNA-sequences and probabilities. Actually, if one of these tests turns out to be positive, for most women it is the beginning of a horror trip. Close to 100% of those women who are confronted with the result "trisomy 21" abort. And - abortion at this stage of pregnancy, being already in the fourth month, is not the end of the story, it is rather the beginning of a long period of pain and suffering.

In addition, many women and couples who are confronted with test results biologists and physician call minor abnormalities find themselves incapable of carrying the pregnancy to term. Barbara Katz Rothman, an anthropologist from New York, wrote a very moving book on the stories of these women. She asks - and this is crucial of the question of hospitality: How does one become parent of a child that enters the world as the embodiment of a diagnosis? She cites one man who struggled with his wife about the test result "XYY", a chromosomal disorder that once some researcher statistically associated with criminality, which turned out to be nonsense. This man says: "If the little boy starts to throw blocks at his baby sister, shall I think he does that because he is two or because he is XYY?"

Back to Peer:

Peer's mother did not do any further testing. When the doctors urged her to undergo amniocentesis because of her so called "high risk status", she refused to see any more physicians and went to a retreat in Finland. She tried not to lose her senses and not to be scared by risk figures, chromosome numbers and predicted symptoms. Beyond medical and genetic information, she was able to make up her mind. Suddenly she knew that this one growing inside of her would be her child, no matter how its health status might be measured. And she knew that she wanted to have a place for *this* child, the child to whom she would give birth to. She wrote to me: "Tom (her boyfriend) and I decided that we would have a place on our farm and a place in our heart, also for a child that might be handicapped".

I still remember Peers first visit in Bremen. He was already two years old when I saw him for the first time. When my friend rang the bell and I opened the door, she held her son in her arms. When I looked at him, I saw a Down syndrome. I saw all the symptoms listed in the medical textbooks. I cannot tell you how ashamed I was. He was the son of my friend, and I only saw the realization of a diagnosis. It took me some hours to get rid of that picture that medical knowledge had put between him and me. When he started looking at me with curiosity, than ate his porridge with great appetite, and then finally started to explore our apartment, I slowly started to see Peer. With his charming smile and his vivid awareness, he opened my heart and made me see.

When I see Peer running around, I know that no test can reveal anything meaningful about him. Like any other person, you have to meet him, to get to know him to see who he is. And no test could have revealed how life with him is. When you meet him, you might like him or not, and he might like you or not - these are the concrete circumstances Ivan talked about last week. Nothing can predict or anticipate this situation.