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It is interesting to see how we have this view of a prototype human being, and if we see something that is different, we have to erase it.

An Interview with Marit Vaula Rasmussen

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Marit Vaula Rasmussen: My name is Marit Vaula Rasmussen. I am 29 years old and I am a doctoral candidate in Social Anthropology. I have an office at the *Center for Women's and Gender Research* and I am also connected with the *Institute of Social Anthropology*, both at the University of Bergen. My doctoral project is about the intersex conditions in Norway, also called "Disorders of Sex Development" (DSD), which is a recent word for this field. In addition to being interested in the actual patient group, I am interested in the larger scale of these themes, such as the history of medicine, the law and the nation-state.

Carlos Motta: What is understood as intersex?

MVA: The definitions vary, but the one that I chose to use in my thesis is: The different kinds of diagnosis that signify a developmental problem that results in newborns developing bodies, or being born with bodies that lie between the general conceptions of manhood or womanhood. For example, children born with something that looks like a large clitoris or a small penis that measure-wise is either too large or too small; or babies that don't have testicles or ovaries according to their supposedly assigned sex. I am interested in what happens when newborns are not easily placed into the traditional two gender boxes. What happens to them socially and physically? How do the medical system, the state administration and the law, deal with these conditions? Usually intersex children are given an assigned gender pretty early, and then they are treated either with hormones or with surgery, or both, at a rather early time in their lives. I chose to define intersex in a way that also includes other larger out-groups that are often not thought of as intersex, like individuals that have Turner syndrome and Klinefelter's syndrome.

CM: Can you explain both of those syndromes?

MVA: Turner syndrome children are usually thought of as girls because they mainly appear as typical women, but do not develop a normal female puberty. They cannot attain female puberty unless they are given artificial female hormones, and of course, they will not bear children because they do not have ovaries of their own. This is actually an issue for the intersex society in Norway: The possibility that young Turner women should detain eggs from other women because they have their own uterus, but they do not have eggs.

Klinefelter's syndrome children on the other hand, are usually thought of as males, they have testicles, but they have usually very low testosterone production, which, in the same manner as with Turner syndrome, makes it difficult for them to develop a normal male puberty. They are also often given artificial hormones for them to appear more masculine.

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CM: Are these two syndromes diagnosed at birth?

MVA: No. The difference between these and most of the other syndromes is that these two larger out-groups are often assigned quite late in life. Not so much now, but before they were often discovered at puberty. Nevertheless, there are other rare diseases that are not discovered until later in life, usually because of late puberty or a puberty that is not considered to develop properly. For instance, I have heard of people not being diagnosed until they are 18 or 20 years old, because it was thought that they were only late bloomers. Not all of these syndromes are very distinctly marked as being gender odd or gender special, but I choose to "lump" all these groups together because I think some of these syndromes are interesting in themselves, and I think of them as intersex because genetically it is obvious to me that they somehow belong together. Especially because they can create some of the same problems, since the body is not showing proper signs of gender.

CM: Could you give me a historical account on the way that intersex has been treated and thought of in Norway from the perspective of the medical establishment and the State?

MVA: The treatment of intersex is relatively new, and I think this is mainly due to technology and surgery. Hormones were discovered in the 1920s, and the production of artificial hormones developed in the 1930s and 1940s. At that point you found artificial hormonal products, like birth control pills and also medication for women in their menopause, etc. This knowledge was later used in the treatment of transsexuals for assisting them to transition to their preferred gender. These are the same technologies used for treating intersexuals. The similarity between the treatment of intersex and transsexualism seems very obvious to me, but there are never discussions of any implications or blurring of these themes.

CM: Even though it is commonly understood within transgender communities that intersex is a form of transgenderism?

