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Head of Regulation
Care Quality Commission (CQC)
151 Buckingham Palace Road
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Dear Sir/Madam,

I am writing to express my very grave concerns regarding the current healthcare provision afforded to young transgender people in the UK. I believe that the current situation is causing untold harm and, in some cases, even death and poses a significant risk to the NHS in the future, in terms of litigation and requests for compensation.

My concerns are manifold;

1. The wholly unacceptable waiting times
2. The reliance on data that has been widely discredited
3. The lengthy assessment processes, which often culminate in a distinct lack of medical management
4. Uncoordinated processes with no continuity of care
5. The reliance on mental health assessments when gender non conformity is not in itself a mental disorder
6. The backward approach of the Clinical Leads
7. The failure to take into consideration the capacity and Fraser competency of the children and the wishes of the parents, to allow the children to self determine their gender.

My background

I am a Consultant Physician of 24 years standing and 34 years of service to the NHS. I qualified in 1982 and retired from the NHS in June 2016.

As a General Physician I have gained experience in multiple areas of General medicine but have had specific training in endocrinology and use of hormones in young people.

Other than my clinical duties, I have held positions of responsibility within the NHS. At a local level I was Clinical Director for Medicine for 10 years and Chief of Staff for Emergency care and Associate Divisional Director for Unscheduled care across 3 hospital sites, for 8 years. At National level I was Training programme Director (TPD) for Acute Medicine Wales and helped develop Acute Medicine models of care across NHS Wales Acute hospitals. I was also Specialist Training Committee (STC) chair for Acute Medicine, Wales, involved in the development and training of Acute Medicine trainees. I sat on the RCP Specialist Advisory Committee (SAC) for AIM and represented the Royal College of Physicians SAC for GIM and AIM on at least 30 occasions, by chairing Penultimate Year Assessment (PYA) committees on behalf of the JRCPTB. I was the Regional Specialty Advisor for Wales and represented the Royal College of Physicians numerous times for Consultant appointment committees (AACs) in both England and Wales.

In terms of transgender care, I have been involved in the management of thousands of transgender patients both in the emergency and non-emergency setting, I am widely read in the field. I am a full member of WPATH (World Professional Association for Transgender Health) and have been part of the GenderGP MDT for the last three years. I have presented multiple academic papers at WPATH in Amsterdam 2016 and Argentina in November 2018. I have over 1400 transgender patients currently under my care including 150 young people. Many of these young people have sought my help because of their complete dissatisfaction with NHS services and more specifically, GIDS.

Taking each of the points above one by one:

1. Waiting times (including RTT)

The waiting times for a first appointment are now being quoted as 18 months. However I have many patients under my care who did not receive appointments for over two years. When I requested data regarding RTT on those eligible for treatment (as an FOI request), GIDS was unable to provide the data.

Following initial referral, parents receive a standard acknowledgement letter which quotes that GIDS 'aims to see patients within 18 weeks' this is unrealistic and untrue. Following the acknowledgement letter, effectively there is 'radio silence' from Tavistock.

There is no triage process for those children most in need or at risk and no provision for early intervention. Tavistock is inflexible in seeing patients at risk.

This wait is agonising for the children and families and there is a high incidence of self harm and suicide attempts (Stonewall). Many of the YP that I see who are waiting to be seen at Tavistock, have evidence of self harm, including slashing of arms and thighs with knives and genital and breast mutilation. I am directly aware of two young people who have sadly committed suicide but I know that GIDS is aware of many others.

The delays in waiting times (and subsequent assessment processes) are particularly acute for children who are going through puberty and many have completed the 'wrong puberty' in between being referred and being treated. This causes serious psychological anguish for the children and parents and leads to complex, mutilating and expensive surgery to rectify the changes of puberty. A broken voice cannot be rectified by surgery and that female will always have a masculine voice. These children in particular should be prioritised.

GIDS states in its service specification that, *'According to the WPATH and the recently updated Endocrine Society guidelines, GnRHa (blockers) may be offered once an adolescent has demonstrated the first signs of physical puberty (Tanner stage 2 in either sex)'. (<https://adc.bmj.com/content/103/7/631>)*

However many peripubertal children referred to GIDS have either completed puberty or are well on their way through it before appropriate treatment is offered.

