

To the Department for Social Affairs

The National Council for Medical Ethics proposes that the Department for Social Affairs tasks three branches of government with building knowledge regarding the assessment and treatment of gender dysphoria in children and young people.

Background

According to the definition used by the National Council for Social Affairs [broadly speaking, the SE equivalent of NICE], gender dysphoria is a “condition of psychological suffering or reduced functional ability in everyday life that is caused by the perception that one’s gender identity is not aligned with one’s registered sex”.

In the past few years, the number of children and young people who turn to health care providers for assessment and treatment of gender dysphoria has increased dramatically. This increase is particularly large in girls. Similar developments can be seen in many high-income countries.

Assessment and treatment of gender dysphoria in children and young people raises a number of difficult ethical questions. These concern the actual need, benefits, risks, agency, integrity and equitable access to healthcare, and how gaps in knowledge and understanding are addressed and managed.

Since 2014, SMER has processed ethical questions around the assessment and treatment of gender dysphoria in children and young people. In 2018 and 2019, we have been in dialogue with representatives of lobby groups including RFSL [a charitable organisation promoting LGBT+ awareness], RFSU [a charitable organisation promoting sex education] and Transammans [a charity and support network for trans persons and their families], the parent network GENID [who are concerned about the current protocols for assessment and treatment of children and young people with gender dysphoria] and KID [<https://psykiatri.sll.se/aktuellt/fragor-och-svar-om-konsdysfori-och-konsbekaftande-behandling-av-unga/>]. A grammatically flawed translation of the page can be accessed by selecting language at the top right corner of the web page] and ANOVA [the Karolinska clinic for andrology, gender medicine, and trans medicine], the two clinical facilities in Stockholm for children and young adults. We have also gathered a significant amount of written reports on ethical questions around gender dysphoria.

In our dialogues with different interest groups, we have encountered disparate opinions and perceptions about assessment and treatment of gender dysphoria, which is reflected also in the academic literature and broader public debate on the subject. The differences concern the factual research itself, how this research is to be interpreted, and the broader values held by the different interest groups.

Regardless of their attitudes and opinions to the current protocols in Swedish health care, these interest groups all emphasise that more research is needed. When SMER have discussed ethical questions around gender dysphoria, gaps and uncertainties in the knowledge we have on the subject has been a central theme.

SMER have concluded that in the first instance the available research should be collated and reviewed, that gaps in knowledge should be identified, observations from existing information should be drawn, and that the current guidance documents issued by the National Council for Social Affairs for the support of children and young persons with gender dysphoria is updated with recent research and experiences from the last few years of treatment of this patient group.

Proposal

SMER proposes that the Department for Social Affairs direct three branches of government to commission reviews and gather knowledge to strengthen the evidential basis for assessment and treatment of children and young persons with gender dysphoria.

1. The national commission for overseeing medical and social protocols and outcomes should be instructed to undertake a systematic review of the scientific evidential basis for assessment of children and young persons with gender dysphoria, and what is known about long-term effects on physical and mental health. This review should also cover what is known about the increase in the number of children and young people, especially girls, who seek medical care for assessment and treatment of gender dysphoria in high-income countries. The public debate cites disparate information about how common it is for children and young people who have started such treatment to later desist and/or regret treatment. What is known about such regrets should also be included in the review of extant research. Within the remit of its activities, the national commission for overseeing medical and social protocols should also be tasked with identifying gaps in knowledge concerning the broader topic of gender dysphoria in children and young people.
2. The department of pharmaceuticals should be tasked with analysing the practice of prescribing off-label puberty blockers and cross-sex hormones to children and young people. What experience can be drawn from prescription patterns – extent, ages, regional differences, etc?
3. The National Council for Social Affairs should be tasked with an immediate update of their guidance document *Good care of children and young people with gender dysphoria* [the guidance documents issued by the National Council for Social Affairs direct practices throughout the Swedish health care system]. In this update, the Council should take into account not just new research and knowledge, but also recorded experiences from the expansion of clinical activity in this area in the last few years. It is especially important

that the Council takes note of the experiences of patients and their families of access to care, assessment and diagnosis, treatment and follow-up efforts.

SMER aim to deepen their ethical analyses of questions regarding gender dysphoria in children and young people. A prerequisite for ethical analyses is that the knowledge about and experience of gender dysphoria care are gathered and collated in a systematic fashion.

The focus of this directive has been discussed at the ordinary meeting of the Council on 22 March 2019. The councillors who contributed to the per capsulam decision of the final version of this directive are Kjell Asplund, Finn Bengtsson, Sven-Olov Edvinsson, Åsa Gyberg Karlsson, Magnus Harjapää, Chatrine Pålsson Ahlgren, Anna-Lena Sörensson and Barbro Westerholm. The scheduling of the matter was preceded by consultation with subject experts Ingemar Engström, Göran Hermerén, Ann Johansson, Olle Olsson, Bengt Rönngren, Nils-Eric Sahiln, Mikael Sandlund, Marie Steen and Elisabet Wennlund.

Signed
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Chair
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