EPATH Response on Cass statement

The finally published Cass report is the long-awaited result of a multiple years long investigation initiated by the United Kingdom's National Health Service (NHS) into the scientific basis of treating transgender youth and the experiences of those involved in transgender care in the UK.[1] It contains 32 recommendations for a reorganization of transgender care for youth in England and Wales. The review took place after concerns arose around the increase in referrals, the evidence base for provided care, and the functioning of the NHS Tavistock Clinic's Gender Identity Development Service (GIDS), the only national service at the time providing care for transgender youth, with a long history of clinical experience and knowledge. Cass advocates for more research, better care availability in multiple locations, and a more multidisciplinary approach, including mental health care for adolescent transgender care. EPATH agrees with much of what Cass recommends, such as a holistic biopsychosocial approach, reducing waiting lists, spreading knowledge, and stimulating more research. EPATH however, also has concerns regarding feasibility of the recommendations, whether it will limit access to care, the weighing of underlying evidence and the ethics of providing care.

More research

The current recommended multidisciplinary care model involving psychosocial care and early medical intervention in indicated cases with puberty suppression and possibly subsequent hormones, had its roots in the Netherlands at the beginning of this century.[2] It is therefore often called the Dutch protocol. This was related to the fact that clinical research evaluations, like Cass now recommends in England, have always been part of adolescent transgender care in the Netherlands, and first studies were published there. [e.g. 3-6] However, follow-up research has also been performed in clinics in e.g. Finland, Germany, Italy, Switzerland, the UK, and the US. [7-12]

Clinics belonging to the earliest specialized transgender care services for youth in Europe often are affiliated to University Medical Centres enabling research evaluation. At many such clinics, a strong connection to scientific research has always been characteristic of care provided. Multi-centre, cross-country research evaluations [e.g.13] of transgender adolescents have been published at baseline and are expected at follow-up. EPATH agrees with Cass that more longitudinal outcome studies are necessary to compare different care contexts as well as research on which young people benefit from which type of care, especially now, as both the demand for care and the variety of young people seeking care is increasing. Such studies are being performed, although it may still take years before results are published.[14]

The weighing of underlying evidence

In contrast to what the Cass review recommends however, EPATH follows the World Professional Association for Transgender Health's Standards of Care (SOC8) and considers that the evidence is sufficient to recommend that providing medical affirming treatment including blockers and/or hormones is helpful when indicated, while withholding such treatment may lead to increased gender dysphoria and adversely affect psychological functioning.[15] Of note, some European countries (e.g., Sweden, Finland) have adapted their

national guidelines such that care should be provided more carefully (not banned, as has sometimes been mistakenly claimed in the media).[16]

EPATH recognizes the right of all trans and gender diverse youth to access scientific evidence-based care with the best quality standards. EPATH points to the fact that the evidence base for many forms of medical care is still growing and expanding, not limited to care for transgender youth. The lack of use of a randomized blinded control group, which would lead to the highest quality of evidence according to some grading scales, is so far contested in transgender adolescent research.[17] Such untreated control groups raise important feasibility and ethical issues since treatment preference could lead to non-participation or withdrawal from a randomized group without blockers and blinding would be impossible due to clinically and physically evident effects. An alternative might be a waiting-list control group or between-clinic comparison with different treatment approaches, although such designs will also have their challenges. Such studies would not only be difficult to perform, but will also need dedicated research funds. So far, dedicated funding for research on transgender care evaluations does not exist; much of the current evidence comes from limited funded clinical evaluation studies.

Feasibility and access to care

Cass also advises making care more broadly accessible for the significant increased referrals, which have led to long waiting lists, a trend also seen in many other European countries. Like Cass recommends, in European countries where care for youth is available, mental health support has always been an important part of care. In accordance with published guidelines, a comprehensive (holistic) assessment of each young person who seeks care is conducted and mental health professionals play a crucial role in the multidisciplinary provision of care. Research and numbers of treated adolescents from several clinical studies in Europe show that only a portion of young, referred people start with medical transgender care (e.g., 37% in the Netherlands).[6] This aligns with the conclusion of the Cass Review that medical treatment is not indicated for all young people and individualized care is recommended. EPATH and WPATH have always advocated such individualized multidisciplinary care.

Cass recommends a care model where young people can initially receive care locally, from where they can be referred to secondary and tertiary treatment centres. Such a care model that significantly expands capacity to ensure the best care for everyone in Europe is necessary and required. EPATH supports the importance of increasing expertise and knowledge of transgender care among all health care providers. Although WPATH's Standards of Care have always recommended the involvement of psychosocial care for transgender adolescents, EPATH sees at present no evidence, as Cass also acknowledges, that a primary focus on psychosocial care and a restriction of access to blockers and hormones (also for 16/17-year-olds) would be effective in relieving the distress that transgender adolescents and their families may experience. Also, while expanding care is important, the key question is whether and how this can be achieved and if the various national health authorities are willing to provide the necessary finances, training and implementation of transgender care outside the existing specialist care services. EPATH would strongly support this and provides with its Summer Schools and Conferences the possibility of learning and exchange of knowledge.

The earlier published interim report of the Cass Review led to the closure of the only national care service in the UK so far, the NHS Tavistock Clinic's Gender Identity Development Service (GIDS). It was the sole UK clinic with a long history of clinical experience and knowledge in transgender adolescent care, while no new clinical hubs are fully operational yet. EPATH is concerned that this has left young transgender and gender diverse people and families with little opportunity to obtain transgender care in the UK, a worrisome situation for transgender youth and their families.

Ethics and nuance

In England, there is what the Cass Review describes as a 'culture war'. Cass describes a debate surrounding transgender care poisoned by polarization. According to the Cass Review, this is not only detrimental to patients, but also to clinicians and research on transgender care. In many European countries the socio-political climate of acceptance and tolerance towards transgender youth was growing in the recent past, a significant factor related to better well-being of transgender youth as several studies have showed. Unfortunately, EPATH increasingly recognizes the polarizing climate described by Cass in other European countries apart from the UK. The growing negativity in media and politics related to transgender youth negatively affect their mental health. EPATH therefore calls for a nuanced, careful and respectful debate on transgender care for youth in Europe; the same carefulness and nuance with which care and research is currently presented, discussed, and debated at EPATH Conferences and Summer Schools.

Meanwhile, EPATH asks that health authorities in the respective European countries take care of their clinicians and researchers, whose work has become increasingly challenging and demanding in a critical and sometimes negative environment. Such clinical work aims to deliver responsible, scientifically evaluated transgender adolescent care with room and time for critical reflection, and research continuously helps us to adapt care according to scientific results.

At the same time, however, while waiting for research results, not providing transgender adolescent care that may include puberty blockers and hormones to adolescents who experience gender incongruence is not a neutral act given that it may have immediate as well as lifelong harmful effects for the young transgender person. Also, asking transgender adolescents to participate in research as the only way to receive puberty blockers, as Cass recommends, is unethical. Finally, from a human rights perspective, considering gender diversity as a normal and expected variation within the broader diversity of the human experience, it is an adolescent's right to participate in their own decision-making process about their health and lives, including access to multidisciplinary transgender health services.

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