Guidelines for health organisations commissioning treatment services for trans people

Parliamentary Forum on Gender Identity

Foreword from Lynne Jones MP, Chair of the Parliamentary Forum on Gender Identity

These guidelines have been produced by the Parliamentary Forum for Gender Identity to assist commissioners to make appropriate decisions in respect of providing funding for all aspects of the treatment required by people experiencing any degree of gender dysphoria. They are complementary to the Department of Health's publication *"Guidance for GPs, other clinicians and health professionals on the care of gender variant people".*

The Forum comprises Parliamentarians and the UK's leading experts on gender identity, in both the legal and medical fields, including Professor Kevan Wylie, Chair of the Committee set up by the Royal College of Psychiatrists in collaboration with the Royal College of Physicians and Surgeons and other colleges and societies to develop new standards of care for the treatment of trans people. Many of the leading advocates from the trans community also take part in our work, including those who have been instrumental in liaising with ministers and senior civil servants to bring about the successful passage and implementation of the *Gender Recognition Act 2004*.

I would like to acknowledge the work done to compile this document for the Forum by the Gender Identity Research and Education Society (GIRES).

Over time, the Forum does expect changes to be made in line with new information. For the latest edition of the document please refer to the GIRES website **www.gires.org.uk/medpros.php** which is the 'home' location of the latest version.

LYNNE JONES MP

Guidelines for health organisations commissioning treatment services for trans people

"The Department of Health is committed to tackling gender inequalities within the healthcare sector by recognising the specific health needs of men, women, and transgender people....The Department's commitment to create a patient-centred service which extends choice and is responsive to all patients and users, especially with regards to the gender perspective, will ensure that any gender differences in treatment and access are eliminated".
(Single Equality Scheme 2007-2010)

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1. Definitions

1.1 Gender dysphoria describes the extreme discomfort that arises when the psychological experience of oneself as a man or as a woman – that is the 'gender identity' – is incongruent with the sex characteristics of the body (phenotype) and with the gender role (the social role) typically associated with that phenotype. When the discomfort is profound and persistent, the individual affected may need medical assistance to facilitate a change of gender role so that it accords with his or her gender identity rather than with the phenotype. This extreme degree of dysphoria is described as transsexualism. Transsexualism should not be confused with sexual orientation; like anyone else, trans people may be gay, lesbian, asexual, bisexual or straight.

1.2 Gender dysphoria sits within a broad spectrum of conditions of inconsistent sex differentiation. Although these, considered individually, are rare, overall they are estimated to occur in about 1% of live births (Blackless *et al*., 2000). Gender dysphoria is estimated to occur much more rarely. However, the figure of approximately 0.00818% (1 in 12,225) of the adult population (Wilson *et al*., 1999) is likely to be a significant underestimate.[1]

1.3 The factors that impinge on the sex differentiation of genitalia, gonads and brain are a combination of genetic, hormonal and environmental. (see Annex: Diagnosis and aetiology, page 9). It is now widely

[1] Reed, B, Rhodes, S, Schofield, P, Wylie, K. Gender Variance: prevalence and trend; presented at LGBT Health Summit (August 20 – 21, 2008).Recent estimates: 21 in 100,000 = 0.02% (1:4,800) over the age of 15; numbers seeking treatment doubling every five years. Available at:

l www.gires.org.uk/assets/LGBTSummit/LGBThealthsummit2008.pdf

acknowledged that severe gender dysphoria/ transsexualism is an innate somatic condition, and is therefore appropriately treated by hormone therapy accompanied by surgery, where required by the service user, rather than by psychotherapeutic interventions alone.

"Severe Gender Dysphoria cannot be alleviated by any conventional psychiatric treatment, whether it be psychoanalytic therapy, eclectic psychiatric treatment, aversion treatment, or by any standard psychiatric drugs" (Green, 1999).

2. Introduction

2.1 Deprived of appropriate treatment, transsexual people are likely to function less well and to suffer ongoing health problems. This can result in a greater cost to the National Health Service than providing treatment. (Wessex Institute for Health Research and Development, 1998).

2.2 The services to which individuals are entitled should be flexible and patient-led, taking into account their particular needs and circumstances. The aim of treatment services is to achieve lasting personal comfort with the gender role.

2.3 Private services may be appropriate in individual circumstances and are not necessarily more expensive than National Health services in this field. Provided they meet contemporaneous standards of care, services from within the private sector can also be commissioned.

3. Terminology

3.1 The language used in the field of gender dysphoria and transsexualism is constantly evolving as understanding and perceptions of these conditions change.