2. The reliance on discredited data

The Clinical Leads at GIDS (Dr Polly Carmichael and Professor Gary Butler) are still fixated on discredited data from Amsterdam that states that 84% of children with GD are likely to desist. This figure was quoted in the Service Specification, is mentioned on the website and is told to the children and families as a justification for the lengthy assessment processes.

The figure was derived from a meta-analysis of several disparate papers from the 1950s onwards, mainly from Canada, the US and the Netherlands.

The data has been widely discredited as being wholly unreliable for the following reasons;

- Many of the children taking part in the study were not transgender in the first instance (some being either gender questioning or homosexual) as such they did not meet the diagnostic criteria for gender variance

- Many of the children were 'lost to follow up' and as such were assumed to have desisted (assumption has no place in a study of this kind)
- Very dubious psychotherapeutic treatments were being practiced on children included in the study, in the earlier years, including conversion therapy which is now illegal in the UK and the US.
- Data handling and interpretation was incorrect

In peripubertal children whose GD is both persistent and insistent, it is widely recognised that the desistance rate approaches 0%.

GIDS has not presented its data on desistance rates in this population of children, however recently in Australia, Dr Michelle Telfer, Associate Professor and head of the Transgender service at the Royal Children's Hospital Gender Service in Melbourne, provided expert witness testimony in the Family Court stating that 96% of children diagnosed with gender dysphoria in her department, continued to identify as transgender into late adolescence.

This was a longitudinal study of over 700 patients over 14 years and implies a desistance rate of only 4%. (<https://www.theage.com.au/national/victoria/i-want-control-over-my-body-transgender-kids-in-landmark-court-win-20171130-gzw6z4.html>)

A good review of this can be found here <https://growinguptransgender.com/2017/12/03/the-end-of-the-desistance-myth/>

A further review paper examining desistance rates in children concludes;

- *The tethering of childhood gender diversity to the framework of "desistance" or "persistence" has stifled advancements in our understanding of children's gender in all its complexity. These follow-up studies fall short in helping us understand what children need. As work begins on the 8th version of the Standards of Care by the World Professional Association for Transgender Health, we call for a more inclusive conceptual framework that takes children's voices seriously. Listening to children's experiences will enable a more comprehensive understanding of the needs of gender-nonconforming children and provide guidance to scientific and lay communities. (A critical commentary on follow-up studies and "desistance" theories about transgender and gender-nonconforming children. Newhook JT, Pyne J, Winters K. International Journal of transgenderism (26 April 2018)*

3. Lengthy assessment processes, which often culminate in a distinct lack of medical management

Many of the patients that I see, tell me that they have undergone an assessment period for as long as two years and have still not been referred to Endocrinology for consideration of hormone treatment. This seems to be particularly relevant to those YP who are around 15 when first seen and whose assessment processes seem 'dragged out' until they are over 17 and can be referred to adult services to face yet more lengthy delays.

This reluctance to treat, I believe, stems from extreme over-caution and an almost inherent 'fear' of doing the wrong thing amongst the Tavistock clinicians.

This assessment process causes intense anxiety and anger in the YP and a significant worsening of the dysphoria.

Many patients have even expressed concerns that they feel 'on trial' and Tavistock clinicians are trying to 'persuade' them that they are not Transgender and are trying to 'catch them out'. Often they do not feel that they are believed and I am seriously concerned that this amounts to conversion therapy and is potentially illegal.

In 2016, following a lengthy consultative process, The House of Commons Women's and Equality Committee report into transgender care, (<https://publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf>) recommended that;

Recommendation 20

Accordingly, we recommend that, in the current review of the service specification and protocol for the Gender Identity Development Service, consideration be given to reducing the amount of time required for the assessment that service-users must undergo before puberty-blockers and cross-sex hormones can be prescribed.

4. Uncoordinated processes with no continuity of care

Once locked into the Tavistock assessment processes, the patients are seen on several occasions which are many months apart.

I am told on a regular basis that the process appears chaotic. There is often no continuity of care, patients are frequently seen by different clinicians at each visit who ask the same questions that they have been asked previously. There is no development of rapport and the whole process is impersonal.

