



**Linköping University**

**RESEARCH CONFERENCES**

ESF-LiU Conference

# The Perfect Body: between Normativity and Consumerism

Scandic Hotel Linköping Väst, Linköping, Sweden  
9-13 October 2009

Chair: **Katrin Grüber**, IMEW (Institut Mensch, Ethik und  
Wissenschaft), DE  
Vice-Chair: **Ursula Naue**, LSG (Life Science Governance  
Research Platform), University of Vienna, AT

[www.esf.org/conferences/09273](http://www.esf.org/conferences/09273)

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## Conference Highlights

*Please provide a brief summary of the conference and its highlights in non-specialist terms (especially for highly technical subjects) for communication and publicity purposes. (ca. 400-500 words)*

The conference “The perfect body – between normativity and consumerism” was organised as an interdisciplinary dialogue and was the first international meeting to bring together scholars from Disability Studies, STS (Science, Technology and Society Studies) and Bioethics, as well as researchers from laboratories working in the field of new technologies.

The conference’s main focus was on enhancement and new technologies (such as robotics and neuro-enhancement) from a so far neglected “disability-perspective”.

Even though discussed very intensively among bioethicists, the line between enhancement and therapy as being something in need of treatment is not clear. As expected, the line gets even more blurred when the disability perspective is included. What might be seen as therapy and necessary from an outside look might be neither necessary nor positive or even better for disabled people (see for example Cochlea implants for deaf people). Hence it was suggested on the conference to replace the term enhancement by a more neutral one such as “altering technologies”.

Normativity, normality and norms were central conference themes. Speakers with different academic background showed that normativity and the concept of normality can play a very important role on human beings and the society. Even despite the fact that normality is a flexible concept and that there is not only one norm it can be an important ground for discrimination, if people do not fit in the prevailing norm. Disabled people have experience this for many years even though the flexibilisation of norms was a positive development for many of them. Additionally, in the last years, obese people have suffered from a similar stigma.

Hence, an important question is how to ensure that people do not feel obliged to alter their body or capacities in order to fulfil the norm. Here, the argument used by transhumanists is important (and questionable), saying that everybody should strive to be perfect. For them, enhancement is not an “upgrade” from certain old established norms, but an “upgrade” for all of us, including disabled persons. Nevertheless, the question remains open, if these “new norms” really differ from discriminating old norms or if they only perpetuate norms as a way to marginalise certain groups in society.

It is important to note in this context that there are different ways to counteract discrimination. “Groups” (certain parts of society) can create new “norms”. Another interesting way to counteract stigmatisation can be portraits of disabled people. By reframing and discussing the context in which they are portrayed, viewers would have no doubts about their dignity, value and recognition (presentation by Garland-Thomson).

The use of certain technologies or shaping the body can be understood as an act of individual freedom and choice – despite the fact that ethical questions and concerns are raised when individuals have the wish to be amputated in order to acquire a “disabled identity”. This, again, questions the impact of norms – and also of possible “new norms” – on understanding disability (as something we should try to avoid).

The above mentioned themes represent only some of the highlights of this conference. In whole, the conference generated a lively discussion about enhancement in relation to disability, leading to a reflection of the concept of enhancement.

We hereby authorize ESF – and the conference partners to use the information contained in the above section on ‘Conference Highlights’ in their communication on the scheme.

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# Scientific Report

## Executive Summary

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(2 pages max)

The conference “The perfect body – between normativity and consumerism” was organised as an interdisciplinary dialogue and was the first international meeting to bring together scholars from Disability Studies, STS (Science, Technology and Society Studies) and Bioethics, as well as basic researchers from laboratories working in the field of new technologies.

The conference started with opening remarks by Naomi Segal in her role as rapporteur for the ESF and the two chairs Katrin Grüber and Ursula Naue.

### Recent Developments and Visions

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In the first session, Paul Verschure (University Pompeu Fabra, Spain) gave an insight into the work of the laboratory SPECS. He talked about his concept of the brain and its consequences for future developments as well as supporting stroke patients in their rehabilitation program.

