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NHS ENGLAND
Standard Contract
for the Gender Identity Development Service for Children and Adolescents
Service Specifications

http://www.england.nhs.uk/wp-content/uploads/2013/06/e13-gender-identity-dev.pdf

The NHSE Clinical Reference Group for Multi-System Disorders adopted the above Service Specifications without stakeholder engagement. The grave flaws in this document necessitate an urgent review. At the same time, the whole configuration of the service may need to be re-examined in the light of (a) the overwhelming growth in referrals and (b) the ability of this Service to reduce substantially the cost of treating adult patients.

Preliminary Appraisal of the Document

1 – The Guidelines to which the document refers are out of date: The document is based on Royal College of Psychiatrist Guidelines that were published in 1998 and the Harry Benjamin International Standards of Care (version 6) which were published in 2001. The latter document has been superseded by version 7, published in 2011 (by which time the Harry Benjamin organisation had adopted a new name: World Professional Association for Transgender Health - WPATH).[1] No reference is made to the authoritative guidelines that were published by the Endocrine Society in 2009.[2] The Diagnostic and Statistical Manual of Mental Disorders version 4 to which it refers, published by the American Psychiatric Association, was replaced by version 5 in May 2013.[3] The BSPED guidelines to which the document refers do not currently appear to be endorsed or even supported by that Society.[4] [5] It should also be noted that the International Classification of Diseases version 10, which is cited in the document, is currently undergoing revision and, with regard to gender identity, is likely to be amended in line with the recommendations of WPATH.[6]

2 – The document ignores recent evidence: The most recent peer reviewed study cited in the document was published in 1997. A wealth of new evidence has been published since then.[7]

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[1] http://www.wpath.org/documents/IJT%20SOC,%20V7.pdf

[2] https://www.endocrine.org/~/media/endosociety/Files/Publications/Clinical%20Practice%20Guidelines/Endocrine-Treatment-of-Transsexual-Persons.pdf

[3] http://www.dsm5.org/Pages/Default.aspx

[4] http://www.bsped.org.uk/clinical/clinical_endorsedguidelines.html

[5] http://www.bsped.org.uk/clinical/clinical_supportedguidelines.html

[6] http://www.wpath.org/documents/WPATH%20ICD-11%20Consensus%20Report_Executive%20Summary_7-7-13.pdf

[7] http://www.ncbi.nlm.nih.gov/pubmed?db=pubmed&cmd=Link&LinkName=pubmed_pubmed&from_uid=11077871

3 – <u>There is no information on the early intervention research project</u>: The document refers to this project. Its rigid application gives rise to serious complaints from families whose children fall outside these arbitrary limits.[8] Many of them are seeking treatment overseas.

4 – <u>The document ignores international best practice</u>: There is mention of collaboration with gender identity clinics in Europe and Canada. Many other well regarded clinics in the USA and Australia have published their experiences of treating such children and adolescents. Many overseas clinics apply protocols that differ significantly from those imposed by the Tavistock and UCL clinics. With regard to puberty suspending medication, the rigid Tavistock/UCL application of arbitrary limits of age (apparently12-14 in the research project) or the even later Tanner stage 5 for other young people, does not take proper account of individual physical and psychological development. Other clinics, for instance in Boston, Melbourne and Toronto offer this treatment before age 12, in line with pubertal psychological and physical development, rather than chronological age.[9] [10] [11] The age of onset of puberty is individually variable. The NHS choices website states that, in those assigned female at birth, it usually occurs around 11 and in boys around 12.[12] The Boston clinic also advocates the use of a long-acting Histrelin implant as a cost-effective method for delivering the puberty suspending medication.[13]

5 – <u>The refusal to treat those who have sought treatment elsewhere seems imprudent</u>: This bar to treatment (see page 10) is not consistent with harm reduction and appears at risk of challenge on ethical as well as legal grounds.[14]

6 – <u>The document omits gender reassignment as a protected characteristic</u>: See page 10.