3.2 Throughout this document, with the exception of material contained in "quotes", the terms trans woman and trans man are used, in accordance with the preference of trans people themselves. An individual who has been assumed to identify as a girl, having been assigned as female at birth according to genital appearance, but who later identifies as a man, may be described as a trans man; likewise, an individual who has been assumed to identify as a boy, having been assigned as male at birth, but who identifies as a woman, may be described as a trans woman. However, it is important to note that many people, after receiving the appropriate medical care do not identify as trans, but simply as men and women. A growing number of people seeking some degree of medical help, do not identify either as men or as women and may live somewhere in between (Burns, 2008).

3.3 A person who is transitioning, or has transitioned and is living in the gender role opposite to that assigned at birth, should be addressed according to the name and title (Mr, Mrs, Miss or Ms) that is deemed to be correct by the person concerned.

4. Legal responsibilities and obligations

4.1 Strategic Health Authorities, Primary Care Trusts and Specialised Commissioning Groups need to be aware of the rights of trans people to be treated for gender dysphoria. There is case law confirming the obligation for Health Authorities to make such treatment available (North West Lancashire Health Authority v A, D & G, Court of Appeal, 1999). A commissioning or funding

group is still permitted to accord any treatment 'low priority'. However, it is unlawful to use this as a 'blanket policy' whereby transsexualism becomes effectively barred from treatment. This case also indicated that gender reassignment is a valid treatment.

4.2 There is an obligation to treat trans people in accordance with current best practice and in the light of the most up-to-date research in the field. Failure to meet the demonstrable medical needs of trans individuals may result in legal challenges. (For further information regarding the legal implications of treatment, see Burns 2008).

4.3 Principle 3 of the NHS Plan (2000) also expresses the need for non-discriminatory practices and comprehensive involvement of individuals with their own treatment plans. Implicit in this Principle is the overriding need for properly informed consent of the person concerned before each stage of treatment.

"The National Health Service of the 21st Century must be responsive to the needs of different groups and individuals within society, and challenge discrimination on the grounds of age, gender, ethnicity, religion, disability and sexuality. The NHS will treat patients as individuals, with respect for their dignity. Patients and citizens will have greater say in the NHS, and the provision of services will be centred on patients' needs" (Principle 3, NHS Plan, 2000).

4.4 The case of Goodwin v UK, and I v UK (July 2002, under Articles 8 and 12) in the European Court of Human Rights, as well as the subsequent enactment of the Gender Recognition Act 2004 in the UK, give a strong indication to all agencies that they are under a positive obligation to treat trans people, in all areas of their lives, with respect and dignity; they should be

accorded equal rights and status with other citizens. Since the implementation of the Gender Recognition Act in 2005, trans people who have undergone transition have been able to obtain legal recognition of their new gender status for all purposes. However, it should never be regarded as an impediment to access to, and provision for, treatment services, that an individual, for whatever reason, chooses not to seek a Gender Recognition Certificate.

Under the Gender Recognition Act (2004) those who hold a gender recognition certificate are entitled to special protection of their privacy. When addressing trans people face-to-face or in correspondence, names, titles and information should be used with sensitivity and should avoid unwarranted disclosure; such disclosure could amount to a criminal offence. As a matter of good practice, the same protection should be accorded to all trans people (Burns, 2008).

If personnel, whether medical or administrative, are in any doubt as to the correct title, they should ask the individual, discreetly, how he or she wishes to be addressed.

4.5 Unnecessary, non-clinical delay in administering hormones or moving to the surgical stage of treatment, where this is desired, could result in legal challenges. Access to treatment should not be affected when a person concerned has moved area.

5. Health commissioners' funding obligations

5.1 The list of treatments under 5.3 and 5.4, to which trans people should have access, is not intended to be prescriptive, but should be used flexibly in response to the various needs and circumstances of the individual service users. The list should be used in conjunction with the Department of Health's publication "*Guidance*

for GPs, other clinicians and health professionals on the care of gender variant people", and may be extended in line with advances in treatment (see also Burns, 2008, annex on commissioning).

5.2 Once it has been established that extreme gender dysphoria is likely to persist, and treatment is initiated, there is an obligation for funding to be provided throughout the entire process of transition and on an ongoing basis following transition. The individual must be given life-long hormone therapy and, where necessary, psychological support. Many people seeking treatment for gender discomfort do not require surgery but, where it is appropriate; it should not be delayed or withheld except on clinical grounds.