Jennifer Fishman (McGill University Montreal, Canada) described new tendencies in anti-aging therapies. The new interdisciplinary field of bio-gerontology emerged only recently. It combines the old vision of eternal youth as described in the painting *The Fountain of Youth* (1546) by Lucas Cranach the Elder with modern techniques in the field of bio-molecular sciences and bio-demography. For bio-gerontologists, aging is not seen as a natural process, but rather as something to be managed.

Marcus Düwell (Utrecht University, NL) gave an overview on the recent developments in the bioethics discourse concerning enhancement technologies. He argued in favour of the principle of precaution for future development and for developing further the ethics of respect in order to counteract negative effects on disabled people.

Robin Mackenzie (University of Kent, UK) described different examples of bodies viewed as perfect as displayed in advertisements (anorexic or muscular models). The use of certain technologies or shaping the body can be seen as an act of individual freedom and choice. However, ethical questions and concerns are raised when individuals have the wish to be amputated in order to acquire a “disabled identity”.

### Therapy and Enhancement - Similarities, Differences, Boundaries

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The second session explored the discourse of the boundary between therapy and enhancement from the bioethicists' and STS scholars' perspective.

Silke Schicktanz (University Medical Center Göttingen, Germany) suggested to analyse and understand better the underlying ideas of utopias/dystopias. This might also help to understand public concerns and hopes. In this context, the question of who defines risks is seen as important issue.

Frida Simonstein (Yezreel Valley College, Israel) highlighted the missing perspective of women/gender and the effect reproductive technologies can have on the health of women.

Inez de Beaufort (Erasmus MC, NL) gave in her paper on ethics of obesity an overview on tendencies of modern societies to deal with obese people. Modern society is to some extent obsessed with weight and consequently obese people are being stigmatised.

Katrin Grüber (IMEW Berlin, Germany) chose the Cochlea implant as a case study to show how important it is not only to talk about chances of technologies, but also about the risks and negative side-effects. She highlighted that what might be seen as therapy and necessary from an outside look might be neither necessary nor positive or even better for disabled people. She recommended to include disabled people in the course of the development of new devices from the beginning.

### The Perfect Body: between Normativity and Consumerism

In her keynote lecture, Barbara Duden (Leibniz Universität Hannover, Germany) took the audience to a time journey to several examples of technology developments and their effects especially on women. In the context of new possibilities to alter the body, women have to make decisions and have to manage their bodies on the basis of an abstract concept. Choices are “offered” to women that are difficult to decide on,

because they are about future risks and are hence beyond time and space. These new technologies work at the same time „without the body“and with the body.

### **Views on Disability**

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The third session highlighted recent developments in disability studies.

Ursula Naue (University of Vienna, Austria) and Simo Vehmas (University of Jyväskylä, Finland) described the difference between the Medical and the Social Model of Disability, doing this from different perspectives (political science and philosophy), which has an effect on the “description” of the impact of these models. Both presenters discussed the consequences of technologies altering the body. According to Naue it would be important in the future to develop enhancement technology in a way that it does not enforce the difference between the disabled and the non-disabled/abled. Vehmas suggested, that “interventions with the aim to improve individuals’ capacities as well as social arrangements should both be parts of a fair institutional response to human diversity.”

Jackie Leach Scully (Newcastle University, UK) started from the statement that “Identity has a role in normative judgements. As body has a role in identity formation”, it is important to include the perspective of disabled people as ‘anomalous’ embodiment which may generate different perspectives on normative standards.” This difference maybe seen in comparison to non-disabled people. Furthermore it should be taken into account that there are differences within the “group” of disabled people.

Lee Monaghan (University of Limerick, Ireland) highlighted the aggressive language being used when talking about the “war on obesity”. The definition of who is obese and who is not can vary over time and is a consequence of committee decisions changing norms such as the BMI (as in this case, the group of North American obese people enlarged over night). To understand discussions about obesity, normativity and the concept of the “multi-dimensional ‘lived body’” should be combined. The reaction of men being diagnosed as obese can vary: some of them start a diet or exercises. Others create new norms in groups (for example the group of “bears” in the gay community) against the prevailing norm of being slim.

