

## **Comments on Ingunn Moser, Policy and Passion. A Complex Relation. Individual and Collective Agencies in the Field of Disabilities.**

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Ladies and gentlemen, before I comment on Ingunn Moser's lecture I would like to tell you a little bit about myself, so you know where I come from and what I want to contribute. I was trained as a political scientist, I majored in political philosophy and I did my thesis on public debates on medical ethical issues (topics like organ transplants, genetic engineering and choices in health care). Once you analyse these debates, you're also inclined and invited to defend arguments of your own and to take a position, and I suppose this explains why I ended up as a halfway ethicist or moral philosopher. I may add that this is a very nice role to have. As an ethicist I am supposed to tell everybody else what to do, whereas my being just a lay philosopher allows me to do so without having to study obscure authors such as Heidegger or Derrida. I feel very fortunate indeed.

Now, as a policy scientist/moral philosopher I would say that if you want to open up a dominant discourse or a ruling consensus on policy, you should do that by questioning its moral aspects. You have to be able to point out that there is something wrong, unjust or one-sided in the ruling consensus. And one of the things I really like about the sort of studies that Ingunn Moser, Jeannette Pols, Annemarie Mol and others do (Science and Technology Studies, Actor Network Theory, ethnographic research or whatever you call it) is that it teaches us to ask new questions and to look for answers in unexpected places. Reading Jeannette Pols's work one starts thinking about right and wrong in washing rituals, reading a new paper of Annemarie Mol last week made me wonder about right and wrong in food and eating rituals.

However, sometimes I feel that for STS researchers showing the other side and explaining ways of life is enough. They do not feel an urgent need to make moral recommendations and sometimes I think that is a pity. So what I would like to do in this presentation is moralise some of Ingunn Moser's findings, in order to enable us to give some moral advice or start a moral discussion.

I have based my talk on some of Moser's published articles and on a version of her lecture which was sent to me yesterday, which is not exactly the same as the one she has held just now, but I hope I at least got the drift of the argument.

So let me try to summarize it.

Moser argues that there is a dominant discourse on disability. Policy makers, pressure groups and professionals all seem to agree on the current policy which is about normalization, integration and compensation. Disabled people should be like able people, they should lead a similar life. If able people live in one family houses or apartments for individuals, in ordinary neighbourhoods along with like minded neighbours in ordinary towns or villages, then so should handicapped people. We should not put them away in large institutions situated in a forest or near the seaside. Normalization.

We, Dutch, British or Swedish, Danish or Norwegian citizen, constitute the people of the Netherlands, the UK, Sweden, Denmark or Norway. We are all equal citizens of our political community and we should treat each other as such. Hence, we ought to make sure that disabled people are treated as equal citizens. We should send disabled children to the schools and youth clubs visited by able bodied children and youngsters. We should help disabled people find a job in the labour market that employs all of us. They should share our public places and our institutions: the streets, the squares, the schools, the universities, the shops, banks, libraries, the factories and companies. Integration.

Obviously, for many disabled people normalization and integration are not easy to accomplish and that is why disabled people are entitled to compensation. Blind people have a right to speech computers, people who can't use their legs should be given wheelchairs, deaf people are entitled to hearing aides and people with serious learning disabilities should be given lots of extra help at school.

Moser argues that the dominant discourse should be challenged by competing visions, other perspectives, leading to different policy choices. I totally agree with her there. If you compare debates on women's emancipation with the current debates on politics with regard to disabled people, you will notice that the women's liberation debate is infinitely more varied (at least in the Netherlands). To be sure there are lots of feminists and policy makers who insist on normalization, integration and compensation of women in male society. But there are many other points of view.

There are people who argue that women should not strive to become like some of our most successful males: dominant, aggressive, arrogant, one-sided workaholics. They argue that women should remain as they are: modest, agreeable, and inclined to divide their attention between their work and their families. Workplaces might benefit from this particular input. There are also men and women who defend the traditional way of life, with the mother at home, baking apple pie and taking care of her children and elderly parents. It seems good for policy areas and policy makers if there are competing policy ideas floating around, it may improve their thinking, even if they decide to stick to their dominant policy discourse after all.

So Moser sets out on a quest for challenging discourses to the dominant one. Several candidates pass by. The first is called the social model, personified by Guro Fjellanger, minister of the environment in Norway. She did not want to become the minister for social affairs, she wanted to do something totally unrelated to disability or any other sort of identity politics. Her disability was a mere hindrance, it did not constitute her identity. She just kept doing her thing in society, calmly and confidently, all the time waiting for obstacles to be removed, entrances widened, buildings adjusted and so on. I must say that I did not really see much difference between the social model and the dominant discourse, apart from the fact that in the normalization discourse it is the handicapped person who should be adapted in order to fit in, whereas in the social model society ought to be rebuilt slightly in order to make room for handicapped people. But both models are about normalization and integration, I would say. The social model is an attractive discourse, but it resembles the dominant discourse too much. It cannot function as a true alternative.

The second possible candidate to challenge the normalization is discourse is called Passion. The advocates of Passion do not care for normalization, integration and compensation, they develop new lifestyles, involving adventures such as rock climbing in wheelchairs, running a marathon on artificial feet and organizing events like the Paralympics. If we want to find examples outside sports we would probably have to look to artists: making paintings with one's toes or one's mouth if one doesn't have hands, turning your impediment or handicap into some sort of added value, a way of living which able bodied people could never have invented. The passion discourse offers handicapped people a choice that is definitely different from the dominant policy discourse. It does not say 'try to be like everybody else, join us and explain what you need in order to be able to do so, because you are entitled to compensation.'

