



Statement of the German Ethics Council on Intersexuality

Ethical Guidelines and Recommendations on Medical Treatment

Friederike Maassen B.A.

Dept. of Medical Ethics and History of Medicine
University of Goettingen/University Medical Center

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Introduction

- In the last 10 to 15 years Intersexuality has been occasionally discussed among politicians
- In 2011 two major interpellation have been presented to the Bundestag
- In December 2010 the government gave assignment to German Ethics Council
 - statement on the current situation of Intersex in Germany
- In February 2012 statement was published

Ethical Guidelines

1. Minimizing the physical risks for the child
2. Minimizing the psychosocial risks for the child
3. Sustainment of the fertility
4. Sustainment/advancement of physical conditions for a fulfilled sex life
5. Keeping options for further treatments open
6. Respecting parental wishes and believes

Recommendations on Medical Treatment

- Considering life/ quality of life in all dimensions
- Forming teams of qualified multidisciplinary experts including the persons concerned and their relatives
- irreversible treatments should be considered thoroughly
 - not without the consent of the patient and/or parents/ relatives
 - postponed until the patient is able to voice an opinion
 - as soon as possible education of the child

Recommendations on Medical Treatment

- Filing of all medical documents for at least 40 years
- PanEuropean anonymous data base
 - constant research
 - preventing mistreatment
 - optimise medical care.

The Next Step?

- so far no reaction of the German government on the statement
- wishes for the future:
 - thorough political examination
 - better training for health personnel
 - better education in school
 - public funding

DSD Life

- Clinical European study of surgical and hormonal therapy and psychological intervention in differences of sex development
- Objectives
 - Improvement of clinical practice in the management of DSD
 - Development of accepted evidence-based clinical guidelines
- Göttingen Research Project within DSD-Life focusing on Ethics and Patients' /Parents' View

Current Ethical Problems and Research Questions

- Patient self-determination
 - How to enhance self-determination in the medical setting?
- Child rights
 - How to enhance child rights?
- Privacy and dignity
 - How to protect privacy and dignity of patients?
- Identity/Normality
 - Which role in coping with intersex should be assigned to medical experts?
- Moral role of parents
 - Which role in protecting patients ' rights should be assigned to parents?

Next Steps

- Gather information from individuals and advocacy groups
- Define ethically relevant aspects and target groups
- Conduct exploratory interviews with stakeholders
- Develop tools for quantitative and qualitative research

Working Group Lead and Involved Experts

- Work group
 - Claudia Wiesemann, Goettingen University, Germany
 - Stephanie Bernstein, Goettingen University, Germany
 - Birgit Köhler, Charité Berlin
 - Margaret Simmonds, AISSG, UK
 - Julia Marie Kriegler, XY parents ' group, Germany
 - and others

Contact: Stephanie Bernstein

Dept. Medical Ethics and History of Medicine, Goettingen University
stephanie.bernstein@medizin.uni-goettingen.de

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Thank you very much
for your attention

Muchas gracias por su atención