### **Picturing Disability**

Rosemarie Garland-Thomson (Emory University Atlanta, US) showed in her keynote speech how art can counteract stigmatisation of disabled people. She gave several impressing examples of painting where artists portrayed disabled people by reframing the context so no viewer would have doubts about their dignity, value and recognition.

### **Normality and Normativity**

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In the fourth session the two speakers Anne Waldschmidt (University of Cologne, Germany) and Joakim Isaksson (Umeå University, Sweden) spoke about the concepts of normality, normativity and deviance. Due to Waldschmidt, the concept of “flexible normalisation” has some advantages for disabled people as it increases the possibilities for “belonging”. Hence, the “relationship between normativity, normality and disability is paradoxical”, Isaksson argued and applied the concept of normality and deviation to pupils in a special needs school where they are part of two discourses: the medical and the pedagogical one. He noticed a twofold effect of applying the concept of normality and deviation to pupils. On the one hand, it might be necessary in order to receive the necessary support, but on the other hand, it can have a discriminating effect.

### **Roundtable Ethical Dimensions of Enhancement**

Judit Sandor (Central European University Budapest, Hungary) was the first speaker in the roundtable discussion on ethical dimensions of enhancement. From the viewpoint of a lawyer, she focused on recent developments in enhancement and the difficulties to make a distinction between therapy and enhancement. In her view it would be better to use the term “altering technologies” to highlight the ambivalent nature of enhancement technologies that can have an effect on society. She recommended to “focus not on analyzing the craft of biotechnologies, but on developing a critical assessment of the concepts, actors and processes of deliberation”.

Marcus Düwell provoked the audience by introducing a sceptical view of a philosopher who could never be sure about his/her findings and should always take into account that the person with the opposite view

might be right. Gregor Wolbring (University of Calgary, Canada) pointed out that from a disabled person's perspective, it would be necessary to scrutinise transhumanism. In order to make a change it would be necessary for disabled people better to understand new technical developments to be able to re-act and counter-act.

### **The Future has started Today?**

In the fifth session Gregor Wolbring and Bertrand Tondu (University of Toulouse, France) focused – from different perspectives – on possible developments in technical devices altering the body (prostheses). Bertrand Tondu gave an overview of old and recent developments of robotics and prostheses and gave an overview on differences and similarities between robots and human beings. He concluded that the “...homeostasis principle common to animal physiology and cybernetic machines like robots is not able to explain the fundamental behavioural differences between intelligent machines and living beings.” Gregor Wolbring explained the concept of Ableism as “the favoritism for certain abilities for example cognition, competitiveness or consumerism and the often negative sentiment towards the lack of favored abilities. “

### **Panel Session: Enhancement and Disability**

Heather Bradshaw (University of Bristol, UK) introduced the concept of “morphological freedom”, concluding that political structures would have to change in order to deal with these new challenges. She argued in favour of a liberal commitment to an open future.

Laura Cabrera (Charles Sturt University, Australia) discussed a transhumanist model of disability and the relationship between “the posthuman” and disability. She concluded that enhancement technologies should try to shift the focus from a medical towards a social model paradigm.

Zoe Goldstein (IMEW Berlin, Germany), gave an overview on certain practices (such as piercing, implants or tongue splitting) and discussed these practices in relation to and as a way of body altering technologies. Martin Weiss (University of Klagenfurt, Austria) presented a historical philosophical overview regarding what can be called the “emancipation from nature”. In this context, he discussed two positions that exist within academia – a “conservative techno-phobic” (e.g. Fukuyama, Habermas) and a “progressive techno-euphoric” (e.g. Bostrom) position.

## **Scientific Content of the Conference**

(1 page min.)