Patients report that many of the clinicians appear untrained and do not seem to have any knowledge of trans issues.

Notes are often absent and there appears to be no obvious pathway that is being followed towards a treatment goal, which means that at each visit, the hopes of the children and family of receiving the treatment they need are crushed.

This has a hugely demoralising effect on the children and leads to many of them refusing to go back for follow up appointments. Instead, they end up seeking help elsewhere. This may be in the private sector, in the US, or of more concern, self medicating through the purchase of illegal hormones bought directly via the internet.

5. The reliance on mental health assessments when gender nonconformity is not in itself a mental disorder

Gender dysphoria was removed from the WHO International classification of disease (ICD) chapter of mental disease in 2018 and was placed in the chapter of sexual health instead.

The House of Commons Women's and Equality Committee report stated;

Recommendation 16

We are concerned that Gender Identity Services continue to be provided as part of mental-health services. This is a relic of the days when trans identity in itself was regarded as a disease or disorder of the mind and contributes to the misleading impression that this continues to be the case. (Paragraph 209)
Consideration must be given to the transfer of these services to some other relevant area of clinical specialism.

The government response was;

We are supportive in looking at how this recommendation can be achieved. Gender dysphoria is not a mental illness.

Despite this, GIDS is heavily reliant on protracted mental health assessments with little or no consideration being given to the wishes of the children and parents.

6. The backward approach of the Clinical Leads

As well as their misinformed beliefs around the 84% desistance rates, the Clinical Leads have firm and unwavering views regarding the management of transgender children. Considering the fact that GIDS is the only service in England and Wales providing hormonal treatment to trans children and that Professor Butler is the only doctor prescribing for children, then this amounts to a monopoly, with process driven only by the personal views of Professor Butler. He has stated that;

'he never has and never would prescribe gender affirming hormones to anyone under the age of 16'

If we look to National and International guidance on this matter, other than the service specifications for NHSE written by Drs Butler and Carmichael there is none other than referring to WPATH criteria. NHS UK (<https://www.nhs.uk/conditions/gender-dysphoria/guidelines/>)

WPATH vers 7 (<https://www.wpath.org/media/cms/Documents/Web%20Transfer/SOC/Standards%20of%20Care%20V7%20-%202011%20WPATH.pdf>) states

- *Adolescents may be eligible to begin feminizing/masculinizing hormone therapy, preferably with parental consent. In many countries, 16-year-olds are legal adults for medical decision-making and do not require parental consent. Ideally, treatment decisions should be made among the adolescent, the family, and the treatment team.*

This **does not** state that adolescents should not receive GAH under 16, merely that they may also require parental consent. Additionally;

- *Refusing timely medical interventions for adolescents might prolong gender dysphoria and contribute to an appearance that could provoke abuse and stigmatization. **As the level of gender-related abuse is strongly associated with the degree of psychiatric distress during adolescence, withholding puberty suppression and subsequent feminizing or masculinizing hormone therapy is not a neutral option for adolescents.***

The largest study into the use of puberty blockers and gender affirming hormones in children has begun and Stephen Rosenthal, one of the lead clinicians for the study (and clinical lead for the gender service at UCSF) has anticipated;

- ***that the study will allow clinicians to discontinue blanket advice to withhold cross-sex hormone (CSH) therapy until age 16 and to allow flexibility on the basis of when a child enters puberty***
- <https://www.nature.com/news/largest-ever-study-of-transgender-teenagers-set-to-kick-off-1.19637>

UCSF center of excellence for Transgender Health (<http://transhealth.ucsf.edu/protocols>) is one of the largest and most respected Gender clinics in the world, it recommends;