MVA: I am not suggesting that the cause is the same. This is a question that people who are interested in my research often ask me, and often the research on gender and sexuality is sort of lumped together. There was a review of the film *XXY*, where the critic used pretty much the entire article just to explain the different types of sexes and sexualities, because people do not know about these issues. People are just starting to understand homosexuality. They are maybe starting to understand transsexualism and the difference between transsexuals and transvestites. So intersex gets added to those groups.

I think it is really interesting that the actual surgery is never talked about, the techniques for creating bodies, because this is what you do with the knives: You take tissue, human flesh, and then you transform it into something else. Of course, not all the techniques are the same, but the whole idea of transforming one type of flesh into another is inherited from the transsexualism surgery, and this is never talked about because neither of the two groups wants to be associated with the other or discuss the different kinds of surgery. These are the kind of paradoxes that I find very intriguing. And, of course, as a social scientist, I am allowed to draw parallels, and I do not have to worry about politics and the way these organizations and also doctors have to guard their fields. It is my privilege and duty to split things up, to look at them from different angles and see if I can find something interesting.

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CM: What has been traditionally the medical narrative in relation to intersexuality in this country?

MVA: I find interesting the way that the medical treatment has developed from a very unstructured kind of procedure done by some doctors in the 1980s to a very structured and very firmly held practice with specialized doctors. This is how the medical field works, they safeguard little nests of medical expertise related to a specific field, instead of spreading knowledge around the different hospitals. Medical expertise related to intersex is mainly concentrated in two hospitals in Norway: the Rikshospitalet in Oslo and the Haukeland University Hospital in Bergen.

CM: Is the issue of intersexuality inherently medical, or has it become so because of social and cultural demands?

MVA: There is so much silence surrounding the theme of intersex. It has been hard to talk about it without turning the conversation into a kind of freak show talk. Some issues of sexuality and gender are actually more easily talked about in terms of pornography than truly for what they are.

CM: Can you explain that?

MVA: Within the different sub-groups of pornography there is a kind of curiosity about everything, and intersex becomes a part of that curiosity. People want to know about everything and see what it is. Thus, intersex, not unlike transsexuality, has become a sexual fetish to people. This has been in a way, the way to make it into a public theme, which, of course, is conceived as stigmatizing by many of the groups that belong to either the intersex or the transsexual groups. But then again, some of them could find it liberating to be embraced by something, or to be affirmed sexually by something or someone. But there has been very little talk about it in the general public, and in the newspaper archives I find almost no interviews, almost no cases, and the cases that are made about intersex mainly just state the fact that it is something which is impossible to talk about. These nonsense articles are interesting in a way, because one can imagine that before they started to say the obvious, this was something that was too difficult to write about. I think this is one way to call attention on some issues: At first no one talks about it, then someone states that no one talks about that, and at this point someone starts talking about it.

CM: Why do you think this subject is so difficult to talk about in society? Is it a fear of threatening the established gender binary?

MVA: As you know, I am a social anthropologist, and one of the first things that we learn in school is the different ways that humans tend to categorize each other, and separating people into women and men is one of the very basic ways of organizing society. This is a very common fact. Every society has established a division between men and women, and there is often a division of labor connected to this, etc. Not everyone fits strictly into the men and women division, but every society has a division related to gender nevertheless. I don't think that breaking the gender binary division in itself becomes dangerous, but breaking one of the most basic dynamics for a society is very dangerous. I don't even know what to compare it to, because what I discovered when I did my master thesis is that people are in a way very afraid of

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gender.

It is very threatening not to fulfill someone's expectations about gender. I think one of the most confusing and, therefore, dangerous things that you can do is to confuse someone about what gender you belong to. We had an interesting case in Norway, which took me by surprise because it reminded me of something that I had heard happened in the United States before: A woman, I think she was a lesbian, who had a kind of a masculine appearance, was drinking beer with some colleagues at a place in Oslo. She went to the toilet, but she was thrown out of the ladies room by the guard. He claimed that she wasn't supposed to be there because she was a man. This is interesting to me, because his fury at her being in the ladies room is not understandable if you believe that he thought her to be a man. He was really mad. I think what actually happened, and what was even more threatening to him than discovering a man in the ladies room, was that he saw a person whose gender was uncertain to him.