- *Summary of the conference sessions focusing on the scientific highlights*
- *Assessment of the results and their potential impact on future research or applications*

The conference looked at enhancement and new technologies (such as robotics or neuro-enhancement) from a so far neglected “disability-perspective”. Even though discussed very intensively among bioethicists or STS scholars, the line between therapy as something in need of treatment and enhancement is not clear. It is mainly distinguished from therapy or prevention by reference to normality. On the conference it became even more obvious than before that there cannot be one definition and that the definitions are not neutral, but stem from different value-driven perspectives which are based upon certain viewpoints and judgements on what constitutes “normality” and human capabilities. These can be very different from one individual and another, between different groups in the society, and they can vary over time (diachronic as well as synchronic differences and changes).

Speakers from different academic backgrounds highlighted the importance of norms on human beings and on society. Despite the fact that normality is a flexible concept and that there is not only one norm, in our liberal societies it can be used as a powerful tool in the context of a disciplinary power that emphasises the individual responsibility. Also, normality can work as a basis for discrimination, when people do not fit into the prevailing set of norms (Fishman, Waldschmidt, Naue). As a consequence of this discrimination, people with a capacity “outside” the generally accepted (or newly created) norm may feel forced as a moral obligation to undergo alterations of their body or their capacities in order to fulfil the norm. For example, some people apply anti-aging care in their 40s and 50s (Fishman) or undergo facial surgery in order to improve their chances on the labour market (Sandor). But also, parents may decide for their deaf child being implanted with Cochlea implant (Grüber) which stresses the fact that disability is not always

understood as “outside” the set of norms. In addition to the above said, since a couple of years a large group of people seen as obese is openly stigmatised (de Beaufort, Monaghan). They are reproached of not acting responsible and causing society to high costs (Monaghan).

Transhumanists question the concept of normality as in their view everybody should strive to be perfect. In contrast, individuals who want to be amputated in order to have a “disabled identity” can be seen as being on the other end of the spectrum. This example shows that the use of certain technologies of shaping the body can be seen as an act of individual freedom and choice. On the other hand, the sum of individual choices can create a “new norm” for the whole society or for groups. Schicktanz sees a normative relationship between the individual and the collective, and Düwell views enhancement technologies as a collective activity.

The conference participants pointed out that not only the reference to normality makes the term enhancement value-driven. The term enhancement in itself implies only positive effects of a technology. It is mainly used in a sense that the state, the capacities or performances, and hence the situation of a person will be improved. This can be the case, but it must not be the case. Hence it was suggested to use a more neutral term such as “altering technologies” (Sandor) or “new technologies” to make the ambiguity of a technology more obvious (Schicktanz). Mackenzie speaks of “somatechnis”, technologies producing bodies.

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New technologies can have an impact on the body and on the relation one has with one’s body. The body can be viewed as an entity being controlled by the brain (Verschure). Importantly, Duden gave different examples where the development of new technologies changed the concept of the body especially for women, doing this by either feeling obliged to manage their body or even in the field of “managing” future risks that seem to be beyond the prevailing concept of time and space. But on the other hand, experiences are embodied and thus shaping the structure of arguments about therapy/enhancement (Leach Scully). This shows how important it is to bring the body back into the discussions within Disability Studies (Vehmas).

The issue of prohibiting the development or application of altering technologies was only raised by some of the speakers. Leach Scully stated that the negative effect of enhancement on identity does not imply that enhancement is impermissible. Hence, an important question is how to ensure that people do not feel obliged to alter their body or capacities in order to fulfil the norm. During the conference, suggestions were made on how to alter the discourse and formulate research projects by introducing a disability perspective. Simonstein showed how important this is for the discussion of enhancement. The discourse in reprogenetics suffers from not taking into consideration the effects that reprogenetics can have on women and their body. The same is true for the case for altering technologies and disabled people. Unless they are not included in the discourse or decision making processes, the risk that the gap between “normal” people and disabled people (or obese or old people) might be increased. Technological development should be shaped in a way that it does not enforce the difference between disabled and the non-disabled/abled people (Naue). An interesting way to counteract stigmatisation can be portraits of disabled people. By reframing and discussing the context in which they are portrayed, viewers would have no doubts about their dignity, value and recognition (Garland-Thomson).