- *Gender-affirming hormones may be added to GnRH analogues to assist in the development of feminizing or masculinizing features in transgender youth.**some specialty clinics and experts now recommend the decision to initiate gender- affirming hormones be individually determined, based***

more on state of development rather than a specific chronological age

- *Length of time on GnRH analogues - for those youth whose endogenous puberty is suppressed in the earliest stages of puberty, waiting until age 16 to add hormones means a potential 5-7 year gap, during which bone mineral density is only accruing at a pre-pubertal rate. This could potentially impact peak bone mineral density, and place youth at risk of relative osteopenia/osteoporosis.*
- **Experiencing puberty in the last years of high school or early college years presents multiple potential challenges. The emotional upheaval that occurs for youth undergoing puberty happens normally at 11 or 12 years of age.** *For those youth who struggle with emotional lability at that age, they do so in a relatively protected environment, regulated by parents/caregivers, and without access to potential dangers such as motor vehicles, drugs, alcohol and adult (or almost adult) peers and sexual partners. Having the physical appearance of a sexually immature 11 year old in high school can present emotional and social challenges that are amplified by gender dysphoria*
- *Awareness of one's gender identity **does not** require cognitive capacity acquired in adolescence or early adulthood, nor does it require a fully myelinated frontal lobe. Gender studies in non-transgender participants have found that children are aware of their gender by the age of five or six, and often earlier*

This view is echoed by other leaders in the field;

- **The age criterion of 16 years for the start of CSH (Cross Sex Hormones) may be problematic.....** *Therefore, psychological maturity and the capacity to give full informed consent may surface as the required criteria for puberty suppression and CSH. Clinicians should realise that it is not only early medical intervention that determines this success (De Vries, Amsterdam)*
- *persistence of gender dysphoria implies a very high likelihood that such individuals will be transgender as adults; in fact, the emergence or worsening of gender dysphoria with onset of puberty is thought to have significant diagnostic value in the determination of being transgender (Rosenthal S. Approach to the Patient: Transgender Youth: Endocrine Considerations. JCEM 99 (12): 4379-4389 (2014).)*
- *including the use of agents to block endogenous puberty at Tanner stage 2 and subsequent use of cross-sex hormones, are based on longitudinal studies demonstrating that those individuals who were first identified as gender-dysphoric in early or middle childhood and who still meet the mental health criteria for being transgender at early puberty are likely to be transgender as adults (Rosenthal S. Approach to the Patient: Transgender Youth: Endocrine Considerations. JCEM 99 (12): 4379-4389 (2014).)*

Other guidance

The Endocrine Society guidelines (<https://academic.oup.com/jcem/article/102/11/3869/4157558>)

have been recently updated (2017) and now state;

- ***We recognize that there may be compelling reasons to initiate sex hormone treatment prior to age 16 years in some adolescents with GD/gender incongruence***
- *In adolescents who request sex hormone treatment (given this is a partly irreversible treatment), we recommend initiating treatment using a gradually increasing dose schedule after a multidisciplinary team of medical and MHPs has confirmed the persistence of GD/gender incongruence and sufficient mental capacity to give informed consent*
- *Medical intervention for transgender individuals (including both hormone therapy and medically indicated surgery) is effective, relatively safe (when appropriately monitored), and has been established as the standard of care*
- *A 2016 survey of endocrinologists, the physicians most likely to care for these patients, found that over 80% have never received training on care of transgender patients*
- *In fact, studies have indicated that 70% of transgender individuals have experienced maltreatment by medical providers, including harassment and violence.*
- ***Transgender individuals who have been denied care show an increased likelihood of committing suicide and self-harm. It is critical that transgender individuals have access to the appropriate treatment and care to ensure their health and well-being.***

The Australian Standards of Care and treatment guidelines for trans and gender diverse children and adolescents (<https://www.rch.org.au/uploadedFiles/Main/Content/adolescent-medicine/australian-standards-of-care-and-treatment-guidelines-for-trans-and-gender-diverse-children-and-adolescents.pdf>)

state;

- *Every child or adolescent who presents with concerns regarding their gender will have a unique clinical presentation and their own individual needs. The options for intervention that are appropriate for one person might not be helpful for another. **Consistent with the above, decision making should be driven by the child or adolescent wherever possible, and this applies to options regarding not only medical intervention but also social transition***
- *Avoiding harm is an important ethical consideration for health professionals when considering different options for medical and surgical intervention. **Withholding of gender affirming treatment is not considered a neutral***

option, and may exacerbate distress in a number of ways including increasing depression, anxiety and suicidality, social withdrawal, as well as possibly increasing chances of young people illegally accessing medications

In order for treatment to be started the following criteria should be met;

