

COMED

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Commissione di etica clinica per le persone con disabilità

c/o

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Introduction to disability

- Disability is not a certain disease, but a pathway to be examined with respect to the clinical expectations of individuals and their families: different views create different rights: the approach should be that of the Humanities, i.e., that which lies on the threshold between culture and medicine
- The clinical model of disability must be correlated with the social model, in which disability is seen as the consequence of an environment and a society that fails to recognize some limitations in some people who are then considered disabled or differently abled

Ethical considerations on disability

- Disability should not automatically be used to assess health status and quality of life, especially in diseases with a stable course, such as the autism spectrum
- Medical care should not take into account the criterion of social utility, in the sense of individual contribution to society
- To prevent the rights of people with disability from being disregarded, their inclusion in the development of guidelines or advices should be encouraged, also to ensure their recognizable equity

The mandate of the DSS to FSC

- The DSS (Dipartimento Sanità e Socialità del Canton Ticino) mandate instructs the Fondazione Sasso Corbaro (FSC) to develop, on an experimental basis over 2 years, a "Clinical Ethics Commission for People with Disabilities«
- The FSC, founded in 2000, is an institute associated with USI, dedicated to promoting education, research, documentation and consulting in the fields of clinical ethics and the Medical Humanities thanks to a dozen collaborators and researchers; it publishes its own monthly NL and the *Rivista per le Medical Humanities*. FSC organizes its own Academy in Medical Humanities and a CAS on "Communication as a Tool for Care" in collaboration with USI and the EOC

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Substance of COMED's mandate

- COMED (italian acronym for the Commission on Ethics for People with Disabilities) is to be thought of as a structure for research and knowledge production. It is not regulatory in nature and it will take into account the various historical-institutional characteristics present in the Ticino area
- COMED should think of itself as a multicenter, collaborative research network, whose reports will be both activity statements and formal articles to be published to publicize the ongoing experience

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Duties of COMED

- Identify, analyze, and clarify, in an interdisciplinary way, the ethical values of a conflicting situation between caregivers and people with disability and their loved ones
- Promote and protect the respect for the dignity and rights of those under care, ensuring their autonomy
- Express advice in case of conflicting ethical values in cantonal institutions for people with disabilities
- Develop and disseminate ethical recommendations in the field of disability among caregivers and administrators
- Promote training in clinical ethics and medical humanities in all areas of disability
- In particular, delve into the issues of advance directives, physical and pharmacological restraint, and communication

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Practical goals of ethics support

- Learning to
 - Respect the wishes of the person in care on a daily basis
 - Delve into reflections on the quality of care practices
 - Take responsibility for the quality of care
 - Acknowledge one's limits in case of ethical dilemma during treatment

Responsibilities of members of an ethics committee

- The most relevant skill is to be able to participate critically in discussions to create transparency, consistency, and differentiation in arguments for contrasting ethical values, dwelling on the similarities of previous clinical cases, and remaining attentive to the overall interests of society
- Empathy, some distance from one's emotions, and an intuitive ability enable one to integrate and order the different positions defended in the discussion from an integrative and transdisciplinary perspective

Reference: Markus Zimmermann, vice-president of the National Ethics Commission, Zwischen Ethik und Politik

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