The ethical analysis should not only take into account the very nature of the interventions, but also the broader socio-ethical trade-offs technology induces. The ethical framework could be an “Ethics of Respect”. Furthermore, the consequences of the application of the concept of human diversity should be explored.

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## Forward Look

(1 page min.)

- *Assessment of the results*
- *Contribution to the future direction of the field – identification of issues in the 5-10 years & timeframe*
- *Identification of emerging topics*

- The conference bears the potential to contribute to future developments in different scientific fields such as bioethics, Disability Studies, STS (Science and Technology Studies) and technology development by merging the perspectives from these different disciplines. The following ideas give the directions for highly relevant research topics that would be worthwhile being explored.
- The conference showed paths on how to re-think and re-contextualise the academic discourse and research on enhancement. This means for bioethics to take into account not only the very nature of the interventions, and the aspects of enhancement affecting the self versus other distinctions, but also the broader socio-ethical trade-offs technology induces especially in the context of a perspective of disability.
- Another very interesting topic emerging from this conference would be to further develop the concept of the body from a disability perspective and to re-introduce the body into Disability Studies. For example, in British Disability Studies there is an ongoing debate about the place of the body in the social model, leaving sometimes out of consideration that the socio-political context nowadays mainly focuses exactly on the body (being responsible for one's own health). Hence, to be able to act and re-act on the societal construction of the concept of disability, it is necessary to include the body into debates about the political reality of the social model and to do empirical studies.
- Another research topic could also be the relationship between individuals, groups and society regarding the issue of enhancement and the application of enhancement technologies. Individual choice and freedom of choice has to be guaranteed to all groups within society. But at the same time, it has to be discussed in the context of a diverse society in which not all groups fit into established norms that allow for altering one's body.
- Also, the question of future (bio)technologies and diverse technical devices which may serve as tools for enhancement should be discussed in relation to a disability perspective on enhancement. Technically possible devices do not always fit into a group's self identity and self understanding and hence, these devices should not be used from a mere "outside-perspective", but always in combination with an "inside-perspective" (user perspective).
- During the conference it became quite clear that another important topic regarding enhancement technologies is the relationship between enhancement and eugenics. At least more "radical" positions within the group of scholars in favour of enhancement (transhumanists) argue quite similar as Galton did when defining eugenics. Although these positions within the enhancement debate do not relate to the term eugenics it is socio-politically-ethically worth discussing the ties and the relationship between the concepts of eugenics and enhancement.

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▪ Is there a need for a foresight-type initiative?

To develop scientific excellence in the field of "enhancement and disability", it would be very helpful to create a basis for a foresight-type initiative. Nevertheless, the discussion about "enhancement and disability" is now at the beginning. Hence, several steps have to be taken before actually starting to build a group of involved research groups.

### Atmosphere and Infrastructure

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▪ *The reaction of the participants to the location and the organization, including networking, and any other relevant comments*

In addition to the anonymous comments in the questionnaires there were positive and even enthusiastic comments from speakers as well as participants during and after the conference. Quite a few of the speakers and the participants argued either during the conference or after the

conference that they would like to intensify the discourse either in the framework of another conference or in common research projects. One of the speakers sees it as an intellectual network that would be worth being part of it. Several of the young researchers said that one of the great advantages of the conference in comparison to others was the opportunity to communicate with a large group of experts in the field, being on a par with the experts. Several contacts were established between experts and young researchers with the potential of cooperation.

As this conference was the first one the ESF organised with participants with a disability, it was necessary to find an accessible hotel and conference venue. In the end, the actual conference venue and hotel was more or less accessible, although the hotel provided accessible rooms only for two persons in a wheelchair.

Some of the participants stated that the atmosphere of the hotel was not exactly what they would have expected, but that the good food and the lively and inspiring atmosphere of the conference itself made up for it.