CM: He reacted in action.

MVA: Yes. I think he reacted to the fact that she was undefinable to him within a gender. To some people, this is one of the most threatening things, because it stirs up their fear that the world cannot always be categorized and understood. I think individuals like him are sort of symptoms of our societies' fear of the world not being comprehensible. If you are a person who is not well adjusted and rounded in your own life, then I think you are sort of doomed to act out on these fears that are inherent to society, and that so many individuals just carry in a much larger sense.

CM: When I watched the film *XXY*, which you mentioned before, I thought that the most significant part of that film was the moment in which the girl and the father were driving in the car. The father tells her in a moving and very humane way that at some point she will be able to choose... and she looks at him and asks why. "Why do I have to choose?" Suggesting that perhaps there is a way of living her life with a kind of *hybrid* sexuality without the necessity to define her gender. Is that a possibility, or would that always be a kind of social transgression?

MVA: What I discovered when I did my master's thesis is that it is possible in a way to get social recognition for in-between gender choices. I used the English umbrella term of *transgender* and I lumped a lot of people into that group. I also used the term to describe gender transgression in general. I was kind of surprised to learn that quite a lot of these people were able to find social support at least from husbands, wives, good friends and family for their choices, and also that some of them had a fighter's approach to the world. They had a gender agenda and were empowered to express themselves in the way they wanted. I think it is possible for people to get recognition for gender uniqueness.

But I also think that this is not necessarily an issue for the intersex group because I get the impression that a lot of them have very normal perceptions of gender, both in general and of themselves. Thus the majority of the intersex population wants to be recognized as either normal men or normal women.

There is an American organization called *Intersex Society of North America* (ISNA), which functions as an umbrella organization for a lot of local organizations around the world. They made up the term "Disorders of Sex Development" (DSD), because they thought it would

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function better: They are interested in improving the communication between the intersex group and the medical field.

Early this year, I saw that the *Norwegian Medical Journal* had published an article using the term DSD almost as if they had always used it. But I know this is a very new term. In any scientific field it usually takes at least a couple of years before new terms and new ways of looking at things get acknowledged. I think there was an expectation in different groups within this field that something new had to happen, because there had been quite a lot of dissatisfaction since the 1950s until now about how the medical field had handled intersexuality. An intersex person that was genetically mutilated in the 1950s founded the *Intersex Society of North America* (ISNA).

CM: Genitally mutilated as a baby?

MVA: Yes, as a way of turning her “undefined” sex into a girl’s... This of course did not work as intended. What actually happened, which was the usual way to go around it in the 1950s and also reflects the way that the female body and female sexuality were looked on then, is that this baby had everything cut off. They did not create a clitoris; they just cut the whole thing off. This person, of course, who I think now calls herself a woman or perhaps not, I am not sure, was left with pretty much no way of expressing her sexuality with her sexual organ. She made it her life project, as it seems to me, to at least make the lives of other intersex persons better.

The way she created this organization is really funny. She published a letter in a newspaper, in the San Francisco Chronicle, I think, which she signed with her name and stated that she was the ISNA spokesperson, although at that time ISNA did not yet exist. But because she expressed her ideas about intersexuality publicly and gave the name of this organization, within a week, the organization had a lot of members. If that is not a clever way of starting an organization, I don’t know what it is!

Anyway, she has been quite influential, and the term, “Disorders of Sex Development,” replaced pretty much the way that the term “intersex” was used before. The creation of this new expression was partly due to the fact that the term “intersex” was sort of borrowed or stolen from gender activists. I know for a fact that activists in Sweden used a version of intersex as a way of describing gender bending, which of course does not necessarily sit well with the people who are actually, medically speaking, intersex. So this term, DSD, was a way of breaking away from gender activism, not necessarily meaning that gender activism is wrong or that it has nothing to do with intersexuality, but to state that these are two different issues.

