

25 YEARS OF THE BELGIAN ADVISORY COMMITTEE ON BIOETHICS  
BIENNIAL CONFERENCE



# autonomy revisited

28 AND 29 APRIL 2021

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*BOOK OF ABSTRACTS*

# Autonomie revisited

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**Wednesday 28<sup>th</sup> April – Academic session**

**16.30 : Mrs Margaret Lock**, Professor Emerita, Mc Gill University, Canada

### **Mutable Environments and Permeable Human Bodies**

Geologists have declared an epochal transition to the Anthropocene, formally recognizing humans as the driving force of destructive global change; a distinction can no longer be made between human history and natural history. Certain commentators argue that Capitalocene better characterizes the situation, given that the effects of planetary decimation and global warming are not equally distributed among humans. A second conceptual change has recently taken place in which genomes are recognized as reactive to environmental stimuli both external and internal to the human body. In the postgenomic era, genes neither initiate life nor drive human development. The science of the burgeoning field of behavioral epigenetics is introduced, followed by illustrative examples of environmentally caused epigenetic changes that impact negatively on health. Epigeneticists routinely limit their attention to detecting measurable changes at the molecular level. I argue that anthropological contributions that incorporate subjective accounts of embodiment involving past and present events are crucial in order to better situate and account for biological differences and health outcomes historically, ecologically, and politically. Discussion of the microbiome provides a cautionary reminder that microbes are the ultimate driving force of health and illness.

**17.30 : Mrs Dominique Memmi**, Head of research at the CNRS in social sciences, France

**“Manufacturing” the subject: The carers’own contribution (since the 60ies, in France: abstract will follow)**

**Thursday 29<sup>th</sup> April – Conference day with input of students**

**9.30 : Mr Nicolas Marquis**, Professor Casper-USLB, ERC Grantee

**Doing good to others in spite of themselves? Revisiting autonomy in psychiatry and mental health**

The worlds of mental health—provide excellent analysers for understanding the position taken by the notion of autonomy and the tensions that this generates. In this presentation, I will show how a new language has taken hold (patient-actor, recovery, mental disability, etc.) and how it reveals that mental health mechanisms are designed to restore people's autonomy so that they can become (again) partners in social life. I will focus in particular on a notion that prevails today both in legal texts and in the daily life of institutions: the care or life “project” that each person is supposed to nurture. Its uses are indicative of how we currently represent what is an acceptable (support) or unacceptable (coercion) form of intervention. But the difficulties that this tool creates in a very tangible way in the care pathways also highlight the sometimes high demands placed by our representations of a person who is always capable of a little more autonomy. I will conclude by stressing the value of a sociological perspective on autonomy, which makes it possible to understand this notion as both a standard, a value and an expectation, which is important to us.

**10.20 : Student group 1:** Section Art-therapy at the Institute Ilya Prigogine in Brussels under supervision of Mrs Marie-Françoise Meurisse

### **Autonomy & Art**

Students in the 'Art Therapy' section of the Ilya Prigogine independent college in Brussels looked at the theme of autonomy from their point of view of artists involved in the world of aid, reception and care. Their practical work, based on both artistic activity and human sciences, often takes place in an interdisciplinary context. Autonomy, seen through concepts such as setting, singularity, sense and goodwill, was considered and addressed in the form of animated drawings.

As a picture paints a thousand words, the future art therapists would like to invite you to their presentation, bringing something to write with...

**11.20 : Student group 2** : 3rd and 4th year *Nursing And Ergotherapy* at *PXL-Hogeschool Hasselt*, under supervision of Mr Jan Coel and Mrs Katrien Ruytjens

### **“Autonomy (re)imagined”**

Students from the third year of Nursing and Occupational Therapy (PXL) were guided by instructors in considering the topic ‘autonomy in care’ through roleplay. A group of eight students volunteered to embark on this in-depth learning process outside their class schedule.

Students and instructors met for half a year in a learning community in which traineeship experiences and in-depth interviews on ‘autonomy in care’ were compared and contrasted with insights from the literature. A learning community can be described as a group of people who have an interest in a topic and want to exchange knowledge with each other and learn from each other. The participants (students and instructors) worked together for half a year to exchange ideas and come up with solutions, but also to give in-depth consideration to the central topic. Every participant also conducted one in-depth interview during that period with a care receiver or caregiver on ‘Autonomy in care’. The payoff of the learning community was twofold: (1) the content of the concept of autonomy was rethought and challenged using seven\* specific views (case studies); (2) the ‘learning community’ methodology, with instructors, students of nursing/occupational therapy and experts in the subject, was a beneficial and intensive process. In the current educational context, in which competence-oriented teaching and evaluation leave little room for ‘slow questions’ or in-depth ethical consideration, participation in a learning community is a constructive plus to the professional growth of both students and instructors.