Instead it invites disabled people to do something different, something truly original that the world has not witnessed before.

The third competing discourse passing by is called Fate. It is a discourse from the past, that says that disabled people have to accept their body, try to be content and pleasant towards other people despite their condition and that they have to be grateful for the help and assistance they receive. From society, from the state and from their nearest and dearest.

It is a discourse which has been discredited widely and in my opinion, not always rightly. Disabled or chronically ill people can teach healthy able people about patience, acceptance, and graceful suffering instead of protesting, complaining and demanding that the world be changed in order to accommodate sick and disabled people. It always strikes me as somewhat unfortunate that Dutch citizens in general love the welfare state but that they do not show much gratitude if they stand to benefit from it. In fact I try to notice it every time somebody has said something to that account and so far I have only two testimonies. The first was my great aunt who died at age 96, and who repeatedly emphasized that she had been so fortunate with her old age pension all these years after she turned sixty-five. Wasn't she living in an extremely decent, pleasant country? The other was a colleague of mine who suffered from a depression and was sick for over a year. He was very grateful that the state had allowed him to be sick and unproductive all this time by paying his medical expenses and giving him and his family a sickness allowance. I think we owe the welfare state some gratitude from time to time, and this goes for all of us who stand to benefit from one or another arrangement, including disabled people. We may compare the Fate discourse to the traditional discourse about women. We need not take that on board completely, but we can at least acknowledge that there was something morally praiseworthy in giving up your career to support your husband, raise your children, do volunteer work of all sorts and take care of your parents. Likewise accepting your fate gracefully and being grateful is morally praiseworthy, so it seems worthwhile to articulate and emphasize this from time to time.

Ingunn Moser argues that the dominant normalization discourse tends to incorporate other discourses, thereby in effect destroying them as proper alternatives. Moser doesn't seem totally happy with that and I agree with her there too. I think that if you want to uphold and advocate competing discourses, you have to tease out and emphasize the moral elements in

them. You have to emphasize that the passion discourse is not just about climbing rocks in a wheelchair, but that it is about creating different ways of life and opening new vistas. You have to revalue the morally praiseworthy elements in the Fate discourse, and not just dismiss them as relics from the past. Moreover you need to create doubts about the normalization discourse. In order to make us see the need for alternatives, you have to convince us that the dominant discourse is morally flawed, or at least partly unjust. So let us try to do just that.

Suppose Stephen is chronically ill and as a consequence severely disabled. He has been taken care of in a rehabilitation clinic, where he has learned to take care of himself. His house has been furnished with an extremely complicated machinery, that allows him to live independently. However, just taking care of himself – washing, getting dressed, getting out of bed, preparing a meal – takes up all his energy. He literally does not have room for anything else. Isn't that too high a price to pay for your independence, for leading a normal life just like your neighbors? In the Netherlands disabled people may choose to have a personal budget which they can spend to hire personal care keepers. This enables them to make their own choices with regard to who is looking after them and when. They have to account for the way they spend their budget and they also have to be good employers for their staff. If all this enables people to do something nice with their life – have a job, take care of family, go rock climbing in a wheelchair – then this budget procedure seems an attractive option. But what if it doesn't? What if it fills up your life, what if you spend your life in essence, organizing your own care? Is that really more attractive than living a life in a sheltered community where care takers are employed by the institution and where you may perhaps make yourself useful by helping other inhabitants of the institution? You may be too sick to have a proper job, but such an institution could arrange all sorts of useful little jobs that you could do. Is that necessarily worse than living independently at all cost?

The normalization discourse has advocated independent living for everybody, for the chronically ill and disabled, for psychiatric patients, for the mentally disabled, for patients suffering from Alzheimer's disease. As a consequence the people who were left behind in the institutions are very severely ill, or very severely mentally disabled. Often these are the people who are not able to communicate with staff members, at least not articulately. This may have changed life in institutions for the worse. I can imagine that it is much easier to be a kind and attentive professional if you get some positive feedback from your clients or patients. It doesn't matter if some of them are unable to give that, but if hardly any of your

clients can say anything at all, you may start wondering what's the point of being kind. You may turn to your colleagues for a nice conversation on the meaning of life, rather than try out some new type of care for your clients. The fact that the most competent, articulate clients have left the institutions to join society may very well have changed institutions for the worse. The prize for normalization may have been paid by those for whom normalization is not a feasible option.

If the normalization and integration of the mildly disabled people were a huge success, we might say that it would be regrettable but still acceptable that severely disabled people have to the prize for it. But the research by Evelien Tonkens, Jeannette Pols and Loes Verplanke has shown us that normalization is certainly not always successful. In Dutch newspapers we can read interviews with mildly disabled people, living independently. They confess to be scared and homesick. A blind, mildly mentally disabled woman was living in an apartment in Zeist, which is a pleasant neighborhood to live, with lots of villas and trees. But she could not appreciate the trees, and despite the help of her personal assistant she was afraid to go to the local shops. She wanted to be back on the terrain for blind people, where she knew her way about, where she had friends and where she could make herself useful in her own way. So she had applied for an apartment on the terrain of her old institution. Many of her former friends had done the same thing, but the organization had not enough room for all of them, because a large part of the old institution had been dismantled. So, she was put on a waiting list and she accepted that gracefully, with words reminding me of the Fate discourse.

So, in conclusion. In order to make room for challenging alternative discourses in disability studies and disability policy, we need to point out the moral disadvantages of the normalization discourse, and emphasize the moral attractions of its alternatives.