CM: Could you also speak about the legacy of the mythical image of the hermaphrodite in relation to this conversation?

MVA: The term hermaphrodite goes back to Plato, to the myth of the creation of man as three different kinds of beings: You had one person made of two men, another person made of two women, and a third person made of a man and a woman. These were really a heterosexual couple and two versions of a homosexual couple. This is a description of love according to which you belong to one person, one person only, and you go through life searching this someone, and when you meet that someone, you feel whole, as if you have merged with your former self, your better half, so to speak. Actually, this heterosexual couple would look like a

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hermaphrodite, and a hermaphrodite is a person who has both male and female genitalia. This was considered to be heterosexuality, but as the years went by, this hermaphrodite became a mythical figure.

The funny thing about this is that this actually does not have much relation to the actual intersex body. A lot of people ask me if an intersex person can fertilize him-or-herself... As you know, some hermaphrodite animals can, and this is quite a paradox, because most intersex people are infertile. Turner syndrome women have a uterus, but they don't have ovaries, so they can, of course, carry a child with artificial insemination of the eggs, but not on their own. The genitalia, and not just the genitalia, but also the whole gendered body with breasts and beards, does not work quite the way the myth of the hermaphrodite shows it. An actual intersex person will not have a beard, a penis and breasts. It would be like an in-between situation, like the person described in the film *XXY*. We never see her or him fully naked, but it is suggested that this person has small breasts and a small penis, and this is quite accurate in terms of describing one type of intersex condition. It is more of an in-between than both, and this also has to do with the sexualization of the intersex condition. In pornographic terms, more is always better, so a person that has big *everything* is sexually interesting; to say that someone is so blurred, is spectacular and, therefore, interesting.

CM: But the term intersex is not as widely known as the term hermaphrodite is, is it?

MVA: No, I think the term intersex is slowly starting to be publicly known, partly due to the film *XXY*. But of course, this film creates new myths; for instance, the main character in the film is obviously not biologically *XXY*, because then she would have Klinefelter's syndrome and she would have the exact opposite problems that she has in the film. This is certainly due to the director of the film taking certain liberties with reality, because the film in itself is kind of dreamlike, since it is very difficult for parents, even if they want to do the kind of social experiment that the parents do in the film, to refuse medical treatment, and to refuse to be embraced by both the State and the medical society. I know for a fact that it would be very difficult in Norway. I suspect, however, that some manage to do it even here.

CM: We could maybe take for a fact that, even to non-intersex people, the State and biology regulate the way we define our gender. That is particularly so in the case of intersex people, in the sense that once you are born, you are in the hands of a doctor. I understand that there is no legal protection here, is there? I know that Colombia is the only country in the world in which the Constitutional Court has granted the family the right to decide what to do in terms of surgery. What is the legal framework in Norway? Is there a debate around this?

MVA: No. One of the reasons why I am researching this theme is because I think this is something that remains largely unspoken. I also have the ambition of starting perhaps a public debate, or at least a debate at some level, on how things are done. I am not saying that I necessarily have any answers, or that I would reveal them if I had them, but I would like people to start thinking about this theme and about gender issues in general.

I wrote an article based on my master's thesis, where I said asked: What is the need for the State to regulate gender? And why doesn't the State make an argument about the need to classify and to organize gender? Because there are obvious needs to organize gender. There isn't an obvious need for the State to separate the population into two kinds of entities. Not in so

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many obvious ways, perhaps in issues of pregnancy and military service (men are obliged to serve in Norway, not women).