- *A diagnosis of Gender Dysphoria in Adolescence, made by a mental health clinician with expertise in child and adolescent development, psychopathology and experience with children and adolescents with gender dysphoria.*
- *Medical assessment including fertility preservation counselling has been completed by a **general practitioner**, paediatrician, adolescent physician or endocrinologist.*
- *The treating team should agree that commencement of oestrogen or testosterone is in the best interest of the adolescent and informed consent from the adolescent has been obtained. Although obtaining consent from parents/guardians for commencement of hormone treatment is ideal, parental consent is not required when the adolescent is considered to be competent to provide informed consent*

In reference to the Endocrine society guidelines in particular, Professor Butler claims to have treated over 1000 young people. It seems inconceivable that he will not have encountered ***'compelling reasons to initiate sex hormone treatment prior to age 16 years in some adolescents with GD/gender incongruence'***

And yet he has stated unequivocally that,

'I never have and never would prescribe gender affirming hormones to anyone under the age of 16'.

In terms of Dr Polly Carmichael, it is of very serious concern that she is still collaborating with Zucker and Steensma,

([J Sex Med](#). 2018 Oct;15(10):1381-1383. doi: 10.1016/j.jsxm.2018.08.002. Epub 2018 Sep 5.) the former sacked from his post as Clinical lead for the Children's Transgender service at CAMHS in Montreal and reputedly an advocate of conversion therapy and the latter responsible for the dissemination of the 84% desistance rate myth which has conceivably caused more harm to Transgender children worldwide than any other report.

The final recommendation of this study is particularly chilling and that is *'the establishment of an international registry'* of transgender children. I am not sure what the Gay, Jewish or Muslim communities would feel if a similar registry was established for them and I believe is inherently discriminatory and transphobic.

7. The failure to take into consideration the capacity and Fraser competency of the children and the wishes of the parents.

The Tavistock (and GIDS) do not take into consideration the capacity and competency of the children and the wishes of the parents and in so doing, contravene Good Medical Practice, the practices of many other International centres of excellence and indeed, the law.

The GMC Good Medical Practice is quite clear that;

- *An assessment of best interests will include what is clinically indicated in particular case. You should also consider, the views of the child or young person, so far as they can express them, including any previously expressed preferences and the views of parents*
- *You must decide whether a young person is able to understand the nature, purpose and possible consequences of investigations or treatments you propose, as well as the consequences of not having treatment. Only if they are able to understand, retain, use and weigh this information, and communicate their decision to others can they consent to that investigation or treatment. That means you must make sure that all relevant information has been provided and thoroughly discussed before deciding whether or not a child or young person has the capacity to consent.*
- *a young person under 16 may have the capacity to consent, depending on their maturity and ability to understand what is involved*

Fraser-Gillick guidance (A child's legal rights. Gillick Competency and Fraser Guidelines. NSPCC.org.uk) states;

- *...whether or not a child is capable of giving the necessary consent will depend on the child's maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent*

The Australian Standards of Care state that,

'decision making should be driven by the child or adolescent wherever possible, and this applies to options regarding not only medical intervention but also social transition'

The Equalities and Womens commission report states that,

'under current protocols: the principle of Gillick competence is not observed in respect of children aged under 16; and parental wishes are not heeded'.

Summary

In Summary, I believe that Tavistock and GIDS are failing the transgender children and young people of the United Kingdom and are both directly and indirectly responsible for them coming to severe harm, including self mutilation, suicide. Taking

these facts into consideration it is not difficult to envisage a situation in which major litigation will be brought against the NHS for disfigurements caused by the 'wrong' puberty, some of which are irreversible.

I cannot see any way forward, without the restructuring of the clinical leadership of this service and particularly those who are entrenched in their archaic views. There needs to be a major overhaul of the referral process, with far greater opportunities for early intervention clinics and access to puberty blockers and gender affirming hormones.

As the doctor to whom all the patients come when they are dissatisfied with their experiences on the NHS, I believe I have a level of insight which would be invaluable and I would be more than happy to lend my expertise to any meaningful audit of the current processes.

I strongly recommend an urgent and detailed inspection of their services taking into account my concerns, the views of current and ex-patients, and the views of interested parties such as support groups and charities working with transgender youth and young adults. I can supply contact details and case studies as required.

Dr M J Webberley