

This is an unofficial translation of the Swedish National Council on Medical Ethics' letter to the Ministry of Health and Social Affairs, sent in April 2019.

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To the Ministry of Health and Social
Affairs

The Swedish National Council on Medical Ethics proposes that the Ministry of Health and Social Affairs instructs three government agencies to strengthen the knowledge base for the assessment and treatment of gender dysphoria among children and adolescents.

Background

According to the definition used by the National Board of Health and Welfare, gender dysphoria is “a state of mental suffering or a deterioration in the ability to function in everyday life caused by the perceived gender identity not being in accordance with the registered gender”.

In recent years, the number of children and adolescents seeking assessment and treatment for gender dysphoria from the health care system has increased dramatically. The increase has been particularly high among girls. A corresponding trend can be observed in many high-income countries.

The assessment and treatment of gender dysphoria among children and young people encompasses a number of difficult ethical issues. There are questions about needs, benefits, risks, self-determination, privacy, equitable access to care, and how to handle knowledge gaps and uncertain knowledge.

Since 2014, the Swedish National Council on Medical Ethics has addressed ethical issues concerning the assessment and treatment of gender dysphoria among children and adolescents. In 2018 and 2019, the Council has held dialogues with representatives of the interest groups RFSL (the Swedish Federation for Lesbian, Gay, Bisexual, Transgender and Queer Rights), RFSU (the Swedish Association for Sexuality Education) and Transammans, the parent network GENID, and KID and ANOVA, the two clinical assessment centres in Stockholm working with children and adolescents and adults respectively. We have also collated extensive written material on ethical issues regarding gender dysphoria.

In our dialogues with stakeholders, we have encountered widely differing views on the assessment and treatment of gender dysphoria, which also characterizes the specialist literature and public debate. These differences are partly about the facts and how they should be interpreted, and partly about values.

Irrespective of their attitude to health care activities in this area, the actors make it clear that the scientific basis needs to be strengthened. When the Swedish National Council on Medical Ethics has discussed ethical issues regarding gender dysphoria, knowledge gaps and uncertain knowledge has been a central theme.

The Council has considered that, it is important in a first stage, to collate the knowledge available, identify knowledge gaps, learn lessons from existing information, and update the National Board of Health and Welfare's knowledge support material on children and young people with gender dysphoria based on recent year's knowledge and experience of gender dysphoria and the care given to this patient group.

Proposals

The Swedish National Council on Medical Ethics proposes that the Ministry of Health and Social Affairs instructs three government agencies to strengthen the knowledge base for the assessment and care of children and adolescents with gender dysphoria.

1. **The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU)** should be tasked with undertaking a systematic literature review of the scientific basis used for assessing children and young people with gender dysphoria, and what is known about the long-term effects on physical and mental health. The assignment should also include a review of what is known about the causes of the increase in the number of children and young people, particularly girls, seeking assessment and treatment for gender dysphoria in high-income countries. Differing claims about how common it is for people, who have begun treatment for gender dysphoria as children or adolescents, to change their minds, occur in the debate. What is known about this should also be included in the review. Within the framework of SBU's work to gather scientific knowledge gaps, the SBU should also be commissioned to identify knowledge gaps in the area of gender dysphoria among children and adolescents.
2. **The Swedish Medical Products Agency** should be commissioned to analyse the off-label prescription of puberty blockers and hormones to children and young people. What lessons can be learned from prescription patterns – scale, age, regional differences, etc?
3. **The National Board of Health and Welfare** should be instructed to urgently update its knowledge support material entitled '*God vård av barn och ungdomar med könsdysfori*' ('Good care for children and adolescents with gender dysphoria'). In such an update, consideration should be given not only to new knowledge, but also to experience gained during the expanding clinical activities of recent years. It is particularly important that, in its review, the Board takes advantage of the experiences that those seeking care and their relatives have of access to care and how assessment, care and follow-up are conducted.

The Swedish National Council on Medical Ethics intends to deepen its ethical analyses on issues concerning gender dysphoria among children and adolescents. Ethical analysis requires that knowledge and experience of gender dysphoria care is collated in a systematic way.

The position expressed in this letter was discussed at the ordinary meeting of the Council on 22 March 2019. The final version of the letter was adopted by circulation by members Kjell Asplund, Finn Bengtsson, Sven-Olov Edvinsson, Åsa Gyberg-Karlsson, Magnus Harjapää, Chatrine Pålsson Ahlgren, Anna-Lena Sörenson and Barbro Westerholm. Experts Ingemar Engström, Göran Hermerén, Ann Johansson, Olle Olsson, Bengt Rönngren, Nils-Eric Sahlin, Mikael Sandlund, Marie Steen and Elisabet Wennlund were also involved in preparing the matter.

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