I think this is my way of using the theme of intersex as a lens to get a closer look at society and to see how we treat people by assigning them gender and making this significant by the way we treat each other. The State, at least in Norway, has made a point of not making statistical facts of certain things. We make statistics all the time about differences between men and women in terms of opinions, and incomes, and there are a lot of things to be said about doing that. But the Norwegian State refuses, for instance, to make statistics about the Sami people. It is believed that it would be inherently bad to make statistics about this people, because it would probably reveal the fact that they are somehow lesser and not so well educated, and don't stand in comparison to the rest of the population.

Nevertheless, I think we do not have the same kind of discussions when it comes to gender. We reflect highly when it comes to things that are related to race, but when it comes to things related to gender the attitude is more like: Well, there are genders, how can we debate it, how can we discuss it? You know, women bare children and there are differences in physiques and so on...

CM: I interviewed Esben Esther in Oslo, who was arguing for a more inclusive understanding of gender. Hir was mentioning seven different “colors in the rainbow” of transgenderism. I do not remember them all right now, but what became interesting in our conversation was the evident ethical challenge for society, for the medical establishment, for the law, and for the families, of narrowing categories down to two: Either you are this or that. Can you reflect on ethics as it concerns intersexuality?

MVA: Yes. I think the ethics concerning intersexuality can be very difficult because, as I have realized researching on this subject, there is a medical reality to take into account. This is not necessarily a matter of choosing between creating a woman, creating a man, or letting the child be, because this last option is in a way a naïve approach. It is so in relation to the fact of planning to raise a child that is gender indifferent in a very gender categorized society.

But there is also a medical aspect to this. I read about a person who was diagnosed with a rare kind of intersex. I think she was around 18 years old, and she had already developed osteoporosis, a disease that usually only old women get. This was due to the fact that her body was so low on estrogen. I think she had even lower estrogen levels than most men have, and this was due to her disease. So she decided to go on hormonal treatment when she was around 19, but it was already too late for her. And of course, this will affect the rest of her life with her getting brittle bones and all these problems that are usually associated with old age.

There is a quality of gender that is actually related to good health: To be a person with normal sex also means that you have a higher probability to be a healthy person and not develop different kinds of diseases that are related to your hormone levels. This is an issue that is also relevant to people who transition within a transsexual context, because once they have transitioned, they have a higher probability to get gender specific disorders. Physically speaking, they are transforming themselves into the opposite sex that their bodies are equipped for, and so they have to find the perfect balance with artificial hormones, and this can be tricky.

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The problem is that if we say that children should be protected, that we should not diagnose children, we should not start treating them on an early basis, we risk creating sick children that will grow up to be sick adults because there is a physical necessity inherent in at least some of these conditions, and there is a need for a medical checkup. I am not saying that it is physically necessary for them to go through surgery, but there is a certain need for them to be under medical supervision and to get hormonal checkup to determine their health. This, of course, does not necessarily have to be done according to the usual medical scheme of things, but I think there is a large gap between this reality and gender activists who claim that people should go through life untouched. There are sort of two different realities: The “don’t-fuck-with-my-gender” issue and the medical field that works with this on a daily basis and do not want to have sick children or children who are uncertain about where they belong.

CM: That points to the distinction between gender as biology and gender as social construction, doesn't it?

MVA: Well, I am not so sure I find that distinction useful, because I think some gender activists are not very well informed about the actual issue. For instance, the homosexual organization in Norway (*LLH*) has the tendency, something also seen in other countries, to acclaim any kind of out-group sometimes without even asking the out-group itself if it is interested in getting protection or getting support. In fact, they have been in conflict with the transsexual organization for trying to cover their field. And they have also started to sniff on the intersex issue... To me it has started to sound strange and a little bit like feminism in the 1970s: I am going to save you whether you like it or not!

As a researcher, it is important for me to use a lot of time to read books, to read medical journals, to actually put myself also in the place of the doctors to see what is it that they have to choose from. Actually, what surprised me is that the picture developing up to now, and I am far from being done with my research project, is that it is actually the parents who are most reluctant to let the question remain open and to wait and see, and all these things that *ISNA* and the groups related to this organization are encouraging parents to do.