5.3 In cases of adult gender dysphoria/transsexualism health commissioners are responsible for funding:

- support from the GP throughout the process (see NHS Guidance);
- referral to a local mental health specialist for the purpose of identifying and providing treatment for any mental health conditions (NHS Guidance, page 34);
- ongoing assessment and psychological support when necessary. This is best provided by a specialist with experience in dealing with gender related issues and may be provided by a counsellor, therapist, specialist nurse or other clinician. (NHS Guidance, pages 10 and 35–52);
- within a gender identity clinic, a package that includes advice on presentation in the new role, and facilities for peer support groups (facilitated or self-led) and relatives' support groups;
- hormone treatment including a referral to an endocrinologist, or other relevant specialist (NHS Guidance, Annex D);

- referral to a specialist in reproductive medicine for advice and information about reproductive options such as cryogenic gamete storage and mechanical sperm retrieval and egg retrieval. Provision of storage of gametes and assisted fertility services should be offered in accordance with existing local policy (Hamilton, 2006);

- Treatments for trans women

  - removal of facial hair and body hair;
  - feminising facial surgery;
  - crico-thyroid approximation;
  - thyroid chondroplasty;
  - breast augmentation;
  - genital surgery could include: hair removal from donor site; orchidectomy and penectomy, vaginoplasty, labioplasty and clitoroplasty.

- Treatments for trans men

  - chest reconstruction
  - hysterectomy, salpingo-oophorectomy, vaginectomy;
  - genital surgery could include: hair removal from donor site, metoidioplasty, scrotoplasty (with prostheses), urethroplasty and phalloplasty (with or without erectile prosthesis).

- Speech and language therapy (typically for trans women, but trans men may also benefit from this);

- appropriate district nurse pre-operative and post-operative advice and support (NHS Guidance, pages 16–17);

- post-operative referral to endocrinologist or other relevant specialist;

- ongoing monitoring of hormone regime (usually by GP or, where appropriate, an endocrinologist);

- follow-up reviews by gender specialist (as necessary).

5.4 In cases of young people experiencing gender dysphoria, their treatment services should be well integrated with adult services. Only a few of the *pre-pubertal children* who exhibit atypical gender behaviours become gender dysphoric adults, whereas those experiencing the condition as *adolescents*, almost invariably require access to adult services (Wren, 2000). In the latter group, endocrine treatment to block endogenous pubertal hormones may be given to carefully screened individuals, in whom the condition is judged to be persistent (Delemarre-van de Waal et al, 2006; NHS, Medical care for gender variant children and young people, 2008).

Commissioners are responsible for funding:

- GP support and liaison;
- referral to specialist child/adolescent gender identity unit;
- referral to paediatric endocrinologist;
- psychological support services.

5.5 After medical treatments to effect harmonisation, adult trans individuals may have mixed biological characteristics. This factor should determine the actual treatment services made available to them, for example, a trans woman should be offered screening for prostate cancer, whereas trans men should not.

5.6 After initial assessment and working diagnosis, treatment may follow the typical triadic pathway, "hormones ➔ real-life experience ➔ surgery"[2] , suggested by the Harry Benjamin guidelines or appropriate variations of these. Hormone therapy may be the initial, and is sometimes the only, treatment required, for instance where there is no intention to change the gender role publicly (n.b. this would not apply to trans men taking testosterone as its effects become very noticeable after a few months). This therapy is, usually, reversible in the short term and may precede steps that are largely irreversible such as living full-time in the opposite role or undergoing genital surgery (NHS guidelines, page 11). Best practice care involves informed consent by the individual concerned, at every stage of treatment.

5.7 If an individual relocates to a different PCT/SHA/SCG or clinic, continuity of care must be maintained. It is not acceptable for individuals to be returned to an earlier stage in their treatment.

6. Outcomes

6.1 Not all the elements of treatment mentioned above will be necessary or desirable in every case, nor will their sequencing conform rigidly to a standard pattern. For instance, for some people extensive surgery may not be appropriate or possible. However, studies using the post-surgery end-point, such as Landén's (1999) showed only a 3.8% regret rate. His study also

[2] The text continues: "… or sometimes real-life experience ➔ hormones ➔ surgery. For some biologic females, the preferred sequence may be hormones ➔ breast surgery ➔ real-life experience. However, the diagnosis of GID (sic) invites the consideration of a variety of therapeutic options, only one of which is the complete therapeutic triad. Clinicians have increasingly become aware that not all persons with gender identity disorders (sic) need or want all three elements of triadic therapy" (Harry Benjamin, 2001).

revealed that regrets were more likely where there was a lack of family support. Poor surgical outcomes were also a factor in some cases. This was echoed in the Smith *et al.* study (2005) which found that no patient was actually dissatisfied, 91.6% were satisfied with their overall appearance and the remaining 8.4% were neutral. A survey in the UK again showed a high level of satisfaction of 98% following genital surgery (Schonfield 2008), and a review of more than 80 qualitatively different case studies over 30 years demonstrated that the treatment is effective (Pfäfflin and Junge, 1998). A study on outcomes in trans women shows that they function well on a physical, emotional, psychological and social level (Weyers et al., 2009).