7 – <u>There is no recognition of the overwhelming growth in referrals</u>: In the five years to March 2012, the Service experienced a 32 % per annum average growth in referrals. In the most recent 12 months, that growth rate has accelerated to 50%.[15] Consequently, families report that the waiting time for a first appointment exceeds 18 weeks. This is a major problem for children experiencing the rapid and highly stressful advance of pubertal development of secondary sex characteristics in conflict with the gender identity. If timely treatment is not then provided, following assessment and diagnosis, those families who in consequence seek treatment in other European treatment centres may be legally entitled to reimbursement by the the NHS for the costs they incur.[16]

We conclude that the flaws in this service specification should be rectified immediately.

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[8] GIRES can provide details of these complaints if needed.

[9] http://www.tandfonline.com/doi/full/10.1080/00918369.2012.653302#.Ueot5ayZeuI

[10] http://www.ncbi.nlm.nih.gov/pubmed/22621149

[11] Personal communication with Professor Kenneth Zucker, head of the child and adolescent gender identity clinic in Toronto, July 2013.

[12] http://www.nhs.uk/Conditions/Puberty/Pages/Symptoms.aspx

[13] http://pediatrics.aappublications.org/content/116/6/e798.full.pdf+html?eaf%2520

[14] Giordano, S,Gender atypical organisation in children and adolescents: ethico-legal issues and a proposal for new guidelines Int J Child Rights 2007;15;65–90

[15] Data provided by the Service.

[16] http://curia.europa.eu/juris/document/document.jsf;jsessionid=9ea7d2dc30dbd07b0c8d07d94bd68a53b44bb0de7266.e34KaxiLc3qMb40Rch0SaxuLbNn0?text=&docid=56965&pageIndex=0&doclang=en&mode=lst&dir=&occ=first&part=1&cid=185040 - Paragraph 149

Need to reconfigure the Service

As well as revising the Service Specification to deal with the flaws identified above, the CRG should examine the way the service is structured and how it relates to CAMHS and the adult clinics. There appears to be substantial scope for innovation.

Given the constraints on NHS funding, the waiting list problem will worsen rapidly unless the Service is cost-effectively and urgently reconfigured. GIRES suggests that pre-pubertal children might remain in the care of CAMHS, supported by training from the Tavistock Clinicians. That task might be shared with GIRES and Mermaids. Apparently, gender dysphoria in the majority of these children ameliorates and they do not seek medical treatment to support a change of gender role.[17]

That would enable the Tavistock Service to concentrate on pubertal children. Note that the document's use of the term "post pubertal" is vague (see page 6). However, if this means "after completion of all pubertal development", it would be at variance with the up to date guidelines and international best practice described above.

Public Health England recommends early intervention.[18] In gender identity treatment the benefits are substantial:

- In trans women (male to female), avoiding the cost of hair removal and feminising surgery (excluding genital surgery), approximately £10,000 to £20,000
- In trans men (female to male), avoiding the cost of chest reconstruction, approximately £5,000.
- In both groups, (a) relieving the pressure that highly stressed trans people place on the general mental health services as well as the gender identity clinics (where referrals are growing at 21% per annum[19]), (b) reducing suicidality (34 % have made at least one attempt[20]) and (c) lessening stigma and hence improving social integration, educational achievement and wellbeing.

The Tavistock is already, unwillingly, relieving the pressure on the adult service by continuing to care for gender dysphoric people aged over 18. The current waiting times for adult services often exceed a year, which makes timely transfer impossible. Meanwhile, those aged 17 and over, face intensely distressing delay because the Tavistock/UCL withhold the physical intervention that is necessary.[21]

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[17] Zucker KJ, Gender identity disorder in children and adolescents, Ann Rev Clin Psychol;2005;1:467–92

[18] Duncan Selbie's presentation, Portcullis House, London SW1, on 15 May 2013.

[19] Data provided by the gender identity clinics.

[20] http://www.pfc.org.uk/pdf/EngenderedPenalties.pdf (page 78)

[21] We have a copy of a recent Tavistock letter to that effect.