Actually, it is perhaps even harder for the parents to accept this in-between gender situation than it is for the doctors, because the parents are dealing with it on a day-to-day basis. They have to take the child home, and answer all the questions: Is it a boy or a girl? What clothes is the child going to wear? It is also much more personal to them. The feeling that I get when I talk to parents or try to get them to take part in my research project is that this theme is beyond being taboo; it is incomprehensible. They want to figure something out and then forget about it.

CM: But the consequences of “forgetting about it” can be messed up lives as adults, which is sometimes what happens with intersex people when an irreversible decision is made against their will; in a kind of arbitrary fast paced way.

MVA: The answer from the medical field now is, as far as I can see, that they know that they have made some mistakes in the past, but their answer is quite the way that *ISNA* and the gender activists expect it. The medical field has recognized that they have made some mistakes in the past. They see that they should not have cut off all those clitorises in the 1950s and that they should not have made a whole bunch of children into women like in the 1970s and the

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1980s. But they have a love for, for lack of a better expression, simple answers. They made a whole other group into girls a generation ago, and that didn't turn out very well. A lot of these girls turned out to be very masculine women, or women that actually preferred to be men... Their answer was: Okay, we can see that we made a mistake, so in the future we are going to make them all men instead. That is perhaps a solution but only in this sort of numerical manner! Maybe they are right, maybe they have a better chance of getting it right in terms of the children growing up to become satisfied with their assigned gender, but to me this is kind of puzzling. They still do not stop and ask themselves a different set of questions.

The answer is still we have to make a decision for the entire group and we have to make it while they are still children. I can very much see the traumatic aspect of this. It is a sensible thing to do, if you compare the intersex group, or rather a sub-section of the intersex group, since most intersex children have not been treated with surgery, to other kinds of medical groups. Nonetheless, I can also see it from the doctors' point of view: This is their profession and their specialty. They are trying to research and make the best of it. If there is something they can do to get a higher success rate, then they will do it. And to sit down and discuss what is this field really about, is just not something that you do.

For me, as a social scientist, it is interesting to twist it around a little and look at it in terms of what are the consequences for society. So I allow myself not to think so much about the tragic outcomes of all this and to see it from a larger perspective. If this is the way some of us are treated, what does that say about all of us and about the treatment of this very small group?

But I still think it reflects how gender is looked upon in general, and also how deformities are looked upon in general. Because the thing is that intersex is not that special if you compare it to the ways that we usually treat physical deformities or phenomena that is perceived as a physical deformity. I have a friend who was born with a second thumb, and she was very little when it was removed. They did not ask her: Do you want a second thumb? Can you use it for anything? Will it be fine for you to have one? Now she has grown rather interested in her former body and what she could have possibly become. It is interesting to see how we have this view of a prototype human being, and if we see something that is different, we have to erase it.

CM: And to normalize everything.

MVA: Yes, that is true. To make someone happy you have to make him/her more average. If there is something special, then we remove it without asking ourselves the questions: Is there anything we can do about it? Can it be fun for the individual? Can it be fun for the friends, the family and the lovers of the individual? There are a lot of seeds of uniqueness that we erase, and as a society, we do not ask ourselves why we do it, what is the purpose. It is very interesting for me to know; not so much if we should or shouldn't do it, but why do we do it. Is there a purpose? What is the purpose? Do we like the purpose? And do we want to keep that purpose? It is my view on all gender categorization and in a larger scale categorization in general, that as a society, we need to be more conscious of the way that we organize our world, and we should not be so afraid that if we stop thinking, the world will suddenly become meaningless. I think the idea of the world being meaningless is meaningless to me. I think it is very obvious that the world has to be meaningful, but there are always a lot of possibilities for that meaning and the meaning could be something else... Well, I guess that is my optimistic vision of the world!