\*Seven views of autonomy

1. “Autonomy, we don’t talk about it”
2. “If the patient is content, are we content too?”
3. Autonomy depends on the care receiver’s system
4. Discussing autonomy support with colleagues: difficult but necessary
5. Supporting autonomy is... having a beer together

6. There is such a thing as learned care dependence
7. The entire healthcare organisation affects autonomy

**13.00 : Student group 3 :** International Master in Public Health Methodology (ULB), under supervision of Mrs Sarah O'Neill and Mrs Katia Castetbon

**Autonomy in Sexual and Reproductive health lifestyle choices in women aged 16-35 years: reflections based on qualitative interviews in Belgium, Nigeria and Cameroon**

*Background:* The fifth sustainable development goal is to achieve female empowerment worldwide, ensuring universal access to sexual and reproductive health rights, and allowing women to make informed decisions in several facets of their lives, including contraceptive use and sexuality. We sought to explore the autonomy and influencing factors in sexual and reproductive lifestyle choices (particularly regarding menstruation and contraceptive use), in young women in both developing and high-income countries.

*Methods:* 18 qualitative interviews were carried out with participants aged 16 – 35 years in Belgium, Nigeria and Cameroon. Data was collected from both males and females via online in-depth interviews, which were recorded, transcribed and thematically analysed.

*Results:* Among all participants, knowledge from formal education, fear of pregnancies or STI and associated stigma, partner's sexual preference, previous experiences and beliefs regarding side effects influenced their contraceptive lifestyle choices. Menstrual hygiene was shaped by both formal and informal education. Cost played a minimal role in these choices.

*Conclusion:* Autonomy in making sexual and reproductive lifestyle decisions in young women is influenced by multiple interwoven factors. To prevent sexually transmissible infections and unwanted pregnancies in this population, there is a need to enforce appropriately fine-tuned formal and informal education.

**13.40 : Student group 4:** Master in Public Health Sciences (Uliège), under supervision of Mrs Florence Caeymaex and Mr Benoît Pétré

### **The case of Samira: between relationships and communication, rethinking decision-making autonomy**

In our modern societies, communication is an essential part of building human relationships. But how do you make your voice heard, when communication skills are impaired by the consequences of a major life event or illness?

We would like to explain Samira's situation to you. This young quadriplegic woman has always been deprived of speech. An Augmentative and Alternative Communication (AAC) tool, based on the use of images, has been gradually implemented to allow her to communicate with those around her. What does communicating through a tool like this mean in practical terms? And what were the material and human factors that ensured the success of this process?

A retrospective analysis of this situation will reveal some of the conditions necessary to create decision-making autonomy. If making one's voice heard is essential for this - how else can one express an expectation, a desire, a will, a choice? - Samira's story reminds us that establishing communication is in itself patient work that involves mutual learning, and that reciprocity nurtures autonomy.

What broader lessons can we learn from this story? Many technical solutions exist for people said to be without "speech", but few have yet been implemented on the ground. We will seek to identify the conditions that we think are essential to successfully establish AAC, but also the obstacles which, in practice, still deprive many people of their voice.

**14.40 : Student group 5** : 3rd year *Nursing at Erasmushogeschool* in Brussels, under supervision of Mrs Ingeburg Digneffe in cooperation with Mr Julien Libbrecht

**Patient asks to continue receiving treatment...**

Does the autonomy of patients also mean that they have the right to continue receiving treatment, even if their state of health seems hopeless to healthcare providers? Very often it is the other way around: patients refuse treatment because they feel that their life cannot offer the necessary quality anymore or because they themselves feel that their condition has become hopeless and they suffer too much.

In the case presented by students of the Erasmushogeschool Brussels, we are confronted with a situation in which the patient, for various reasons, chooses not to continue receiving treatment. The case is analysed using a method of moral reflection (Heracleitos). The students come to a result in which everyone finds his/her place: the patient, the family, the caregivers. This case reveals that all possibilities are taken into account: treatment, palliative care, ...it is not an either-or story, but an and-and story.

**15.20 : Mrs Jeanette Pols**, Professor Dr., University of Amsterdam,  
Netherlands

**Autonomy in practice. From abstract principles towards everyday life ethics**

In today's world, ethics have changed from an attitude that aims to be helpful in dealing with the specific problems of everyday life to an abstract concept, guided by principles, that makes universal claims to distinguish good from evil. In combination with a social-sciences research style that focuses on general, large groups of people, ethics and science have difficulty to understand *specific* situations. And so they also have difficulty to understand care. Specific situations are very much part of care. Care focuses on supporting a particular patient in a particular specific situation. Caregivers 'translate' general principles such as autonomy into these situations, but in daily care they also have to deal with other values, and they need these as well, to orientate their work.

The question is, how can we learn something about specific situations in care and daily life? In this lecture, I suggest that this can be done by looking at how specific situations are linked to social situations. So, specific situations are not mainly unique, but are partly formed by various social practices. Hence we do not obtain a single picture of something universal that applies everywhere, and we do not generalise in one way about individuals, but we acquire the tools to interpret specific situations in various ways and place them in a meaningful context. This calls for new forms of daily life ethics that focus on negotiating about and compromising on values every day. This applies to researchers, intellectuals and ethicists, too: they have to be a lot clearer about which methodological choices they make and why they do so. The lecture consolidates these thoughts firmly with examples from an ethnographic study on autonomy in care for people with a mental impairment.

**Secretary of the Belgian Advisory Committee on Bioethics:**

**avenue Galilée 5/2  
1210 BRUSSELS  
BELGIUM**

[info.bioeth@health.fgov.be](mailto:info.bioeth@health.fgov.be)

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