Annex

Diagnosis and aetiology

The International Statistical Classification of Diseases published by the World Health Organisation (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) offer the following diagnostic criteria:

Gender Identity Disorder (DSM-IV) is a condition in which there is:

"a strong and persistent cross-gender identification and a persistent discomfort with the sex or a sense of inappropriateness in the gender role of that sex".

Transsexualism (ICD-10) is experienced when there is:

"*a desire to live and be accepted as a member of the opposite sex, usually accompanied by a sense of discomfort with, or inappropriateness of, one's anatomic sex and a wish to have hormonal treatment and surgery to make one's body as congruent as possible with the preferred sex".* The condition may be diagnosed when "*the transsexual identity has been present persistently for at least two years".*

The ICD-10/DSM-IV entries provide useful reference points for the medical practitioner. These entries are due for review. Meanwhile, in the UK, trans people continue to qualify for treatment in law, on the basis of the case of North West Lancashire v A, D & G, 1999).

Over the last few years, the understanding of gender dysphoria has increased in line with the clinical observations of medical practitioners and the personal experiences and insights of trans people themselves, as well as the associated biological evidence that emerges from a variety of scientific studies (GIRES *et al.*, 2006).

It should be noted that medical and scientific findings are often amended and clarified but the right of individuals to appropriate care and respect remains.

Transsexualism is a complex condition. Aetiological pathways vary from individual to individual so no single route to its development is likely to be identified. The influences on outcomes will be multifactorial and will depend, not only on individual circumstances, but on cultural norms and mores. In cultures where greater allowance is made for gender expression that is less distinctly either masculine or feminine, the discomfort of those experiencing transsexualism seems considerably lessened. It is suggested that the likelihood of associated psychological stress may thereby be reduced (Connolly, 2003).

The factors that impinge on the sex differentiation of genitalia, gonads and brain, may be a combination of genetic, hormonal and environmental. The histories of conditions characterised by ambiguous genitalia in the newborn, associated with genetic and hormone anomalies, or accidental damage neonatally, demonstrate that gender identity may resolve independently of genital appearance and the gender of rearing (Diamond and Sigmundson, 1997; Kipnis and Diamond, 1998; Reiner, 2004; Hines, 2004; Dessens, 2005). This supports the view that pre-natal sex hormones (and/or direct genetic effects, Dewing *et al*, 2003) have an indelible impact on brain development and may trigger an inconsistent gender identity that is resistant to social pressures (Diamond, 2004; Reiner, 2004).

Unusual genetic patterns have been found to be associated with male to female transsexualism (Henningsson *et al.* 2005; Hare *et al*., 2008). Studies on twins and on other family co-occurrences of severe gender dysphoria, indicate that these are unlikely to be random and the potential for a genetic link in a subset of these individuals is thus inferred (Green, 2000; Diamond and Hawk, 2003).

Certain chromosome disorders in those with male phenotype are associated with a raised incidence of individuals who identity as women (Snaith *et al*., 1991; Diamond and Watson, 2004). Additionally, low androgen input to an XY fetus, associated with medication to the pregnant mother gives rise to a raised incidence of individuals identifying as women (Dessens *et al.*1999).

Cerebral lateralisation of hearing in the non-trans male and female populations is distinct and well-recorded. A recent study on hearing in trans individuals found that trans women's hearing is significantly different from non-trans males and, in fact, resembles the non-trans *female* pattern (Govier *et al*. submitted 2008). The same study also confirmed previous studies that demonstrated a marked correlation with non-right-handedness in both trans men and trans women (Green and Young, 2001; Zucker *et al*. 2001; Govier *et al*. submitted 2008).

Three post-mortem studies of small cohorts of transsexual individuals, small areas of the brain, known to be sex-dimorphic, have shown the potential for neural differentiation in opposition to genital and gonadal characteristics. Considered in the context of the other research, cited above, these brain studies support the paradigm that the neurobiology of the brain is an important element in the development of transsexualism (Zhou *et al*., 1995; Kruijver *et al*., 2000; Garci-Falgueras and Swaab, 2008).

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